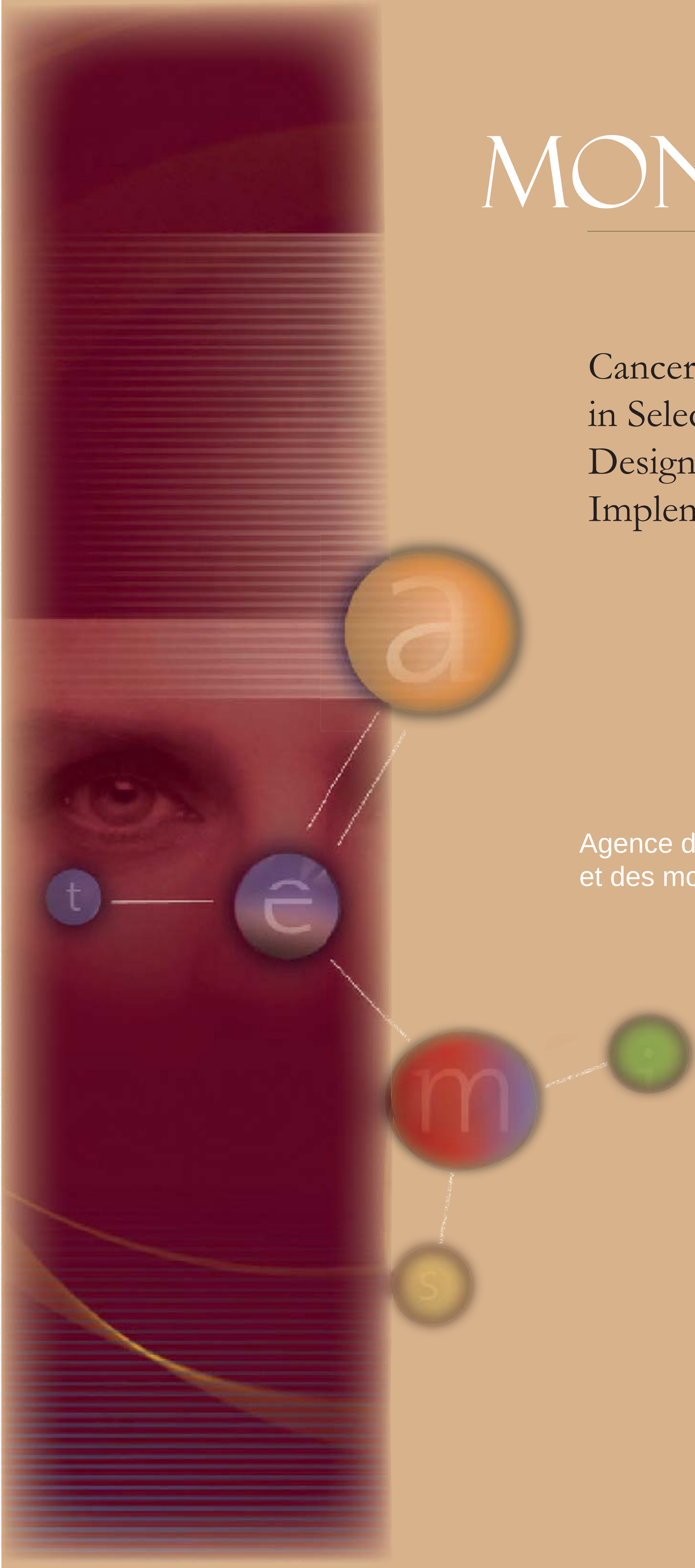

MONOGRAPH

Cancer Control Interventions in Selected Jurisdictions: Design, Governance, and Implementation

Agence d'évaluation des technologies
et des modes d'intervention en santé

Agence d'évaluation
des technologies
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Québec

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Cancer Control Interventions in Selected Jurisdictions: Design, Governance, and Implementation

Monograph prepared for AETMIS by

Lorraine Caron, Mirella De Civita and Susan Law with the collaboration of Isabelle Brault

May 2008

20 ans
AVEC VOUS
POUR LA SANTÉ

Agence d'évaluation
des technologies
et des modes
d'intervention en santé
Québec

The content of this monograph is available in PDF format on the Agency's Web site.

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How to cite this document:
Lorraine Caron, Mirella De Civita and Susan Law with the collaboration of Isabelle Brault. Cancer Control Interventions in Selected Jurisdictions: Design, Governance, and Implementation, monograph. (AETMIS 07-08a). Montréal: AETMIS, 2008. 353 p.

Legal deposit
Bibliothèque et Archives nationales du Québec, 2008
Library and Archives Canada, 2008
ISBN 978-2-550-52596-7 (PDF)
ISBN 978-2-550-52597-4 (Print)

NOTE TO READERS

This monograph is an organized collection of information on cancer control strategies, plans and programs in Canada, England, France, New Zealand as well as in five Canadian provinces, namely Alberta, British Columbia, Nova Scotia, Ontario and Québec. It refers to the jurisdictions' past and ongoing initiatives in cancer control as of the end of 2006.

This monograph was used as a reference source for the production of a final AETMIS report, which provides a targeted comparative analysis of cancer control strategies and programs in selected jurisdictions. The final AETMIS report, published in October 2007, is available in French on the AETMIS website.

ACKNOWLEDGEMENTS

This monograph was prepared at the request of the Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS) by **Lorraine Caron,** PhD (Biomedical Sciences - Bioethics), **Mirella De Civita,** PhD (Psychology) and **Susan Law,** MHSc (Health Administration), with the collaboration of **Isabelle Brault,** N, PhD (c) (Public Health).

Lorraine Caron was responsible for designing, developing and managing the second phase of this project (2005-2007) and for drafting and finalizing this monograph. She also played a substantial role in preparing a preliminary report submitted to the Ministerial Cancer Task Force (MCTF) in 2003.

Mirella De Civita played a substantial role in drafting this monograph and in the data design, gathering and analysis for the monograph.

Susan Law played a substantial role in designing, developing and managing the first phase of the project (2002-2004), including conducting interviews, preparing the preliminary report submitted to the MCTF, and critically reading the monograph.

Isabelle Brault played a substantial role in designing, developing and coordinating the initial phase of the project (2002-2003), including conducting interviews and preparing the preliminary report submitted to the MCTF.

AETMIS wishes to call attention to the contribution by **Vicki Foerster, MD, MSc,** who conducted most of the interviews, and by **Megan Edmiston, BA,** who transcribed and coded them.

AETMIS cordially thanks the following individuals:

Véronique Déry, MD, MSc, for her guidance, suggestions and encouragement throughout the research and the drafting of this monograph.

Jean-Marie R. Lance, MSc, and **Gilles Pineau, MD,** for their support and feedback while this monograph was being drafted.

We also thank all of the interviewees, everyone who provided information for this project, and especially the following people, who played a role in validating the descriptions of the strategies and programs pertaining to their jurisdiction that are profiled in this monograph:

Anthony Fields, **MD**, Vice President, Medical Affairs and Community Oncology, Alberta Cancer Board.

Antoine Loutfi, MD, Director, and **Brigitte Laflamme**, Assistant Director, Direction de la lutte contre le cancer, Ministère de la Santé et des Services sociaux, Québec.

Mandy Jacklin, Deputy Head, Cancer Team, Department of Health, England.

Andrew Padmos, MD, Chief Executive Officer, Royal College of Physicians and Surgeons of Canada, and former Commissioner (1998-2006) of Cancer Care Nova Scotia.

Maurice Soustiel, MD, Director of Cooperation with Developing Countries, Institut national du cancer, France.

Terry Sullivan, **PhD,** President and Chief Executive Officer, and **Helen Angus**, Vice President, Planning and Strategic Implementation, Cancer Care Ontario.

Simon Sutcliffe, **MD,** President, British Columbia Cancer Agency.

AETMIS finally thanks the **members of the Centre de coordination de la lutte contre le cancer au Québec (2001-2004),** Ministère de la Santé et des Services sociaux, and **Reiner Banken, MD, MSc**, for their contribution in guiding the first phase of this project (2002-2004) and the **members of the Direction de la lutte contre le cancer,** Ministère de la Santé et des Services sociaux, for their contribution during the second phase (2005-2007).

ABBREVIATIONS AND ACRONYMS

ACB	Alberta Cancer Board
ACCAP	Alberta cancer control action plan
ACCCC	Alberta Coordinating Council for Cancer Control
ARH	Agence régionale d'hospitalisation (France)
BC	British Columbia
BCCA	British Columbia Cancer Agency
CCLCQ	Centre de coordination de la lutte contre le cancer au Québec
CCM	Chronic care model
CCNS	Cancer Care Nova Scotia
CCO	Cancer Care Ontario
CCPC	Comprehensive cancer prevention and control
CEPO	Comité de l'évolution de la pratique en oncologie (Québec)
CPACC	Canadian Partnership Against Cancer Corporation
CQCO	Cancer Quality Council of Ontario
CSC	Cancer Services Collaborative (England)
CSCC	Canadian strategy for cancer control
CSQI	Cancer system quality index (Ontario)
CSSS	Centre de santé et de services sociaux (Québec)
CT	Cancer Taskforce (Angleterre)
DCP	District cancer program (Nova Scotia)
DCPC	Division of Cancer Prevention and Control (USA)
DGS	Direction générale de la santé (France)
DGSP	Direction générale de la santé publique, MSSS (Québec)
DGSSMU	Direction générale des services de santé et de la médecine universitaire, MSSS (Québec)
DH	Department of Health (England, Nova Scotia)
DHA	District Health Authority (Nova Scotia)
DHB	District Health Board (New Zealand)
DHOS	Direction de l'hospitalisation et de l'organisation des soins (France)
DHPP	Department of Health Promotion and Prevention (Nova Scotia)
DLCC	Direction de la lutte contre le cancer (Québec)
DREES	Direction de la recherche, des études, de l'évaluation et des statistiques, ministère de la Santé (France)
FCCHU	Fédération de cancérologie des centres hospitaliers universitaires
FNCLCC	Fédération nationale des centres de lutte contre le cancer

GCLC	Groupe conseil de lutte contre le cancer (Québec)
HAS	Haute autorité de santé (France)
HCC	Healthcare Commission (England)
ICCC	Innovative care for chronic conditions
ICP	Integrated cancer program (Ontario)
INCa	Institut national du cancer (France)
INPES	Institut national de prévention et d’éducation à la santé (France)
INSERM	Institut national de la santé et de la recherche médicale (France)
INSPQ	Institut national de santé publique (Québec)
INVS	Institut national de veille sanitaire (France)
IOG	Improving outcomes guidance (NICE, England)
IOM	Institute of Medicine (USA)
LHIN	Local Health Integration Network (Ontario)
MH	Ministry of Health
MHLTC	Ministry of Health and Long Term Care (Ontario)
MHP	Ministry of Health Promotion (Ontario)
MSSS	Ministère de la Santé et des Services sociaux (Québec)
NCAT	National Cancer Action Team (England)
NCCP	National cancer control program (WHO)
NCD	National Cancer Director (England)
NCIC	National Cancer Institute of Canada
NGO	Non governmental organization
NHS	National Health and Social Services (England)
NICE	National Institute for Health and Clinical Excellence (England)
NSBSP	Nova Scotia breast screening program
NZ	New Zealand
NZCCAP	New Zealand cancer control action plan
OPIS	Oncology patient information system (Nova Scotia)
PCT	Primary Care Trust (England)
PHAC	Public Health Agency of Canada
PHSA	Provincial Health Services Authority (British Columbia)
PQLC	Programme québécois de lutte contre le cancer
QCCC	Quality in the continuum of cancer care (USA)
RLS	Réseau local de services de santé et de services sociaux (Québec)
RUIS	Réseau universitaire intégré de santé (Québec)
SGAS	Système de gestion de l’accès aux services (Québec)

SHA	Strategic Health Authority (England)
SPO	Structure-process-outcome
SROS	Schéma régional d’organisation sanitaire (France)
UNESCO	United Nations Educational Scientific and Cultural Organization
USA	United States of America
WHO	World Health Organization

TABLE OF CONTENTS

Appendices

Figures and tables

1. INTRODUCTION

1.1 SCOPE OF THE CANCER PROBLEM

Cancer is the first cause of death in Québec,[1] and the leading cause of premature death in Canada.[2] In 2006, Statistics Canada estimated that 153,100 new cases of cancer would be diagnosed in Canada (of which 38,300 would be in Québec), leading to 70,400 deaths (of which 19,100 will be in Québec).[3] Moreover, the number of people living with or having been diagnosed with cancer is increasing at roughly twice the rate of new cases of cancer.[4] Not only does cancer pose a significantly high disease burden on individuals, it is associated with substantial economic and social consequences for their families and society. If these current trends continue, it is estimated that, over the next 30 years, the direct health care costs of cancer will be more than $176 billion in Canada only.[5]

1.2 POLICY CONTEXT

In April 2003, the newly elected Minister of Health and Social Services (Dr. Philippe Couillard) established cancer as one of his top priorities. A *Groupe de travail ministériel en cancer* (Ministerial Cancer Working Group) was established to make recommendations on how to improve the management and impact of the *Programme québecois de lutte contre le cancer* (the 1998 Québec Cancer Control Program or PQLC).[6] AETMIS was asked to provide the Ministerial Cancer Working Group with a brief synthesis of its ongoing study of cancer control strategies/programs and governance models in jurisdictions outside Québec. Such study was commissioned in early 2003 by the Ministry of Health and Social Services as part of a wider project examining evidence-based approaches to cancer services organization. In response to the Ministerial Cancer Working Group's request, preliminary unpublished material was presented to the Group in October 2003. The Ministerial Cancer Working Group report was released in the spring of 2004.[7] The Minister of Health and Social Services then presented it's three-year working plan, based on the priorities established in the Ministerial Cancer Working Group Report, at the First Annual Forum of the *Coalition Priorité Cancer au Québec* in April 2004.[8] The Minister also announced the creation of a *Direction de la lutte contre le cancer* (Division for

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[1] In Québec, deaths from cancers surpassed death from cardiovascular diseases in 2000. See Institut National de Santé Publique du Québec. Portrait de santé du Québec et de ses régions 2006. Deuxième rapport national sur l'état de santé de la population du Québec. Les analyses, p. 47.

[2] Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada April 2006, p. 56.

[3] Canadian Cancer Statistics 2006, p. 23.

[4] Health Canada. Population and Public Health Branch. Centre for Chronic Disease Prevention and Control. Progress report on cancer control in Canada, 2004, p. 5.

[5] Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, April 2006, p. 8.

[6] Ministère de la Santé et des Services Sociaux. *Programme québécois de lutte contre le cancer : Pour lutter efficacement contre le cancer, formons équipe*. Québec, Ministère de la santé et des services sociaux, 1998, 186 p.

[7] Ministère de la santé et des services sociaux. Groupe de travail ministériel en cancer (Luc Deschênes, Chair), Unifier notre action contre le cancer. Rapport de la démarche ministérielle visant l'amélioration de la gestion et de l'impact du programme québécois de lutte contre le cancer, 2004, 53 p.

[8] See Dr. Philippe Couillard speech, Forum de la Coalition Priorité Cancer au Québec, April 23, 2004. Available at: http://msssa4.msss.gouv.qc.ca/fr/document/dossierpresse.nsf/9990d07f20130db985256dce00553853/457a96acec118aa185256e7f00629782?OpenDocument Accessed October 20, 2006.

Cancer Control) to ensure strong leadership in the implementation of the Minister's working plan. In January 2005, a Cancer Control Director was appointed to oversee cancer control efforts in Québec. In November 2006, highlights of this monograph was presented to the Québec Cancer Control Director who requested that Québec cancer control intervention be examined using a similar framework.

1.3 PURPOSE AND POTENTIAL IMPACT

This author monograph builds upon and completes the preliminary data submitted to the Ministerial Cancer Working Group in 2003. It provides a detailed portrait of cancer control interventions (i.e. policies, programs, as well as strategies, and actions plans)[9] in four countries (Canada, England, France, New Zealand) and five Canadian provinces (Alberta, British Columbia, Nova Scotia, Ontario and Québec), with a particular focus on their design, governance, and implementation. This monograph is to serve as the reference document for the production of the final AETMIS report that will provide a comparative overview of cancer control strategies and programs in selected jurisdictions, including Québec.

The benefits gained from learning about cancer control initiatives in different jurisdictions are increasingly acknowledged, as evidenced from the ongoing work conducted by the World Health Organization as well as the work presented at the annual International Cancer Control Congress, and the annual Forum of the *Coalition Priorité Cancer* among others. The body of knowledge presented in this monograph regarding the planning and implementation of cancer control interventions may prove to be useful in informing cancer control policy initiatives in Québec and elsewhere. Such a descriptive analysis could also be used as a starting point for research on exemplar attributes of cancer control interventions. In addition, the information herein can also contribute to a broader understanding of the structural and contextual factors influencing the planning and implemention strategies adopted by various jurisdictions.

1.4 SUMMARY OF CONTENT

Chapter 2 describes our *Approach and Methods* for the study of cancer control interventions in the selected jurisdictions. Chapter 3 presents an *Integrated framework* that was created to guide the selection of elements to be analyzed. Chapter 4 provides an overview of the *History of Policy Development*, examining jurisdictions' approach toward the development of provincial or national cancer control programs, strategies and/or action plans.

Chapter 5 on *Design* describes a number of essential features pertaining to the conceptual aspects of cancer control interventions - namely, goals and priorities, underlying values, guiding

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[9] We use the expression "cancer control intervention" as a catch –all term to include cancer control policy, strategy, action plan and program. It also better captures the differences among jurisdictions regarding the object of our inquiry. In some jurisdictions, cancer control initiatives are stemming from an ongoing cancer control program with or without additional strategies or actions plans. In others, the cancer control intervention is mainly coming from a unique cancer control plan or strategy. However, the object of our analysis must be distinguished from the "cancer control system" as defined by the National Cancer Institute of Canada, which is a broader concept, comprising 4 inter-related components: fundamental research, intervention research, service delivery programs and monitoring and surveillance. See Advisory Committee on Cancer Control, National Cancer Institute of Canada. Canadian Medical Association Journal, 1994;151(8):1141-1146.

principles and organizing concepts, the spectrum of cancer control services, approaches to health services organization (organizational architecture), the strategies and mechanisms for sustaining and improving service quality (service quality facilitators), as well as targets/indicators chosen to monitor progress and/or assess outcome.

Chapter 6 on *Governance* provides a general overview of the key actors involved in cancer program/action plan implementation, with a focus on levels of implication (national, regional, local) and relationships with the health ministry/department. In addition, the chapter describes a number of features of the main organizations appointed to oversee policy/program implementation, regarding their legal status, vision and missions, internal structure, functions, resources available for implementation and accountability.

Chapter 7 on *Main Accomplishments* first describes jurisdictions' progress regarding their planned reform in service organization and then moves into presenting the service quality facilitator initiatives that are currently in place. This chapter ends by presenting one distinctive feature for each jurisdiction.

Chapter 8 on *Impact* summarises jurisdictions' achievements toward reaching their program/cancer plans' goals and targets, based on available litterature of program and/or action plan assessments.

Finally, chapter 9 presents an overview of *Cancer Control in Québec*, providing within a single chapter, information similar to what was gathered for the other eight jurisdictions.

2. APPROACH AND METHODS

The request for examining cancer control interventions[10] in other jurisdictions was prompted by a policy review in Québec. The Ministry of Health and Social Services expressed interest in having information about specific features characterizing cancer control programs and strategies/action plans in other countries as well as in other Canadian provinces.

2.1 RESEARCH QUESTION AND GUIDING OBJECTIVES

Based on multiple discussions with policy-makers to identify information needs and the policy context, the following main researchable question was formulated to guide our study of cancer control interventions:

What can Québec learn from other jurisdictions regarding cancer control priorities, governance models, effective service organization, strategies for ensuring evidence-based clinical practice, and successful ways to implement change?

To address this question, we established the following objectives:

1. Describe cancer control policies, programs, strategies, and action plans (interventions), including intended reform in the organization of cancer service delivery;
2. Describe the governance of cancer control interventions, including the status, structure, accountability, functions, and partnerships of the main governing organizations;
3. Highlight main accomplishments with regard to intervention implementation, including key informants' experience of reform, and the synthesis of available data from published audit reports and/or evaluations;
4. Compare jurisdictions along the aforementioned (1 to 3) components and draw lessons for cancer control planning and reform implementation.

2.2 UNDERLYING CONCEPTUAL APPROACH

This study is best described as a *descriptive inquiry*, aiming to highlight cross-jurisdiction differences and similarities in the development of cancer control interventions, while acknowledging the role of the socio-political context in shaping the way in which complex

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[10] Contandriopoulos *et al* define an intervention as "an organized system of actions (in a specific context and at a given time) seeking to produce services in order to correct a problematic situation" (p. 522). See Contandriopoulos AP, Champagne F, Denis JL, Avarques MC. L'évaluation dans le domaine de la santé : concepts et méthodes. Revue en épidémiologie et en santé publique, 2000;48:517-539. Similarly, Pawson *et al* use the word intervention to refer to policy, program, service delivery, or treatment. See Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review – a new method of systematic review designed for complex policy interventions. J Health Serv Res Policy 10(suppl 1) July 2005: S1:21-34. While a policy can be broadly defined as a statement of preferred outcomes or direction of change in relation to a perceived issue or problem, a program refers to the specific means adopted to give effect to a policy. However, a distinction cannot always be rigorously drawn. See Cabinet Office. Government's Center for Management and Policy Studies. Beyond the Horizon: Workbook -- A Framework for Policy Comparison, p. 9.

interventions are developed and delivered. Our approach seeks to describe and classify by *juxtaposing*[11] jurisdictions along selected features, thereby generating insights for policy analysis.

2.3 SCOPE AND LEVEL OF INQUIRY

Considered at a strategic management/organizational level,[12] cancer control interventions are complex and involve a substantial health system response at multiple levels. Thus within the resources available for this study, it was necessary to balance comprehensiveness with selectivity in reviewing their critical features. The selection of the features to be described and analyzed was determined by considering the perspective of decision-makers and by using an integrated framework developed after a review of existing models for cancer control planning (see Chapter 3). The object of inquiry comprises many levels of analysis, including: (1) programs, strategies and action plans; (2) organizations appointed to govern those programs or action plans; and (3) partnerships between the government, the appointed organizations, as well as relevant organizations within the health care system, including non-governmental organizations.

For the most part, the study focuses on policy level (macro level) aspects that corresponded to the needs of the policy-makers within the Québec Ministry of Health and Social Services. This means that we did not examine how the cancer control interventions are translated at the level of institutional functioning (meso level), nor how they influence the relationship between patients and health care professionals (micro level). However, information gathered on some selected elements (e.g., governance, organization of service delivery, factors influencing change) provide insights into how certain components of cancer control interventions are being implemented at the level of institutions, communities, and local regions. More specifically, the dimensions examined include the following:

- History and context of cancer control policy development, as well as major general health system reforms;
- Design features of cancer control interventions, including goals, values and principles, spectrum of services, models of service delivery, strategies and mechanisms for quality assurance/improvement and for health care system sustainability, as well as set targets and indicators;

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[11] The different stages wherein each jurisdiction rested along the cancer control planning and implementation continuum rendered the task of making a true comparison inappropriate (See Mark et al, 2000, p. 201). We thus use the term juxtaposition to refer to a type of broad policy comparison. See Cabinet Office. Government's Center for Management and Policy Studies. Beyond the Horizon: Workbook -- A Framework for Policy Comparison. Available at: www.policyhub.gov.uk/docs/workbook.pdf

[12] While our inquiry comprises multiple levels and dimensions, it cannot be truly defined as a system analysis since it does not examine all of the relevant organizations, programs, and resources that comprise each jurisdiction's cancer control service delivery system, nor does it examine the dynamic relationships between those components. Hence we characterize this study as a strategic management/organizational perspective, which would touch upon the *network/partnership* level and the *system* level, according to the nomenclature used by Wanke M, Juzwishin D, Thornley R, Chan L. An exploratory review of evaluations of health technology assessment agencies. HTA initiative #16, Alberta Heritage Foundation for Medical Research, 2006, p. 15.

- Governance of cancer control interventions, including the role of key players (government and health care system), collaborative partnerships, as well as the structures and functions of governing organizations and their relationship with government;
- Resources dedicated to implement the strategies, actions plans or to operate the programs;
- Jurisdictions' priorities for action, main accomplishments, highlights of some distinctive features, and available reports on impact; and
- Key informants' views on strengths and weaknesses, priorities for reform, facilitators and barriers to reform, and lessons learned from planning and implementation.

In summary, this study seeks to provide a systematic understanding of cancer control interventions in terms of how those interventions came onto being (development history) what they intend to achieve (design), how they are managed (governance), what they achieved and how (implementation), and what contextual factors may be shaping and influencing them (see chapter 3 for more details on the integrated framework used, and the description of the main analytical categories).

2.4 SELECTION OF JURISDICTIONS

Jurisdictions were selected in consultation with Health Ministry policy-makers.[13] The criteria for selection included: (1) relevance to Québec context; (2) comprehensive cancer control interventions (continuum of services) supported by a publicly funded health care system; (3) jurisdictions (countries and Canadian provinces) perceived to be forerunners in cancer control; (4) available documentation for analysis; (5) varying models of governance, (6) varying experiences in cancer control reform; (7) potential promising practices; and (8) experience with implementing change. Eight jurisdictions were initially selected for inclusion in this study, comprising four countries: Canada, England, France, New Zealand, and four Canadian provinces-namely, Alberta, British Columbia, Nova Scotia and Ontario.[14] Québec was then added at the request of the newly appointed Québec Cancer Control Director.

2.5 DATA SOURCES

A document and literature review as well as interviews with selected program personnel, stakeholders, and other informants served as the primary sources of information for describing the cancer control interventions. We did not conduct site visits to observe the actual circumstances in which the various programs operated.

2.5.1 Document and literature review

This sudy examined two primary data sources of literature: grey literature – as that available from websites of government, academic and stakeholder organizations - and published literature.

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[13] Policy-makers were members of the *Centre de coordination de lutte contre le cancer,* a ministerial cancer organization that was abolished in 2004 and replaced with the *Direction de lutte contre le cancer*.

[14] Although we acknowledge that other jurisdictions such as Australia would have offered interesting examples, our selection was limited by available time and resources. It was felt that the eight selected jurisdictions would offer the needed insights and information regarding planning and implementation of cancer control programs.

Documents regarding cancer control programs, strategies and action plans, progress reports, financial reports, and evaluation reports of the jurisdictions, as well as the business plans, annual reports, newsletters, research and technical reports of governing organizations were drawn from the websites of governments (health ministries/departments) and appointed cancer control organizations. Documents no longer available online were retrieved from libraries, when possible. Although these documents served as the main source for the inquiry, other sources were also used such as conference proceedings, reports from patient and other stakeholder coalitions, newspaper articles, as well as documentation forwarded to study authors by key informants, and personal correspondence between study authors and government officials and/or cancer control experts.

In addition, targeted searches in *PubMed* on cancer control programs and policy interventions in each of the selected jurisdictions were conducted to complement the grey literature with published papers on program components, activities, and accomplishments. The search of documentation covered two periods: (1) from 1995 to October 2003 (on which the preliminary report to the Cancer Ministry Committee was based) and (2) from October 2003 to June 2006. Following a validation process of the jurisdictions' portrait with the Cancer program directors (see section 2.6), some updated information was included, so that this monograph provides information that is current as of the end of 2006.[15]

2.5.2 Interviews with key informants

Interviews with key informants in the field of cancer control policy and program delivery served as a focal point for the work conducted in relation to the initial request made by the Ministry of Health. One important goal was to gain insights regarding the perceived strengths and weaknesses of cancer control programs and strategic plans as well as the lessons learned with respect to reform implementation. These semi-structured interviews, conducted from April 2003 to April 2004, provided a historical perspective and contained "insider" information about events and activities that shed light on the publicly available documentation. The interviews provided an opportunity to validate the descriptive and analytical information obtained from other sources.

The interview guide (see Appendix 2A) was developed iteratively in consultation with Québec policy-makers. A convenience sample was selected mainly based on the snow-balling technique, with the aim to recruit 3-4 interviewees involved at each level of decision-making (see Table 1).

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[15] It is important to bear in mind that information on cancer control planning and implementation is rapidly changing, therefore, some information may be outdated.

Table 1. Sampling framework for key informants

Level of decision-making	**Interviewees**
Macro	Government National strategy Agency/Program
Meso	Regional health authorities Networks Institutions/Centers
Micro	Clinical leaders Community resources Patient groups/representatives

Inclusion of jurisdictions for the interviews was based on the following criteria: (1) jurisdictions that, following initial review of available written documentation, appeared to be leaders in implementing change; (2) jurisdictions where substantial and rapid changes were taking place that could not be appropriately tracked with available written documentation; and (3) jurisdictions for which the available literature (published and grey) was not sufficient to properly document the components retained for analysis. Evidently, not all jurisdictions were included. For example, interviews were not conducted in France because regular progress reports (at 6, 10, 12, and 24 months) published by the Ministry of Health were sufficient. Forty-three interviews were conducted in five jurisdictions: 13 for Canada; 10 for British Columbia; 8 for Ontario; 7 for England; and 5 for New Zealand.

Interviews were transcribed and imported in NVIVO software for coding and analysis. A coding scheme was developed based on the topics in the interview guide and on major themes that emerged following the independent reading of a subset of interviews by four researchers. The final version of the coding scheme was validated by reaching consensus among the researchers.

2.6 VALIDATION BY PROGRAM DIRECTORS

For all nine jurisdictions, cancer control program/agency directors or a key member of the national/provincial cancer governing organization were invited to provide feedback on this monograph. Jurisdictions' representatives were instructed to comment on the accuracy and completeness of the information gathered relating to their respective jurisdiction. All jurisdictions have been validated except for Canada and New Zealand.

3. INTEGRATED FRAMEWORK

An *integrated* framework was designed to provide a systematic approach to describing and juxtaposing dimensions of cancer control interventions operating within the selected jurisdictions. The framework acknowledges the following considerations:

1. Cancer is a chronic condition, requiring a comprehensive approach that includes prevention and screening, as well as a full spectrum of organized health care services
2. Complex health policy and programs (interventions) cannot be treated as black boxes independent of their social and political context
3. An assessment of the relevance, coherence, and effectiveness of cancer control interventions must begin with a clear descriptive account of their design, governing approach, means of implementation, main accomplishments, and impact.

This chapter presents the main steps leading to the development of this integrated framework. Our building process begins by first emphasizing cancer as a chronic condition and examining the scope of cancer control. Next, we highlight the commonalities and differences among a selected group of existing frameworks pertaining to cancer control planning and implementation, prevention and management of chronic conditions in general, and the delivery of care in health systems. The resulting integrated framework is then presented, mapping its elements to the main analytical categories guiding our review: design, governance, implementation, and context.

3.1 CANCER AND THE SCOPE OF CANCER CONTROL

Cancer encompasses more than 100 different diseases characterized by uncontrolled cell growth, affecting different organs and tissues (WHO, 2002).[16] While some cancers evolve slowly or respond well to treatment, others can be highly aggressive or almost always lethal. The cause for many cancers remains uncertain, albeit a number of modifiable risk factors have been identified.[17]

Cancer is viewed as a *chronic* condition,[18] and, like all chronic conditions, it requires "*ongoing management over a period of years or decade,*" [19] and it may have "*a prolonged course that does not resolve spontaneously, and for which a complete cure is rarely achieved.*" [20] For example,

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[16] World Health Organization (WHO) National cancer control programmes. Policies and managerial guidelines, 2nd edition, 2002.

[17] Certain risk factors tend to be more commonly involved in the manifestation of specific cancers (e.g., exposure to ultraviolet radiation from the sun and skin cancer; tobacco in lung cancer), whereas other risk factors such as unhealthy food habits and physical inactivity tend to be implicated in more than one type of cancers. See Brownson, RC and Petitti, DB. Applied Epidemiology, Oxford University Press, New York, 1998.

[18] Chronic conditions include: (1) non-communicable diseases (e.g., cancer, heart disease, diabetes, and asthma), (2) persistent communicable conditions (e.g., HIV/AIDS, tuberculosis), (3) long-term mental disorders (e.g., major depression, schizophrenia), and (4) ongoing physical/structural impairments (e.g., amputations, blindness, and joint disorders). See World Health Organization. Innovative Care for Chronic Conditions: building blocks for action; global report. WHO Geneva, 2002, p. 11.

[19] World Health Organization. Innovative Care for Chronic Conditions: building blocks for action; global report. WHO Geneva, 2002, p. 11.

[20] Brownson, RC and Petitti, DB. Applied Epidemiology, Oxford University Press, New York, 1998.

once a cancerous condition is diagnosed, a treatment program is implemented that includes managing side effects. After treatment is completed, life-long surveillance and compliance with recommended treatment (e.g., maintaining a healthy lifestyle; taking medication; rehabilitation) should continue to prevent recurrence of the cancer or the development of a new cancer.[21] Cancer and chronic conditions alike challenge the efficiency and effectiveness of the health care system, wherein the primary focus is to respond to acute problems. At a global level, it has been recognized that the provision of quality care that responds to the needs of individuals with long-term health problems requires making a paradigm shift in the way that health care systems operate and interact.[22] Such a shift would have direct implications for patients, families, health care workers, as well as organizations, communities, and the health policy environment.

In the past, governments at all levels have viewed cancer as a disease to fight through care and treatment.[23] Over the years, a different approach to fighting cancer has emerged, backed up by evidence that cancer could be prevented. Indeed, it has been estimated that about one third of cancers worldwide[24] and about one-half of cancers in Canada[25] can be prevented with the implementation of evidence-based strategies in health promotion, prevention and screening. This approach is best characterized as ***cancer control:***

"Cancer control refers to the application of existing knowledge regarding approaches designed to actively prevent, cure or manage cancer. These approaches range from prevention through early detection and screening to treatment, encompassing rehabilitation, pain relief and other forms of palliative care. Cancer surveillance is a key component of cancer control." [26, 27]

Table 2 illustrates the progression from the cancer *treatment*, to cancer *care*, and cancer *control* perspectives,[28] highlighting differing focal points-namely; (1) the target population; (2) the structural features related to service delivery; (3) the level of integration related to service delivery; and (4) management. The three perspectives of cancer treatment, care, and control must

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[21] Zapka JG, Taplin SH, Solberg LI, Manos MM. A framework for improving the quality of cancer care: The case of breast and cervical cancer screening. Cancer Epidemiology, Biomarkers, & Prevention, 2003;12: 4-13. See p. 5.

[22] World Health Organization. Innovative Care for Chronic Conditions: Building blocks for action; global report. WHO Geneva, 2002, 99p.

[23] Canadian Strategy for Cancer Control. Establishing the strategic framework for the Canadian strategy for cancer control, 2005, p. 5-6.

[24] World Health Organization (2003). Global cancer rates could increase by 50% to 15 billion. World Cancer Report provides clear evidence that action on smoking, diet and infections can prevent one third of cancers, another third can be cured. Available at : http://www.who.int/mediacentre/news/releases/2003/pr27/en/

[25] Health Canada. Progress report on cancer control in Canada, 2004, p. 5. Available at: http://www.phac-aspc.gc.ca/publicat/prccc-relccc/pdf/F244_HC_Cancer_Rpt_English.pdf

[26] See Canadian Cancer Society website at: http://www.cancer.ca/ccs/internet/standard/0,2704,3172_367655_16416_langId-en,00.html

[27] Cancer control is an evolving concept which can also be defined more broadly as "the identification, development, promotion, diffusion, and delivery of effective and ethical cancer prevention, screening, and care services and programs for individuals and groups, always with their active participation." See p. 1141 in Advisory Committee on Cancer Control, National Cancer Institute of Canada. Canadian Medical Association Journal, 1994;151(8). This definition seeks to encompass all activities that contribute to reducing the burden of cancer, including research, advocacy, fund-raising, public education in addition to service delivery.

[28] Such shift in the scope of cancer interventions was first mentionned to us by a key informant from British Columbia, and is alluded to in the 2003 BC Cancer Agency Strategic Plan (updated version, September 2005), pp. 8-9.

be viewed as concentric circles, since each shift (from treatment to care, and from care to control) moves closer to a more globalized approach: from a hospital-based to a system-based delivery setting;[29] from a focus on discrete episodes of care to the notion of continuum of care;[30] from providing treatment to promoting health and preventing disease; from caring for individual patients to ensuring healthy populations; and from working in silos to linking systems.

Table 2. Progression from cancer *treatment,* to cancer *care*, and cancer *control*

Approach	**Cancer treatment**	**Cancer care**	**Cancer control**
Target population	Patients diagnosed with cancer	Patients diagnosed with cancer and individuals suspected of having cancer	Multiple populations: Healthy, suspected of cancer, diagnosed with cancer, in remission, at the end-of-life
Structural features	Facilities: Centers and hospitals	Multidisciplinary teams Patient navigators Networks of providers *(within and across regions*) Integrated care programs *(at local, regional, national levels)*	Intersectoral (e.g., health and education) and intrasectoral (e.g. public health and health care system) collaborations Systemic approach to knowledge formation, exchange, transfer, and application Participatory decision-making for patients and the public.
Level of integration in service delivery	Integrated care protocols *(care episode)*	Seamless trajectory of care across services and places *(continuum of services)*	Linkages among public health, health care delivery system, and community services *(health system)*
Management focus	Institutional *(silo)*	Continuity/coordination of health care services (*transitions between services and places*)	Health system performance *(sustainable, responsive, and efficient health system)*

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[29] Shortell SM, Gillies RR, Devers KJ. Reinventing the American hospital. Millbank Quarterly, 1995, 73(2): 131-160.

[30] “The continuum of cancer care spans prevention, early detection, and screening, diagnosis and treatment of new cancer cases, care of survivors, palliative care, and finally support for terminally ill patients and their families.” Institute of Medicine. Ensuring quality of cancer care, 1999, p. 22.

3.2 REVIEW OF RELEVANT FRAMEWORKS

The following frameworks described in the literature were reviewed to guide the development of a specific framework for our descriptive review:

- Donabedian's Structure-Process-Outcome (SPO) framework[31]
- World Health Organization's Innovative Care for Chronic Conditions (WHO-ICCC) framework[32]
- World Health Organization's framework for a National Cancer Control Program (WHO-NCCP)[33]
- The Quality in the Continuum of Cancer Care (QCCC) framework (USA)[34]
- USA Division of Cancer Prevention and Control's framework for Comprehensive Cancer Prevention and Control (DCPC-CCPC)[35]
- The National Cancer Institute of Canada (NCIC) framework[36]

The information drawn from these frameworks was organized according to selected features- namely, purpose; scope; guiding values/principles; targeted components; planning process; approach to implementation; and key partners. The result of this analysis is presented in Table 3 below (see Appendix 3A for a detailed description of the individual frameworks). In the following paragraphs, we examine the commonalities and differences among the selected frameworks, draw a number of lessons from this review, and provide reasons why we developed a new integrated framework. The chapter ends with a presentation of our framework.

Comparing frameworks not specific to cancer control: It is apparent that the SPO framework limits its scope to the health care setting. The WHO-ICCC framework, in contrast, views the larger community and the policy environment as playing influential roles. Both frameworks encourage the gathering of information (as defined by the framework's main components) to guide the planning process and the targeting of specific aspects of care when implementing changes. However, given the differences in scope, it is not surprising that the process of planning and implementation advanced by the WHO-ICCC framework includes the larger community within which patients and families live and health care organizations operate as well as the political environment.

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[31] Donabedian A. Evaluating the quality of medical care. 1966. Milbank Quarterly, 2005; 83(4):691-729; Donabedian A. The quality of care. How can it be assessed? JAMA, 1988;260(12):1743-8.

[32] World Health Organization. Innovative Care for Chronic Conditions: building blocks for action; global report. WHO Geneva, 2002.

[33] Available in: World Health Organization. National Cancer Control Programmes. Policies and Managerial Guidelines, 2nd Edition, WHO Geneva, 2002, 203p. Available at: http://www.who.int/cancer/media/en/408.pdf

[34] Zapka JG, Taplin SH, Solberg LI, Manos MM. A framework for improving the quality of cancer care: The case of breast and cervical cancer screening. Cancer Epidemiology, Biomarkers, & Prevention, 2003;12: 4-13.

[35] Abed J, Reilley B, Butler MO, Kean T, Wong F, Hohman, K. Journal of Public Health Management Practice, 2000;6(2):67-78.

[36] Advisory Committee on Cancer Control, National Cancer Institute of Canada. Canadian Medical Association Journal, 1994;151(8):1141-1146.

Comparing frameworks for cancer control: The QCCC framework is the only one whose scope is limited to cancer care activities within health care settings; albeit the authors of the framework do emphasize the importance of forming collaborative partnerships with community resources to facilitate patient participation in health-related activities. Although the scope of the DCPC-CCPC framework is at both the state and local levels, the iterative process for planning and implementation can be applied at a national level. In fact, the WHO-NCCP framework incorporates the DCPC-CCPC four phases of cancer program planning and implementation. Both the WHO-NCCP and the NCIC frameworks are aimed at national levels. However, the WHO-NCCP framework advances the cancer care program as part of other health care programs, thereby underscoring a plan that is more akin to a population-based approach. In contrast, the NCIC framework emphasizes the systematic design and evaluation of cancer control programs and the assessment of the effectiveness of the interventions delivered by such programs.

When examining the target components of the four frameworks, it is clear to see that components within the WHO-NCCP framework form the types of care scrutinized within the QCCC framework. Moreover, these same components are encompassed within the intervention research component of the NCIC framework. What sets the NCIC framework apart from these two frameworks is its explicit message regarding the importance of basic, clinical, and intervention research as guiding decisions regarding the planning and implementation of cancer activities. Activities and information emerging from the four components of the NCIC framework are expected to provide answers to questions such as: What do we know? Does it work? How should programs be delivered? and Where are we? Similar questions guide the four phases of planning and implementation advanced by the DCPC-CCPC framework and adopted by the WHO-NCCP framework.

Juxtaposing all frameworks: When comparing all the existing frameworks presented in Table 3, a few observations are worth noting. First, the SPO framework and the QCCC framework both focus on improving the quality of care. Both frameworks target similar components of care, but use a different organizational scheme. The QCCC framework organizes the analysis of care by specific strategies, which could easily have been organized according to structure, process, and outcome. The SPO framework makes no reference to who would be primarily responsible for reviewing and bringing about needed changes in care; whereas in the QCCC framework, changes would rest with the leadership of the health care organization. Second, a systems view of the health care setting underpinning the SPO framework is also advocated within the WHO-NCCP framework. In the WHO-NCCP framework, structure-process-outcome categories translate into inputs-processes-outputs-outcomes. The “inputs” refer to the resources, including the health care facilities; The “processes” refer to how the program organizes the resources; The “outputs” refer to the direct products of the program activities in actual number figures from the number of individuals served by the program to the amount of resources allocated. Finally, the “outcomes” refer to the impacts of the program on the people participating in the program, including measures such as the increase in knowkledge among customers and the reduction in incidence and mortality rates.

Third, both the QCCC and the WHO-ICCC frameworks are informed by the Chronic Care Model (CCM),[37] which was developed to improve the management of chronic diseases in a health care organization. The QCCC framework, however, applies the CCM strategies to improve the delivery of care and the transition between the types of care for cancer. In the ICCC framework, these strategies are reorganized according to the levels of the health-care system (micro, meso, macro). The WHO-ICCC framework expands on the CCM model by positing that the broader political environment is comprised of elements that could conceivably serve as strategies (e.g., consistent financing, integrated policies, supportive legislative frameworks, development and allocation of human resources). Fourth, the WHO-NCCP framework can be considered as the counterpart of the WHO-ICCC framework to planning efforts specific to cancer control. As with the WHO-ICCC framework, the WHO-NCCP framework situates essential components of a cancer care program within other health care programs, which are both linked to the larger health system and are tailored to the broad social (political and medical) context. A final observation is a consensus that the purpose - whether it relates to improving care or cancer control specifically - is achieved when multiple key players are involved.

Lessons drawn from the existing frameworks**:** Cancer and chronic disease control programs ought to have a clear purpose, with priorities based on the needs of the target population. Values and principles should guide program activities, planning, and implementation. Targeted components must include program activities that define the spectrum of care from prevention to palliation; strategies that improve and ensure quality of care; leadership for decision making, as well as health care systems (which would include patients, families, health care organizations, communities, and the policy environment). The scope of the cancer and chronic disease control programs ought to be in line with their intended purpose and must guide planning and implementation efforts. Decisions on the next course of action must be guided by evidence-based knowledge emerging from the program outputs and outcomes, as well as the social and political context. In fact, such programs must remain responsive and flexible to the context in which they were originally created and in which they must continue to function. Partnerships ought to be built with individuals across disciplines and activities, as well as within governments and voluntary sectors, including patients and their families.

The need for an integrated framework: Although one could argue that one or more of the reviewed frameworks could have been adopted for our purposes, it is important to point out that neither one alone would have been sufficient, considering: (1) the *purpose* of our study, which is to <u>describe</u> cancer control interventions in their planning, governance, and implementation (and not plan, prioritise or make decisions); (2) the *scope* of our study, which pertains to the main characteristics of cancer control interventions, i.e., cancer service delivery programs, cancer control strategies and action plans (and not the quality of care or requirements for effective health interventions); and (3) the *targeted components*, which are focused on macro level aspects, with little emphasis on the patient-health care providers' interactions. Moreover, the different points along which the jurisdictions rested in terms of planning and implementation of cancer control interventions, in addition to social and political context called for the need to adopt a descriptive

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[37] The Chronic Care Model (CCM) was not described in detail given that both the QCCC and the ICCC frameworks are expansions of this model. The four components of the CCM as adopted by the QCCC framework and rephrased as building blocks (micro-meso-macro levels) within the ICCC framework are elements of a systems approach to improving care of patients with chronic illness. See Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. Milbank Quarterly. 1996;74(4):511-44.

inquiry, albeit with some comparative approach. The review of existing frameworks nevertheless allowed for the selection of components that were, in general, represented within the selected jurisdictions’ cancer control programs/plans.

Table 3. Frameworks relevant for cancer control planning and evaluation

Selected features			Specific to cancer control			
	SPO	WHO-ICCC	WHO-NCCP	QCCC	DCPC-CCPC	NCIC
Primary purpose	To assess and improve the quality of health care delivery	To improve prevention and management of chronic conditions through changes in the health care system (expansion of the CCM)	To guide the development of national cancer control programs	To guide quality improvement studies and research on the trajectory of cancer care	To ensure a more comprehensive approach to cancer prevention and control	To facilitate ressource allocation in cancer control research and interventions through structured process for priority setting.
Scope	The attributes of health care quality, including the interrelatedness between the structures, processes, and outcomes of health care	Requirements for appropriate and effective health care at the patient (micro), organization (meso), and policy (macro) levels	Cancer control programs aiming to reduce cancer incidence and mortality, as well as to improve quality of life of cancer patients and families	The cancer care continuum, from prevention to palliation in health care settings	Evidence-based and participative decision-making processes to comprehensive cancer control planning and implementation at the state-local level	The bridging of the know-do gap with respect to all types of cancer control activities, including research, advocacy, service delivery, etc. (see targeted components)
Guiding values /principles	• Efficacy • Effectiveness • Efficiency • Optimality • Acceptability • Accessibility • Legitimacy • Equity *(these are defined as attributes of care- see Appendix 3A)*	• Evidence-based decision making • Population focus • Prevention focus • Quality focus • Integration • Flexibility/ adaptability	• Goal orientation • Focused on needs of people • Systematic decision making • Systemic and comprehensive approach • Leadership • Partnership • Continual improvement, innovation and creativity	• Patient involvement • Productive interactions between providers and patients • Accountability (*these are implicitly advocated by the framework- see Appendix 3A)*	• Partnerships • Flexibility • Practicality (*these are implicitly advocated by the framework- see Appendix 3A)*	• Accountability • Ethics • Empowerment • Efficiency

Table 3. Continued

Selected features			Specific to cancer control			
	SPO	WHO-ICCC	WHO-NCCP	QCCC	DCPC-CCPC	NCIC
Targeted components	Structures: • *Material resources* • *Human resources* • *Financial resources* • *Organizational structure* Processes: • *Patient activities in seeking care and carrying these out* • *Provider activities in making diagnosis and treatment implementation* Outcomes: • *Patient knowledge, health status and lifestyle changes* • *Patient satisfaction with care*	Levels of care: Micro level (triad): • *Patients and families* • *Community partners* • *Health care team* Meso level: • *Community* • *Health care organization* Macro level: • *Policy environment*	Cancer control programs, namely: • *Prevention* • *Early detection* • *Treatment* • *Palliative Care*	Improvement in the quality of care by enhancing: • *Leadership* • *Delivery system design** • *Clinical decision support** • *Clinical information systems** • *Patient self-management support** (*adopted from the CCM)	Four phases related to cancer control planning and implementation: • *Setting optimal objectives* • *Determining possible strategies* • *Planning feasible strategies* • *Implementing effective strategies* • *Knowledge for decision making*, as a separate component	Range of cancer control activities classified in 4 categories: • *Fundamental research* • *Intervention research* • *Program delivery* • *Surveillance and monitoring* And linked to a fifth category, which is the hub of the framework: • *Knowledge synthesis and decision-making*
Planning process	Based on the understanding/tracking of the chain of events of a specific care trajectory (e.g., diagnosis to treatment)	Based on the analysis of the components within the triad and the available resources	Based on the DCPC-CCPC framework's 4 phases	Rests with the leadership of health care organizations, but would likely include key partners	Information from the 4 phases feed into central decision making	Evidence from the 4 categories is synthesized to guide decision-making

Table 3. Continued

			Specific to cancer control			
Selected features	SPO	WHO-ICCC	WHO-NCCP	QCCC	DCPC-CCPC	NCIC
Approach to reform	Correct those indicators affecting quality of care	Begin by making changes where feasible among the components	Integrate cancer control program to: • *Other health programs* • *Health system* • *Broad social context*	Identify high priority areas for improvement	Informed by the lessons learned during the first cycle of planning and implementation	Interventions are provided wide-scale after assessment of their effectiveness is established
Key partners	Would involve: • Patients • Providers • Administrators • Care managers	• Patients • Families • Health care teams • Community partners • Community leaders from local and international organizations, support groups • Senior/influential leaders within health care organizations • Policy makers • Service planners • Researchers • Information technology designers • Support personnel	• Government and non governmental organizations • Health professionals with experience in disease control • Cancer experts • Patient groups • Other health service works • Other representatives • A leadership team, with a Program Coordinator • Board of the cancer control program • Network of local coordinators, backed up by Local leaders • Public	• Providers of care • Patients • Leaders within organized delivery systems • Health maintenance organizations • Public policy-makers	• State and community partners in cancer control and prevention • State cancer control staff	• Individuals involved in all four categories • Health care providers • Fund-raisers • Policy-makers • Administrator • Volunteers • Educators • Epidemiologists

3.3 RESULTING INTEGRATED FRAMEWORK

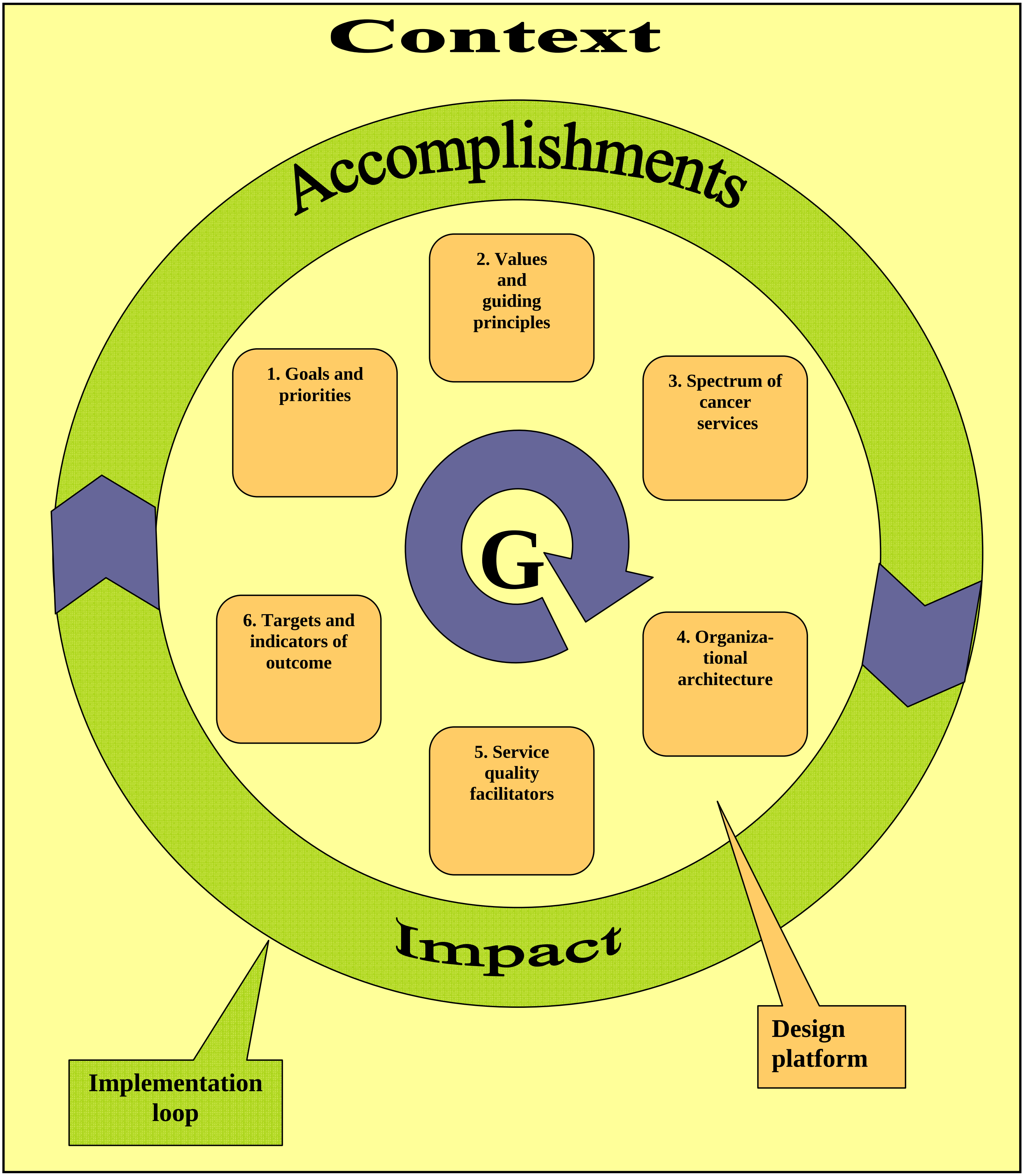
The resulting *integrated framework*, illustrated in Figure 1, synthesizes the relevant components presented in the six reviewed frameworks and maps these components onto four basic structural features, corresponding to the main analytical categories of this report: ***governance, design, implementation, and context***. The organization of the integrated framework elements in a circle underscores the iterative process to cancer control planning, implementation, and evaluation advanced by the DCPC-CCPC, the WHO-NCCP, and the NCIC frameworks. This circle is embedded in a rectangular background to highlight the role of the political and social context that shapes and determines how the interventions are planned, delivered, monitored, and evaluated. The organization of selected components according to design, governance, implementation, and context seeks to generate insights into the links from program design to program implementation, while considering the governance and the socio-political context.

Governance: Starting at the core of the framework, the circular arrow with the letter “G” denotes the dimension of *Governance,* which is the hub of the cancer control intervention. Governance plays a central role in the planning, development, management, implementation, monitoring, and evaluation of cancer control interventions. Governance refers to the purposeful efforts by social, political, and administrative actors to guide, steer, control, and manage the effective implementation of the intervention. It is similar in notion to the component of leadership in the QCCC model. In this study, the governance of cancer control intervention includes a description of key players, structures, functions, and resources. In the field of cancer control, the main governing actors include executive authorities of government, as well as board of directors and executive teams of cancer control governing organizations (see Chapter 6).

Design: The circular platform comprising six components refers to the dimension of *Design*, which is used to refer to the blueprint of cancer control interventions. It sets out statements expressed and agreed upon by key players about how cancer is to be prevented and controlled through planned strategies, components, structures, activities, and targets. The intervention design can be understood from a review of official statements and expressed rationales in cancer control programs, strategies and action plans, as well as in business plans put forth by recognized governing bodies responsible for cancer control. Akin to the input of a system (WHO-NCCP framework), the design platform is characterized by the following six components:

1. Goals and priorities
2. Values and guiding principles
3. Spectrum of cancer services
4. Organizational architecture
5. Service quality facilitators
6. Targets and indicators of outcome

Figure 1. An integrated framework for analysis of cancer control intervention



By describing these components, this study articulates cancer control interventions as they are planned by the jurisdictions, and it also provides a basis for cross-jurisdiction examination of similarities and differences (see Chapter 5). Some of those components, namely the organizational architecture, the service quality facilitators, and the targets/indicators of outcome will then be revisited as part of the *Implementation* dimension (see below).

Goals and priorities: A clear statement of goals (sometimes referred to as overall purposes or aims) is the first step of the planning process. Goals define the optimal state of affairs that can be attained as a result of program actions or activities.[38] Whereas the goals express the most desirable, the priorities are a selection of the most necessary actions to be taken, considering the actual policy and socio-economic context. The setting of priorities for cancer control intervention may be informed by a number of aspects including: the current health policy priorities; the values of the governing organization; the health gains associated with the different goals and actions being considered; and the available resources (referring to people, staff, finance, facilities, techniques, methods, among others - as explained in the DCPC-CCPC and WHO-NCCP frameworks).

Values and guiding principles: Cancer control plans and programs, as well as cancer control governing organizations usually make reference to a number of values, guiding principles and/or key concepts (such as patient-centered care, population-based approach, etc.) to guide the actions to be taken. An examination of these values, guiding principles, and concepts sheds light on design by informing the logic between the stated goals and the different components and activities.

Spectrum of cancer services: In cancer control, the range of health services provided is conceived of as a continuum that includes activities in prevention through palliation. This spectrum is similar to the types of care encompassed within the cancer care continuum described in the QCCC framework and to the program delivery component of the NCIC framework. However, such a spectrum is only one facet of cancer plan/program activities. Another facet includes effective service delivery, namely the *organizational architectures* and the strategies and infrastructures that will provide ongoing improvement of health services quality (*service quality facilitators*). These facets of plan/program activities are considered below as separate components in our framework. And while cancer research and education are often considered as part of a comprehensive approach to cancer control (as in the NCIC framework), they are not included here, since this component in our integrated framework focuses on delivery of care.

Organizational architecture: Another component of design is deciding how to organize service delivery efficiently. The organizational architecture[39] of cancer care services refers to the particular configuration through which these services are organized and delivered. This relates to the approaches or models for organizing stuctures and settings in which care is delivered, not the actual basket of services. This component is similar, in notion, to the “structure” component of Donabedian’s SPO framework in that it describes the attributes of the settings in which care is

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[38] Rossi Ph, Freeman HE, Lipsey MW. Evaluation. A systematic approach. Sixth edition, Thousand Oaks, CA, Sage, 1999, p. 167.

[39] Descriptor borrowed from Kewell B, Hawkins C, Ferlie E. Calman-Hine reassessed: a survey of cancer network development in England, 1999-2000. Journal of Evaluation in Clinical Practice, 8(3):303-311.

delivered. However, in our framework the organizational architecture of cancer care services not only includes structures that are visible to patients and their families such as hospitals, community clinics, and patient navigators, but also those that are less obvious such as networks of facilities and of professionals, levels of services (primary, secondary, tertiary), referral patterns, etc. These less obvious structures provide 'hidden' support for many aspects of professional practice, service delivery, and the management of care.[40] While the jurisdictions' description of the proposed approach to service configuration is part of the *Design* component, the accomplishments and progress in organizational reform are considered in the *Implementation* component.

Service quality facilitators: Also part of design are service quality facilitators, which refer to activities, tools/procedures and/or systems that enable the cancer control system to meet the growing demand for cancer services while ensuring the best quality of care possible for all cancer patients and individuals suspected of having cancer. This component can be related to the organizational strategies to improve quality included in the QCCC framework. For the purpose of our study, two categories have been retained for examining this component: (1) System capacity and sustainability; and (2) Quality assurance and improvement. The service quality facilitators that pertain to the *system capacity and sustainability* category relate to the structure and infrastructure of the health care system and its workforce. These elements provide the means for adequate delivery of services and, therefore, are considered as prerequisites to service quality. The DCPC-CCPC framework, for example, considers efforts at building infrastructure for performance evaluation or reporting procedures as part of the planning process.

The service quality facilitators that pertain to *quality assurance and improvement* comprise tools, procedures, and activities aimed at assuring and improving the quality of the cancer services delivered. Quality assurance most specifically refers to maintaining gains in the delivery of quality services, while quality improvement most specifically refers to supporting the enhancement of service quality.[41] Although quality assurance and improvement activities can be distinguished as noted above, they have been put toghether since many initiatives can contribute to both quality assurance and improvement.[42] While the comparison of jurisdictions over the range of service quality facilitators that have been planned or set up is part of the *Design* component, a closer examination of their respective accomplishments is considered in the *Implementation* component.

Targets and indicators of outcome: Once programs and plans have set their goals and priorities, and have proposed ways and means to accomplish these goals and priorities, they need to have

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[40] Kewell B, Hawkins C, Ferlie E. Calman-Hine reassessed: a survey of cancer network development in England, 1999-2000. Journal of Evaluation in Clinical Practice, 8(3), p. 303.

[41] *Quality assurance* seeks to demonstrate that a service fulfills or meets a set of requirements or criteria. Conducting quality assurance activities involve comparing actual processes and/or outcomes of health care services to pre-defined criteria or pre-selected requirements. *Quality improvement* refers to the betterment or enhancement of a service. When enhancements are ongoing or occur repeatedly over time, the process is known as *continuous quality improvement*.

[42] For example, the New Zealand Minister of Health (See Improving quality: A systems approach for the New Zealand health and disability sector, 2003) views quality improvement as including continuous quality improvement and quality assurance even though there are statements to the effect that quality assurance is focused on maintaining gains, whereas quality improvement activities center mostly on the search for continuous improvement in services.

specific end-points that will assist in determining whether progress is being made and, most importantly, whether the goals, priorities, and actions have been achieved. This last component of design makes reference to cancer control plans and programs that have explicitly stipulated some measurable targets or indicators of outcome. While the description of the actual end-points is part of the *Design* component, the assessments conducted by the jurisdictions (via independent bodies or by their cancer control governing organizations) to determine the impact of the cancer plan or program is considered in the *Implementation* component.

Implementation: The outer ring of the integrated framework, divided into two sections, represents the *Implementation* of the cancer control interventions. In its usual meaning, the term implementation refers to a process that involves a complex mix of strategies, resources, structures, and tasks to move a planned intervention into action or practice in order to achieve the intended goal.[43] For the purpose of this study, we use the term implementation to comprise two elements: (1) *Main Accomplishments*, as in the concrete actions to fulfilling the cancer control plan and/or program and (2) *Impact* as it relates to activities conducted to assess the outcomes of such program/plan. This last component underscores the "outcome" indicator of the SPO framework. Accordingly, then, the emphasis is not on describing the processes by which strategies, resources, or tasks were put into practice,[44] but on describing the *results* of such processes. That is, the focus is on describing the initiatives that have been put into place (main accomplishments) and the progress made in terms of achieving stated goals by meeting targets and indicators of outcome (impact). More specifically, *Main Accomplishments* comprise a description of major achievements in cancer control plan/program implementation, including service organization reform and service quality facilitators. Also considered in this component are distinctive features of the jurisdictions that could be viewed as exemplar attributes. The *Impact* component acknowledges available internal and external assessments of the cancer control plan/program.

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[43] Beyond the horizon. A framework for policy comparisons. CMPS Workbook, p. 8.

[44] Our restricted and mostly static view of implementation should not be confused with the usual topics of implementation studies, which may include: (a) describing case stories about implementation experiences, (b) measuring the extent and processes of implementation attempts, (c) explaining the discrepancy between the planned intervention and its practical translation and/or (d) providing guidance about how to anticipate implementation problems. See Denis JL, Champagne F. L'analyse de l'implantation : modèles et méthodes. The Canadian Journal of Program Evaluation, 1990;5(2):47-67.

Context: Context refers to the "*physical, organizational, cultural and political settings in which programs and actors are embedded and in particular those setting aspects that influence program success.*" [45] Considering the context of cancer control interventions allows for a better understanding of the particular trajectory of each jurisdiction. The influence of context on the planning and the implementation of cancer control programs is well underscored by the WHO-NCCP, the DCPC-CCPC and the NCIC frameworks. Elements of context are also included in the QCCC and WHO-ICCC frameworks as the broader community and the policy environment respectively. Elements of context that are considered in this study include: historical development of cancer control programs or plans; epidemiology data; health care systems within which cancer control programs or plans must operate; cancer control investments; and availability of resources within the larger health system, among others.

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[45] Mark MM, Henry GT, Julnes G. Evaluation. An integrated framework for understanding, guiding, and improving public and non-profit policies and programs. Jossey-Bass, San Francisco, 2000, p. 195.

4. HISTORY OF POLICY DEVELOPMENT

This chapter provides a succinct description of the major features of cancer control policy and program development for each selected jurisdiction outside Québec. The policy development history was delineated by mapping official documents and records of salient events along five stages of the policy development and implementation process: (1) Strategic development; (2) Formal Strategy, Action Plan and/or Program; (3) Progress of Implementation; (4) Evaluation of Implementation; and (5) Outcome assessment.[46] Such classification of the available policy material is presented in the form of a milestone table included in appendix 4A. This exercice suggests that the selected jurisdictions are at different stages in their policy and program development. While the task of comparing jurisdictions for "best approach" or "most efficient strategy" is not the purpose of the present study, we can nevertheless draw insightful conclusions from juxtapositing their histories.

4.1 HIGHLIGHTS OF THE JURISDICTIONS

All jurisdictions have an interesting history regarding the development of their cancer control policy. For the purpose of brevity, we have grouped jurisdictions according to hallmarks of their development history. These groups are not mutually exclusive; some jurisdictions could fit in more than one.

Canada, France and New Zealand: Progress linked to cancer becoming a national priority

A first observation worth noting is that most jurisdictions underwent multiple attempts at cancer control reform. In both Canada and France for example, the planning and implementation of the 2002 Canadian Strategy for Cancer Control and 2003-07 Cancer Plan (France) were preceded by the publication of reports and action plans that failed to be implemented (see shaded boxes below). Similarly, New Zealand was very near to producing a strategy in 1996, but the initiatives were slowed down by changes in government (in 1996) and changes in health system governance.[47] In all three cases, the development and/or implementation of current strategies was set in motion by newly elected governments that considered cancer as a top priority. In 1999 a new government was elected in New Zealand and cancer became one of thirteen priorities of the NZ Health Strategy. In France, the need for a national cancer control strategy has been supported by medical consensus and patients' demands. In addition, substantial progress followed the election of President Chirac in May 2002, who declared that cancer control would be a top priority during his five-year mandate. In Canada, the recently elected conservative government

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[46] Although these five stages are presented in a linear fashion, the development and implementation of cancer control policy is truly an iterative process: First, a jurisdiction may go through multiple attempts at establishing a successful (agreed upon and implemented) policy. Each renewed attempts can be viewed as "strategic planning cycles" interspersed by transforming events and characterized by the multiple strategic planning documents being published at regular intervals. Second, the process underlying policy development and implementation is iterative in the sense that cancer control strategies and programs evolve with time, and lessons learned about what works or does not work during a previous "cycle of operations" provides the impetus to bring some changes to the next cycle. For example, new strategies can be added to address different facets of the problem; new priorities can be formulated and enforced; different implementation strategies can be tested if previous ones were not deemed effective; and a new approach to the problem could be developed altogether.

[47] Based on interviews with New Zealand key informants.

(2006) committed 260 million dollars toward the implementation of the Canadian Strategy for Cancer Control over the next 5 years.

History of policy/program development – Canada

The first significant efforts to develop a national strategy for cancer control originated in the late 1980's. The *Cancer 2000 Report,* published in 1992, comprised more than a hundred recommendations, but the concerned authorities did not act on those recommendations. In 1999, senior executives from government (Health Canada) and non-governmental organizations (Canadian Cancer Society, National Cancer Institute of Canada and the Canadian Association of Provincial Cancer Agencies) formed a Steering Committee to initiate and lead a new strategic development process. In 2001, a meeting was held to establish top priorities and to finalize governance structure. In 2002, The *Canadian Strategy for Cancer Control* (CSCC) was established and the Steering Committee was dissolved. A new *Canadian Council for Cancer Control* took over to oversee the implementation of the CSCC priorities. The CSCC is aimed at creating a virtual network among all cancer stakeholder organizations and governments to facilitate sharing of cancer knowledge and best practices. The CSCC planning and consultation process involved over 700 Canadians from the health and allied professions, academia, the voluntary sector, all levels of government and cancer patients/survivors. Until 2006, however, lack of political commitment, coordination, and sustained funding impeded the implementation of this national strategy. Important efforts had to be deployed by the CSCC Council and advocacy and support groups (National Cancer Leadership Forum, Canadian cancer Society, Cancer Advocacy Coalition of Canada) to keep the national strategy on the political agenda (including the *Campaign to Control Cancer*). The most prominent impact from this mobilization included: (1) the introduction in February 2005 of a Bill (S-26) to the Senate that would ensure the recognition of the national strategy; (2) the publication in April 2005 of *Establishing the Strategic Framework for the Canadian Strategy for Cancer Control*, updating key reports published on the CSCC and introducing a scheme for measuring the cost-benefit ratio of successful implementation of the National Strategy; and (3) a vote in the House of Commons on June 7 2005, in favour of a motion to fully fund and implement the CSCC. In April 2006, a new government was elected that committed 260 million dollars for the implementation of the CSCC over the next five-years (2006-2010). The implementation is guided and supported by the Council's *2006-2010 Business Plan for the CSCC* and governed by the newly established Canadian Partnership Against Cancer Corporation.

History of policy/program development – France

In France, much progress has occured since President Chirac signed the Paris Charter in 2000,[48] and declared after re-election in May 2002 that cancer control would be a top priority during his second five-year mandate. This new momentum comes after a series of public reports (1998 to 2001),[49] depicting the failure of prior policy initiatives and the unmet needs of patients. In 1998 and 2000 for example, the League against Cancer organized two patient conventions that allowed patients to voice their suffering, needs and expectations to the Health Minister. The Minister responded by the publication of the *Programme national de lutte contre le cancer 2000-2005*, which unfortunately was not implemented due to lack of funding and leadership. After re-election of President Chirac in May 2002, a *Commission d'orientation sur le cancer* (Steering Commission on cancer) was set up to document the current situation. The Commission benefited from the input of many groups, including patients, health care professionals, and associations involved in the field. The Commission noted that France had the worst premature mortality rate in cancer across Europe and that research efforts were not sufficient. The Commission's report, published in January 2003, comprised 11 recommendations that formed the basis for the drafting, by the Minister of Health and the Minister of Research, of the five-year strategic plan, entitled: *Cancer. A nation-wide mobilization plan.* This five-year Cancer Plan (2003-2007) was submitted to the President of the Republic who presented it to the public in March 2003. The Plan comprises 70 measures to be implemented by 2007 according to a strict timeline and to be monitored using key indicators. The creation of an *Institut national du cancer (*INCa, National Cancer Institute*)*, one of the Commission's recommendation, was made into law in 2004 (France's new Public Health Law). Implementation of the new Cancer Plan began in 2003 under the governance of a *Mission interministérielle (*National Project Taskforce), appointed by the Prime Minister to coordinate and monitor the first phase of the implementation. It operated from 2003-2005, until the newly created National Cancer Institute took over in 2005. Renewed momentum was prompted by a speech given by the President of the Republic in April 2006, which provided an update on the accomplishments of the National Cancer Institute and announced new projects.

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[48] The Paris Charter is a founding text that recognises the fight against cancer as an international priority. It was signed by President Chirac during the World Summit Against Cancer for the New Millennium, hosted by UNESCO in Paris in 2000.

[49] For details see: Sénat. Rapport d'information #31 sur la politique de lutte contre le cancer de la Commission des finances du Sénat, October 1998; Ligue nationale contre le cancer. Les malades prennent la parole. Le livre blanc des 1ers États généraux des malades du cancer. Paris, France : Ramsay, 1999; Cours des comptes. Rapport sur la sécurité sociale. Chapitre 7. La mise en œuvre de la politique de santé : l'exemple de la lutte contre le cancer, September 2000; Ligue national contre le cancer. Deuxièmes États généraux des malades contre le cancer, November 2000; Sénat. Rapport de la Mission d'information sur la politique de lutte contre le cancer à la Commission des affaires sociales du Sénat, June 2001.

History of policy/program development – New Zealand

Work to develop a broad level framework for cancer control dates back to 1996, when a number of working parties were set up to look at palliative care and the non-surgical aspects of cancer treatment. The working parties produced documents in 1999, which were later published by the Ministry of Health as a reference paper entitled: *Improving Non-surgical Cancer Treatment Services* (2001). Also in 1999, a workshop was organized by the NZ Cancer Society to address the rising incidence of cancer. At the end of that year a new government was elected and cancer became one of 13 priorities of the *NZ Health Strategy* (2000). In 2001, a Cancer Control Trust was established as a partnership between the Ministry of Health, The NZ Cancer Society and other non-governmental organizations. The Cancer Control Trust prepared two reports that laid the groundwork for the development of a National Strategy. In addition, *the NZ Palliative Care Strategy* was released by the Ministry of Health. Later that year, a Cancer Control Steering Group was set up along with a number of expert working groups to establish priorities, following the Canadian model. In December 2002, a first draft of the National Strategy was submitted for public consultation. One important goal of the Strategy would be to improve access and care fo the Māori and Pacific populations that had the worst health outcomes. The *NZ Cancer Control Strategy* was finally launched by the Health Minister in 2003. Later that year, a national workshop entitled *From Policy to Action: Working Together to Implement the Cancer Control Strategy* was held to begin the planning for the implementation. The Workshop provided an opportunity for those with expertise and responsibility in various aspects of cancer control to identify what was needed to ensure effective and ongoing implementation and to contribute to the development of an implementation plan. A Cancer Control Taskforce was then set up to produce an action plan. The *NZ Cancer Control Strategy: Action plan* was published in March 2005. A *Cancer Control Council* was then appointed by the Health Minister and a first meeting of Council took place in June 2005. Moreover, a *Ministry of Health Principal Advisor Cancer Control* was nominated to provide guidance to the Director-General of Health, the Ministry of Health and to the Minister of Health on issues relating to cancer control. In 2006, *a Cancer Control Work Programme Steering Group* comprising representatives from the Health Ministry and the Cancer Control Council, oncology experts, and other stakeholders, was formed to begin implementation.

Ontario: A second start in the aftermath of the “radiotherapy delay” crisis

Ontario also witnessed multiple attempts at cancer control reform. However, its path is somewhat different from that of either Canada, France or New Zealand. Ontario’s policy and program development can be described in two major phases: The first extends from 1994 to 2000, and the second began in 2001 with the appointment of Alan Hudson as head of the Cancer Services Implementation Committee and shortly thereafter as CEO of Cancer Care Ontario (2002-2004). In between those two phases, however, Ontario experienced an important crisis regarding long delays for radiotherapy, which led to the transfer of many patients to the United States for their treatment. While this problem was not unique to Ontario – it surfaced during our analysis of British Columbia and New Zealand, and it also affected Québec – the Ontario Ministry of Health and Long Term Care responded by bringing radical changes in both the cancer Agency’s mandate, governance, and organization of cancer service delivery. In 2004 Cancer Care Ontario launched the Ontario Cancer Plan 2005-2008 an evidenced-based provincial roadmap, which builds on a sustained strategic planning efforts (that led to several specific planning documents, see shaded box below) to reduce cancer rates and to improve the quality of care.

History of policy/program development – Ontario

In Ontario, initiatives to improve cancer control date back to the early 1990s. A first assessment of the entire system was undertaken and recommendations were published in 1994 in a report entitled *Life to gain : A Cancer Strategy for Ontario*. It highlighted a number of problems including the lack of service coordination, lack of clinical practice standards, variations in access to care, and the lack of the patient perspective in cancer policy planning. This report, which can be considered as the first provincial cancer control strategy, suggested the development of a *Provincial Cancer Network*. Such a Network, established by the Ministry of Health and Long Term Care, was mandated to develop a provincial framework for cancer control that would be implemented through regional networks. Following a long consultation process, the Provincial Cancer Network recommended the creation of *Cancer Care Ontario* (CCO) to monitor and coordinate the provincial cancer control system. CCO was launched by the Ontario Premier in 1997 with the mandate to integrate and coordinate all cancer services in the province. CCO took over *the Ontario Cancer Treatment and Research Foundation* that had been established in 1943. In 1999, a crisis occured in the management of cancer services in Ontario. The *Provincial Auditor of Ontario* found that only 32% of patients received radiotherapy within the four-week recommended waiting period. Many patients were sent to the United States to get treatment. The Government requested a thorough review of CCO and cancer services implementation thoughout Ontario. The *Cancer Services Implementation Committee* submitted its report in 2001. The report recommended important changes in the Cancer Agency’s mandate so that it would no longer be responsible for the direct delivery of care through its regional cancer centers. CCO would instead become an advisory body to the Ministry on all aspects of cancer control and services. In addition, CCO would be responsible for planning and coordinating all cancer services across the province. In 2002 a Cancer Quality Council of Ontario (CQCO) was created that would come to serve as CCO’s impetus to move toward cancer control system performance monitoring, managing, and reporting. From 2002 to 2004, CCO published important strategic plans including an *Information Management Strategy* (2002), “*Cancer 2020*” which is an action plan for cancer prevention and early detection prepared jointly with the Canadian Cancer Society (2003), and a *Four-Point Strategy* to reduce waiting time, prepared by the Cancer Quality Council (2004). Also in 2003, CCO senior executives published *Strengthening the Quality of Cancer Services in Ontario* , which provided an assessment of the quality of cancer services in Ontario and identified gaps in the ability to measure quality. In November 2004, CCO published the *Ontario Cancer Plan 2005-2008*. The development of the cancer plan involved more than 3000 people across the continuum of care. The plan was informed by a regional planning process, a corporate planning process, and it also underwent a formal review by international experts. Progress of implementation is reported in *Ontario Cancer Plan: 2005 progress report* and in *Report on Cancer 2020: A Call for Renewed Action on Cancer Prevention and Detection in Ontario,* published in June 2006.

England: A concerted health policy effort to overcome poor cancer survival rates

In England, efforts at a concerted policy approach to improve cancer care began in the mid nineties when results from the Eurocare study examining 5 year cancer survival rates in European countries demonstrated that England was faring well below (by 5%) the European average for all common cancers (lung, breast, colorectal and prostate).[50] Moreover, around the same time as this study, regional variations in cancer treatments and outcomes aross the UK were surfacing. The reason underlying Britian's poor performance in cancer control was attributed to the quality of care and its integration,[51] including:

- low numbers of radiotherapists and medical oncologists;
- poor access to specialist cancer care;
- lower use of chemotherapy;
- wide variations in drug accessibility depending on health authority, which means similar patients treated at the same cancer center may have different treatments depending on where they live (postcode lottery); and
- wide variation in clinical outcomes for common cancers in differents hospitals, which in some cases could be linked to a volume effect.

In 1995 a landmark report was published that recommended a fundamental restructuring of cancer services in England and in Wales (Calman-Hine report), which would include the creation of cancer services networks. Soon thereafter a number of important initiatives were undertaken, namely to reduce variations in care. In 1999 reforms took a faster pace, with the creation of a *National Cancer Action Team* to oversee the creation of cancer networks, and the appointment of a *National Cancer Director* with the mandate to prepare a cancer plan specific for cancer. The NHS Cancer Plan was published in 2000. This plan is the first-ever comprehensive strategy for tackling cancer from prevention to palliative care, at a national level in England.

History of policy/program development – England

In 1994, the Chief Medical Officers of England (Dr. Kenneth Calman) and Wales (Dr. Deidre Hine) established the *Expert Advisory Group on Cancer* to develop a policy framework for commissioning cancer services. The Expert Advisory Group on Cancer reviewed the international literature on cancer survival in relation to patterns of care and noted that improved outcomes were associated with access to specialised care. Building on previously published reports by the Association of Cancer Physicians, the Royal College of Physicians and the Royal College of Radiologists, the Expert Advisory Group on Cancer prepared a report entitled: *A Policy Framework for Commissioning Cancer Services* that recommended a fundamental restructuration of cancer services in England and in Wales (widely known as the Calman-Hine report). Other major recommendations included a shift toward patient-centered care, the development of palliative care services, professional education, audit activities and entry of patients into clinical trials. In 1996, the Department of Health began the production of a series of evidence-based reports setting out how services for each type of cancer should be organized and commissioned (*Improving Outcomes Guidance).* In 1999, a target was set of a maximum 2-week wait between an urgent referral from a General Physician and a hospital clinic appointment for breast cancer.[52] Important steps

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[50] Coebergh J, Sant M, Berrino F, Verdecchia A. Survival of adult cancer patients in Europe diagnosed from 1978-1989: the EUROCARE II study. European Journal of Cancer, 1998;34:2137-2278.

[51] Sikora K. Cancer survival in Britain. Is poorer than that of her comparable European neighbours. BMJ 1999;319:461-2.

[52] Department of Health. Health Service Circular 1999/205: Cancer waiting times achieving the two week targets. Available at: http://www.dh.gov.uk/PublicationsAndStatistics/LettersAndCirculars/HealthServiceCirculars/HealthServiceCircularsArticle/fs/en?CONTENT_ID=4004481&chk=ZPJu67

were taken to improve the pace of reform: (1) a national Cancer Action Team was established to oversee cancer networks implementation; (2) a National Cancer Director (NCD) was appointed to develop and implement a national cancer program for England; and (3) a cancer services collaborative was established to support the NHS in England and its partner organizations in the task of redesigning more efficient services and improving experiences and outcomes for patients. In July 2000, the National Health Service (NHS) launched *The NHS Plan*, which sets out a 10-year process reform and a program of sustained investment to make the NHS more responsive to patients.[53] In that same year, a manual describing the standards and performance indicators for the management of cancer services by cancer networks was also published. In September 2000, the Department of Health launched *The NHS Cancer Plan for England*, which provided a policy framework for cancer services. A Cancer Taskforce was then secured into place to lead national implementation of the plan, supported by a substantial financial commitment by the government. Progress of implementation has been documented in many different reports, including progress reports published in 2001, 2003 and 2004 by the National Cancer Director and newsletter from the National Cancer Action Team, financial tracking exercises by the Department of Health, and independent assessments and audits. In 2006, the Secretary of State asked the NCD to head a *Reform Strategy Board* to develop the next strategy for cancer services in England.

Nova Scotia: Changing governing structures and focusing on improving care

Nova Scotia's first comprehensive cancer management strategy came amidst an important reform in the governance of cancer services that was marked by the abolishment, in 1996, of the *Cancer Treatment and Research Foundation of Nova Scotia*, a provincial organization dedicated to cancer treatment, surveillance and research. In 1998, a provincial program called *Cancer Care Nova Scotia* (CCNS) was established within the Department of Health and a Commissioner was appointed. The strategic directions that were then taken by the Department of Health regarding cancer control were based on the *Cancer Action Committee* 1996 Report entitled "*Cancer Care Nova Scotia, A Plan for Action.*" Those strategic directions were detailed in the Commissioner's contract, whose appendix states the objectives, principles, activities and responsibilities of all concerned parties.[54] While the *Cancer Care Nova Scotia* (CCNS) Program is addressing cancer prevention and screening, a strong focus is however given to : (1) improving patients' experience of care; and (2) improving service quality. In 2006, the Commissioner resigned.

History of policy/program development -- Nova Scotia

From 1981 to the mid nineties, the management of cancer services delivery and the cancer registry as well as the coordination of cancer research and treatment development were the mandate of the *Cancer Treatment and Research Foundation of Nova Scotia*, a Crown society.[55] During the nineties, serious concerns were raised regarding access to, and quality of, oncology services. At that time, the Province had among the highest rates of cancer incidence and mortality in Canada. In 1993, an Advisory Committee from the Metropolitan Hospital was asked to review cancer services delivery and organization in the Province, with a focus on the Halifax region. The report submitted by the Advisory Committee to the

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[53] Department of Health. The NHS Improvement Plan: Putting People at the Heart of Public Services. June 24, 2004. Accessed November 9, 2004. Available at: http://www.dh.gov.uk/assetRoot/04/08/45/22/04084522.pdf.
[54] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.
[55] Nova Scotia Archives and records Management. Government Administrative Histories Online. Available at: http://www.gov.ns.ca/nsarm/gaho/authority.asp?ID=20

Department of Health identified a number of important problems with the provision of cancer services in Nova Scotia and proposed a comprehensive framework to improve the provincial cancer control system.[56] The report suggested the creation of a cancer care governing body, *Cancer Care Nova Scotia* (CCNS), to reduce the fragmentation of cancer services and programs that had developed in the Province. In 1994, an important reform of the health care system occured, that led to the abolishment of hospital governing boards and the creation of Regional and Community Health Boards. In 1995, the Department of Health established the *Nova Scotia Cancer Action Committee* to develop an action plan for a coordinated and systematic approach to cancer care. The Cancer Action Committee was made up of physicians, academics, nurses, administrators as well as representatives of the Canadian Cancer Society and of the Department of Health. The Comittee submitted its report to the Deputy Minister of Health in 1996. The Report, entitled *"Cancer Care Nova Scotia: A Plan for Action"* was presented as a comprehensive, integrated and accountable cancer management strategy on cancer care, standard setting, and evaluation. One of the recommendation of the Committee was to establish *Cancer Care Nova Scotia* (CCNS) as a separate legal entity with a governing board and an appointed CEO to coordinate, strengthen, and evaluate cancer activities in the Province. However, this was the only recommendation not supported by the Department of Health at that time. The *Cancer Treatment and Research Foundation* was abolished,[57] but its activities were confided to the Queen Elizabeth (QE) II Health Sciences Centre in Halifax until 1998, when CCNS was established as a provincial program of the Department of Health. A Commissioner was then recruted who combined the following three roles: (1) Commissioner and director of CCNS, accountable to the Deputy Minister of Health; (2) Director of the Cancer programme at QEII Health Sciences Centre; and (3) Associate Dean in oncology at the Faculty of Medicine of Dalhousie University. Hence the Commissioner's position was designed to be an intersection for all cancer control activities and plans.[58] Following the appointment of the Commissioner, the CCNS work program was undertaken, first with the creation of cancer site teams (1999) responsible for producing clinical practice guidelines and second with the establishment of several initiatives including: CCNS District Cancer Model (2000) for integrating primary and secondary cancer services; Action in your Community against Tobacco program (jointly with the Canadian Cancer Society, 2001), and the CCNS Patient Navigation program (2002) following a one-year consultation process with all cancer stakeholders in 2000. A mid-course assessment of the CCNS governance, leadership, and program implementation was performed in 2001, which noted that (1) substantial progress was made, albeit most activities were considered to be *works in progress*. This assessment also indicated that the most urgent issues needing attention were related to standards development and the implementation of a quality program with clear accountability structures and procedures to deal with variations in care. In 2004 and 2005, a survey of cancer patients' experience with the provision of care showed high satisfaction rates. In 2006, the Commissioner resigned.

Alberta and British Columbia: New provincial strategies after longstanding cancer control programs

Alberta and British Columbia are renowned for their well developed cancer control programs that are governed by provincial agencies, the Alberta Cancer Board (ACB) and the BC Cancer Agency (BCCA) respectively. However, the fact that those jurisdictions have a specific organization managing a well developed program for cancer control research and service delivery does not preclude the need to improve their provincial cancer control systems.

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[56] Metropolitan Hospital Advisory Committee. Oncology services : A strategy for comprehensive cancer control in Nova Scotia. Halifax; 1993.

[57] Cancer Treatment Reseach Foundation Act R.S. 1989, c.55. repealed 1995-96, c18 - February 27 1996.

[58] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

Alberta: Aligning with the Canadian Strategy for Cancer Control

In 1999, Alberta began the process of developing a provincial cancer control strategy that culminated with the publication of the *Alberta Cancer Control Action Plan* in 2004. The 48% increase in new cancer cases from 1996 to 2006 in Alberta[59] may explain the substantial investment committed by the government in 2006, and the aggressive goals identified for the year 2025 regarding projected cancer incidence and mortality reduction.[60].

History of policy/program development – Alberta
In Alberta, cancer control activities are led by the *Alberta Cancer Board* (ACB), a provincial health council created in 1967, and mandated by the Albertan government to deliver cancer care services and to coordinate, in collaboration with the nine regional health authorities, the planning of all the cancer control activities in the province. In 1999, ACB established the Alberta Coordinating Council for Cancer Control (ACCCC) to foster collaboration among health authorities (including ACB), the Canadian Cancer Society, and Alberta Health and Wellness in cancer control activities. ACCCC took the lead in 2002, to develop a provincial cancer control plan in response to the Canadian Strategy for Cancer Control and the provincial Mazankowski Report. A planning forum was held, wherein a steering committee and expert groups were mandated to develop a plan. The *Alberta Cancer Control Action Plan* (ACCAP) published in 2004, is a customization of the priorities proposed by the 2002 Canadian Strategy for Cancer Control. The Plan also builds on the existing cancer control programs in Alberta and on the recommendations from the *Premier's Advisory Council on Health Report* (Mazankowski's Report, 2002) . In 2006, the Alberta government committed a 500 million dollars endowment for research, screening, and prevention through the *Alberta Cancer Prevention Act*. This Act was introduced to solidify commitment to the following three goals set by the government for the year 2025: (1) reduce the projected incidence of cancer by 35 percent; (2) reduce the projected mortality from cancer by 50 percent; and (3) ensure that Albertans diagnosed with cancer do not suffer.

British Columbia: New provincal and regional initiatives to enhance the BCCA's provincial program

British Columbia is the Canadian province with the lowest cancer incidence and mortality rates.[61] This province is viewed as a pioneer in cancer control in Canada on several fronts. It launched Canada's first cervical screening program in 1949, which included many components of an organized screening program.[62] In 1996, the BCCA established population-based provincial programs that would be regionally delivered and, in early 2000, it established provincial networks, including one for surgical oncology.[63] Until 2001, BCCA received its funding directly from the Ministry of Health Services.[64] In 2001, a major health system reform occured, that

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[59] Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

[60] Alberta Cancer Board & Foundation. Possible. Alberta's cancer free future. Alberta Cancer Board and Foundation Annual review 2005/2006. 2025 Milestones. Prevent cancers. Saves lives. Eliminate suffering, 48 p. Available at: http://www.cancerboard.ab.ca/pdf/about_acb/AnnualReview_2005-06_2.pdf

[61] Canadian Cancer Statistics 2006, p. 13. Available at: http://129.33.170.32/vgn/images/portal/cit_86751114/31/21/935505792cw_2006stats_en.pdf.pdf See Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

[62] Canadian Cancer Statistics 2006 p. 72.

[63] Carlow DR. The British Columbia Cancer Agency: A comprehensive and integrated system of cancer control. Hospital Quarterly, 2000;3(3):31-45.

[64] Based on an interview with a BCCA key informant.

involved the abolition of the 52 regional governing entities, and the creation of 5 geographic Health Authorities and the Provincial Health Services Authority (PHSA). The PHSA was created to fund and oversee eight provincial agencies, including BCCA. Major changes in governance subsequently occured for BCCA when the PHSA was created (see governance Chapter for details). More recently, collaborative initiatives were established between the BCCA and the BC and Yukon division of the Canadian Cancer Society to develop the Canadian Strategy for Cancer Control – BC and Yukon, and between the BCCA and the Northern Health Authority to develop a Northern Cancer Control Plan (see shaded box below).

History of policy/program development -- British Columbia

In British Columbia, cancer control is led by the British Columbia Cancer Agency (BCCA), a provincial agency established in 1974. BCCA is mandated by the BC government to develop and manage a cancer control program for the entire province. The Agency is a “population-based” cancer control organization, with a well-developed, stable platform for its service, education, and research mandate. As part of the PHSA strategic process that began in 2003, a new *Strategic Plan* was developed by BCCA to sustain its current provincial cancer control program, while orienting the Agency toward "translational research" activities to further enhance health outcomes. In addition to this new governing arrangement of the BC cancer control system, new provincal and regional initiatives have emerged to enhance the existing BCCA’s provincial program, directed at the specific needs of the populations living in the northern part of the province. In 2004 a *BC and Yukon Council of the Canadian Strategy for Cancer Control*, made up of more than a dozen stakeholders from across the public health spectrum, was formed with the financial support of the BCCA, the BC and Yukon division of the Canadian Cancer Society, and the PHSA. This Council was set up to begin the process of developing a *BC and Yukon Cancer Control Strategy*[65] to be adapted from the *Canadian Strategy for Cancer Control*. The Council set up three working groups focusing on prevention, colorectal screening, and end-of-life/palliative care. This strategy has yet to be published. Moreover, in 2005, the BCCA and the Northern Health Authority jointly proposed the *Northern BC Cancer Control Strategy,* in response to *BC Premier’s Consultation on Improved Cancer Care in Northern BC*. This consultation was set up to determine how to design a comprehensive and integrated cancer care system that could best meet the unique needs of the people of Northern BC, which have the highest mortality rates in the province for all forms of cancer. The BCCA/Northern Health Authority jointly proposed strategy is focused on reviewing and expanding cancer services in Northern BC, proposing “short term” improvements (e.g., to develop a comprehensive tobacco control strategy, to develop travel assistance, to increase capacity in systemic therapy, etc.) and addressing the need for a Northern cancer program, that would be developed around the creation of a new BCCA Regional Cancer Centre. The Premier’s consultation meetings ended in April 2006, no final report has been made public yet.

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[65] While the number of new cancer cases rose by 16% in BC from 1996 to 2006, it did so by 58% in Yukon. See Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

4.2 KEY FACTORS DEFINING A FAVORABLE CONTEXT FOR CHANGE

Our analysis of each jurisdiction's cancer control policy development and implementation trajectories indicates that common problems have directed attention to the importance of strengthening cancer control through coherent strategies and programs. These problems include:

- Higher incidence and/or mortality rates compared with other jurisdictions
- Significant inequalities among social and/or ethnic groups with respect to access and provision of services
- Problems in the quality of care provision, including variations in quality as well as the lack of continuity and coordination of care

In addition, an examination of the policy development history suggests that the impetus for cancer control reform implementation has several roots: Some may originate from a turnaround in policy priorities altogether, often as a result of a change in government. In others, even within an established government, a particular crisis (e.g., poor or suboptimal access to services) can capture the attention of policy makers. This can then trigger significant restructuring of priorities and refocusing of resources. Equally possible, a change may be initiated by the cancer control program's governing body as a result of feedback either from progress monitoring of activities or program evaluation.

It would appear that it can take a number of years, sometimes up to 5 years following the publication of a cancer strategy, before there is evidence of its implementation. Although we have not performed a detailed analysis of the factors responsible for the timing of implementation regarding cancer control reforms, we have questionned cancer control key informants about the barriers and facilitators of implementing reform (see Appendix 4B for a synthesis of those factors). Among the factors described by key informants, we note the importance of achieving political commitment, having adequate resources, displaying strong leadership, securing clinician and user involvement, as well as establishing frameworks and providing incentives to promote change (and improve performance). Combining the views of key informants with the observations we made through this Chapter, we conclude that cancer control policies, strategies or plans that translate into concrete action are associated with the following conditions:

- Cancer control is declared a top priority by the established national or provincial government
- A clear strategy is elaborated, which includes an action plan and specific targets
- A strong leadership is secured in place and held publicly accountable
- Significant financial resources are committed to implement reforms
- Active participation of all stakeholders is promoted in policy planning and implementation
- Rigorous and regular follow-up of progress is established that entails public reporting.

5. DESIGN

The notion of *Design* refers to the blueprint of the cancer control intervention. It is an expression of how key players involved in cancer control conceive of the cancer problem and of the approaches needed to address it. As defined by our integrated framework (Chapter 3), design describes a number of essential features pertaining to the conceptual aspects of the cancer control intervention; namely: (1) established goals and priorities; (2) underlying values, guiding principles and key concepts; (3) spectrum of planned health services; (4) approaches to health services organization (organizational architecture); (5) strategies and mechanisms for sustaining and improving service quality (system quality facilitators); and (6) targets and indicators to monitor progress and/or assess outcome.

This chapter first presents an overview of each jurisdiction's cancer control intervention design, focusing on the policy context within which each jurisdiction must operate. The second section is devoted to highlighting commonalities and differences among the jurisdictions with respect to the six design components. Several tables and shaded boxes were prepared to facilitate understanding of comparative analysis. Some tables and shaded boxes are included directly in the text, whereas others are to be found in Appendices.

5.1 HIGHLIGHTS OF THE JURISDICTIONS

Alberta, British Columbia and Canada: A national strategy to complement and enhance provincial cancer control

In Alberta and British Columbia, the design of cancer control intervention shows similarities, given that both Canadian provinces have: (1) an appointed organization responsible for cancer control research and service delivery for the entire province; and (2) plans (completed or in progress) for customizing the Canadian Strategy for cancer control to their unique provincial needs. For these jurisdictions, cancer control design rests on a two-prong approach: (1) the core business and strategic direction of the appointed organization; and (2) the recent addition of an overarching provincial cancer control action plan that seeks to increase emphasis on primary prevention and supportive/palliative care, drive quality care (through standards, guidelines, surveillance data, and human resource strategy), and promote research (see below for overview of Canadian Strategy for Cancer Control (CSCC)).

Alberta: The Alberta Cancer Board's (ACB) core activities focus on patient care, research, and on prevention/screening. With regard to patient care, the priorities set in the ACB business plan (2005-06) relate to improving access to services across the province, improving the quality of care, and ensuring adequate facilities for patient care. Efforts in prevention are focused on the coordination of screening programs and the development of prevention programs for cancer and other chronic diseases. The ACB is also responsible for enhancing capacity and coordinating cancer control research in Alberta. Finally another important goal for ACB is to ensure financial health and organizational effectiveness through appropriate use of resources (human, equipment, information, money), including the implementation of a provincial process for approval, management, and evaluation of cancer drugs. In addition to the ACB cancer control program, Alberta has developed the Alberta Cancer Control Action Plan (2004) to provide a provincial framework targeting the broad range of services that characterizes the spectrum of cancer control (from prevention to palliation). This provincial plan sets out five priorities, drawn from the CSCC priority areas: (1) Standards and guidelines; (2) Primary prevention; (3) Integration and access to psychosocial, supportive, rehabilitative, and palliative care; (4) Human resource planning; and (5) Research.

British Columbia: Cancer control research and service delivery is also overseen by a provincial body in British Columbia - The British Columbia Cancer Agency (BCCA). BCCA's core activities focus on the operation of provincial cancer programs for screening, treatment, and care. BCCA is also putting a strong emphasis on research and on producing and disseminating standards and clinical practice guidelines. The BCCA cancer control program is considered by its leaders to have reached a satisfactory state, to the extent where further improvements in health outcomes would now require a "translational research" strategy [66] in addition to continuous enhancement of the BCCA's cancer control program. BCCA's translational research agenda is at the heart of the Agency's most recent strategic plan (2003). Such an approach is intended to support the clinical application of new knowledge to enhance cancer control at the individual and at the population level. This most recent strategic focus is different from most other jurisdictions studied, that have chosen to put strong emphasis on primary prevention (and more specifically on tobacco control) in order to reduce cancer incidence.[67] However, this is not to say that the BCCA is not engaged in, or does not put a priority on cancer control. There are many initiatives on cancer control through the Provincial Cancer Prevention Program of the BCCA, directed at the community, surgical waiting lists, etc, as well as recently published evidence-based list on Tobacco Control and Obesity from the BCCA and Canadian Cancer Society – BC and Yukon sponsorship. In tobacco control however, BCCA places a lot of emphasis on collaboration with the Ministry of Health (Act Now), the BC Health Living Alliance, and CCS – BC and Yukon to ensure a program based on risk factor control in the "non-cancer" populations in the community. Moreover, tobacco control is an important aspect of the *Northern BC Cancer Control Strategy,* jointly proposed in 2005 by the BCCA and the Northern Health Authority in response to BC Premier's recently completed consultation on improved cancer care in Northern BC.

Canada: Key players in both Alberta and British Columbia have been leaders in the establishment of the CSCC (BCCA's current president was the chairman of the CSCC Council and is now the VP of the newly created Canadian Partnership Against Cancer Corporation, the arm's length governance Board of the CSCC). The Canadian Strategy is based on a "system-inspired" approach for ensuring knowledge formation, exchange, and application within the following seven priority areas across all Canadian jurisdictions, sectors, and disciplines: (1) primary prevention; (2) standards; (3) clinical practice guidelines; (4) rebalance focus (psycho-social, supportive and palliative care); (5) human resources; (6) surveillance; and (7) research.[68] Activities related to knowledge formation are intended to coordinate and cross-reference as many data points and items to arrive at a complete knowledge of cancer in the Canadian population. The knowledge exchange component seeks to ensure the creation of a central information

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[66] Translational research seeks to link fundamental (pre-clinical) research to clinical research and applications.

[67] Regarding health promotion and prevention, most efforts are provided by the Health Ministry (e.g., the BC Center for Disease Control) and by the BC & Yukon division of the Canadian Cancer Society.

[68] More recently, two additional action areas were defined: (1) screening/early detection; and (2) performance and quality.

technology-based repository that would enable different stakeholders to contribute their knowledge and to cross reference practices and techniques. The knowledge application component aims to secure in place a common point of reference for provinces and regions to understand their current and projected cancer experiences in the context of Canada, as well as offer evidence-based information for setting local strategic priorities, assessing, and evaluating outcomes.

England, France and New Zealand: National plans to improve the cancer patient's journey

For England, France and New Zealand, the fight against cancer is a nation wide effort, beginning with the national government serving as the impetus behind all efforts. For these jurisdictions, there are clear synergies between priorities for action endorsed in cancer control action plans and some other government health policies, strategies, and guidelines. Each jurisdiction developed a cancer action plan that addresses the full spectrum of cancer control, which includes all dimensions of the continuum of care (spanning from prevention to palliation) in addition to surveillance, education, and research. Moreover, these three national jurisdictions have engaged in service organization reforms that involve the establishment of cancer networks to improve service integration and continuity of care.

England: The design of England's cancer control intervention can be inferred from the content of the NHS Cancer Plan (2000-2010), which comprises eleven chapters, nine of which are devoted to improving the core dimensions of the cancer control spectrum: improving prevention; screening; treatment and care; improving cancer services in the community; cutting waiting times for diagnosis and treatment; investing in staff and in facilities; and research. A main pillar for reform is the creation of cancer networks, as stipulated in the Calman-Hine report, to improve integration of cancer services and to enhance the role of primary care in cancer control; thereby ensuring better continuity and coordination of care. Another important pillar for reform is the production and dissemination of evidence-based guidance and standards for clinical practice and service delivery. Also noteworthy is the focus on achieving timely access to diagnosis and treatment through the setting of maximum waiting time targets. The approach advocated to achieve more efficiency in the process of care, and hence meet those targets, is based on the mapping of the patient pathway across the health system and subsequent identification of bottlenecks, duplication and fragmentation, combined with a capacity/demand analysis (a service redesign process, under the leadership of the Cancer Services Collaborative). Also worthy of interest is the focus and significant investment in palliative care.

France: In France, cancer control intervention is shaped by the 2003-2007 Cancer plan (*Cancer: A nation-wide Mobilization Plan*). The cancer plan comprises 70 measures organized by six priority areas spanning the continuum of cancer control: prevention, screening, care (treatment, psycho-social and palliative care), social support, training and research. The cancer plan has a strong prevention focus that aims to bring about a change in culture in terms of reducing smoking, drinking and exposure to work- and environment-related risk factors. A most noticable aspect of the plan is attention directed toward reducing cancer patients' social exclusion (e.g. to keep cancer patients in their jobs, to broaden patients' access to loans and insurance, to increase at-home health care services, etc.). The overall plan is to bring about changes in the way cancer treatment and care is provided by: (1) identifying a cancer coordination center (3C) in all institutions offering care to cancer patients; (2) creating multidisciplinary teams; (3) establishing a more humane and supportive cancer diagnosis disclosure procedure; (4) providing better access to diagnostic and therapeutic innovations (including expensive drugs); and (5) coordinating all the players involved through the creation of Regional Cancer Networks. There is also emphasis on supporting research and its role in guiding clinical practice by setting up *cancéropôles* (research teams linked with referral and best practices hospitals, i.e., teaching hospitals and the *Centres de lutte contre le cancer*) at the regional and interregional levels. *Cancéropôles* would, in turn, be connected to the *Réseaux régionaux de cancérologie* (Regional cancer care networks).

New Zealand: In New Zealand, the NZ Cancer Control Strategy and NZ Cancer Control Action Plan 2005-2010 provide the framework for an integrated approach to the planning, development and delivery of existing and new cancer control activities and services. The Strategy has six goals covering the cancer control continuum: primary prevention; screening and early detection; diagnosis and treatment; supportive; rehabilitative; and palliative care, as well as research and considerations regarding cancer workforce, surveillance, consumer involvement, and accessibility of cancer control programs to the Māori population. Also worth noting is the consideration given to “whānau” (close friends) in addition to the patient and its family. New Zealand also has a *Palliative Care Strategy*, which is aligned to the Cancer Control Strategy. The Ministry of Health and District Health Boards (DHBs) are working to implement actions identified by the Action Plan through a structured *Cancer Control Work Programme* focusing on several national projects related to: (1) Guidance to improve cancer care; (2) Integrating care for cancer patients (cancer networks); (3) Improving care provided to adolescents with cancer; (4) Improving palliative care; (5) Supporting workforce planning; (6) Reducing inequalities; and (7) Coordinating development of cancer data management.

Nova Scotia and Ontario: Driving comprehensive, high quality cancer services, albeit with a differing focus

In Nova Scotia and Ontario, the design of cancer control intervention shows similarities: First, both Canadian provincial jurisdictions have a specific cancer control body, Cancer Care Nova Scotia (CCNS) and Cancer Care Ontario (CCO), respectively. CCNS and CCO are mandated to advise the Health Ministry on cancer control issues as well as to ensure comprehensive high quality cancer control programs. However, both are not involved in the direct delivery of cancer control services. Second, both organizations must deal with a number of players (government, district health boards or local health integration networks, hospitals, specialized cancer centers, community groups, non-governmental organizations, universities etc.) in the planning and coordination of cancer services at the local, regional, and provincial levels. Third, neither Nova Scotia nor Ontario have articulated plans to adapt the CSCC for their provincial needs. Also, of interest to note is that both organizations are supporting provincial service delivery procedures organized via regional integrated cancer programs (District cancer programs in Nova Scotia and Regional cancer programs in Ontario). The major difference between these jurisdictions is their focus on initiatives to drive the quality of cancer services. CCO is embracing a system’s level approach with investments and efforts directed at managing system performance; whereas CCNS is mostly involved in improving patient care through patient navigation and community outreach, including patient education and information.

Nova Scotia: The design of cancer control intervention in Nova Scotia becomes evident when merging a number of documents and initiatives from the Cancer Care Nova Scotia (CCNS) Program in the Department of Health, including the 1996 *Cancer Action Plan*, a Report prepared by a Cancer Action Committee for the Deputy Minister of Health and the Appendix to contract for Commissioner for CCNS.[69] In the 1996 Report, the Cancer Action Committee made twenty recommendations. These recommendations are grouped and identified under eight priorities: (1) Create a governing organization to coordinate, strenghten and evaluate the cancer system in Nova Scotia; (2) Establish tumour groups to develop clinical practice guidelines and cancer treatment policies; (3) Strenghten the role of the family physician in cancer care coordination; (4) CCNS to collaborate with key players to improve services in the areas of prevention, screening, rehabilitation, supportive and palliative care; (5) CCNS to assume responsibility for a provincial drug formulary; (6) CCNS to foster a full spectrum of cancer research (from basic mechanisms of disease to behavioural and outcomes research); (7) CCNS to provide standards for and conduct cancer facilities/ program approval and review; and (8) CCNS to set up and provide operational support for a network that will promote the broad exchange of information among all groups and organizations involved in any aspect of cancer care. In addition to the creation of the CCNS Program in 1998, the most notable actions following these recommendations included: (1) the setting up of Cancer Site Teams (tumour groups) and of a CCNS surveillance and epidemiology unit; (2) the development, implementation, and evaluation of a Patient Navigation Program; (3) the publication of a Cancer District Program model; and (4) the building of a Cancer Patient Family Network.

Ontario: Efforts to redesign Ontario's cancer control system began following the submission to the Ontario Government of the Cancer Services Implementation Committee Report in December 2001. The Committee recommended that an integrated cancer system be established and that Cancer Care Ontario be transformed into an evidence-based organization that would use data to plan, fund, and report on the overall performance of the cancer system. The subsequent assessment of the quality of cancer services in Ontario that was published as a book entitled *Strengthening the Quality of Cancer Services in Ontario* (2003), helped inform the development of the Ontario Cancer Plan and the organization of work within Cancer Care Ontario. Other CCO policy documents that contributed to the development of an integrated cancer system include Ontario's Cancer Prevention and Screening Action Plan (Cancer 2020), the Cancer Quality Council of Ontario's Four-point Strategy to reduce waiting times in Ontario, the Cancer Plan for the Greater Toronto Area (GTA 2014 Report) and, most recently, the Ontario Cancer Plan (2004), which is a provincial plan based on the input of 11 regional plans. The Ontario Cancer Plan incorporates the Cancer 2020 Action Plan and the Aboriginal Cancer Strategy. The Ontario Cancer Plan has six priorities relating to: (1) expanding the use of provincial standards and evidence-based guidelines to the delivery of cancer services; (2) implementing regional cancer programs; (3) reducing demand for cancer services through the implementation of the Cancer 2020 plan and by increasing capacity and resources; (4) developing rapid access strategies; (5) investing in performance measurement and accountability, and (6) coordinating cancer research efforts across Ontario.

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[69] The *Appendix to contract for Commissioner* was referred to by the former Commissioner as the strategic plan for cancer control in Nova Scotia and "continues to function as the "manifesto" for cancer control in Nova Scotia". Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

5.2 COMMONALITIES AND DIFFERENCES IN DESIGN

5.2.1 The goals and priorities for cancer control

Explicit statements regarding goals and priorities in cancer control for each jurisdiction can be found under different key words such as goal, purpose, aim, outcome goal, or priority goal. Regardless of the terminology used, each jurisdiction has a set of planned actions, which can be viewed as a framework comprising: stated goals → priorities, → objectives → intended action items (see Appendix 5A for a description of the goals and priorities of each jurisdiction's main strategies, programs and actions plans). Stated goals and priorities are either expressed as actions to be carried out to resolve problems currently faced (e.g. to improve the quality of care) and/or to articulate the optimal state of affairs as a result of planned actions (e.g. to reduce health inequalities).[70] Whereas goals express the most desirable outcome, priorities are a selection of the most necessary actions to be taken while acknowledging the jurisdiction's actual policy and socio-economic context. When deciding on priorities, a number of aspects are considered such as the current health policy priorities, the values of the governing organization, the health gains associated with different goals and actions, and availability of resources (including people, finance, facilities, techniques, methods, among others).[71]

As summarized in Table 4, the goals and priority statements cover different domains of cancer control such as improving health outcomes, reducing inequalities, service quality improvement, better effectiveness in service delivery, enhancement of research, securing of resources (human, equipement, etc.), patient empowerment as well as the importance of strenghtening governance underlying the cancer system. Our review indicates that all jurisdictions have stated goals regarding the improvement of health outcomes, namely the reduction of cancer mortality. Only France and England have not included the reduction of cancer incidence as an explicit goal. The aim of improving the quality of life of cancer patients and their families is also stated explicitely by more than half of the selected jurisdictions. Reducing health inequalites with respect to cancer among specific groups is a central aim in England and in New Zealand. In most other jurisdictions, the focus is on improving access to care for all. In British Columbia, the issue of access is specific to the Northern Region. In England, New Zealand, and Ontario, it is timely access (as in reducing waiting time) that is a central goal orientation.

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[70] Hence, if one goal statement is not represented in a specific jurisdiction, it is either because there is no such problem, the problematic situation has been resolved, the priority was put somewhere else or it is reflected at a lower level in the design framework for planned actions. The current overview is focused on the content and domains reflected at the highest level of direction setting- the goals and priorities. For a detailed description of goals, priorities, and associated objectives and action by jurisdictions, refer to Appendix 5A.

[71] As explained in the DCPC-CCPC and WHO-NCCP frameworks.

Table 4. Stated goals and priorities for cancer control intervention by jurisdictions

	Alberta	British Columbia	Canada	England	France	New Zealand	Nova Scotia	Ontario
Domain 1: Improving health outcomes								√
Reduce cancer incidence	√	√	√			√	√	√
Reduce cancer mortality	√	√	√	√	√	√	√	√
Reduce cancer morbidity/severity of illness	√		√			√		
Improve well-being/quality of life (patients and families)	√	√	√			√	√	
Improve survival		√						
Domain 2: Reducing inequalities and/or improving access to care							√	
Reduce health inequalities among specific groups				√		√		
Improve access to services for socially disadvantaged groups or specific populations	√	√		√		√		
Improve access to quality care for all	√		√		√		√	√
Establish timely access for cancer services		√		√		√		√
Domain 3: Improving quality of service provided	√			√				
Develop health promotion and primary prevention	√	√	√	√	√	√	√	√
Develop/organize screening	√	√		√	√	√	√	√
Improve diagnosis		√				√		
Improve treatment (drugs/radiotherapy, etc.)		√		√	√	√	√	√
Develop/improve psychosocial, supportive, rehabilitative and palliative care	√	√	√	√	√	√	√	√
Rebalance/integrate/strenghten cancer control efforts across the spectrum: from prevention to palliation	√		√		√		√	√
Develop standards and guidelines		√	√	√		√	√	√
Ensure compliance with evidence-based practice		√					√	√
Establish multidisciplinary care					√	√		
Ensure innovation in cancer activities/services		√			√			√
Domain 4: Ensuring integration/coordination and effectiveness of service delivery	√							√
Improving cancer services in the community		√		√	√	√	√	
Develop central role for family physicians/navigators		√		√	√		√	
Develop networks/ regional cancer programs		√		√	√	√	√	√

Ensure patient-centered care					√	√	√	√
Process improvement projects		√				√		√
Domain 5: Research and surveillance								√
Ensure/develop/enhance/coordinate cancer research	√	√	√	√	√	√	√	√
Improve knowledge of cancer through surveillance		√	√		√	√	√	
Develop cancer registry					√		√	
Domain 6: Enhancing resources (human, facilities)								
Cancer workforce attraction/retention	√	√	√	√		√	√	
Health professional training/education		√			√		√	
Capital equipment acquisition/inprovement	√	√		√				√
Create new facilities	√	√		√				√
Domain 7: Empowerment								
Empower patients and families regarding their care	√				√		√	
Promote active involvement of consumer representatives in cancer control						√		
Create a well-informed patient and population				√			√	
Domain 8: Cancer system governance and efficiency								√
Information management/improving measurement	√	√	√				√	√
Evaluation focusing on outcomes		√		√	√		√	
Ensure accountability in all services/activities								√
Ensure through cooperative action, excellence in cancer care, research, education, and system management							√	
Link goals, plans, strategies across governments/health regions/organizations	√	√						
Support health care partners with the implementation of cancer control programs		√					√	√
Manage drug costs	√	√						

Note: The goals and priorities identified by an √ pertain to those **identified at the highest levels of the jurisdiction's goal orientation statements in available published documents ending in 2006** and hence do not reflect a complete factual description of each jurisdiction's integral strategy or program components. If one goal or priority is not represented in a specific jurisdiction, it is either because : (1) we could not find such goal or priority stated at the highest levels in available published documents; (2) such goal or priority is stated at a lower level in the strategy or action plan framework; or (3) it is not applicable because there is no such problem or the problematic situation has been resolved. The range of goal and priority statements (lefthand side of the table) used for comparative analysis is intended to capture the diversity, and to minimize redundancy, without compromising the intended meaning of the actual statements found in each jurisdiction. See Appendix 5A for specific wording of goals and priorities, and for details about the associated objectives and actions.

Across the jurisdictions, we also observed that the goal statements also make reference to the spectrum of cancer control services and to supporting elements such as education, research, and human resources. This is particularly evident in Alberta, British Columbia, England, New Zealand, and Nova Scotia. When not expressed at the level of goals, these domains are well represented in priority statements. The priority given to improving primary prevention emerged as a strong trend, which is not surprising given the generalized goal of reducing cancer incidence. Also noteworthy is attention given to patient information, education and empowerment by Alberta, England, France, New Zealand, and Nova Scotia. These priorities underscore the importance of promoting the active participation of patients regarding their care.

5.2.2 Values, guiding principle and key concepts

Values represent the deeply held beliefs about the qualities considered worthwhile or desirable, and can operate at the level of individuals, institutions, and society.[72] Whether expressed by the organization or within a policy document, values are a crucial part of cancer control intervention design as they shape the intervention's main directions and associated actions. This component of design is understood broadly to include guiding principles and key concepts. In fact, values may also be expressed as guiding principles that more concretely provide guidance to how the organization will act. Key concepts can also be considered values since they reflect specific approaches *advocated* in the cancer control literature-namely, the population-health approach; patient-centered care; evidence-based care; integrated care; and knowledge translation (see Figure 2 below for definitions of these concepts).

Values, guiding principles, and key concepts can be expressed explicitely or can be inferred from descriptions of actions, specific approaches or directions in cancer control programs or strategic plans. Table 5 compares jurisdictions according to a number of values, principles and concepts endorsed by the jurisdictions (see shaded boxes in Appendix 5B for a detailed description of values articulated by each jurisdiction). A first notable observation is a core set of values shared by most jurisdictions; namely-

1. Collaboration/cooperation among different actors/sectors
2. Efficient and responsible use of resources
3. Equity/equitable access/accessibility
4. Evidence-based approach to health care
5. Integration across diseases, services/activities
6. Patient-centered care approach
7. Performance-oriented/outcome-focused
8. Population-based approach to health planning and interventions

The value of equity was mostly linked to reducing health inequalities, but in some cases was associated with guaranteeing access to health care closer to where individuals live (Alberta), guaranteeing standards for access and quality of care (British Columbia), and ensuring fairness across regions (Ontario). The value of *integration* made reference to integrating activities across chronic diseases (Alberta), integrating services across levels of care (British Columbia) or both

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[72] Schwartz (1993, p. 155), cited in Giacomini M, Hurley J, Gold I, Smith P, Abelson J. Values in Canadian Health Policy Analysis: What are we taking about? Canadian Health Services research Foundation report, October 2001 p. 9.

Table 5. Values and principles guiding cancer control intervention by jurisdictions

Values and guiding principles	Alberta	British Columbia	Canada	England	France	New Zealand	Nova Scotia	Ontario
Accountability/responsibility/reliability	√	√	√				√	√
Caregivers’ support/education				√			√	
Collaboration/cooperation/partnerships/consultation	√	√	√	√	√	√	√	√
Comprehensiveness of cancer control		implicit	√				√	
Consumer/user involvement				√		√		Implicit
Coordination/continuity				√	√	√	√	Implicit
Courage	√							
Display leadership/action oriented/active engagement	√	implicit					√	√
Efficient/responsible use of resources	√	√	√	√		√	√	√
Equity/equitable access/accessibility	√	√	Implicit	√	√	√	Implicit	√
Evidence-based (scientific rigour/expertise)	√	√	√	√	√	√	√	√
Humanism and Compassion	√				√		√	
Integration (across diseases, services/activities)	√	√	√	√	Implicit	√	√	√
Integrity	√						√	
Optimism/hope					√			√
Patient-centered care (respect/support)		√	√	√	Implicit	√	√	Implicit
Performance-oriented/outcome-focused/excellence	√	√	√	√		√	√	√
Population health-based	√	√	Implicit	Implicit	Implicit	√	√	√
Precautionary principle								√
Research/knowledge translation/innovation driven	√	√	√		√			√
Respect for cultural diversity						√	√	Implicit
Respectful of jurisdictions/regions	√		√		√			Implicit
Sustainability/human resources	√	√				√		Implicit
Technology driven		√						
Timeliness				√		√		
Transparency			√		√			√

Note: When a value is not marked by a √, it was not explicitly stated in either published cancer control programs or strategic plans for cancer control. For a value to be marked as ‘implicit’, it had to be identified through descriptions of specific approaches or actions, or statements of vision, directions or organisational principles in cancer control programs or strategic plans. Appendix 5B entitled “Values and Guiding Principles by Jurisdictions” provide information regarding specific wording and distinction between explicit and implicit findings. Grey shaded lines represent the values and principles that are shared by most jurisdictions.

(New Zealand). For the remaining jurisdictions, the value of integration referred to the organizational, professional, and clinical levels (e.g., Nova Scotia, in providing continuity and coherence in the process of care delivery). Also worthy of interest is the place given to research and knowledge tranfer as the foundation of cancer control activities in Alberta, British Columbia, Canada, and France.

Figure 2. Key concepts definitions

Evidence-based health care/policy:
The consistent use of scientific evidence to guide clinical practice [73] as well as decision-making within health care settings.[74] Policy makers, managers, and clinicians view evidence as an important lever that ensures health care practice is more effective, thereby representing value for money.[75,76]

Health system integration:
An approach that underscores the 'coming together' of all elements related to delivering care, including the alignment and collaboration between health institutions and health care providers, as well as the connectedness among services.[77] Integrated delivery system theory suggests that there are three dimensions of health system integration, and these dimensions develop at different times as a system matures.[78] At the clinical level, integration occurs by providing continuity, cooperation, and coherence in the process of care delivery[79]; At the professional level, integration refers to the extent to which physicians depend economically on the system, use the sytem's services and facilities, and actively participate in its planning, management, and governance. At the functional level, integration refers to the coordination of key administrative support functions and activities, such as planning, information systems, and financial management. Clinical integration extends both horizontally and vertically.[80] Horizontal integration constitutes the coordination of patient care services across care sites that are at *the same stage* of services delivery. Horizontal integration is often operationalized when two acute care hospitals merge or share clinical services. Vertical integration refers to the coordination of patient care activities across care sites that are at *different stages* of service delivery, such as coordinating services

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[73] Sackett D, Rosenberg W, Gray M, Haynes B, Richardson S. Evidence based medicine: What it is and what it isn't. BMJ 1996;312:71-72.

[74] Denis JL., & Langley, A. Forum: Introduction. Health Care Management Review, 2002;27(3):32-34.

[75] Dopson S, Fitzgerald L, Ferlie E, Gabbay J, Locock L. No magic targets! Changing clinical practice to become more evidence based. Health Care Management Review 2002; 27(3):35-47.

[76] Champagne F, Lemieux-Charles L, Mcguire W. Introduction: Towards a broader understanding of the use of knowledge and evidence in health care. In: Lemieux-Charles L, Champagne F, editors.*Using Knowledge And Evidence In Health Care: Multidisciplinary Perspectives*. Toronto: University of Toronto Press, 2004: 3-17.

[77] Lloyd J, Wait S. Integrated care: A guide for policymakers. International Longevity Center & Alliance for Health and the Future, 2006. Report from a workshop on Integrated Care, European Social Network Conference, July 5th 2005, Edinburgh. Available at: http://www.ilcuk.org.uk/downloads/Integrated%20Care%20-%20A%20Guide%20for%20Policymakers.pdf

[78] Shortell SM, Gillies RR, Anderson DA, Mitchell JB, Morgan KL. Creating organized delivery systems: The barriers and facilitators. Hospital and Health Services Administration, 1993;38(4):447-466; Shortell SM, Gillies RR, Anderson DA, Morgan EK, Mitchell JB. *Remaking Health Care in America: Building Organized Delivery Systems*. San Francisco: Jossey- Bass, 1996; Conrad DA. Coordinating patient care services in regional health systems: the challenge of clinical integration. Hospital & Health Services Administration, 1993;38(4):491-508.

[79] Crabtree Tonges M. Clinical integration in organized delivery system. Responding to new challenges in health care. Chapter one pp. 3-17. In: Crabtree Tonges M (Ed.) Clinical Integration. Strategies and practices for organized delivery systems, Jossey-Bass Publishers, San Francisco, 1998.

[80] Conrad DA. Coordinating patient care services in regional health systems: the challenge of clinical integration. Hospital & Health Services Administration, 1993;38(4):491-508.

among primary care, hospital and home care providers. The creation of integrated healthcare networks to manage the health problems of a population is an example of vertical integration.

Knowledge transfer/translation:
A spectrum of activities occuring between the creation of new knowledge and the application of such knowledge into practice for the purpose of yielding beneficial outcomes for society.[81,82] Applied in the context of cancer control, it makes reference to the uptake of well-researched and tested interventions in cancer prevention and care to inform best practices and decision-making regarding the next course of action.[83] The process of utilizing the research knowledge is complex and may involve attention to factors that influence the link between knowledge and evidence, and their use for decision-making in health care settings.[84, 85]

Patient-centered care:
An approach that consciously adopts the patient's perspective,[86] which may have several implications such as: (1) care providers acknowledging not only the disease, but also the patient's illness experience[87]; (2) care is delivered to patients in a manner that is respectful of, and responsive to, individual patient preferences, needs, and values[88]; and (3) care is organized in a way that emphasizes the patient as being the locus of control, and that the experience of such care is seamless across environments-namely, the hospital setting, patient's home, work place, and community.[89]

Population-health based approach: [90,91]
An approach that focuses on the interrelated conditions and factors that influence the health of populations over the life course, identifies systematic variations in their patterns of occurrence, and applies the resulting knowledge to develop and implement policies and actions to improve the health and well-being of those populations. This extends beyond responding to diseases and treating those who are sick to focusing on the health of the population as a whole and sub-groups within the population. The overarching goals of a population-based approach to health policy are to maintain and improve the health status of the entire population as well as to reduce health inequalities between specific populations groups.

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[81] Innovation in action: Knowledge translation strategy. Canadian Institute for Health Research Report, Ottawa, ON, 2004, p. 4.

[82] Birdsell JM, Atkinson-Grosjean K., Landry R. Knowledge translation in two new programs: Achieving the Pasteur effect. Canadian Institute of Health Research, 2002.

[83] See p. 1142 in: Advisory Committee on Cancer Control, National Cancer Institute of Canada. Canadian Medical Association Journal, 1994;151(8):1141-1146.

[84] See pp. 15-16 in Champagne F, Lemieux-Charles L, Mcguire W. Introduction: Towards a broader understanding of the use of knowledge and evidence in health care. In: Lemieux-Charles L, Champagne F, editors.*Using Knowledge And Evidence In Health Care: Multidisciplinary Perspectives*. Toronto: University of Toronto Press, 2004: 3-17.

[85] Lomas, J. Postscript : Understanding evidence-based decision-making- or, why keyboards are irrational. In: Lemieux-Charles L, Champagne F, editors.*Using Knowledge And Evidence In Health Care: Multidisciplinary Perspectives*. Toronto: University of Toronto Press, 2004: 281-289.

[86] Gerteis et al (eds). Through the Patient's eyes, 1993, p. 5

[87] Stewart M, Brown JB, Weston WW, McWhinney IR, McWilliam C, Freeman TR. Patient-centered Medicine: Transforming the clinical method. Radcliffe Medical Press Second Edition, 2003.

[88] Institute of Medicine. Crossing the quality chasm, 2001 p. 6.

[89] See p. 20 in Perlin, JB, Kolodner RM, Roswell RH. The Veterans Health Administration: Quality, value, accountability, and information as transforming strategies for patient-centered care. Healthcare Papers, 2005;5:10-24.

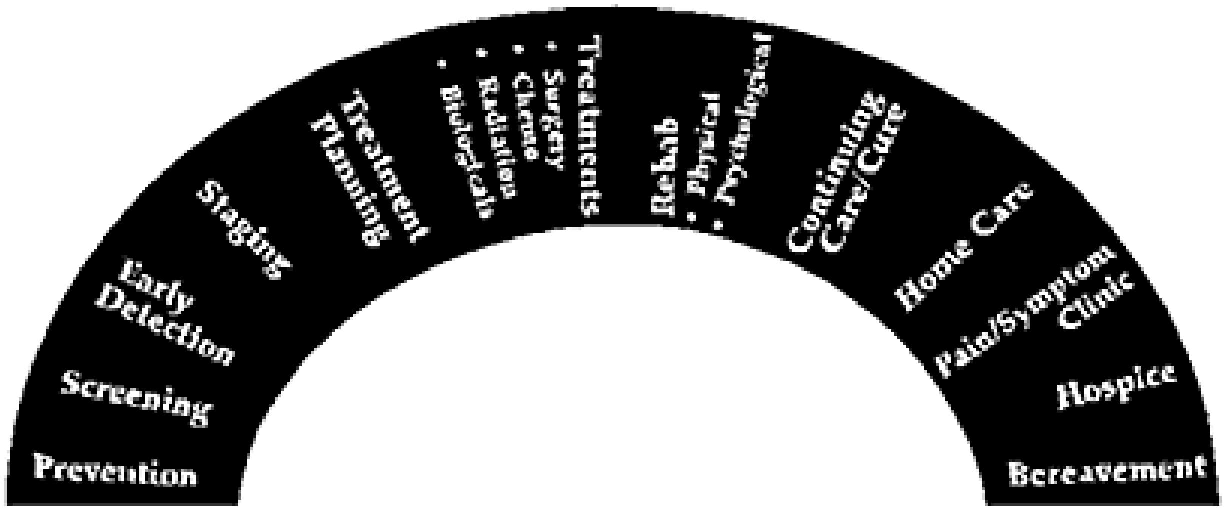
[90] Federal, Provincial, Territorial Advisory Committee on Population Health, 1997. Cited in : The population health template. Key elements and actions that define a population health approach. July 2001 draft, Health Canada, p. 2.

[91] Measuring the impact of asthma on the quality of life in the Australian population. Australian Institute of Health and Welfare, Australian government. December 2004, p. 4.

5.2.3 The spectrum of cancer services

The spectrum of cancer services refers to the care continuum that spans prevention, screening, diagnosis and treatment (systemic therapy, radiotherapy, surgery), supportive care and palliative care. The cancer care continuum may also include continuing care, home care, pain management, and bereavement support.[92,93]

Figure 3. The cancer care continuum[94]



Although cancer research, education, and surveillance are often considered as part of a comprehensive approach to cancer control, they are not included here as this section focuses on cancer service delivery. Highlights of each jurisdiction's main policies, commitments and/or programs in place for each component of the cancer services continuum is presented in the following paragraphs. A more detailed description is to be found in shaded boxes inserted below in the text.

Our review indicates that while all cancer control programs and action plans cover cancer diagnosis and treatment, the emphasis on prevention, screening and on supportive and palliative care is more variable. The Canadian Strategy for Cancer Control, however, purposely seeks to rebalance the focus by putting a strong commitment toward primary prevention as well as supportive and palliative care. In most jurisdictions, the prevention initiatives are under the responsibility of the Ministry or Department of health and the focus is on tobacco control. With the law recently announced in France[95] and the public smoking ban to take effect in 2008 in

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[92] Institute of Medicine (1999) Ensuring quality cancer care, p. 22. Mandelblatt J, Yabroff KR, Kerner J. Equitable access to cancer services. A review of barriers to quality of care. Cancer vol. 86, no 11, pp. 2378-2390.

[93] http://www.ons.org/publications/positions/QualityCancerCare.shtml

[94] Fountain M & Aull R. Cancer Care In the Next Millennium. The Academy Journal, 1999, vol. 2, p. 2.

[95] Interdiction de fumer dans les lieux publics à partir du 1er février 2007. October 9, 2006 Press release available on the INCa website.

British Columbia,[96] all jurisdictions now have laws that prohibit smoking in enclosed public places.

Organized[97] cancer screening programs vary in scope and in number, the smallest common denominator being the establishment of a breast screening program. While BC's breast and cervical programs are the oldest, England is the only one to have secured in place a program for colorectal screening. All other jurisdictions are considering it.

Diagnosis and treatment are central components of the cancer control spectrum in all jurisdictions; albeit with differences in priorities for development. British Columbia has well developed programs in terms of production and dissemination of clinical practice guidelines, coordination of surgical oncology, and management of access (and waiting time) to radiotherapy. While cancer services organization "reform" is no longer a priority for BCCA (but cancer services organization and delivery is a key direction of its strategic plan), it is an important one in England, France, New Zealand, Nova Scotia, and Ontario. A second significant focus across most jurisdictions is the production and dissemination of clinical practice guidelines to improve service quality.

Supportive care addresses psychological, spiritual, social, practical, and information needs of cancer patients and their families. It is a cross-cutting component given that care needs may span the whole continuum, beginning with the early detection phase. That may explain why it is sometimes considered together with rehabilitation and palliative care. However, for the purpose of planning services, it stands as one distinct component in most jurisdictions studied. One good example of supportive care is the Patient Navigation program in Nova Scotia.

All jurisdictions are putting significant emphasis on palliative care. In Alberta, palliative care is well developed in one region. In fact, one goal of the Alberta Cancer Control Action Plan is to establish a provincial framework for the integration and access to supportive and palliative care. In England and Ontario, substantial investment was committed to palliative care.[98] In France and New Zealand, the challenge is to drive forward the implementation of existing national policies on palliative care.

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[96] B.C. to tighten smoking restrictions. Canadian Press, November 4, 2006. Available at: http://www.theglobeandmail.com/servlet/stry/RTGAM.20061104

[97] Organized screening has important quality advantages over "unorganized" screening: predictable and thorough recruitment, patient recall and follow-up by way of a central registry, ongoing quality assurance, and quality control and evaluation. Definition taken form Ontario Cancer system quality Index at: http://www.cancercare.on.ca/qualityindex2006/access/breastScreening/index.html

[98] http://www.health.gov.on.ca/english/media/news_releases/archives/nr_05/nr_100405.pdf

Spectrum of cancer services -- Alberta

Prevention:

- Alberta Health and Wellness: *Reducing Tobacco Use in Alberta: A Comprehensive Strategy* (2002)
- Alberta Health and Wellness: *Alberta Smoke-free Places Act* (2005), where indoor smoking is however only prohibited in places where children are allowed.
- Alberta Cancer Control Action Plan (ACCAP) includes priority to support the implementation of a province-wide system for integrated chronic disease prevention and health promotion through the Alberta Healthy Living Network
- Alberta Cancer Board (ACB) and Foundation: *Sunright* program. Three-year pilot sun safety campaign (2003-06)
- ACB Prevention program within its Division of population health and information
- ACB plans to increase its provincial capacity to deliver primary care prevention by supporting the implementation of a province-wide *System for Integrated Chronic Disease Prevention* through the *Alberta Healthy Living Network* [99,100]

Screening:

- Alberta Cancer Board (ACB): *Screen Test* (program for the early detection of breast cancer, in operation since 1990)
- Alberta Health and Wellness: Organized provincial cervical screening program, announced in 2000, initiated in 2004 and coordinated by ACB
- Alberta Health and Wellness: Organized provincial breast screening program, announced in 2000 and 2004, to be implemented in 2007 and to be coordinated by ACB
- ACB to assess feasibility of an organized provincial colorectal screening program

Diagnosis and treatments:

- Diagnostic and treatment services provided through the ACB provincial cancer program
- ACB business plan includes priority to reduce wait times for diagnosis and treatment
- ACB business plan includes priority to improve cancer surgery coordination and practice
- ACB business plan includes priority to strenghten provincial process for approval, management and evaluation of cancer drugs, as well as to obtain lowest possible cancer drug purchase price
- ACB: Tumour group council (6 cancer sites)

Supportive care:

- ACB: Services provided through the *Psychosocial Oncology Network*[101] include individual and family counseling, group programs, and educational supports to cancer patients and their families. The Network extends services to the Regional Cancer Centers, the Associate Cancer Centers, and the Community Cancer Centers.
- ACCAP includes goal to establish a provincial framework for the integration and access to psychosocial, supportive, rehabilitation and palliative care
- ACB – Pain and palliative care teams: plan to develop a provincial *Patient Navigation System.*[102,103]

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[99] ACCAP (2004)

[100] ACB Business Plan 2005-2006

[101] ACB. Medical Affairs and Community Oncology. What is psychosocial oncology? http://www.cancerboard.ab.ca/maco/initiatives_psychosocial.htm

[102] ACB Business Plan 2005-2006

[103] Special projects. http://www.cancerboard.ab.ca/maco/initiatives_special.htm

Palliative care:
- Capital Health Region-Community Care Services: Regional palliative care program (in Edmonton since 1995)
- Calgary Health Region: Regional palliative care program
- ACB: Palliative Care Network Initiative, established in 1998 and renamed the *Hospice Palliative Care Network* in 2003. The Hospice Palliative Care Network works with RHAs and other key stakeholders to ensure that all patients across the province have access to quality hospice palliative care no matter where they live.[104] Another important role of the Network is to ensure seamless palliative care service delivery between communities and the ACB's Tertiary Cancer Centers.[105]

Spectrum of cancer services -- British Columbia

Prevention:
- British Columbia: *Tobacco Control Act* (2006, to be implemented in 2008)
- British Columbia: *ActNow BC* (healthy living strategy, 2005)
- British Columbia: *Targeting our efforts* (tobacco control strategy, 2004)
- Canadian Cancer Society - BC /Yukon Division: *Prevention Strategy* (2003)
- BCCA: prevention program created in 2003. Activities are mostly geared toward the youth. Recent initiative includes the recruitment of community prevention coordinators to create supportive environments for cancer prevention in communities (2006)
- BCCA and BC Provincial Medical Genetics Program: Hereditary cancer program

Screening:
- BCCA: Organized cervical cancer screening program (since 1949)
- BCCA: Screening mammography program of BC (organized program since 1988)
- BCCA: Submitted proposals for provincial colorectal screening and provincial cervical screening/Human papilloma virus screening

Diagnosis and treatments:
- Diagnostic and treatment services and cancer management guidelines provided through the BCCA provincial cancer program. Radiotherapy only provided in BCCA's regional cancer centers. Chemotherapy provided in BCCA centers as well as in the Communities Oncology Network.
- BCCA and Vancouver Island Health Authority: TeleCare program
- Surgical Oncology Network (since 2001)
- Family Practice Oncology Network
- Pediatric Hematology – Oncology Network (with BC Children's Hospital)
- Oral Oncology Network
- Nursing Oncology Network
- A Breast Cancer Surgical Center will be developed to improve access to diagnostic and treatment services. It is expected that tissue collection will enhance research in breast cancer.[106]
- Provincial tumour Groups

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[104] ACB. What is hospice palliative care? http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm
[105] ACB. Business Plan 2002/03 to 2004/05
[106] PHSA. (April 2003). Health service design plan. From vision to reality 2003. . http://www.phsa.ca/

Supportive care:

- BCCA: A *Provincial Oncology Nutrition Network*[107] coordinates functions and ensures consistency of care related to oncology nutrition across all BCCA centers. The Network includes registered dietitians from all BC Cancer Centers
- BCCA: A *Provincial Cancer Rehabilitation Network*[108] coordinates regional cancer centre activities for patient and family counseling, psychiatry, and nutrition services. The Network also works with host hospitals to provide speech pathology and physiotherapy services.
- BCCA: The *Psychosocial Oncology Network*, still under development,[109] is a provincial network of health care practitioners and health care organizations under BCCA. Its mandate will be to coordinate psychosocial activities based in the community.[110]
- BCCA: Two *Patient Navigation Programs* are available to patients- one for newly diagnosed patients with breast cancer situated in the Breast Health Center[111] and the second in a rural region assisting patients with all tumour sites.[112]

Palliative care:

- BC Ministry of Health: A provincial framework for end-of-life care (2006)
- There is a Palliative Care/End of Life Care Network, composed of BCCA, Regional Health Authorities, hospices and palliative care units. The Network links with the CSCC – BC and Yukon Palliative/End of Life Strategy. It has promulgated best practices, standards and guidelines, minimum data sets, etc.[113]
- BCCA: Each of BCCA's regional cancer center has a symptom management and palliative care team to assist patients and families who are having problems with their symptoms or dealing with the knowledge that their cancer is not curable. For example:
- BCCA: Palliative Care and Symptom Control Network since 1994.[114,115,116] Palliative care mostly happens in the community. BCCA helps link patients with care providers in their home area.
- BCCA: Pain and symptom management/palliative care Program at the Center for Southern Interior.

Spectrum of cancer services -- Canada

Prevention:

- Tobacco Law 1997, ch. 13.
- Health Canada: *The federal tobacco contol stategy. A framework for action* (2001)
- Public Health Agency of Canada (PHAC): *The integrated pan-canadian healthy living strategy* (2005)
- Canadian Strategy for Cancer Control (CSCC) includes priority on primary prevention which aims to establish a Canada-wide primary prevention system that supports evidence-based practice for policies

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[107] BCCA. Oncology Nurtrition Network. http://www.bccancer.bc.ca/HPI/NutritionalCare/ONN/default.htm
[108] BCCA Sociobehavioural Oncology Connections. Winter 2006 (issue 4). http://www.bccancer.bc.ca/RES/SBR/
[109] Sociobehavioural Oncology Connections, Winter 2006 (issue 4). Mapping our Future: Psychosocial Oncology at the 2005 BCCA Annual Cancer Conference.
[110] Personal communication with Richard Doll, July 7, 2006.
[111] BCCA (2005). Helping patients navigate the cancer system. Sociobehavioural Oncology Connections. (Spring).
[112] BCCA (2004). What is a patient navigator? Surgical Oncology Network (Spring).www.bccancer.bc.ca/son
[113] Personnal communication, Dr. Simon Sutcliffe, President, BCCA, January 29, 2007 letter.
[114] BCCA (2005). Strategic Plan.
[115] PHAS. Three years of progress. April 2002-2005
[116] McKensie MR. BC Network to improve palliative care. CMAJ, 1995, 152;(9): 1378.

and programs and addresses the population-based risk factors for cancer (e.g. develop national sun safety program; develop national environmental and occupational exposure program, etc.)

Screening:

- PHAC, Center for Chronic Disease Prevention and Control (CCDPC), Cancer program: This program hosts many activities including a Cervical Cancer Prevention Network, and the Canadian Breast Cancer Initiative, which includes an initiative to promote the development of organized quality screening programs and the development and use of a national database.

Diagnosis and treatments:

- No health services are provided to the population as this is of provincial jurisdiction.
- PHAC, CCDPC, Cancer program: Canadian Breast Cancer Initiative includes breast cancer communication tools for physicians and patients, as well as clinical and practice guidelines for the care and treatment of breast cancer.
- Canadian Strategy for Cancer Control (CSCC) inludes priority on clinical practice guidelines and on standards.

Supportive care:

- PHAC, CCDPC, Cancer program: Canadian Breast Cancer Initiative includes Information Exchange Pilot Projects. It also published a study investigating and assessing the navigator role in meeting the needs of women with breast cancer (2002).
- Canadian Strategy for Cancer Control (CSCC) includes priority to rebalance the focus that seeks to ensure that patients’ needs are better served by Canada’s health care system.

Palliative care:

- Health Canada Secretariat on Palliative and End-of-life Care: Several activities conducted toward the development of a Canadian Strategy on Palliative and End-of-life Care by a coordinating committee and working groups (2002-2004), including a five-year action plan (2002).

Spectrum of cancer services -- England

Prevention:

- Department of Health (DH): *Smoking Kills* (UK tobacco control strategy, 1998)
- DH: Choosing health: making healthier choices easier (2004)
- Government: Health Bill passed in 2006 (banning smoking in all enclosed places for 2007)
- NHS Cancer Plan includes priority on primary prevention, namely to set national and local targets to reduce smoking in disadvantaged groups.
- NHS: Cessation programmes and nicotine replacement therapy

Screening:

- National Health Service (NHS) screening programs: Organized breast screening program (1988)
- NHS: Organized cervical screening program (1988)
- NHS: Organized bowel cancer screening program based on FOBT (2006)
- NHS: National prostate cancer risk management program (not organized but informed choice)
- NHS Cancer Plan includes priority on improving screening, namely to tackle inequalitites in cervical screening

Diagnosis and treatments:

- Most services are provided through 34 Cancer Sevices Networks, with primary care having a central role
- NHS Cancer Plan includes priority on cutting waiting times for diagnosis and treatment
- NHS Cancer Plan includes priority on improving treatment, namely that care for all patients to be reviewed by specialist teams
- NICE: appraisal of cancer drugs and extension of "Improving Outcomes" guidance for all cancers

Supportive care:

- NHS Cancer Plan includes priority on improving care; namely- to develop a new supportive care strategy
- NICE: Guidance on supportive and palliative care for adults with cancer (2004)
- The NHS Integrated Cancer Care Program, launched in 2004, is intended to develop and deliver a model to help patients better navigate the health system, specifically the transition from primary to secondary care, and to empower them to make decisions that suit their personal circumstances.[117]

Palliative care:

- NHS Cancer Plan includes priority on improving cancer services in the community, namely to invest on training of district palliative care nurses
- DH: 50 million invested in 2004 for hospices and to improve access to specialist palliative care
- NHS: End-of-life Care Program (2004)
- DH: End of life care strategy in preparation (announced in 2006)

Spectrum of cancer services -- France

Prevention:

- Government: Décret du 15 novembre 2006 modifiant la *Loi Evin* (tobacco control legislation, 1991) prohibiting smoking in indoor public places to be implemented in 2007
- Government: public consultation on banning smoking in enclosed public places (2006)
- Institut national de prévention et d'éducation pour la santé (INPES): programs for education and smoking cessation
- Cancer Plan includes a priority to develop a comprehensive anti-smoking strategy

Screening:

- Ministry of Health (MH): Organized breast cancer screening (since 1988). The Cancer Plan includes a priority to generalize systematic breast cancer screening by end of 2003. Program managed at national level by INCa, at regional levels by DRASS
- MH: Organized cervical screening in 5 health departments but nationwide generalisation not planned. Cancer Plan includes a priority to encourage individual non-compulsory screening for cervical cancer
- MH: Organized Colorectal cancer screening announced in 2006 to be generalized in 2007. Cancer Plan includes a priority to facilitate development of nation-wide colon cancer screening

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[117] The NHS Cancer Plan and the New NHS. Providing a patient-centred service (2004). http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4092531&chk=2OgU1i

Diagnosis and treatments:

- Cancer Plan includes a priority to ensure there is systematic coordination of all players through the establishment of Regional cancer Networks and through the grading of health care institutions
- Cancer Plan includes a measure ensuring that all new cancer patient to benefit from multidisciplionary input into their case and benefit from a customized care program
- Cancer Plan includes a measure providing patients with improved “breaking the bad news” consultation
- Cancer Plan includes a measure facilitating at-home chemotherapy and more generally at-home care

Supportive care:

- Cancer Plan includes a measure to increase the availability to patients of supportive care
- Cancer Plan includes measures to improve the mechanisms allowing patients to retain their jobs, to recover their jobs, and to take leave to support a friend or relative
- Cancer Plan includes measures encouraging patients and user groups to participate in hospital life by defining the scope of such paticipation

Palliative care:

- Integrated in hospital mission since 1991
- Law of June 9th, 1999 that stipulates and organises palliative care as to ensure access to palliative care services. Three-year action plan (2002-05) to improive service implementation
- Cancer Plan includes a measure to support the national program to develop palliative care

Spectrum of cancer services -- New Zealand

Prevention:

- Ministry of Health (MH): *Clearing the Smoke. A five-year plan for tobacco control in NZ 2004-2009*
- MH: *Smoke-free Environments Amendment Act* (2003)
- NZ Cancer Control Action Plan (NZCCAP) priority includes implementation of *Healthy Eating-Healthy Action*

Screening:

- MH-National Screening Unit (NSU): BreastScreen Aotearoa (national organized breast screening program since 1998)
- MH-NSU: National cervical screening program since 1991
- MH-NSU: Policy work undertaken on colorectral screening (2005-06)
- NZCCAP priority includes the improvement of coverage for BreastScreen program

Diagnosis and treatments:

- Diagnostic and treatment (radiotherapy and systemic therapy) services mostly provided through 6 regional cancer centers
- NZCCAP priority includes the establishment of Regional Cancer Networks
- NZCCAP priority includes establishments of standards for timely access to services

Supportive care:

- NZCCAC priority includes the establishment of integrated programs of supportive care and rehabilitation with defined leadership

Palliative care:

- MH: NZ Palliative Care Strategy (2001)
- NZCCAC priority includes the implementation of the Palliative Care Strategy

Spectrum of cancer services -- Nova Scotia

Prevention:

- Department of Health Promotion and Prevention (DHPP, since 2006): *A comprehensive tobacco control strategy for Nova Scotia* (2001)
- DHPP and partners: *Chronic disease prevention strategy* (2003)
- DHPP: *Smoke-Free Places Act* (2002). A new amendment in 2006 bans smoking in all indoor public places, workplaces, and at outdoor eating and drinking establishments.[118]
- Canadian Cancer Society - NS division and CCNS: *Action in your Community against Tobacco* Program. This initiative directly supports the community development component of the provincial Tobacco Control Strategy. [119]

Screening:

- DH: Nova Scotia breast screening program (since 1991)
- CCNS: Cervical cancer prevention program (DH 1991, integrated to CCNS in 2002)
- Districts, CCNS and partners: consensus reached for developing an organized colorectal screening program (2003), albeit it has not yet been implemented

Diagnosis and treatments:

- Diagnostic and treatment services provided through cancer care programs at two specialized centers
- CCNS and District Health Boards: District Cancer Programs in development
- CCNS: A *Provincial Surgical Oncology Network*, established in 2001, is a forum for surgeons across the province that focuses on guideline development and exchange of information about advances in the surgical treatment of cancer and research. Activities thus far have mainly focused on conducting annual educational events (e.g., Sentinal Node Biopsy in 2005 and Thyroid Cancer in 2006).[120,121]
- CCNS: Thirteen Cancer Site Teams mandated to develop cancer management guidelines
- Nova Scotia telehealth network: one of its clinical program is oncology

Supportive care:

- CCNS: Breast cancer link program (since 2001)
- CCNS: Patient navigation program (since 2001)
- CCNS: Patient Navigation Community Liaison (since 2002)

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[118] CCNS newsletter, January 2006.

[119] ACT 2005 Formative evaluation: Shedding light on community capacity. Stylus Consulting Inc. for the ACT Initiative

[120] CCNS. Report to community 1998-2000

[121] Personal communication with Jill Petrella at CCNS

- CCNS: The *Cancer Patient Family Network*, established in 2001, is as a formal venue for providing support and information to cancer patients, survivors, and family members.[122]

Palliative care:

- DH: Continuing Care Strategy (2006) includes an announcement to develop a palliative care program
- Queen Elizabeth II Palliative Care program
- CCNS: Palliative care front-line education program (2003, education)
- CCNS and others: Working toward implementing palliative and supportive care as a core service of the DH, which would require every district to meet defined standards and have a core palliative care team.

Spectrum of cancer control services -- Ontario

Prevention:

- Ministry of Health Promotion (MHP): Comprehensive tobacco control strategy (2006)
- MHP: *Smoke-Free Ontario Act*, prohibiting smoking in all enclosed workplaces and enclosed public places in Ontario as of May 31, 2006 (replaces the 1994 *Tobacco Control Act*)
- MHP: Ontario's Action plan for healthy eating and active living (2006)
- CCO and Canadian Cancer Society: *Cancer 2020 Action Plan* (2003)
- CCO's Aboriginal Cancer Unit: *Aboriginal Tobacco Strategy*

Screening:

- CCO: Ontario Breast Screening Program (since 1990). Organized breast screening program for women 50 years and over, operated by CCO and funded by MOHLTC.
- CCO: Ontario Cervical Screening Program (since 2000). Organized cervical screening program, operated by CCO and funded by MOHLTC.
- CCO: Plans to set up an organized colorectal screening program using FOBT

Diagnosis and treatments:

- Chemotherapy and cancer surgery are offered in many hospitals throughout Ontario. Radiation therapy is available only at Regional Cancer Centers
- CCO: Surgical oncology program (since 1998)
- CCO: The New Drug Funding Program funds most of the newer anti-cancer drugs. The formulary is one aspect of that program.
- CCO: Clinical practice guidelines and standards development led by the Program in Evidence Based Care (see Ontario's distinctive feature in Chapter 7 and Appendix 7A for details)

Supportive care:

- Regional Cancer Centers: integration and coordination of supportive care services now devolved to the regional cancer programs

Palliative care:

- Ministry of Health and Long Term Care (MHLTC): Ontario End-of-life Care Strategy (since 2005).
- CCO has an initiative called the Palliative Care Integration Project which is pushing out tools and standards to improve the quality of palliative care across the province. By the end of 2006, CCO will

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[122] CCNS. Cancer Patient Family Network. www.cancercare.ns.ca/media//documents/CPFNFactSheet. pdf

have regional improvement coordinators working to implement these tools and standards across the province. The initial work will focus on lung cancer patients.[123]

5.2.4 Organizational architecture of cancer care services

As defined in our integrated framework, the *organizational architecture* of cancer care services refers to the particular configuration through which these services are organized and delivered. The cancer care configurations that we examined pertain to the provision of care to cancer patients. Therefore, they do not focus on the organization of health promotion, prevention, and screening programs. Our review[124] suggests that the design of organizational architecture of cancer care services is informed by the following characteristics:

1. Adoption of the *regionalization* of their cancer care services.
2. Development of a *hierarchy of services*, defining facilities and professionals that will be authorized to provide different types and levels of care.
3. Aim to improve the *integration* of cancer services to ensure coordination and continuity of care between the primary, secondary and tertiary care levels, across health care facilities, and between the curative, supportive, and palliative care interfaces.

Shaped by the above organizing characteristics (or principles), configurations of cancer care delivery take on the general form of ***regional cancer programs or networks***. In contrast to silos of professionals and facilities, such configurations formally recognize collaborative links among care providers and deliberately employ a structure to facilitate the coordination of services across providers at primary, secondary, and tertiary levels, as well as work together to ensure that services are planned and delivered in line with clearly defined national/provincial standards. These regional cancer programs and networks generally seek to:

- Provide equitable access to a common core of cancer services throughout the jurisdiction (for all geographical areas covered by the network or program)
- Improve the quality of care by reducing fragmentation and variations in care
- Provide care closer to home, while fostering formal referral patterns and communication channels between service providers

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[123] CCO's CEO personal communication, October 23, 2006.

[124] Canada is not included in this analysis since the delivery of health care services is of provincial jurisdiction. Each Canadian province and territory independently plans the delivery of cancer-related services and, as such, each has secured in place its own organizational architecture. This being said, the Canadian Strategy for Cancer Control (CSCC) does work with Canada's system of federal government and province-directed health care by creating networks of experts whose goal is to inform the CSCC Council regarding new knowledge formation, priority setting, and how to manage and implement cancer control activities in their area of expertise.[124] However, they do not make recommendations regarding the modes of operation through which services ought to be delivered across the provinces and territories.

- Ensure the provision of services according to homogeneous (national, provincial); standards (through designation of teams and accreditation of facilities)
- Promote regional flexibility and building on existing strengths as long as minimum standards are met.

Another approach to promoting a seamless cancer journey that does not necessitate major reforms in health care services organization and that closely matches expressed patients' needs is "Patient Navigation." Patient navigation programs aim to help patients during their journey through a complex and fragmented cancer system through the provision of information as well as coordinated support and care.

5.2.4.1 Highlights of jurisdictions' models of cancer care delivery

In the following paragraphs we sketch the main features of the approach jurisdictions have taken to structure their cancer services delivery system, highlighting major commonalities and differences. Details of progress toward establishing such organizational architecture are presented in Chapter 7 on *Main Accomplishments*.

Alberta and British Columbia: A provincial (agency) cancer program model

In both Alberta and British Columbia, the organizational architecture can be characterized as an *Agency-governed* cancer control program, delivered regionally through specialized cancer centers, supported by a community outreach system. In Alberta, the organizational architecture for service delivery is a *Provincial Cancer Network* of centrally-operated (by the Alberta Cancer Board) facilities comprising two tertiary cancer centers, four associate cancer centers, and eleven community cancer centers. Alberta's facilities operated by ACB also include two fixed breast screening sites and three mobile breast screening services visiting small urban and rural communities throughout the province (Screen test program).

In BC, the *Provincial Cancer Program* is an integration of Cancer Centres, Research Centres, Tumour Groups, Provincial programs (eg Radiation Therapy, Systemic Therapy), Provincial Networks and Community Cancer Centres and Clinics. The facilities include four BCCA-operated regional cancer centers, linked to 21 community cancer centers, six community cancer services, and twelve consultative (outreach) clinics. In general, the community outreach system involves partnerships between the cancer governing body (e.g. provincial cancer agency) and the health authority governing the facilities (community centers and clinics) providing cancer services. Both ACB and BCCA are responsible for coordinating the community cancer program throughout the province, while the host hospital/health authority is responsible for providing the space, maintenance and other supports.

England, France and New Zealand: A regional cancer network model

In England, France, and New Zealand, the organizational architecture can be characterized as a *nationally-guided* (by a national cancer plan), *network-governed* cancer control program, delivered regionally through cancer networks. In England, for example the current service delivery configuration was formerly proposed in 1995, when the Calman-Hine report indicated a need for horizontal integration of cancer services on a tumour site specific basis and recommended a fundamental restructuring of cancer services. The proposed new structure for cancer services provision was based on a *network* of expertise in cancer care, integrating primary care (to be the focus of care), secondary care (designated Cancer Units in district hospitals), and tertiary care (designated Cancer Centers).[125] The Calman-Hine report also recommended that multidisciplinary teams of all relevant specialists on a cancer site specific basis should be formed to provide advice on primary treatment and on relapsed disease. Moreover, it recommended the establishment of clear pathways of referral and follow-up between general practitioners, cancer units and cancer centers. The overall purpose of this integrated and systematized configuration of services was to improve access to, and provide uniform standards for, high quality care. The NHS Cancer Plan (2000) has taken this proposed organizational architecture forward by facilitating the creation of 34 *Cancer Networks*, which would integrate all cancer services providers within 1-2 million population catchment areas.

In France the organization of health care services is dictated by the Health Ministry and is then regionally planned by the *Agences régionales d'hospitalisation* (ARH) that translate Ministry guidance into three-year regional plans called "*Schéma régional d'organisation sanitaire (SROS).*" In 2006, the new SROS (SROS III) included cancer care as a compulsory theme. The approach to cancer services organization described in the SROS III was informed by a legal document, published in February 2005, devoted to cancer services organization. The legal document was informed by the vision put forth in national cancer plan 2003-2007. The SROS III sets out a regional organization of cancer services that involves 2 kinds of facilities:
(1) Treatment cancer centers and (2) Associate local facilities for follow-up care, general medicine, and home care.[126] The treatment cancer centers and associate local facilities are to be organized into *Regional and Territorial Cancer Care Networks*. These networks are expected to establish links with other existing health care networks (e.g. palliative care). The *Regional Cancer Care Networks* are responsible for coordinating service providers and Territorial Cancer Care Networks, and for developing clinical guidelines. The *Territorial Cancer Care Networks* are responsible for ensuring continuity of cancer care at the local level. Each Regional Cancer Care Network will have a *Regional Cancer Pole* dedicated to specialized cancer care services (including appeals and expertise), clinical research, teaching and innovations. Cancer treatment facilities and radiotherapy centers will be acrreditated by the National Cancer Institute, which will grant permission to perform surgery, systemic therapy and other specific treatments. This organizational scheme also stipulates that the facilities providing cancer services will have to host a *Cancer Coordination Center* (3C) to allow cancer related activities to become more visible within the organization. The 3Cs must also promote the development of personalized follow-up and establish the foundations for a quality assurance process. In addition, these 3Cs are to facilitate the medical coordination of cancer care within the facility, in particular the implementation of a concerted and multidisciplinary approach to cancer care via multidisciplinary consultation meetings. Their responsibilities include quality assurance of the

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[125] Cancer Units are the designated structure for the diagnosis and treatment of common cancers and must undertake a sufficient volume of work to maintain sub-specialization skills. The Calman-Hine report recommended that local cancer units have input from non surgical oncology (clinical and medical oncology) and that cancer unit services development and cancer site specific protocol implementation be coordinated by a lead clinician. As for the small number of units providing needed radiotherapy, they would have to be linked to Cancer Centers, which are the designated facilities for specialist cancer care and for radiotherapy.

[126] http://www.veille-arh-paca.com/plan_cancer/rubrique.php3?id_rubrique=23

customized care program by ensuring that all patients receive customized care, receive individual follow-up, including support and help in their management, as well as ensure that all medical files comply with care standards. The intent is to make the 3Cs a one-stop contact in the hospital for patients (by providing patients with a unique medical contact person and contacts for patient associations). Finally it is hoped that, as a result of better logistical organization**,** the 3Cs will free-up providers' time for improving communication with their patients.

In New Zealand, the current organizational architecture for cancer services rests on six urban-based Regional Cancer Centers with a secondary/tertiary care focus, acting as hubs in a "hub and spoke" model.[127] The establishment of *Regional Cancer Networks* as proposed in the NZ Cancer Control Strategy and NZ Cancer Control Action Plan, is intended to formalize existing collaborative initiatives on a wide-range of projects.[128,129] These Regional Cancer Networks are intended to facilitate coordination of cancer services across health providers at the primary, secondary, and tertiary levels and to serve as a vehicle through which organizations and stakeholders can work together to plan and coordinate services in accordance with defined national standards of treatment. These Regional Cancer Networks will take the form of managed virtual bodies linking cancer care providers (tertiary, secondary, and primary), private health care providers, non governmental organization (NGO) providers, public health organizations, consumer organizations, and District Health Boards (DHBs) throughout defined geographical areas to ensure delivery of quality co-ordinated, comprehensive cancer services across the cancer control continuum.[130]

Nova Scotia and Ontario: A regional cancer program model

In both Nova Scotia and Ontario, where provincial cancer control agencies are not involved in the delivery of health care services, the organizational architecture can be characterized as a *provincially-guided* (by the cancer agency's plan and programs), *regionally-governed* cancer control program, delivered regionally through specialized cancer centers and community services. In Nova Scotia, cancer services delivery is organized around three *Specialized Cancer Centers* that provide tertiary level cancer services. The two adut cancer centers in Halifax and Cape Breton assess about two thirds of new oncology patients.[131] The regional hospitals of District Health Authorities provide primary and secondary cancer services such as surgery and chemotherapy along with supportive and usually palliative care.[132] Some District Health Authorities, in partnership with the two adult provincial cancer centers, have opened *Cancer Outreach Clinics* wherein medical and radiation oncologists can monitor current patients and see new patients for assessment and care planning. [133, 134] This system is also supported by a Patient

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[127] Hub and spoke model: Any architecture that uses a central connecting point. It is the same as a star topology in a network. In this case the Regional cancer centers act as the hub and the primary and secondary services providers as the spoke. Barber J, Hewitt J, Long J. Midland DHBs Cancer Control Network.Progress to date. Presentation at the Ministry of Health seminar titled: Establishing Regional Cancer Networks in New Zealand, March 30, 2006.

[128] NZ action plan p. 7; p. 71

[129] NZ government. Regional Cancer Networks help cancer patients (2006)http://www.beehive.govt.nz/hodgson

[130] Childs, J. Establishing Regional Cancer Networks in New Zealand. Benefits and Challenges. Presentation at the Ministry of Health seminar titled: Establishing Regional Cancer Networks in New Zealand, March 30, 2006.

[131] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

[132] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

[133] CCNS. http://www.cancercare.ns.ca/inside.asp?cmPageID=93; Accessed : March 6, 2006

[134] CCNS. District Cancer Program. http://www.cancercare.ns.ca/media//documents/DCPFactSheet.pdf.

Navigation Program. Such configuration of service delivery is progressively being transformed with the implementation of the *District Cancer Program*s (DCPs), an approach that stresses the importance of taking cancer care into communities. DCPs essentially underscore the importance of working with communities in developing cancer services from prevention to palliation, and delivering such services closer to the patient's residence.[135] In the DCP model, care is provided by physicians, DHA staff (nurses, pharmacists, support staff) and other health care providers in the district. The model is intended not only to reduce the travel burden for patients, but also to help streamline communication and to clarify roles of care providers.

In Ontario, significant changes that followed the Cancer Services Implementation Committee Report in 2001 led CCO to abandon the delivery of cancer services through agency-owned facilities model, an approach that has worked well in Alberta and British Columbia. Instead, the newly proposed organizational architecture is based on *Regional Cancer Programs* that will link cancer services of surrounding referring hospitals and healthcare facilities within a defined geographical area.[136,137,138] Regional Cancer Programs will have as their hub an *Integrated Cancer Program*, which was created by the integration of CCO's former Regional Cancer Centres with their host hospitals. These regional programs will be governed by their respective Regional Cancer Centers. In addition to their role in building regional systems of cancer care, Regional Cancer Programs will be responsible for improving the quality of cancer services by implementing provincial guidelines and standards.

Our overview of organizational architecture reveals that the integration of cancer care services involves a geographically distributed and connected network of services, managed and operated through the following structures:

- Regional Cancer Networks or Programs
- Regional Cancer Centers linked to a community outreach system
- University-based hospitals and/or specialized cancer centers as Network Hubs
- Integration (or not) of Cancer Centers with host hospitals
- Leadership Teams or Coordination Centers within facilities offering cancer services
- Multidisciplinary Teams of service providers

And, in some cases, a Patient Navigation Program is considered. Moreover, ensuring that integrated cancer care is delivered closer to home takes various forms, including:

- Community-based cancer centers/units, which may be linked to tertiary cancer centers
- Outreach centers/clinics- linked to community cancer centers or tertiary centers

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[135] Cancer Care Nova Scotia. Many Hearts, Many Minds, One Goal: Report to the Community 1998-2000. Accessed November 8, 2004. Available at: http://cancercare.ns.ca/media//documents/CCNSReport_72dpi.pdf

[136] Hudson ,A. The First 200 days: cancer leadership in Ontario. Hospital Quarterly, 2002;6(1):30-34.

[137] Sullivan T, Dobrow M, Thompson L, Hudson A. Reconstructing cancer services in Ontario. Commentary. Healthcare papers, 2004;5(1):69-80.

[138] Cancer Care Ontario. Ontario Cancer News. March 2003; 1(1). Accessed December 9, 2004. Available at: http://www.cancercare.on.ca/OntarioCancerNewsArchives/200303/index.html.

- Mobile care teams or home-based care
- Teleconsultations

One major difference between the jurisdictions resides in the ***governance*** of cancer service delivery. Some jurisdictions had a centralized approach to planning, funding, and service delivery (Alberta and British Columbia); whereas others adopted a more distributed approach (England, France, New Zealand, Nova Scotia, Ontario) such as the involvement of Primary Care Trusts and Cancer Networks in England or the collaboration between the Health Ministry, the ARH and INCa in France. In the latter situations, planning is most generally done at the national or provincial level (the cancer plans and programs), and subsequently translated into regional and local service plans.

5.2.5 Service Quality Facilitators

Equally defined in our integrated framework, are the *service quality facilitators*, which refer to activities, tools/procedures and/or systems that enable the cancer control system to meet the growing demand for cancer services while ensuring the best quality of care possible for all cancer patients and individuals suspected of having cancer. The service quality facilitators that are examined in this report were grouped into two categories: (1) System capacity and sustainability and (2) Quality assurance and improvement.

Four main action areas were included in the *System capacity and sustainability* category:

(i) Cancer drugs management systems (e.g. review process and formulary for determing access to medications)
(ii) Capital investments (building construction and new equipment)
(iii) Human resources management initiatives (workforce recruitment and retention)
(iv) Information management systems (IT systems for health data collection, analysis and projection, namely registries for surveillance and service planning).

Eight main action areas were included in the *Quality assurance and improvement* category:

(i) Accountability agreements and performance contracts (to ensure that organizations delivering cancer services meet defined standards or targets)
(ii) Accreditation procedures (for organizational structures such as multidisciplinary teams, cancer networks, and cancer centers)
(iii) Evidence-based clinical practice guidelines (provided by designated tumor groups or appropriate national organizations, e.g. NICE)
(iv) Patient participation intitatives (from consultation to direct involvement in cancer policy and/or in service improvement process)
(v) Professional training and certification programs
(vi) Service delivery standards

(vii) Service redesign initiatives

(viii) Service performance tracking (using audit reviews, monitoring of performance, satisfaction surveys, recognized quality indicators and waiting time measurements, which could further serve to ensure internal and external accountability).

Table 6 provides a general overview of the eight jurisdictions regarding the main action areas related to service quality facilitators that were part of their cancer plans and/or ongoing program priorities. Our review suggests that ensuring cancer control system capacity and sustainability through various activities such as planning and/or investments in cancer drugs, facilities and equipments, human resources, as well as information technologies is high on the agenda in all jurisdictions. A strong emphasis on quality assurance and improvement is reflected mainly by the central importance given to the development and dissemination of evidence-based clinical practice guidelines, the development of service standards, and their adherence through various accreditation and certification procedures, as well as the tracking of service performance. Varibility is evident mostly with elements such as the promotion of patient participation in cancer policy, efforts aimed at improving professional training, and cancer services redesign initiatives. Such variability could be explained by differing priorities and/or approaches to service quality. Alternatively, such facilitators could very well be part of more general health system initiatives that were not captured by our review.

Table 6. Service Quality Facilitators: Main Action Areas*

	Alberta	British Columbia	Canada	England	France	New Zealand	Nova Scotia	Ontario
1. System capacity and sustainability								
• Cancer drugs management systems *(review process and formulary)*	√	√	√	√	√	√	√	√
• Capital investments *(building construction and new equipment)*	√	√	??	√	√	√		√
• Human resources management initiatives *(workforce recruitment and retention)*	√	√	√	√	√	√	√	√
• Information management systems *(IT systems for health data collection, analysis and projection)*	√	√	√	√	√	√	√	√
2. Quality assurance and improvement								
• Accountability agreements and performance contracts	√	√	??	√	√	√		√
• Accreditation procedures *(centers, networks, multidisciplinary teams)*	√	√	√	√	√	√	√	√
• Evidence-based clinical guidelines *(treatment protocols and best care practices)*	√	√	√	√	√	√	√	√
• Patient participation in cancer policy *(from consultation to direct involvement)*			√	√	√	√	√	√
• Professional training and certification	√	√	??	√	√	??	√	√
• Service delivery standards	√	√	√	√	√	√	√	√
• Service redesign initiatives			??	√	√	√		√
• Service performance tracking *(including satisfaction surveys)*	√	√	√	√	√	√	√	√

*** Note**: A √ in a specific service quality facilitator category required indication of such as part of either: (1) a goal/priority within the cancer plan; (2) cancer program operations; or (3) a specific "cancer application/subcomponent" of a more general health ministry policy or activity. The categories included do not constitute an exhaustive view of existing health care service facilitators, but essentially reflect the various types of facilitators found within the cancer plans and ongoing programs of the eight jurisdictions selected for this study.

5.2.6 Targets and indicators of outcome

Targets and indicators of outcome are end-points that jurisdictions have stipulated to determine whether progress is being made and, most importantly, whether the goals that have been defined are achieved. These end-points allow for conducting assessments to determine the *impact* of the cancer plan or program. Such impact may be characterized, for example, as the reduction of waiting time for radiation therapy (process outcome), or the reduction of cancer incidence rates (health outcome). End-points were worded as either targets, milestones, key indicators, measures, performance measures, or outcomes/results. The following paragraphs highlight these end-points. Available information on stated targets and indicators of outcome is summarized in Appendix 5C.

5.2.6.1 Highlights of stated targets and indicators of outcome

Cancer mortality: Although reducing cancer mortality is a central goal in the cancer plans and programs of all jurisdictions, only a few have stated specific measurable targets. In Alberta, targets have been proposed for reducing mortality rates for breast, cervical, lung, and prostate cancers, as well as an overall target of a 50% reduction from the predicted 2025 rate. In England the major target is a 20% drop in overall cancer mortality rate among people under 75 by 2010. In France a similar reduction is proposed for the whole population by 2007. The goal of the Nova Scotia breast screening program is to reduce mortality from breast cancer in women aged 50-69 years by 30% within 10 years following the development of a province wide screening program (the actual program started in 1991).

Smoking rates: Regarding tobacco control, Alberta, British Columbia, England, France and New Zealand have measurable targets with set deadlines. Alberta is aiming for a 50% reduction in the consumption of tobacco products from 2001 to 2011; France is aimimg for a 20% reduction in adult smokers by 2007; The same for New Zealand by 2009. In New Zealand, tobacco control targets are set to reach three goals : (1) to significantly reduce levels of tobacco consumption and smoking prevalence; (2) to reduce inequalities in health outcomes; and (3) to reduce Maori smoking prevalence to at least the same leval as that of non-Maori. England has also multiple targets which reflect a willingness to reduce inequalities between manual workers, socio-economically deprived groups and the general population. In Ontario, the Cancer 2020 action plan prepared by CCO and the Canadian Cancer Society has proposed the most ambitious target, aimimg for a proposed prevalence of 5% of adult smokers by 2020. This proposal has however not yet been endorsed and integrated in Ontario's mandatory health programs and services guidelines.[139]

Breast screening: The efficiency of organized breast cancer screening programs is, in part, related to the participation rate. A participation rate of at least 70 % or higher is advocated by the scientific community for a screening program to substantially reduce mortality in a population.[140]

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[139] Report on cancer 2020. A call for renewed action on cancer prevention and detection in Ontario, Issue 1, June 2006, p. 10. Available at: http://www.cancercare.on.ca/documents/2006Cancer2020Report-English.pdf

[140] Kerlikowske K, Grady D, Rubin SM, Sandrock C, Ernster VL. Efficacy of screening mammography, A meta-analysis. JAMA; 273:149-54. Cited in Health Canada Report from the Evaluation indicators working group. Guidelines for monitoring breast screening program performance, 2002.

Among the jurisdictions reviewed, only Alberta, France and Ontario have proposed more ambitious targets with 80% participation rate among women aged 50-69 years in Alberta, 80% participation rate by 2007 among women aged 50-74 years in France and 90% participation rate by 2020 (70% by 2010) among women aged 50-69 years in Ontario.[141] All other jurisdictions adopted the 70% target.

Radiation therapy: Long delays before having radiotherapy treatment has been a well documented problem in many jurisdictions at one point in their history of cancer control. Hence, many jurisdictions have focused on strategies, actions, and targets to reduce waiting time in radiotherapy. It is, however, difficult to compare jurisdictions in this respect since the waiting time periods and associated targets are defined differently across the jurisdictions. In December 2005, a Pan-Canadian benchmark was defined for provinces and territories, which stated the treatment of cancer within four weeks of patients ready to treat.

In Alberta the target is the following: For 90% of patients, achieve target wait times of four weeks from referral to consultation with an oncologist and two weeks from consultation to treatment for all tumor groups where medically appropriate. In BC, the target is similar to the canadian benchmarck, which is that at least 90% of ready to treat patients should wait no longer than four weeks before getting radiotherapy. While the Ontario government announced specific targets for cancer surgery in December 2005, it did not provide any for radiation therapy. In Nova Scotia, a Provincial Wait Time Project Steering Committee recommended in 2004 that CCNS lead a process to create a province-wide priority tool and target wait times for referrals from general practitioner to specialist in medical oncology. The Steering Committee recommended that upon creation of this standard, the information system used by CCNS would then be modified to collect and report on this information.[142]

England has had waiting time targets since 2000, which consists of a 4-week maximum wait from diagnosis to treatment and 8-week wait from urgent general physician referral to treatment for all cancers by 2005. In contrast, France does not have any specific waiting time targets for radiation therapy. New Zealand has been monitoring radiotherapy waiting times in its six regional oncology centers since 1998.[143] In 2002, new wait times measures were formulated that covered the interval between the referral from a medical practitioner to the oncology department, and the beginning of radiation treatment (in other words the interval between decision to treat and treatment). The criteria used to set the wait times are linked to the following priorities: Priority A (urgent): within 24 hours; Priority B (curative); within 2 weeks; Priority C (palliative and other radical): within four weeks; Priority D (combined chemotherapy and radiation treatment): start date is booked according to treatment schedule.

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[141] As of 2006, the targets proposed by CCO in Cancer 2020 have not yet been endorsed by the Ontario Ministry of Health.

[142] Implementation plan of the Nova Scotia wait time monitoring project steering committee, 2004, p. 8. Available at: http://www.gov.ns.ca/heal/waittimes/wait-time implement.pdf#search=%22wait%20time%20targets%20nova%20scotia%22

[143] See NZ Health Ministry FAQs about radiation treatment at: http://www.moh.govt.nz/moh.nsf/indexmh/cancercontrol-faqs

6. GOVERNANCE AND MANAGEMENT

6.1 INTRODUCTION

Governance is a policy term used broadly, as in corporate governance, good governance, international governance, among others. [144] In general, it relates to the exercise of authority with regard to systems of accountability and control. In the traditional sense of the word, governance is used in reference to actions of a Board of Directors of a given organization with respect to their actions of establishing and monitoring the direction of the organization.[145] The term itself has been used interchangeably with public *management* and public *administration*.[146] This may be due to the fact that management not only includes the conduct of daily operations, but also encompasses several elements, often attributed to governance *per se*, such as strategic planning, collaboration, and leadership.

Contemporary use of the term in the field of public policy recognizes the growing participation of a broad network of actors in addition to the public administration sector, whether this be public, private, voluntary, professional, and the general population. Given this trend, there is a need to distinguish between "government" and "governance". In this context, governance would reflect the interaction of multiple decision-makers and stakeholders;[147, 148] whereas, the government per se would adopt a position that is more or less central and dominant. Interesting to note, however, that prevailing governing practices, especially in the public sector, are still very close to the traditional model of public administration and management. Broadly speaking, these practices favour a hierarchical control over policy by ministries and public administrations. This is also the case for cancer control policy development and policy/program implementation. Although Chapter 4 brought to light a notable shift toward the inclusion of non-governmental organizations (i.e., the voluntary health and advocacy sectors) in the processes of policy initiation and development, other important players in cancer control governance also include health care organizations and research foundations/institutes.

The act of governing refers to purposeful efforts to guide, steer, control, and manage public policy.[149] Governing activities can include the setting of policy visions, goals and priorities, the creation of structures and mandates, the allocation of resources, the management of programs,

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[144] Bresssers HTA & Kuks SM. "What does governance mean? From concept to elaboration" in: Hans Th. A. Bressers & Walter A. Rosenbaum (Eds.), Achieving sustainable development: The challenge of governance across social scales, New York-Westpoint-London: Praeger (2003).

[145] Definition taken from The Nonprofit Good Practice Guide, available at: http://www.npgoodpractice.org/CompleteGlossary.aspx?ID=-1

[146] Heinrich CJ, Hill CJ, Lynn LE. "Governance as an organizing theme for empirical research" In: The Art of Governance. Analyzing Management and Administration. Ingraham PW & Lynn LE (eds), Georgetown University Press, Washington DC, 2004, pp. 3-19.

[147] Lemieux, V. « Government roles in governance processes » Chapter 3 In : Modernizing governance: A preliminary exploration. Ottawa, Canadian Center for Management Development, 2000. Available at http://ccmd-ccg.gc.ca/.

[148] Bresssers HTA & Kuks SM. "What does governance mean? From concept to elaboration" in: Hans Th. A. Bressers & Walter A. Rosenbaum (Eds.), Achieving sustainable development: The challenge of governance across social scales, New York-Westpoint-London: Praeger (2003).

[149] Lemieux, V. « Government roles in governance processes » Chapter 3 In : Modernizing governance: A preliminary exploration. Ottawa, Canadian Center for Management Development, 2000.

the delivery of services, the setting of benchmarks and desired outcomes, as well as the monitoring of progress and the assessment of results.[150]

For the purpose of this report, the term *governance* will be used to refer to both “governance and management”, which we view as an umbrella concept referring to the means employed by public administrators to organize and manage the implementation of cancer control programs and action plans. Although we recognize that governance applies to all phases of policy making (policy development through implementation and evaluation),[151] this Chapter on governance will focus on the features of governance as they relate to the *implementation* of cancer control program/action plan and we will limit our analysis to the organizations (bodies, agencies, or officials) created or appointed to manage the cancer control program and/or the implementation of the cancer plan.

Our review indicates that the governance/management of cancer control programs and action plans is usually done by: (1) the government with varying ties or arrangements between the health ministry and its department and (2) a nominated organization such as a cancer agency, council, institute and/or an appointed official (national cancer director, principal advisor, commissioner, etc.). Such appointed bodies are mandated to oversee a number of functions related to cancer control policy development, implementation and evaluation.

Several analytical frameworks have been proposed for conceptualizing and interpreting empirical studies of public governance approaches.[152,153] In this report, the analysis of cancer control governance approach adopted by each jurisdiction is based on the description of the following elements:

1. Key actors involved, levels of intervention (national, regional, local), relationships with the health ministry/department, and general lines of accountability;
2. Features of the main organizations appointed to oversee policy/program implementation, including their legal status, vision and missions, internal structure, functions, resources available for implementation and accountability.

The final part of this Chapter presents a categorization of the different governance approaches adopted by the jurisdictions, according to the type of organization and its ties with the government.

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[150] Prince MJ. Governing in an Integrated Fashion : Lessons form the Disability Domain. CPRN Discussion paper No. F 14, June 2001. Canadian Policy Research Networks. See p. 15.

[151] Policy initiation and development activities such as the setting of policy visions, goals and priorities have been described in the previous sections on history/development (section 4.1) and program design (section 4.2).

[152] Heinrich CJ, Hill CJ, Lynn LE. “Governance as an organizing theme for empirical research” In: The Art of Governance. Analyzing Management and Administration. Ingraham PW & Lynn LE (eds), Georgetown University Press, Washington DC, 2004, pp. 3-19.

[153] Bresssers HTA & Kuks SM. “What does governance mean? From concept to elaboration” in: Hans Th. A. Bressers & Walter A. Rosenbaum (Eds.), Achieving sustainable development: The challenge of governance across social scales, New York-Westpoint-London: Praeger (2003).

6.2 HIGHLIGHTS OF GOVERNANCE FEATURES

Each jurisdiction has adopted governance features, unique to their context, to sustain, coordinate, and monitor cancer program/action plan implementation. The description and discussion of these governance features are based on a comparative analysis of information that was obtained by triangulation of relevant sources of data available via websites, grey literature, and semi-structured interviews with key informants.

6.2.1 Key actors and levels of involvement

The following section deals specifically with describing the role of key players involved in cancer control policy/program development and implementation. Details of the major key playors and their accountability relationships are provided in Appendix 6A and 6B respectively.

At the national or provincial level:

Although for all jurisdictions, Health Ministries/Departments are the ultimate level of accountability, their role in cancer control governance tends to vary. One jurisdiction wherein the Health Ministry/Department plays a central and direct role at the national level is England. In England, the National Cancer Director is one of several National Clinical Directors appointed by the Department of Health to spearhead change and ensure implementation of NHS service frameworks (in this case the NHS Cancer Plan). The Director is assisted by a national Cancer Action Team. A Cancer Taskforce was created in 2000, which is chaired by the National Cancer Director, to oversee the NHS Cancer Plan implementation.

In the other jurisdictions, Health Ministries/Departments play an indirect role, having entrusted the cancer control governance to national/provincial governing bodies that are either part of the government, such as in British Columbia (BCCA) and Nova Scotia (CCNS) or separate from the Ministry (but still accountable to their respective Health Ministers), such as in Alberta (ACB), Ontario (CCO), France (INCa), and New Zealand (NZ Council).

New Zealand is the only jurisdiction that has both arrangements. That is, the NZ Minister of Health has proceeded with the establishment of a Cancer Control Council to provide independent oversight of actions related to control cancer and the implementation of the NZ Cancer Control Strategy. In addition, the Director-General of Health appointed a Principal Advisor to drive the implementation of the Strategy from within the Ministry of Health. Finally, a Cancer Control Work Programme under the leadership of the Principal Advisor and involving the Health Ministry, District Health Boards, the Cancer Control Council, and other cancer control stakeholders, was recently created by the Health Mnistry to set up concrete actions for implementation.

In Canada, the CSCC Council was established as an independant coalition of major cancer control organizations, appointed by stakeholder groups, outside the mandate of the Government. The Council served as the board of directors for the CSCC. Such governing approach was said to promote collective responsibility, inclusiveness, and an evidence-based decision-making process.[154] In November 2006, the Council was replaced by the Canadian Partnership Against Cancer Corporation (CPACC), an independent, not-for-profit, organization that will operate at arm's length from the government, and report to the Federal Minister of Health.

Summary of key points:

- Central role of Health Ministry/Department: England's National Cancer Director, Cancer Action Team and Cancer TaskForce; New Zealand's Principal Advisor Cancer Control
- Governance entrusted in bodies within the Health Ministry/Department: BCCA, CCNS
- Governance entrusted in bodies separate from Health Ministry/Department: ACB, CCO, INCa, New Zealand's Cancer Control Council
- Governance independent, but accountable to Government: CPACC

Cancer control programs and action plans involve multiple activities, including the provision of health services that span the continuum of care. In most jurisdictions, the health ministry is responsible for prevention strategies and programs (tobacco control strategy, healthy diet and other health promotion and prevention programs), while the treatment component is governed by the cancer control governing entity. The governance of screening programs is less homogeneous, with some jurisdictions having delegated the management of those programs to cancer control bodies (Alberta, British Columbia, Ontario, France), while others have those programs located within one ministry or department's core business (England, New Zealand).

Nova Scotia has both arrangements. The Nova Scotia Breast Screening Program is governed by the Department of Health, while the Nova Scotia Gynecological Cancer Screening Program is under the responsibility of the Cancer Care Nova Scotia program since 2002. However, the 1996 Cancer Plan and many deliberations that followed envisaged the eventual integration of the Breast screening program into CCNS, as was the case for the Gynecological program, to generate economies of scale, but this proposition was never accepted by the breast sceening program.[155]

Summary of key points:

- Screening programs within Health Ministry/Department: England, New Zealand, Nova Scotia
- Screening programs managed by appointed cancer control bodies: Alberta, British Columbia, Ontario, France, Nova Scotia

<u>At the regional and local levels:</u>

In most of the jurisdictions studied, it is at the regional level that cancer control plans and programs are implemented. The regional authorities in France (Agences Régionales d'Hospitalisation), Nova Scotia (District Health Authorities), New Zealand (District Health Boards), and in Alberta and British Columbia (Regional Health Authorities) play an active role in the planning, and delivery of cancer control services, in collaboration with the appointed

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[154] 2006-2010 Business plan for the Canadian Strategy for Cancer Control, p.14.

[155] Personnal communication, Dr Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

cancer control bodies. Ontario recently created 14 Local Integrated Health Networks, which will be involved in the implementation of regional cancer programs. In England, the cancer plan implementation is under the responsibility of the 34 Cancer Services Networks, with each covering population of 1-2 million. These networks are guided by Strategic Health Authorities, responsible for strategic planning and performance monitoring, while the Primary Care Trusts and Acute Care Trusts are responsible for funding services.

Non-governmental organizations:

In all jurisdictions, non-governmental organizations (NGOs) play an important role in cancer control policy initiation, development, and implementation. At the policy initiation and development phases, NGOs might be involved in producing relevant data on the cancer burden and cancer services, creating a sense of urgency, mobilizing action, achieving political commitment, and/or promoting the patient and public perspective through their knowledge of community issues. At the implementation phase their roles may include sharing expertise, participating in local, provincial and national initiatives, educating the public, being involved in prevention, supportive care, palliative care, and raising funds for research.

Particularly notheworthy regarding policy initiation and development is Canada and New Zealand. In New Zealand for example, the groundwork for developing the NZ Strategy was financed in good part by the Cancer Society of New Zealand and the Child Cancer Foundation. These NGOs, were members of the Cancer Control Trust, a partnership between the NGOs and the Ministry of Health. In Canada, the Canadian Cancer Society and National Cancer Institute of Canada were among the founders of the CSCC, The Canadian Strategy is the product of many hundreds of stakeholders, including many patient/survivor advocacy groups and professional associations. Provincial divisions of the Canadian Cancer Society are also playing a major role in initiatives to customize the CSCC in Alberta and in British Columbia for example.

The New Zealand Cancer Society is also involved in the Cancer Control working program steering group and participate to several projects that are part of phase 1 implemenation of the Action Plan. Also of interest regarding cancer control program and action plan implementation is England, where the Macmillan Cancer Relief charity directly funds some cancer networks activities regarding patient supportive care. Another example is British Columbia, where the BC and Yukon Division of the Canadian Cancer Society delivers community-based support programs and prevention information for all types of cancer in British Columbia and the Yukon.

Summary of key points

- Central role of NGOs in policy/program initiation and development: Alberta, BC, Canada, France, New Zealand, Ontario
- Central role of NGOs in program/action plan implementation: British Columbia, Canada, England, Nova Scotia, New Zealand.

6.2.2 Main governing bodies

The main bodies governing cancer control programs and/or action plans are described in the shaded boxes below. A description of the internal structure of the identified governing bodies is also presented in organizational charts (see Appendix 6C).

Alberta Cancer Board

Legal status:
The Alberta cancer Board (ACB) is a provincial health board, initially established in 1967, that now operates under the authority of the Cancer Programs Act Chapter C-2, Revised Statutes of Alberta, 2000. It is part of the Health Authorities, which are separate from the Health Ministry.

Vision:
"Excellence in cancer control" (until 2003) and "A Cancer Free Future" (since 2004).

Mission:
Reduce the burden of cancer through prevention, screening, diagnosis, treatment, palliation, education and research.

Accountability:
Alberta Cancer Board is accountable to the Alberta Health and Wellness Minister through multi-year performance agreements and approval of ACB business plans by the Health Ministry.

Board of directors:
ACB's Board of Directors is comprised of 11 members that are appointed by the Minister of Health. The Board is charged to ensure that ACB's objectives are fulfilled, to manage the assets of ACB, to appoint the trustees of the Alberta Cancer Foundation (ACF) as well as to identify the priorities for ACF fundraising. The ACB Board of Directors has four subcommittees: (1) Finance; (2) Governance; (3) Quality and Performance Measurment; and (4) Capital Planning.

President and CEO:
The President and CEO is accountable to the Board of Directors.

Executive team:
The Corporate Executive Committee is the senior management team of ACB and is accountable to the President and CEO.

Functions:
ACB is mandated by the government to provide cancer services from prevention to care, and to coordinate the planning, development and delivery of programs and services in collaboration with the 9 Regional Health Authorities (RHAs). The Alberta Cancer Programs Act also mandates the ACB to operate the Alberta Cancer Registry, and makes cancer a reportable disease. ACB is also mandated to manage fundamental and applied cancer research programs. Its services include: cancer prevention and screening, patient and professional education, diagnosis and treatment, and basic and applied research. ACB has also been given the lead role in coordinating the overall implementation of the *Alberta Cancer Control Action Plan.*

Funding:
ACB's core operations are funded by the government of Alberta, based on government's fiscal priorities, and a proposed budget and business plan submitted annually by ACB. ACB also derives some revenue from the treatment of non-albertan patients and from donations to the Alberta Cancer Foundation (ACF). ACF is corporate entity in itself, governed by the Alberta Cancer Programs Act , which raises and receives fund on behalf of the Alberta Cancer Board. About 70% of ACF funding supports research, while the remaining part supports patient programs, equipment purchase and cancer care across Alberta.Total revenue for ACB in 2005-06 was 300 millions, including 245 million from Alberta Health and Wellness and 3 million from other government contributions.

Annual expenditures related to cancer:
All of ACB's expenditures are related to cancer, which would include ACB's budget and an additional $25 million for extramurally funded research and about $15 million for ACF funding including research, prevention, education and services to patients.[156] For 2005-06, overall cancer services and infrastructure expenditures was approximately 285 million and about 9 million for administration.[157] About 10% of ACB's budget goes to research and education, 25% to diagnostic and therapeutic services, and 25% to facility based outpatient acute services.

Additional funding for service improvement and reform implementation:
In 2006, the government of Alberta established a $500 million endowment governed by the Alberta Cancer Prevention Legacy Act, the proceeds of the fund to be used for cancer prevention and cancer research..[158]

British Columbia Cancer Agency

Legal status:
The British Columbia Cancer Agency (BCCA) is a provincial agency created in 1974 under the *Society Act,* and mandated by the BC government to develop and manage a provincial program for cancer control.[159] The BCCA is a public hospital (Hospitals Act), a teaching hospital, a separate legal entity (Society Act), and a Branch Society of the Provincial Health Services Authority (PHSA).

Vision:
"A cancer free society."

Mission:
To reduce the incidence of cancer; to reduce the mortality rate of people with cancer; and to improve the quality of life of people living with cancer.

Accountability:
Since 2001, BCCA is governed by the PHSA, one of six Health Authorities that are part of the BC Health Ministry. PHSA's mandate is to ensure the planning, coordination, accessibility, quality, efficiency and effectiveness of selected province-wide health care programs and services. Since the integration of BCCA to the PHSA, BCCA no longer has its own Board. The BCCA Board is the PHSA Board, which oversees nine different entities, including the BCCA. The BCCA President is now accountable to the PHSA CEO and PHSA Board of directors as well.

President and CEO:
BCCA has a President

Executive team:
The executive team is comprised of senior staff with leadership positions in the Agency. The executive team is assisted by a *Priorities and Evaluation Committee*, with the responsibility of conducting annual reviews of new program proposals and ranking them on the basis of evidence (and cost/benefit ratio). The Committee then provides recommendations regarding funding to the agency's executive team and budget

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[156] Personnal communication, Dr Anthony Fields, VP Medical Affairs and Community Oncology, ACB, February 1 2007 letter.

[157] ACB 2005-06 Business plan, p. 27. Available at: http://www.cancerboard.ab.ca/pdf/about_acb/busplan_2005.pdf

[158] Alberta Cancer Prevention Legacy Act. Available at : www.assembly.ab.ca/bills/2006/bill-001.doc

[159] The Cancer Control Agency of BC (now called BCCA) was established through the tripartite agreement of the Province of BC, the BC Cancer Treatment and Research Foundation and the Cancer Control Agency of BC. The Agreement amalgamated the cancer treatment operations (BC Cancer Institute, Victoria Cancer Clinic and consultative clinics) to form one of two basic operational components of the BCCA, the other being devoted to education, epidemiology, prevention regional programs and research. A permanent relationship was also established between the BCCA and the BC Cancer Foundation. See BCCA Strategic plan, p. 8.

committee. The executive team is also assisted by *leadership teams* heading each of the regional cancer centres. There are also *provincial program teams* made up of representatives of the programs from across the province.

Functions:

The BC Cancer Agency provides a comprehensive cancer control program for the people of BC, including prevention, screening and early detection programs, research and education, and care and treatment. BCCA is involved in cancer control program development and implementation, service provision, research and clinical practice guidelines development among other things. It is responsible for service delivery in regional cancer centers (through service contracts with hospitals). The BCCA is responsible for cancer service delivery in regional cancer centres. In addition, BCCA enters into service contracts with host hospitals for a range of medical and support services provided by host hospitals/Regional Health Authorities.. BCCA is also responsible for managing the funds raised by the BC Cancer Foundation.

Funding:

BCCA's operations are funded by the Ministry of Heath and through the PHSA operating grant. The BCCA also reveives a small revenue form out-of-province patients. The operating budget of BCCA doubled between 1996 and 2002.[160] For 2005/06, BCCA revenues (and expenditures) were 246 millions.[161] For 2004-05, chemotherapy drugs cost 74 millions, radiation therapy program cost 38 millions, and operation of screening programs cost 21 millions.

Annual expenditures related to cancer:

A budget could be provided for for 05/06 if required.

Additional funding for service improvement and reform implementation:

In 2002/03, federal and BC governments each contributed 27,8 million dollars to the BC cancer Foundation for a new 95-million cancer research center managed and operated by the BCCA that opened in March 2005. In 2004, PHSA contributed 5 million dollars to BCCA to replace two radiotherapy machines, 20 million dollars to improve radiotherapy services and improve access to treatments, and paid for a PET/CT scanner. PHSA funding is, in effect, BC MoH funding. All initiatives identified above are negotiated with the MoH as part of capital plans.[162]

Canadian Partnership Against Cancer Corporation (CPACC), and previous Canadian Council for Cancer Control (2002-2006)

Note: In November 24, 2006, the Prime Minister of Canada announced the establishement of the Canadian Partnership Against Cancer. The Canadian Council for Cancer Control (CSCC Council) is to be replaced by the CPACC Board in 2007.

Vision of the Canadian Strategy for Cancer Control:

"Through the application of existing knowledge and the generation of new knowledge by research across the cancer control spectrum, the Canadian Strategy for Cancer Control will reduce the expected number of Canadians being diagnosed with cancer, reduce the severity of the illness, enhance the quality of life of those with cancer, and reduce the likelihood of dying from the disease."

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[160] Cancer Advocacy Coalition of Canada. Provincial spending on cancer agencies. Available at: http://www.canceradvocacy.ca/reportcard/2004/Provincial.spending.cancer.agencies.pdf

[161] PHSA Three year service plan 2005/06 to 2007/08, June 2005, p.27. Available at: http://www.phsa.ca/NR/rdonlyres/5C49C179-7AE6-48DD-8659-021013278DFC/10000/ApprovedServicePlanSections123UpdatedAug1005.pdf

[162] Personnal communication, Dr Simon Sutcliffe, President, BCCA, January 29, 2007 letter.

I. Canadian Partnership Against Cancer Corporation (2006-):

Legal status and mandate:

The Canadian Partnership Against Cancer is an independent, not-for-profit corporation created to implement the Canadian Strategy for Cancer Control. The CPACC will serve as a clearing house for evidence-based, up-to-date, information on prevention, screening, diagnosis and treatment of cancer.[163]

CPACC board composition and accountability:

The CPACC board of directors will comprise representatives from cancer stakeholder organizations; the provinces and territories; patient, family and survivor groups; Canada's Aboriginal peoples; and the federal government. This pan-canadian corporation will operate at arm's length from the government and report to the Federal Health Minister.[164] According to the proposed governance model, the "CSCC entity and board" (hence the newly formed CPACC and its board) would have both performance-based and financial accountability to the Federal Minitser of Health. The model also proposed that it would have performance-based accountability to provincial and territorial Ministers of Health and to cancer community stakeholders through the use of advisory and performance evaluation committees and risk-based performance evaluation information platforms.[165]

CPACC board functions:

According to the proposed governance model, the Board would be responsible for administering the CSCC, establishing the priorities and outcome-based goals of the CSCC and ensuring that the CSCC is implemented in accordance with the views of all the stakeholders.[166]

CPACC advisory council:

According to the proposed governance model, an Advisory Council would also be created with the following responsibilities: 1) To advise the Board on national targets for cancer control and on strategic directions, goals and priorities related to the achievements of these national targets; 2) To create robust links through the cancer control community; and 3) To establish and maintain the pan-Canadian networks of cancer experts and stakeholders (CSCC Action groups) that will drive elements of the CSCC forward.[167]

Funding:

In its May 2006 budget, the federal government commited 260 million dollars over the next 5 years for implementing the CSCC.

Annual expenditures related to cancer:

In Canada, provision of cancer control services is a provincial responsibility. In 1998, cancer cost the national economy $2.5 billion in direct costs for treatment, care and rehabilitation. It was estimated that over the next 30 years, cancer will cost the health care system more that 176 billion in directs health care costs.[168]

II. CSCC Council (2002-2006):

Legal status:

The Canadian Council for Cancer Control or CSCC Council was a coalition comprised of representatives from various stakeholders' organizations created to provide national leadership for advancing the vision

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[163] Prime Minister announces Canadaian partnership Against cancer. November 24, 2006. Available at: http://www.pm.gc.ca/eng/media.asp?id=1418

[164] St. Micheal's Hospital CEO and Canada's top health-care executive to lead new cancer partnership. Toronto November 24, 2006. Available at: http://www.stmichaelshospital.com/media/news_release_2006-11-24.php

[165] CSCC. The Canadian Strategy for Cancer Control: A cancer action plan. Discussion paper, July 2006, p. 15.

[166] CSCC. The Canadian Strategy for Cancer Control: A cancer action plan. Discussion paper, July 2006, p. 16.

[167] CSCC. The Canadian Strategy for Cancer Control: A cancer action plan. Discussion paper, July 2006, p. 17.

[168] CSCC. 2006-2010 business plan for the CSCC. Ottawa, 2006, p. 8.

of the Canadian Strategy for Cancer Control. It was appointed by stakeholder groups, outside the mandate of the Government to serve as the board of directors for the CSCC.

Mandate:

To advance the CSCC by encouraging, facilitating and supporting collaborative initiatives within the community of cancer control organizations and agencies. The Council also represented the consensus position on priority cancer control issues to influence public policy.

Accountability:

The Council was accountable to the Canadian population (moral ownership) and to a Forum of stakeholders' organizations. The CSCC Council has secured in place a performance management system to track/evaluate the performance of the CSCC Priority Areas Action Groups.[169]

Council members:

The CSCC Council consisted of 30 members,[170] including five representatives from patients/survivors/advocates appointed by the Canadian Cancer Advocacy Network (CCAN) and one representative from the following: provincial cancer agencies/programs where they exist or the Ministry of Health in other provinces/territories, the Canadian Cancer Society (CCS), Canadian research institutes (CIHR, NCIC), the Canadian Association of Provincial Cancer Agencies (CAPCA) and the federal government (Health Canada). Council members are nominated for three years.

Council chairs:

The Council was headed by a Chair. In addition, each Priority Areas Action Group was headed by a Chair who was directly accountable to the Council for the activities of the Group. The CSCC has a Quality and Performance Assurance Working Group and seven Priority Areas Action Groups: (1) Standards; (2) Clinical practice guidelines; (3) Primary prevention; (4) Rebalance focus; (5) Human resources; (6) Surveillance; and (7) Research.

Executive team:

From 1999 to 2004 the CSCC Secretariat and Executive director were from Health Canada's Center for Disease Prevention and Control. The executive director was managing financial oparations and ensuring links with the Council. The executive director was accountable to the Council Chair and the funding partners (namely, Health Canada). The Secretariat supported the Council and its Action Groups.

Functions:

A major (key) function of Council was to ensure the development of CSCC priorities, i.e., Action Groups, and the implementation of their recommendations to enhance cancer control outcomes in Canada.The Council's leadership responsibilities included the following: policy development, advice to governments on cancer control initiatives, organization of stakeholders' forums, monitoring and reporting on progress toward implementation of CSCC and achievement of cancer control targets. Its corporate responsibilities were to maintain and revitalize the CSCC as a dynamic overall strategic plan, to conceive and publish a five-year revolving plan, an annual action plan and a budget, to review and evaluate the previous year's activities, and to report the abovementioned plans and evaluations to the Conference of Deputy Ministers, the forum of stakeholders, and to CCAN.

Funding for CSCC development:

The Canadian Cancer Society and National Cancer Institute of Canada contributed financially for the initiation and development of the CSCC. From 1999-2004, CSCC was receiving 1.15 million dollars annually (including 900,000 from Health Canada).

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[169] CSCC 2006-2010 Business Plan. April 2006

[170] CSCC 2006-2010 Business Plan. April 2006, Appendix 1

England's Cancer governing organizations

Structure:
The system governing the NHS Cancer Plan is composed of various entities and individuals within the National Health Service (NHS) and Department of Health (DH). At the national level, the main bodies are: the National Cancer Director, the Cancer Taskforce, and the Cancer Action Team. At the regional level the main bodies are the Strategic Health Authorities (SHAs). At the local level, the main governing entities are the Primary Care Trusts (PCTs) and the Cancer Services Networks.

Vision:
"By 2010, England's five year survival rates for cancer will compare with the best in Europe." (as stated by the National Cancer Director in Cancer Action Team's Newsletter of december 2000)

Accountability:
The National Cancer Director and Cancer Taskforce are accountable to the Department of Health. The Cancer Action Team is accountable to the National Cancer Director. The SHAs are accountable to the Chief Executive of the NHS.The Primary Care Trusts are accountable to SHAs for performance and to the DH for the money they receive. The Cancer Services Networks are accountable to their Board of Directors composed of representatives of PCTs and SHAs. The Networks' Board of Directors are accountable to their SHA (see Figure 4 in this chapter).

National Cancer Director (NCD):
The National Cancer Director is responsible for achieving national cancer targets set out in the NHS Cancer Plan.

Cancer Taskforce (CT):
The Cancer Taskforce was set up to lead national implementation of the Cancer Plan. The Taskforce is chaired by the National Cancer Director. It monitors progress and identifies policy development needs.

Cancer Action Team (CAT):
The Cancer Action Team supports the development of Cancer Services Networks and implementation of the Cancer Plan. It also leads on quality assurance of cancer services through the *Peer Review Program* that monitors standards in cancer care, and through development of standards for auditing, based on NICE Clinical Outcomes Guidance.

Strategic Health Authorities (SHAs):
The Strategic Health Authorities are responsible for the strategic direction of services in their locality and for overall achievements of national parties. There are now 10 SHAs in England,[171] serving as the local headquarters of the NHS. The mandate of the SHAs around cancer is to make sure that the Primary Care Trusts, and the Cancer Networks in their area meet the national priorities at the local level.

Primary Care Trusts (PCTs):
The Primary Care Trusts are a group of general physicians and local administrators and practitioners that are responsible for planning services for populations of about 100,000 to 200,000. PCTs set priorities and allocate resources to implement national targets. The PCTs do not have an earmarked fund for cancer, it is part of their global budget.The performance of PCTs is monitored by Strategic Health Authorities (SHAs).

Cancer Services Networks:
The 34 existing Cancer Services Networks are large and complex non-statutory organizations that plan services for populations of one to 2 million people. They are virtual organizations that could be hosted anywhere but are usually hosted by a statutory organization, increasingly the PCTs. The Networks are the service delivery structure, bringing together all levels of care. They are responsible for the local implementation of the NHS Cancer Plan. The Network's executive team is composed of: a Network

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[171] Health Secretary announces new architecture of the local NHS. April 12, 2006. Available at: http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4133759&chk=40QEXO

Director, a Medical Director (or Lead Clinician), a Nurse Director (or Lead), a Modernization Lead and administration staff. The Networks' role is to streamline services across the spectrum of cancer care offered by multiple organizations and health and social care professionals in the community, local hospitals, specialist cancer centers, cancer units, and hospices. They are accredited following a peer review, and funded by Primary Care Trusts based on the submission of action plans. The Network board is composed of the Chief Executives of those organizations both commissioning and providing services within that network. (Acute Care Trusts and Primary Care Trusts). This Board is accountable to its SHA.

Funding:

No information available.

Annual expenditures related to cancer:

It was estimated in 2000[172] that cancer services accounted for 6.3 % (approximately 1.5 billion pounds) of NHS hospital expenditure in England. This excludes cancer services not provided on an in-patient basis, for example screening programs, ambulatory chemotherapy, radiotherapy and community palliative cancer services. 75% of the NHS funding to buy health care goes to the Primary Care Trusts, the remaining is held centrally and spent for national initiatives such as the Screening Programs, the Cancer Services Collaborative, the National Research Clinical Trials Network, etc. The funding comes from the Department of Health and the Treasury.

Additional funding for NHS Cancer Plan implementation and service improvement:

The NHS Cancer Plan stated that cancer services would receive an extra investment of 280 million pounds in 2001/02, rising to 407 million in 2002/03 and 570 million by 2003/04. A tracking exercise of investments in cancer services revealed that 639 million pounds were spent.

France's National Cancer Institute (INCa)

The overall governing system includes the Health Ministry, and a number of national agencies in addition to INCa, such as the Institut national de veille sanitaire (INVS), the Institut national de prévention et d'éducation à la santé (INPES) and the Haute autorité de santé (HAS).

Legal status:

The Institute (INCa) was created under the *Public Health Law* (art. L1415-2) of 2004 as a Public Interest Group charged with the coordination of all cancer control initiatives in France. It is not part of the Health Ministry. Its legal status (Public Interest Group) allows the organization to get financing from sources outside the Govenement.

Vision (of cancer plan):

"The fight against cancer is fought by patients, their families and friends, and the medical and nursing teams alike."

Mandate of INCa:

It is defined by the Public health law of 2004: "To imagine and promote the fight against cancer in the future years " (taken from INCa strategic plan)

Missions:

(1) To observe and assess the system in place to fight cancer; (2) To define benchmarks for good practices and care in the field of oncology and the criteria for certifying institutions and professionals in the field of oncology; (3) To inform professionals and the public; (4) To participate in the implementation and validation of continuing education for doctors and paramedical personnel; (5) To implement, finance and coordinate research projects in collaboration with the relevant public research organisations and charitable

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[172] The UK Parliament. House of Commons hansard answers for 12 Aprril 2000 (pt 16). Available at: http://www.parliament.the-stationery-office.co.uk/pa/cm199900/cmhansrd/vo000412/text/00412w16.htm

associations; (6) To develop and monitor public/private actions in the areas of prevention, epidemiology, screening, research, education, care and evaluation; (7) To participate in developing European and worldwide actions; and (8) To prepare expert reports on oncology and cancer issues at the request of the relevant ministries.

Accountability:

INCa is accountable both to the Ministry for Health and Solidarities and to the Ministry for Research.

Board of members:

The Institute's Board is composed of 27 voting members, including six government representatives, among which are the Chair, appointed by decree in accordance with the Public Health Code, three representatives appointed by the Minister of Health, and two representatives appointed by the Minister of Research. Other members include INCa partners' representatives, experts appointed by the Ministries for Health and for Research and some individuals selected for their interest in cancer. Sixty per cent of the members are State representatives, including the Chair. The founding members represented on the Board are entitled to appoint replacement members. The Board is informed by an *International Scientific Council*, a *Patient/users Committee* and a *Deontology Committee.*

President and Director General:

The Institute has a President and a Director General. The actual President is also Chairman of the board of members.

Executive teams:

Several executive teams are housed under various departments that span the research, care and international leadership missions of INCa. INCa also works in close collaboration with Health and Research Ministries, several Health Protection and Monitoring Agencies, national research organizations (INSERM, CNRS), patient organizations, national health insurance plans, and several federations of hospital/health facilities.

Functions:

The Institute's role is to coordinate all actors (public and private) in cancer control and to give international visibility to cancer control efforts in France. Its *2005-2007 strategic plan* has 3 priorities: 1) Implement and coordinate the national cancer control policy, 2) Define and finance the cancer research policy, and 3) Fight against cancer in Europe and elsewhere in the world.

Funding:

The Institute's operations are funded by the Health Ministry and the Research Ministry, which provided 70 million euros in 2005, 80 million in 2006, and plan to provide 100 million euro in 2007. 85% of funding goes to cancer control initiatives external to the Institute; 15 % goes to internal activities, mainly the Institute's research mandate and the rest to administration.

Annual expenditures related to cancer:

7-15 billion euros.

Additional funding for Cancer Plan implementation:

1,64 billion euros was committed for 2003-2007.

New Zealand Cancer Control Council and Principal Advisor

Legal Status:
In 2005, the Minister of Health established a *Cancer Control Council*, under Section 11 of the *New Zealand Health and Disability Act*, to provide an independent and sustainable leadership in cancer control. The Council is at arm's length from the Health Ministry. A Principal Advisor was appointed by the Director-General of Health to provide leadership, advice, information and guidance to the Director-General of Health, the Ministry of Health and the Minister of Health on issues relating to cancer control. This position is located within the Ministry's Clinical Services Directorate and has a close working relationship with the Deputy Director-General of Clinical Services.

Overall purpose of the Strategy:
"(1) Reduce the incidence and impact of cancer; and (2) reduce inequalities with respect to cancer."

Accountability:
The Council is accountable to the Health Minister. The Principal Advisor Cancer Control is accountable to the Director-General of Health. It may also report to the Minister of Health on cancer control issues, having first notified the Director-General of Health.

Council members/functions:
The Council is comprised of 10 members that are appointed by the Minister of Health, including the Chair and Deputy Chair, and the Principal Advisor Cancer Control who is an ex officio member of the Cancer Control Council. The Council's objective is to lead the cancer control sector to successfully implement New Zealand's Cancer Control Strategy. The Council's task is to monitor and review implementation of the Strategy and to foster collaboration and coordination, as well as providing opportunities for non-government involvement.

Principal Advisor Cancer Control:
The Principal Advisor is leading the *Cancer Control Work Programme*, established by the Health Ministry to implement the Cancer Control Action Plan (see below).

Cancer Control Work Programme:
The Ministry of Health and the 21 District Health Boards (DHBs) are working to implement actions identified by the *New Zealand Cancer Control Strategy Action Plan 2005-10* through a structured cancer control work programme. Stakeholders involved in the cancer control work programme include:

- the Ministry of Health and DHBs, which are jointly managing the programme via a Steering Group
- the New Zealand Cancer Treatment Working Party (NZCTWP) and its workgroups, representing the professional cancer control community, which are contributing to the design and execution of many of the projects in the programme
- the Principal Advisor Cancer Control, who is leading the programme, working closely with DHBs and the cancer control community and linking with the Cancer Control Council as an ex-offico member
- consumer groups and other important stakeholders, who will be consulted as an important aspect of all of the projects
- the Cancer Control Council, which will review progress in the Action Plan, advise on cancer control, and report to the Minister about progress towards achieving the goals of the Cancer Control Strategy.

Funding:
Both the Cancer Control Work Programme and the operations of the Principal Advisor and Council are funded by the Health Ministry.

Additional funding for Strategy development and implementation:
Development of the National Strategy was funded by the Health Ministry and the Cancer Control Trust. Between 2001 and 2004 the Cancer Society of New Zealand together with the Child Cancer Foundation gave 700,000 dollars to the Cancer Control Trust for the development of the National Strategy. In 2005, the Government committed 40 million dollars funding for cancer control in the first phase (2005-06) of the Cancer Control Strategy Action Plan. The package is distributed along the following: 13.2 million for

breastscreen age extension and evaluation of colorectal screening policy; 6.4 million in primary prevention activities; 2.2 million for smoking prevention and cessation services; 6.0 million for palliative care, support and rehabilitation; 5.3 million for treatment services including an extra 4 million for cancer drugs; 3.2 million in research and development; and 1.1 million in workforce development. This 40 million will then become part of baseline funding for the next four years. This funding is on top of cancer control initiatives already happening at District Health Board and national levels. As part of phase I implementation of the Action plan, 1.75 million (Implementation Fund) were allocated to fund 23 local projects proposed by the DHB's and NGO's[173].

Cancer Care Nova Scotia Program, and former Commissioner (1998-2006)

Legal status:
Cancer Care Nova Scotia (CCNS) is one of the Provincial Programs in the Acute and Tertiary Care Branch of the Department of Health.[174] These Provincial Programs address health issues across sectors of the health system which are beyond the mandate of any single District Health Authority or health organization. CCNS is responsible for ensuring a high quality cancer system through partnerships with health districts, health providers, Academic research centers, community organizations, as wel as patients and family members.

Vision:
"CCNS will reduce the effects of cancer on individuals and families through research, prevention and screening, and will lessen the fear of cancer through education and information. Nova Scotians diagnosed with cancer, together with family, friends, and community will find all aspects of cancer care excellent in quality, professional in focus, compassionate in delivery, and caring in spirit." (CCNS website)

Mission:
"This provincial program, in collaboration with other agencies organizations and individuals will: (1) Protect and promote the physical , psychological, social and emotional well-being of people living with cancer; (2) Reduce the incidence and mortality rate of cancer by strengthening cancer control programs in prevention, early detection and research; (3) Provide leadership in developing standards for cancer care and treatment facilities and promote enhanced compliance with evidence-based protocols through evaluation focusing on outcomes; (4) Working with existing infrastructure in the province, develop and enhance the provincial cancer registry, a cancer control and epidemiology research unit and implement information systems to fulfill the mission and mandate; (5) Ensure and enhance through co-operative action, excellence in cancer care, research, education and system management; and (6) Improve the quality of life of persons living with cancer by focusing on patient needs and services, by ensuring easy navigation through the complex cancer system and by establishing quality management and improvement programs in all componenets of the cancer system." (Appendix to contract for Commissioner)

Mandate:
(1) To serve as the primary advisor to the Minister and the Department of Health (DH) on matters pertaining to the cancer system, cancer control and cancer care; (2) To provide leadership, analysis and evaluation of components and programs of the cancer system including guidance and planning advice to the DH in planning and operating cancer system programs, facilities and evaluations; (3) To establish provincial policies for cancer care and treatment including clinical practice guidelines developed by

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[173] Cancer Control i New Zealand. Canncer Control Work Programme. Available at: http://www.moh.govt.nz/moh.nsf/indexmh/cancercontrol-workprogramme

[174] From its inception, and until March 2004, the CCNS program was defined as a program of the Nova Scotia Department of Health *in partnership with* Dalhousie University's Faculty of Medicine and the Queen Elizabeth II Health Sciences Center (see CCNS Newsletters). Since March 2004, CCNS is defined only as a program of the Nova Scotia Department of Health.

multi-disciplinary specialty groups and professions; (4) To advise on policies, standards, and guidelines for the appointment of oncology specialists in medical, radiation and surgical disciplines; (5) To review and advise on cancer program operating plans and budgets in health care facilities across the province, including review of new programs, facilities, equipment and services; (6) To do an annual review and analysis of cancer programs acroos the province and to make recommendations regarding funding of such matters as capital projects, major equipment purchases and human resources inventory; (7) To establish, develop and lead a coalition of organizations, volunteers and individuals in intersectorial cancer prevention strategies and programs; (8) To develop supportive care for cancer patients and their families in co-operation with the family physicians and local health facilities and volunteer organizations; (9) To develop community-based programs for cancer information, prevention, screening, treatment (where appropriate), rehabilitation follow-up, palliation and support; (10) To co-ordinate, support and promote education and research activities to ensure that health facilities and health professionals remain current with emerging knowledge, guidelines and policies for the prevention and treatment of cancer; (11) To be responsible for the co-ordination, with existing provincial infrastructure, of provincial cancer data collection, cancer registry operations and cancer control and epidemiologic research to integrate with federal cancer control strategies, all provincial health care facilities and inter-institutional cancer programs; and (12) To work with charitable foundations… to foster and enhance charitable donations, bequests and fundraising to support the care of cancer patients, education and information programs and basic and applied cancer research activities. (Appendix to contract for Commissioner)

Accountability:

The Chair of the CCNS Board of directors reports directly to the Minister of Health. The Commissioner reports directly to the Deputy Minister of Health. The Chief Operating Officer is accountable to the Commisioner in respect of performance of duties.[175]

Board of directors:

CCNS Board of Directors is comprised of 23 members, half of which is appointed by the government. Members are health care professionals in the field of cancer, researchers, volunteers, patients and their family members and representants from the Canadian Cancer Society. The Commissioner is an ex-officio member of the CCNS board. The CCNS board is advisory.

Commissioner:

The Commissioner of CCNS is responsible for achieving the vision of Cancer Care Nova Scotia. The Commissioner’s original appointment was a conjoint trilateral appointment for: (1) Commissioner of CCNS provincial program, (2) Head of the Cancer Care Program at the QE II Health Sciences Centre, and (3) Associate Dean for Cancer Programs at Dalhousie University in the school of Medicine. This arrangement was deemed essential to foster links between the provincial coordinating body, the cancer service providers and the academic (research) activities. These arrangements are spelled out in the *Appendix to the contract of the Commissioner*, a ten-page document which itemize duties, responsibilities, goals and objectives, as well as part of the contract between the Commissioner and the three legal entities, namely the province, the QE II HSC, and the university.[176] In 2003, the Commissioner was also recruited as VP of Research and Academic Affairs at the Capital Health District.[177] The Commissioner’s role was to foster integration of cancer control sectors by working with academics, clinicians, health professionals, cancer patients and survivors to ensure that a quality, coordinated and patient-focused system is in place for Nova Scotians. Since its inception (1998), CCNS had one Commissioner, who resigned in 2006.

Executive team:

The strategic and operational planning, as well as management and operations of CCNS activities are under the responsibility of the Commissioner and, through the Commissioner, to the Chief Operating

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[175] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter

[176] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

[177] CCNS Newsletter, July 2006. http://www.cancercare.ns.ca/media/documents/NewsletterJuly2006.pdf

Officer (COO).[178] The Commissioner and COO are assisted by a core CCNS staff of approximately 20 people. Another 10 staff are with the Cancer Registry and the Surveillance and Epidemiology Unit, while another 10 staff are with the Gynecologic Cancer ssreening program.

Functions:

CCNS conducts surveys and roundtables to identify needs and develops programs accordingly that are usually associated with an evaluation component. CCNS also coordinates and improves cancer services, namely by developing service standards and monitoring their achievement. CCNS provides advice to the Department of Health, the Regional Health Boards and care providers based on best practices, stakeholders' input and research-based evidence. It does not deliver services, does not have research centers and does not make fundraising. Working with others in the field of cancer and health, CCNS programs cover prevention, screening, patient and health professional education, treatment, follow-up care and palliation.

Funding:

The Department of Health funds CCNS for its operations. CCNS budget by.has been stable for the last three years and amounts to 5 million dollars annually.[179] This does not include any cancer treatment activity.

Annual expenditures related to cancer:

Overall cancer expenditures in Nova Scotia, including cancer specific in-atient care, surgery and chemotherapy would was estimated to be in the range of 50-60 million dollars. The 2006 budget for the Cancer Care Program of the QE II/Capital Health District was about 39 million, while the one for the Cape Breton Cancer Center activities ranges between 3.5 to 4 million per year. Figures cannot be accurately determined for cancer program expenditures in other DHA's or for the IWK Health Center.[180]

Additional funding for program implementation and reform:

In its most recent budget, the Nova Scotia Government announced that it would invest $15.9 million in oncology drug costs, specialists and treatment support for cancer programs in the Capital Health and Cape Breton Districts.[181]

Cancer Care Ontario

Legal status:

Cancer Care Ontario (CCO) is an operational service agency within the Management Board of Cabinet Establishment and Scheduling of Agencies Directives (for details see organizational chart of Ontario Health Ministry in appendix 6B). CCO is independant from the Ministry of Health and Long Term Care (MOHLTC) and from the Ministry of Health Promotion. CCO steers and coordinates Ontario's cancer services and prevention efforts. CCO is governed by the *Cancer Act* (L.R.O. 1990).

Vision:

"Working together to create the best cancer system in the world."

Mission:

"Driving quality, accountability, and innovation throughout the cancer system."

Accountability:

CCO is accountable to the Minister of Health and Long-Term Care in exercising its mandate. The details of CCO's relationship with the Ministry of Health and Long-Term Care are laid out in a formal Memorandum of Understanding.

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[178] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

[179] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

[180] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

[181] Nova Scotia 2006-2007 budget address. Available at; http://www.gov.ns.ca/finance/budget06/BudgetAddress2006_07.pdf

Board of directors:
The *Cancer Act* requires that the government appoint, by order-in-council, the members of Cancer Care Ontario's Board of Directors. The corporate bylaw: names the Board as the governing body with the sole power and authority to direct all policy making in the organization, ensures that Cancer Care Ontario's mandate is being fulfilled and is in compliance with government legislation and policies, and approves Cancer Care Ontario's strategic plan and annual operating plans. Several Board Committees are set up to support the development and assessment of policy options and their implementation, and to fulfill other delegated responsibilities.

President and CEO:
The President and CEO is accountable to the Board of Directors.

Executive team:
The Executive team is supported by several Councils that are accountable to the CEO. These include: (1) the Provincial Leadership Council, (2) the Clinical Council, (3) the Provincial Cancer Prevention and Screening Council, and (4) the Ontario Cancer Information Management Network (which has replaced the former Information Management Strategic Council). The *Clinical Council* comprises clinical program leaders with the mandate to establish and facilitate the implementation of clinical standards for the cancer system.[182] The *Provincial Leadership Council* provides leadership for the development, execution, and monitoring of the cancer plan.[183] The Provincial Leadership Council further aims to foster alignment between community, regional, and provincial activities throughout Ontario and CCO. The *Provincial Cancer Prevention and Screening Council* aim sto address cancer prevention and screening initiatives as well as to work with other chronic disease initiatives at the provincial and national level.[184] The *Ontario Cancer Information Management Network* is comprised of representatives of CCO and Regional Cancer Programs. It is accountable for the sharing and exchanging of information, providing input and advice in areas of information management (data collection, data standards, quality monitoring, etc.) and ensuring two way communications to and between CCO and the Regional Cancer Programs.

Functions:
Cancer Care Ontario steers and coordinates Ontario's cancer services and prevention efforts. CCO has an advisory, planning and a funding role. Cancer Care Ontario advises the Ontario government on all aspects of provincial cancer care, provides information to health care providers and decision-makers, and motivates better cancer system performance.

Funding:
CCO operations are funded by the Ministry of Health and Long Term Care. CCO's budget was 393,4 million dollars for year 2004 (85% is coming from the Ontario Health Ministry) and CCO spent 404,8 million dollars, that were divided up among the following categories: salaries (98,3 millions), Integrated Cancer Programs (68,2), drugs (72,2), medical and surgical service provision (29,4) and others. CCO is now responsible for approximately 30% of the Province's cancer expenditures.

Annual expenditures related to cancer:
Two billion dollars in 2003.

Additional funding for program reform and Action Plan implementation:
In 2005, the Government of Ontario invested more than 80 millions to increase the capacity of cancer services, including capital improvements, facility expansion, equipment acquisition, and reducing surgery wait times. Commitments were made for the creation of 4 new cancer centers. In January, 2006, the Ontario government announced $19.8-million in operating funds for new and expanded programs at five regional cancer centres. Investments needed for implementation of CCO 2004 Action Plan amounts to approximately 587 millions in the next three years (2006-09).

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[182] Ontario Cancer Plan

[183] CCO. Introducing CCO's advisory councils .http://www.cancercare.on.ca/OntarioCancerNews Archives/200310/index_1003Story3.html.

[184] CCO. Ontario Cancer News. .http://www.cancercare.on.ca/OntarioCancerNewsArchives/ 200311/index_1003Story3.html.

Legal status:

Most of the governing organizations reviewed are statutory bodies in the sense that they were established by laws (cancer acts or other laws) passed by the government. This is the case for: ACB, BCCA, CCO, INCa, and the NZ Cancer Control Council. England's Taskforce and Nova Scotia's CCNS program are the exception, albeit they are part of the government's internal structure. As for Canada, the chosen governance model was that of an independent organization: the previous CSCC Council was accountable to the population and to a Forum of stakeholders, while the new CPACC is accountable to the federal Health Minister, yet operating at arm's length.

Summary of key points:

- Authority of the body derived from legislation: ACB, BCCA, CCO, INCa, NZ Cancer Control Council
- Authority of the body derived from its position within Health Ministry/Department: CCNS, England's National Cancer Director, Cancer Action Team and Taskforce
- Authority of the body derived from its composition and its position (arm's length) with respect to the government: CPACC

Vision and mission (and values):

The vision, mission, and values of an organization are essential elements in providing the structure under which a cancer control program or plan is delivered to a target population. Each of these elements serves as an essential step toward formulating the other (Peters, 1995).[185] Articulating an organization's values and/or guiding principles, as well as establishing its vision and mission(s), is a process that engages the entire organization and, in some cases, the different stakeholder groups.

The *vision statement* of an organization reflects the ideal future the organization is striving to achieve. "Effective visions provide a word picture of what the organization intends ultimately to become - which may be five, ten, or fifteen years in the future." (Niven 2003, p. 116).[186] With a shared vision, the organization can then stipulate a clear mission for itself. The *mission* of the organization defines "the core purpose of the organization, i.e., why it exists" (Niven 2003, p. 102), which subsequently inspires the organization's actions.

The *values* represent "the deeply held beliefs within the organization about the qualities considered worthwhile or desirable" (Niven 2003, p. 111). They shape the vision and guide the organization's day-to-day actions. Values may also be expressed as guiding principles that more concretely provide guidance to how the organization will act in a manner that is consistent with the mission and along the path to achieving its vision (Peters, 1995). The values, guiding

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[185] Peters DA Outcomes: the mainstay of a framework for quality care. J Nurs Care Qual. 1995 Oct;10 (1):61-9 (pp. 62;65).

[186] Niven PR. Balanced Scorecard. Step by Step for Governments and Nonprofits. John Wiley & Sons, Hoboken, New Jersey, 2003.

principles and fundamental views (concepts) which can be found in jurisdictions' design of cancer control strategies, programs and actions plans, have been described in chapter 5. In this chapter, we compare cancer control governing entities with respect to their vision.

For national jurisdictions such as Canada, England, France, and New Zealand, where development of a national cancer strategy has preceded the creation of a governing organization, the vision for cancer control can usually be found in the strategy or action plan, when explicitely stated (see shaded boxes). For example, France's vision for cancer control, also expressed in the name of the action plan -- Cancer a nationwide mobilization plan --, stresses the importance of collaboration, and of the need to organize all stakeholders and activities into a coherent system. While not explicitely identified as such, England's vision for cancer control is to dramatically improve survival rates. This vision, focused on health outcomes, is understandable given that England had high incidence and mortality rates and among the worst survival rates in Europe at the end of the nineties. In New Zealand, no such thing as a vision or mission could be explicitely found in the policy documents or in the Cancer Control Council's terms of reference. The vision and mission may be comprised within 2 overall purposes guiding the NZ cancer control strategy and action plan: (1) to reduce the incidence and impact of cancer; and (2) to reduce inequalities with respect to cancer. In Canada, given that health services delivery is a provincial responsibility, the vision of the CSCC reflects the potential contributions of a cancer control strategy to improving health outcomes at the federal level, namely the production and sharing of knowledge and best practices.

Interestingly, all four provincial jurisdictions have clear vision statements for their main cancer control governing bodies, however, with differing ambitions. Not surprisingly, these statements also reflect each jurisdiction's specific context and challenges. The BC Cancer Agency, which operates in the province with the lowest cancer incidence and mortality rates in Canada, provides the boldest vision, that of a "Cancer free society." The Alberta Cancer Board, whose main priorities are service provision and research, used to have a vision focused on its traditional core business- "excellence in cancer control." However, it has recently defined a new and more challenging vision - "Cancer free future." This vision arose out of internal planning by ACB and was inspired by the opportunity afforded by Alberta's wealth and strong foundations in cancer control and research organization, programs and facilities.[187] Cancer Care Ontario, whose renewed mandate is to foster integration of cancer services and prevention efforts, while only controlling 30% of the province cancer expenditures, is setting the bar high with the following statement- "working together to create the best cancer system in the world." For Nova Scotia, its vision is that "CCNS will reduce the effects of cancer on individuals and families through research, prevention and screening, and will lessen the fear of cancer through education and information. Nova Scotians diagnosed with cancer, together with family, friends, and community will find all aspects of cancer care excellent in quality, professional in focus, compassionate in delivery, and caring in spirit." The vision of Cancer Care Nova Scotia suggests a focus on reducing the burden of cancer on individuals and families rather than a focus on optimizing the system.

Summary of key points:

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[187] Personnal communication, Dr Anthony Fields, VP Medical Affairs and Community Oncology, ACB, February 1, 2007 letter.

- Vision focused on *cancer control system* organization, quality or performance: France, CCO
- Vision focused on *health outcomes*: ACB, BCCA, Canada, England, New Zealand
- Vision focused on *improvingthe well-being of people with cancer*: CCNS

Structure:

The structure is the formal system of working relationships within an organization, delineating the reporting relationships between different functions and positions of the governance in relation to management teams. The structure of each jurisdiction's governing body or organization is represented in the form of organizational charts (see Appendix 6C). In addition to the governance and management structure, these charts depict the organization's programs and infrastructure. The intent of these charts is to shed light (notwithstanding limitations) on the formal and visible ways organizations carry their mission/mandate through planning, creation of programs and networks, research, education and evaluation activities, information management, communications, and funding.

Boards and councils:

A *Board of Directors* is a group of persons who, whether elected or appointed, are responsible for governance and supervision of the policies and affairs of the organization, its committees, and its officers. The Board of Directors carry out the purpose of the organization. A *Council* is a body of people elected or appointed to serve as administrators, legislators, or advisors. A Council may also be responsible for governance and supervision of policies. The Board and Council may delegate tasks and expertise to committees or working groups. Because committees or working groups may include external members, they are also a means of expanding input and decision-making.

The cancer control governing entities that have their own Board of directors are ACB, CCO, CCNS, CPACC and INCa. In Ontario, the *Cancer Act* requires that the government appoint, by order-in-council, the members of CCO's board. In Alberta, the members of ACB's board are appointed by the Minister of Alberta Health and Wellness. Although ACB and CCO are not positioned within their respective provincial Health Ministry/Department, their Board may be viewed as "political" since members are named by the government.

In Canada, the CSCC Council was superceded by the CPACC Board, that has representatives from the federal government, the provinces and territories as well as various cancer control stakeholder organizations. The main difference between the previous Council and the newly created Board is in the accountability structure as well as in the powers associated with a 5-year financing from the federal government.

In France, the Board is composed of 27 voting members, including six government representatives, among which are the Chair, appointed by decree in accordance with the Public Health Code, three representatives appointed by the Minister of Health, and two representatives appointed by the Minister of Research. Other members include INCa partners' representatives, experts appointed by the Ministries for Health and for Research and some individuals selected for their interest in cancer. The government holds majority with 60% of the vote. The founding members represented on the Board are entitled to appoint replacement members.

In Nova Scotia, the government also appoints the Board, which is an advisory body to the Minister of Heath. CCNS's inaugural Board comprised 35 members with indefinite mandate, and included representatives from the Canadian Cancer Society, health care professionals, academics, administrators, volunteers, patients, survivors, and family members. In September 2005, the CCNS Board was comprised of 23 members and 4 ex-officio members, including the Commissioner.[188] A report evaluating CCNS (2001) recommended that the CCNS Board be given legislated authority and responsibility for the quality of the provincial cancer system. They hence proposed a shift from an advisory function to a governing function in order to solidify and make permanent the commitment to improving cancer care in Nova Scotia.[189] As of now, no action has resulted from this recommendation.[190]

A less familiar approach is for the governing entity to report to an upper level Board. This is the case for BCCA. As a result of the creation of the PHSA in 2001, the BCCA Board disappeared and the Agency became accountable to the PHSA COO. Since then, the BCCA operational plans are integrated in the PHSA's planning documents. In 2003, BCCA managed to reposition itself in a satisfying relationship with the PHSA that would maintain BCCA powers to set strategies and goals around the budgets and the directions. The President of BCCA now reports to the PHSA CEO and the PHSA Board.

Another approach is that of the Council. In Canada, the previous CSCC Council was created to promote and implement the CSCC and to generate consensus positions emerging from the cancer control community. In New Zealand, the Cancer Control Council was created to provide independent oversight of actions to control cancer and implement the NZ Cancer Control Strategy.

Finally, in England, the structure is complex and the structures and lines of accountability are not always very clear. The Department of Health (DH) is governed by a Board of directors, chaired by the DH Permanent Secretary. The National Cancer Director who chairs the Cancer Taskforce, reports to the DH and hence, ultimately reports to the Chair of the DH Board (See Organizational charts for England in Appendix 6B and 6C).

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[188] Cancer Care. Many hearts, many minds one goal. CCNS Newsletter, vol. 6, no. 4, September 2005.

[189] Taken from CCNS Newsletter, vol. 2, no. 3, July 2001. The Report's recommendations concerning the board were the following: (1) CCNS should have a governing board constituted under appropriate provincial legislation accountable to the Minister of Health for a provincial program of cancer control services; (2) The Board should be responsible for developing and monitoring appropriate strategic initiatives to meet the mandate of CCNS; (3) The Board size should be capped at 12-15 members who should be representative of the geography and diversity of Nova Scotia; and (4) Representatives of the many organizations involved in cancer care may appropriately serve the cause by membership on committees advisory to the Board.

[190] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

Summary of key points:

- Governing entity with its own board of directors: ACB, CCO, CCNS, CPACC, INCa
- Governing entity with upper level board of directors: BCCA, England's Cancer Taskforce
- Councils: Canada's former CSCC Council, NZ Cancer Control Council

Executive teams:

The *executive team* is the group of individuals responsible for managing staff and carrying on the organization's daily activities. This senior level management team is usually led by a President, Chief Executive Officer (CEO) and/or Executive Director. The CEO or Executive Director and the Chair of the Board or Council together provide leadership in achieving the organization's mission.

There is a wide variation in the composition of the executive teams. A first distinction must be made between Councils and organizations with Board of Directors. In jurisdictions with Councils or a Taskforce (such as New Zealand and England), the executive team can be defined as the group assisting the Chair. In England, the Taskforce Chair is also the National Cancer Director. In New Zealand, the Council Chair is assisted by a Secretariat. However, another structure was recently set up to steer the implementation of the NZ Strategy: The Cancer Control Work Programme Steering Group, led by the Principal Advisor for Cancer Control and comprising representatives from the Ministry of Health, the DHB's and the Cancer Control Council (see snapshot of New Zealand governance above).

Organizations with Boards of Directors can be divided in two: France, and three Canadian provincial bodies on the one hand, and CCNS on the other. In France, the INCa President is assisted by a Managing Director, who, in turn, is assisted by more than a dozen departmental directors. ACB, BCCA and CCO have Presidents who also cumulate the function of CEO (with the exception of BCCA), and who are assited by a number of Vice-Presidents responsible for the main divisions of the organization. While ACB has a simple and light structure, CCO is more complex, considering that CCO's President is also assisted by a number of advisory councils, which reflects the central advisory function of the organization.

In Nova Scotia, the CCNS Board is advisory. The board chair directly reports to the Ministry of Health. The Commissioner is responsible for the management and operations of CCNS and is an ex-officio member of the Board. The Commissioner directly reports to the Deputy Minister of Health. He is assisted by the Chief Operations Officer and a core staff of 20 people at CCNS. Since the Commissioner's departure in 2006, a Physician Clinical Advisor was appointed to provide support and advice to the Board of CCNS and the COO and staff in respect of any medical aspects of cancer control, cancer care, and cancer treatment. This is a part-time responsibility that is discharged by the current Medical Director of the the Gynecological screening program. A decision on if and how to replce the Commissioner in a similar role to that found from 1998-2006 has not been made. A consultation report of stakeholder opinion has been submitted to the Department of Health in September 2006, but no response as yet been forthcoming.[191]

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[191] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

It is too early to provide details on the CPACC Board, but the governance model proposed by the CSCC Council in 2006 stipulated that the Board will be supported by an Advisory Council to establish and maintain the various CSCC Action Groups that were created based on the CSCC priority areas.

Functions:

Table 7 compares the various functions associated with the main cancer control governing bodies. Major differences are highlighted (see grey shaded lines within Table) which relate to the following functions: (a) advising government; (b) planning services; (c) delivering services; and (d) research.

Table 7. Functions of provincial/national cancer control governing bodies

Functions	**ACB**	**BCCA**	**CPACC**	**England's Taskforce**	**INCa**	**NZ Council**	**CCNS**	**CCO**
Advising government	**No**	**No**	**X**	**X**	**X**	**X**	**X**	**X**
Program planning	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
Ensuring program implementation	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
Monitoring progress implementation	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
Coordinating stakeholders	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
Service planning	**X**	**X**	**N/A**	**Networks** **PCTs**	**DGS** **DHOS**	**DHBs**	**DHAs**	**X**
Service purchasing	**X**	**X**	**N/A**	**PCTs**	**No**	**DHBs**	**No**	**X**
Coordinating service provision	**X**	**X**	**N/A**	**Networks**	**Networks**	**Networks**	**DCPs**	**ICP-LHINs**
Service delivery	**X**	**X**	**N/A**	**Networks**	**No**	**Networks**	**No**	**ICP-LHINs**
Quality improvement	**X**	**X**	**X**	**CAT**	**X**	**X**	**X**	**CQCO**
Performance management	**X**	**X**	**N/A**	**SHAs**	**No**	**DH**	**No**	**X**
Evaluation	**X**	**X**	**X**	**CAT**	**X**	**X**	**X**	**X**
Public information	**X**	**X**	**X**	**CAT**	**X**	**X**	**X**	**No**
Research funding and production	**X**	**X**	**No**	**No**	**X**	**No**	**No**	**X**

Legend: **CAT**: Cancer Action Team; **CQCO:** Cancer Quality Coucil Ontario; **DCPs**: Distrrict Cancer Programs; **DGS**: Direction générale de la santé; **DH**: Department of Health; **DHAs**: District Health Authorities; **DHBs**: District Health Boards; **DHOS**: Direction de l'hospitalisation et de l'organisation des soins; **ICP-LHINs**: Integrated Cancer Programs in Local Health Integrated Networks; **N/A**: Not applicable; **PCTs**: Primary Care Trusts; **SHAs**: Strategic Health Authorities.

For both ACB and BCCA, the main function is that of providing cancer control services. They are also the only two bodies whose main official functions do not include advising the government on cancer control issues. In contrast, CCO's recent reorganization in 2002 resulted in a move away from being a direct service delivery agency to becoming the government's principal advisor on cancer control issues. However, given CCO's mandate is also to develop a province-wide cancer control program of services, it does play an ever-increasing role in purchasing services and establishing performance contracts with service providers. CCNS is mainly responsible for coordinating all cancer control stakeholders in order to strenghten the cancer control system and to foster cancer research, although it does not produce or find the research. In that respect, it share similarities with France's INCa, except for INCa's major role in funding research and its European/International scope.

There is some difference regarding service planning between most Canadian provincial bodies and the National governing bodies of England, France and New Zealand. While most Canadian provincial cancer control bodies are responsible for some or all of tthe cancer services planning (whether or not they provide services), the national governing organizations in England, France and New Zealand are mainly responsible for ensuring and monitoring cancer plan implementation, which involves collaboration with their respective Health Ministries, regional authorities, and/or networks for service planning. Cancer Care Nova Scotia, which is a program within the Department of Health also plays a collaborative role in service planning, namely by promoting the creation of District Cancer Commitees and Programs in partnerships with the Nova Scotia District Health Boards.

A final element that distinguishes the cancer control main governing bodies in the selected jurisdictions is their involvement in the funding of research, or the fact that they operate or not research centers. France's INCa is the only national level governing body that has a major commitment to research funding. In Canada, New Zealand and England, this responsibility is not part of the mandates of the governing bodies, but of course that does not mean that cancer control research is not otherwise strong in these countries.

All Canadian provincial bodies except CCNS have chosen to retain major control over research by having their own research facilities and/or by funding extramural projects. In Nova Scotia, CCNS played a key role in facilitating a collaborative partnership known as the Dalhousie Cancer Research Program (DCRP) whose chair was the CCNS Commissioner.This partnership resulted in a substantial increase in cancer research capacity and programming across all aspects of cancer control research in Halifax and Nova Scotia.[192]

Summary of key points:

- Main function in service delivery: ACB, BCCA
- Main function is advisory: CCNS, CCO, CPACC, England's Taskforce, INCa, NZ Cancer Control Council
- Substantial responsibility for service planning: ACB, BCCA, CCO
- Research funding/producers: ACB (and Foundation), BCCA (and Foundation), CCO, INCa

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[192] CCNS Newsletter, July 2006. Available at: http://www.cancercare.ns.ca/media/documents/NewsletterJuly2006.pdf

Investments in cancer control:

Investments in cancer control are, for the most part, provided by governments although in some governing organizations (for example ACB), a small amount of the organization's revenues may come from charities. The $ figure for BCCA does not include research revenues (2006 – $75M).[193]

Table 8 attempts to capture jurisdictions' investments in cancer control according to three different dimensions- namely, the jurisdiction's global annual cancer expenditures, the budget allocated to the main governing organization, and the funding commited by the governments for program improvement or action plan implementation. The data used for this compilation, also reproduced in the shaded boxes describing cancer control bodies (see below), were drawn from annual reports, media releases on relevant websites, action plans, progress reports, audit report and personnal communications.

Table 8. Investments in cancer control by jurisdictions

Jurisdiction population (2003)	**Annual budget of main governing organization**	**Additional funding for upgrade/ reform implementation**	**Global annual cancer expenditures (estimates)**
Alberta 3 146 066	ACB: 300 million CAN dollars (2005-06), including 245 million from Alberta Health and Wellness.	In 2006: 500 million endowment, the proceeds to be used to upgrade cancer prevention and research	ACB: 285 million for cancer services and infrastructure and 9 million for administration (2005-06)
British Columbia 4 162 535	BCCA: 246 million CAN dollars (2004-05)	25 million (2004)	Through BCCA's budget
Canada 31 629 677	CSCC Council: 1,15 million CAN dollars (2003-04)	In 2006: 260 million for 2006-2010	2.5 billion in direct costs for treatment, care and rehabilitation (1998)
England 49 852 500	Information not found	From 2001-2004: 570 million pounds; (639 million spent) *[1,3 billion CAN]*	1.5 billion pounds for in-patient services only (2000) *[3 billion CAN]*
France 60 180 529	INCa: 70 million euros (2005-06) *[98 million CAN]*	From 2003-2007: 1,6 billion euros *[2,3 billion CAN]*	15 billion euros (2006)[194] *[20 billion CAN]*
New Zealand 3 997 500	Information not found	From 2005-2010: 200 million *[145 million CAN]*	Information not found
Nova Scotia 944 286	CCNS: 5 million CAN dollars	16 million for 2006-07	50-60 million dollars[195]
Ontario 12 141 863	CCO: 393 million CAN dollars (2004-05) (includes some services)	In 2005: > 80 million.	2 billion dollars (2003)

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[193] Personnal communication, Dr Simon Sutcliffe, President, BCCA, January 29, 2007 letter.

[194] http://www.premier-ministre.gouv.fr/chantiers/cancer_673/

[195] Personnal communication, Dr Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

Although we recognize the limitations due to incomplete data, we are able to make the following observations: Alberta's economy is doing extremely well, while cancer incidence have seen a sharp rise. This situation might explain the recent investments made in cancer control. In British Columbia, the annual operating budget of BCCA has not changed significantly over the last 3-4 years. Significant increments to funding were made by the Ministry of Health to the Provincial Drug Budget, expanding screening mammography and in capital (facilities and equipement). In Canada, after a year or two of uncertainty, the newly elected conservative party committed 260 million over 5 years to implement the strategy.

In England, total investment in cancer services was 639 million pounds by the end of the three year period 2001-2004, set against a commitment of 570 million. In France, the government also committed a substantial amount of money for implementing its cancer plan. Details of the spendings were included in the Interministerial Taskforce's first and second-year progress reports. In New Zealand, the five-year funding plan for the implementation of the NZ cancer control strategy has not yet been provided. However, 40 million new funding was announced for the first phase (2005-06), which will then be part of baseline funding for cancer control initiatives for each of the next four years. This commitment is on top of initiatives already conducted by District Health Boards. In Ontario, CCO's 2005 progress report showed significant government investments of more than 80 million dollars toward the implementation of CCO's action plan. CCO has asked for twice that amount for each year over the next four years.

<u>Accountability:</u>

Accountability refers to the organization's responsibility to justify the money spent, the decisions made, and the activities performed. In the formulation of policy frameworks and programs of service delivery, accountability can be viewed either in a centralized and hierarchical way or in a way that allows for sharing responsibility among partners. In any case, effective accountability mechanisms include clear roles and responsibilities, performance expectations balanced against capabilities, well-defined management structures, specific evaluation provisions, and appropriate monitoring systems.[196]

The jurisdictions studied provide many examples of interesting approaches to accountability. Accountability can first be examined through the accountability relationships within and among organizations. One example is provided in Figure 4 below which illustrates the structure of a typical Cancer Services Network in England, as well as its relationship with and accountability to its Primary Care Trusts and Strategic Health Authority. Another important aspect of accountability pertains to contractual arrangements between organizations involved in cancer control. Two examples are discussed below that are intended to enhance accountability, and to measure performance related to health reform: (1) ACB's Multi-Year Performance Agreement (MYPA) with Alberta Health and Wellness; and (2) CCO's Clinical Accountability Framework (CAF) with the Regional Cancer Program partners.

Since 2003, ACB is bound by a two-year MYPA with the Minister of Health and Wellness. The MYPA is a reciprocal agreement between the Minister and ACB binding both parties: ACB to

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[196] Prince MJ. Governing in an Integrated Fashion : Lessons form the Disability Domain. CPRN Discussion paper No. F 14, June 2001. Canadian Policy Research Networks. See p. 12.

meet expectations specified by the Minister, and obligations of the Minister to support the ACB in doing so. The document provides ACB with, (1) benchmarks against which ACB will measure how effectively it has fulfilled the responsibilities conferred upon it by the Minister and (2) specific information on support it can expect from the Ministry. A self-assessment of ACB's performance is included in ACB annual reports.[197]

In 2005, CCO's board approved the use of the Clinical Accountability Framework (CAF) to foster accountability for quality improvement within Ontario's 14 Integrated Cancer Programs (ICPs) and Regional Cancer Program partners. CCO's ICP Regional Vice Presidents are responsible for implementating the CAF within each region. This will be achieved through the following: (a) Developing and monitoring guidelines, standards and indicators; (b) Knowledge brokering; (c) Linking funding advice to quality improvement; and (d) Promoting innovation. To assist the regions in fulfilling their accountabilities for quality improvement, each CCO Clinical Program Head will form a program-specific committee of regional representatives from across the province. This Framework is a central strategy for furthering CCO's mission to improve the performance of the cancer system.

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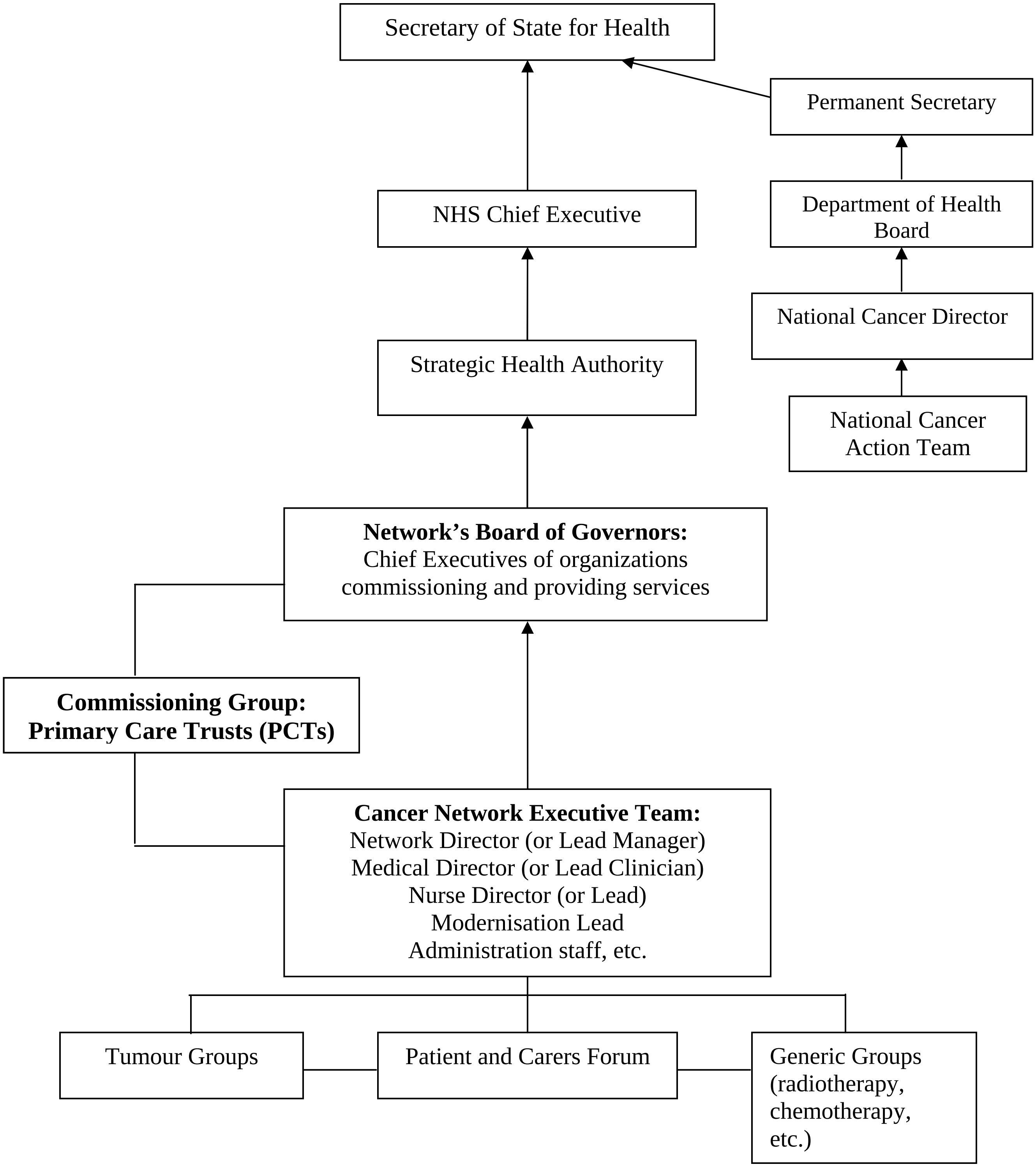
[197] ACB. Annual Report 2004-2005. Patient care, Research, Prevention, 2005. Available at: http://www.cancerboard.ab.ca/pdf/about_acb/ar_2004-05.pdf

Figure 4. Structure and accountability of a typical cancer services network in England



6.3 Characterizing cancer control governance

One important finding from this review of cancer control governance is that each jurisdiction’s cancer control governing system has complex and specific features, which are linked to the jurisdiction’s unique context, namely their health system structure and health policy history. The differences that were described in terms of the appointed entities’ internal structure of governing and the extent (or degree of accountability) of its ties with the government can nevertheless be grouped under three different approaches:

1. Organizations or positions within the Health Ministry (BCCA, CCNS)

2. Organizations that operate at arm’s length from the Health Ministry, with accountability to the Health Minister (ACB, CCO, CPACC, INCa)

3. Combinations of the two preceding approaches:
    - Commissioner for CCNS (#2) and CCNS (#1) (1998-2006)
    - National Cancer Director (#2) chairing the Cancer Action Team and the Cancer Taskforce (#1) in England
    - New Zealand Cancer Control Council (#2) and Principal Cancer Advisor (#1)

Such a classification only provides one facet of an otherwise multifaceted reality. As was shown in this Chapter, considering additional features for classification would lead to as many categories as there are jurisdictions.

7. MAIN ACCOMPLISHMENTS

The present chapter on *Main Accomplishments* describes: (1) progress regarding planned reform in service organization across the jurisdictions; and (2) service quality facilitator initiatives that are up and running. Our review on main accomplishments ends with a more detailed description of one distinctive feature for each jurisdiction. As defined in our *Integrated Framework*, the main accomplishments (this Chapter) and impact (reviewed in Chapter 8) are part of the main analytical category of program/plan implementation.

7.1 PROGRESS IN ORGANIZATIONAL ARCHITECTURE REFORM

As previously defined in Chapter 5 on design, the organizational architecture refers to the different modes of organizations through which services are delivered. This section provides highlights of each jurisdiction's current service organization and progress in reform implementation. Shaded boxes, included in the text, provide a snapshot view of the structures that support cancer control services, at the primary, secondary and tertiary care levels for each jurisdiction.[198]

Alberta and British Columbia: Expanding the current service configuration to meet growing demand

In the early 2000, just prior to the major health system reform of 2002, the Alberta Cancer Board's (ACB) major concerns were the rising rate of cancer incidence and drug costs. ACB's main priorities included the recruitment of oncology specialists and capital investments, which also comprised the construction of research facilities. At that time, the ACB's model of service delivery comprised comprised 14 facilities, including two *Tertiary Cancer Centers* and a *Community Network* [199] of clinics offering selected treatment procedures and follow-up. These

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[198] **Primary care:** "Care provided by physicians specifically trained for and skilled in comprehensive first contact and continuing care for persons with any undiagnosed sign, symptom or health concern (the "undifferentiated" patient) not limited by problem origin (biological, behavioral or social), organ system, gender or diagnosis. Primary care includes health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in a variety of health care settings (e.g., office, inpatient, critical care, long-term care, home care, day care, etc.). Primary care is performed and managed by a personal physician, utilizing other health professionals, consultation, and/or referral as appropriate." Kahn NB, Ostergaard DJ, Graham R. AAFP constructs definitions related to primary care – American Family Physician, 1994;50(6):1211, 1214-15, 1218.
Secondary care: Care provided by a specialist health care professional usually after referral from a primary care physician. Secondary care can be provided in specialised ambulatory clinic and/or local hospital. See NHS Jargon at http://www.health-direction.co.uk/hdl/hcs_index_nhs_jargon.php
Tertiary care: Tertiary care is provided by specialists in designated specialized hospitals and/or departments which are often linked to medical schools and considered to be teaching hospitals. Specialists treat patients with complex conditions who have usually been referred by other hospitals or specialist doctors. See Glossary, Public Health Electronic Library at: http://www.phel.gov.uk/glossary/glossaryAZ.asp?getletter=T

[199] The Community Cancer Network links the ACB main Treatment Centres, Associate Cancer Centres, and the Division of Population Health and Information with regional and community facilities and programs, including the Community Cancer Centres jointly established by the Alberta Cancer Board and the Regional Health Authorities. (http://www.cancerboard.ab.ca/about/about_about_divisions_cancer.html) ACB's provincial networking initiatives in prevention, screening, palliative, and supportive care integrate community cancer control planning and implementation between the ACB and the nine health regions. (ACB annual report 2003-04). In the 2005 business plan, this community network is now called the ACB's provincial network of cancer centers.

clinics are located throughout the province to enable patients to receive care closer to home. In the early 2000, this Community Network included four *Associate Cancer Centers* and eight small *Community Cancer Centers* jointly established by ACB and the Health Regions. Already at that time, the Tertiary Centers were models of translational research, exemplifying strong integration between research and care.

This service delivery model has not changed significantly over the more recent years. The facilities have been integrated into a provincial network through a computerized system (*Integrated Cancer Care Network*); three new Community Cancer Centers have opened; hours and hospital space were extended so that in 2006, there are now 18 facilities, including 11 Community Cancer Centers and one additional site (Holy Cross Site) in Calgary (see shaded box). ACB also makes use of Alberta's telehealth networks to improve access to clinical services.

Organizational architecture of cancer services – Alberta

Tertiary care level:

- Two *Tertiary Cancer Centers* provide cancer diagnosis, treatment (radiation, chemotherapy, MRI, follow-up), research and education for the entire nine health regions: (1) Cross Cancer Institute in Edmonton and (2) Tom Baker Cancer Centre in Calgary.[200]
- A second site in Calgary (Holy Cross Site) opened in 2003 and offers some services and programs to Alberta cancer patients.
- Still in the early stages of implementation is the inclusion of a *Comprehensive Breast Center* in the Cross Cancer Institute in Edmonton.[201]

Secondary care level:

- Four *Associate Cancer Centers* located in regional hospitals offering primary and secondary care services including initial oncology consultation on diagnosed patients, evaluation, treatment (chemotherapy, but not radiation therapy), follow-up, and supportive services.

Primary care level:

- Eleven *Community Cancer Centers* across rural areas offering standard chemotherapy and follow-up. These centers also serve as a focus to other community cancer control activities.[202]
- Alberta also has more than 140 mobile *Screen Test* sites that offer mammograms.

There are parallels to be drawn between Alberta and British Columbia regarding their recent approach to cancer services growth. A decade ago however, the BC Cancer Agency undertook an important service reorganization, moving from regional center-based services with multiple different standards to a more homogeneous and centralized approach to service quality. This goal was achieved by establishing population-based, provincial programs that would be regionally

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[200] ACB Business Plan 2005-2006

[201] Alberta Government. Cross Cancer Institute begins planning expansion. http://www.gov.ab.ca/acn/200410/172 56124432FA-1B4D-4FBC-8E995808D44D76F7

[202] ACB Annual Plan 2002-2003

delivered.[203] This redesign of the organizational arcitecture was to improve cure rates, survival, and the quality of life of cancer patients. While cancer care services were decentralized to the regional centers and their communities, the activities of strategic planning, policy-making and budgeting were performed centrally, with provincial programs establishing province-wide standards as well.[204]

Another important change was the construction of two new *Regional Cancer Centers* in 1995 (Fraser Valley) and in 1998 (Southern Interior) to increase capacity, i.e., to complement the Vancouver and Vancouver Islands Centers established in the 1940s,[205] and to offer treatment closer to home.[206] Additional initiatives continued throughout 2000, including the setting up of the *Provincial Surgical Oncology Network* in 2001, and the replacement of the old Vancouver Island Cancer Center with new facilities.[207]

From 1995 to 2005, BCCA constructed 3 Regional Cancer Centers to meet growing service demand and alleviate travel time to the other Cancer Centers. As of 2006, BCCA has four *Regional Cancer Centres* (with a fifth under construction- all located in the southern part of BC (see shaded box below). A sixth Cancer Center has been proposed to improve cancer care services for Northerners. The BCCA also has partnerships with other health care providers (physicians, pharmacists, nurses and others) and regional hospitals and clinics across British Columbia to bring care closer to home for those who do not live in urban centres through a *Communities Oncology Network*, comprising 21 *Community Cancer Centres* (usually based in hospitals),[208] six *Community Cancer Services*, and 12 *Consultative Clinics*. In addition to the Community Cancer Centers and Community Cancer Services, the Network also supports appropriate delivery of cancer patient care and support in 33 *community hospitals* and *care centers.*[209] Moreover, outside the four Regional Cancer Centres, the *BCCA Pharmacy* reimburses 70 community hospitals to dispense drugs that enable cancer patients to access their treatment closer to home. The health care providers' prescriptions are filed electronically with the pharmacists. There are also telehealth programs with real time consultations.

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[203] Carlow DR. The British Columbia Cancer Agency: A comprehensive and integrated system of cancer control. Hospital Quarterly, 2000;3(3):31-45.

[204] Taken from an interview with a BCCA key informant.

[205] BC Cancer Foundation 2005 Report to donors.

[206] In the end of the nineties, BC had long waits for radiotherapy and some patients had to be sent to the United States for timely treatment. (Taken form an interview with a BCCA key informant).

[207] BCCA newsletter, 28/01/2001.

[208] Community Cancer Centers are jointly funded by the BCCA and the local region/community. Criteria for BCCA funding include: clinical leadership, oncology nurse, physical space, pharmacy, and social support. If these criteria are met, then the BCCA pays 50% of the staff and operating costs, 100% of the chemotherapy costs. (Interview with BCCA key informant).

[209] BCCA. Regional Services. Http://www.bccancer.bc.ca

Organizational architecture of cancer services – British Columbia

Tertiary and secondary care levels:

- Four *Regional Cancer Centres* (*RCCs*):

(1) Vancouver Cancer Centre (with inpatient services);

(2) Vancouver Island Cancer Centre (located adjacent to Royal Jubilee hospital);

(3) Center for the Southern Interior (located adjacent to Kelowna General Hospital); and

(4) Fraser Valley Cancer Centre (located adjacent to Surrey Memorial Hospital). [210,211]

The Regional Cancer Centres are BCCA staffed facilities, operated by the BCCA with close links to host hospitals. These Centers provide assessment, diagnosis, therapy planning, chemotherapy and radiation therapy, nursing care, patient/family counseling services, nutrition counseling, pharmacy services, pain/symptom control service, and follow-up care. In addition, there are activities related to teaching and research, including a cancer information library.[212]

- A fifth Regional Cancer Centre (the Abbotsford Cancer Centre), which will be integrated with the new Abbotsford Hospital, is expected to open in 2008.[213]
- A sixth Cancer Centre has been proposed to improve cancer care in the BC Northern health region.

Primary and secondary care levels:

- Twenty-one *Community Cancer Centers*, providing a full range of systemic therapy.[214]
- Six *Community Cancer Services*, providing a range of oncology nursing resources relating to education.[215]
- Twelve *Consultative (Outreach) Clinics*, situated in rural areas.
- Twenty-three *Regional Colposcopy Clinics* offering follow-up to cervical cancer screening.

In both Alberta and British Columbia, the approach to organized service delivery is based on a core of tertiary cancer centers operated by the governing agencies, whose services are complemented by a network of clinics and associate centers. These network clinics are under the joint responsibility of the cancer agencies and the health regions. This organizational architecture seeks to achieve two goals: high volume of specialized procedures, secured through the tertiary centers, and closer to home access to basic and common procedures provided through the network. The recent cancer control policy developments in these two Canadian provinces suggest that the priority is to increase the general capacity and competence of care in rural communities, instead of bringing all patients to existing Cancer Centers.

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[210] BCCA. About BCCA. http://www.bccancer.bc.ca

[211] http://www.phsa.ca/WhoWeAre/Agencies/BCCancerAgency.htm

[212] BCCA (2005). Regional services. Http://www.bccancer.bc.ca/RS/default.htm

[213] BCCA. (2005) Cancer Services. http://www.bccancer.bc.ca/RS/AbbotsfordCentre/Abbotsford.htm

[214] BCCA. (2005). Communities Oncology Network-Community Cancer Centers http://www.bccancer.bc.ca/RS/CommunitiesOncologyNetwork/CommunityCancerCenters/default.htm

[215] BCCA. (2005). Community Cancer Services http://www.bccancer.bc.ca/RS/CommunitiesOncologyNetwork/CommunityCancerServices/default.htm

England, France and New Zealand: Building networks as vehicles for improving service integration and ensuring highest standards of quality

In England, France, and New Zealand, the proposed organizational architecture requires important reforms in the actual service configuration. This is in contrast to Alberta and British Columbia, wherein no change in organizational architecture occurred,or is planned, only expansion of an existing framework (such as construction of new facilities, and linkages in care).

In England, 34 *Cancer Services Networks*[216] facilitate cross-organizational collaboration between primary, secondary, and tertiary care providers in the community, local hospitals, cancer centers, and hospices. Such networks enable planning and coordinating services in-line with national guidance, as well as improving and monitoring of quality of local service delivery. Cancer Networks bring together primary care, health service commissioners and providers, community hospitals, specialist cancer centers, district hospital, the voluntary sector,and local NHS bodies within their respective boundaries.[217,218,219] Although networks were advocated as early as 1995 following the Calman-Hine report, it is not until 2000 that their development reached a steady course. Between 1996-2000, the NHS executive regional offices, together with district health authorities, oversaw the reorganization of cancer services. The priority was given to the identification of putative centres of excellence (the cancer centres) as a first step toward the creation of the networks' hubs in a "hub and spoke model to service provision.[220] The Cancer Units (considered as spokes within the networks) were intended to provide diagnosis and treatment for routine cases of common cancers. During those years there was uneven development of transitional networks. In 1999, there was recognition by the political authorities that the pace of change was not fast enough. Cancer became a top priority, a national cancer director was appointed, and there was an agreement to develop a comprehensive cancer plan, that was published at the end of 2000.[221]

Beginning in 2000, the national Cancer Action Team (CAT) led a network development program to facilitate the development of cancer networks.[222] By early 2001, all English cancer services were reorganized into 34 Cancer Networks covering the whole of England, each serving a population of between 700,000 and 3 million based on the catchment area for a radiotherapy department. Such Networks were also aligned with the 28 strategic health authorities.[223,224] In

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[216] All Party Parlimentary group on cancer report. p. 14

[217] Department of Health. NHS Cancer Plan. Three year progress report: Maintaining the momentum. October 2003. Accessed ***. Available at: http://www.doh.gov.uk/cancer/progressreport2003.

[218] All Party Parlimentary group on cancer report

[219] NHS Cancer Plan Progress Report. p. 9

[220] Kewell B, Hawkins C, Ferlie E. Calman-Hine reassessed: a survey of cancer network development in England, 1999-2000. Journal of Evaluation in Clinical Practice, 8(3):303-311.

[221] M. Richards. The Politics of Change in Healtcare – The example of cancer in England. Power point presentation.

[222] http://www.dh.gov.uk/assetRoot/04/06/64/40/04066440.pdf

[223] NAO. The NHS cancer Plan. A progress report. 2005. http://www.nao.org.uk/publications/nao_reports/04-05/0405343.pdf#search=%22nao%20nhs%20cancer%20plan%22

[224] James R. Commentary on Kewell et al. (2002), Calman-Hine reassessed: a survey of cancer network development in England, 1999-2000. Journal of Evaluation in Clinical Practice, 8(3):303-311, Journal of Evaluation in Clinical Practice, 8(3):299-301.

2002, each network published a 3-year service development plan to take advantage of the financial commitments for cancer, which were announced in 2001 (570 million pounds).[225]

Organizational architecture of cancer services – England

Tertiary care level:

- *Specialist Cancer Centers*, situated in regional hospitals, are responsible for providing expertise in the management of all cancers for local patients and the less common cancers as referral centers and specialist support services.[226]
- *Cancer Multidisciplinary Teams*, within each regional hospital, assist in the delivery of coordinated care.[227] These teams comprise professionals across the spectrum of cancer care, namely: surgeons, radiologists, pathologists, oncologists, nurse specialists and palliative care specialists to ensure patients receive the appropriate investigations and treatment.[228] There could be more than 1 multidisciplinary team per specific cancer organ site. For example, in 2001, there were 182 teams in breast cancer.[229]

Primary and secondary care levels:

- *Cancer Units*, situated in district general hospitals, provide support to clinical teams with facilities and expertise to manage the most common cancers.[230]
- The NHS Integrated Cancer Care Program, launched in 2004, is intended to develop and deliver a model to help patients better navigate the health system, specifically the transition from primary to secondary care, and to empower them to make decisions that suit their personal circumstances. Nine pilot sites have been selected for this program, which appears to have the elements of a patient navigation system.[231]

In France, the organization of cancer services was originally defined in a 1998 Health Ministry circular.[232] The 1998 circular stipulated a two-level configuration of cancer services: 1) *sites de référence* (referral sites) and *sites orientés* (dedicated sites). Referral sites were made up of the Regional/University Health Centres, the 20 *Centres de lutte contre le cancer* (CLCC, regional cancer centres), hospitals, private facilities participating to the public health system (PSPH) and private practices. Dedicated sites were made up of hospitals, private clinics, and PSPHs.[233] Some providers within these sites were also organized into regional networks.

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[225] James R. Commentary on Kewell et al. (2002), Calman-Hine reassessed: a survey of cancer network development in England, 1999-2000. Journal of Evaluation in Clinical Practice, 8(3):303-311, Journal of Evaluation in Clinical Practice, 8(3):299-301.

[226] National Institute for Clinical Excellence (NICE). National Service Frameworks. 2004. Accessed December 8, 2004. Available at: http://www.nice.org.uk/page.aspx?o=323

[227] NHS Cancer Plan. Three year progress report

[228] NHS. (October 2004) Multi-disciplinary coordinators: induction pack. Pan-Birmingham Cancer Network.

[229] NHS Cancer Plan. Three year progress report

[230] National Institute for Clinical Excellence (NICE). National Service Frameworks. 2004. Accessed December 8, 2004.

[231] The NHS Cancer Plan and the New NHS. Providing a patient-centred service. Available at: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4092531&chk=2OgU1i

[232] Circulaire DGS/DH/AFS no 98-213 du 24 mars 1998 relative à l’organisation des soins en cancérologie.

[233] Commission d’orientation sur le cancer. p. 165.

The 2003 Cancer Plan renewed the organization of cancer services by focusing on their local and regional organization. The Plan proposed the formalisation of *Réseaux régionaux de cancérologie* (Regional Cancer Care Networks*)* with an explicit mandate for quality assurance and assessment. These Regional Cancer Care Networks would comprise two types of facilities: (1) Treatment Cancer Centers and (2) Associate local facilities for follow-up care, general medicine, and home care.[234] These regional networks will include a number of *réseaux territoriaux de proximité* (Territorial Cancer Care Networks) and one *pôle regional* (Regional Cancer Pole).

Regional Cancer Care Networks are to ensure coordinated care across sites such as hospitals, clinics, and community-based centers and a smooth transition between types of care from diagnosis to treatment. All facilities providing cancer care will have a *Centre de coordination en cancérologie* or 3C, (Cancer Coordination Center) where alignment, integration and monitoring of all cancer services delivered in the facility will take place. The Territorial and Regional Networks will link with other health care and local networks to ensure coordination of services across the continuum of cancer services, which also include care delivered at home. The Regional and Territorial networks will enable rapid access to a diagnosis, promote a multidisciplinary approach to care, enable implementation of customized care programs, enable the organization of tools for information management, and enable the application of quality standards. In addition, these networks will have to ensure that patients benefit from a multidisciplinary approach to treatment, by the inclusion of all health care providers involved in offering cancer care.[235] Patients will benefit from a multidisciplinary approach to treatment via their participation at *Réunions de concertation pluridisciplinaires* (Multidisciplinary Consultation Meetings*)*. Patients also currently benefit from *Mobile Palliative Care Teams, Nurse Care at Home*, and receive chemotherapy via *At-Home Hospital Care*.

This organizational architecture, set forth in the 2003 Cancer Plan, was subsequently detailed in a 2005 Health Ministry Circular, [236] to be translated at the regional level by the *Agences régionales d'hospitalisation* (Regional authorities) and integrated into regional plans referred to as the *Schéma régionaux d'organisation sanitaire* (SROS). Hence, the 2005 circular is the blueprint for the planning of cancer services within 3rd generation of SROS (SROS III) that are in preparation for 2006-2011.

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[234] http://www.veille-arh-paca.com/plan_cancer/rubrique.php3?id_rubrique=23

[235] MILCC: cancer plan p. 22

[236] Circulaire DHOS/SDO no 2005-101 du 22 février 2005 relative à l'organisation des soins en cancérologie.

Organizational architecture of cancer services – France

Tertiary care level:

- *Pôles régionaux de cancérologie (Regional Cancer Poles):*
  The Regional Cancer Poles are health care referral and appeal structures that can take the form of a regional institute, a community of facilities or a contractual agreement between facilities. Facilities or cancer sites making up the Regional Cancer Pole play an essential role in the Regional Cancer Care Networks, garanteeing that patients have access to complex highly specialized care and innovative technologies. Regional Cancer Poles will act as the hub (but not the head) of the Regional Cancer Care Networks, with responsibilities also including standard care, clinical research and education. Regional Cancer Poles are to be designated by the ARHs (Agences régionales d'hospitalisation). ARHs have compiled a list of facilities that will comprise a RCP. Examples include the existing 20 Cancer Centers (CLCCs), the CHU (Centres Hospitaliers Universitaires) providing specialized cancer care, and eventually CH/clinics highly specialized in oncology.[237] There are now 7 Regional Cancer Poles established.

Primary and secondary care levels:

- *Réseaux régionaux de cancérologie (Regional Cancer Care Networks):*
  The networks are virtual organizations responsible for: (1) coordinating together all the players involved for a given geographical area: hospitals, clinics, community physicians and nurses, including those working in private settings; (2) federating existing Territorial Cancer Care Networks or ensuring the management of patients if no such Territorial network exists; and (3) organizing tools for good communication and quality assurance/improvement, namely: information system and sharing of medical files, clinical professional guidelines, reference pathways, evaluation of network members, continuous medical education and professional training, as well as patient and professional information. There are now 23 Regional Cancer Care Networks established, with plans for 26 by 2007.[238,239]

Primary care level:

- *Réseaux territoriaux de proximité (Territorial Cancer Care Networks):*
  The Territorial (or local) Cancer Care networks link the private medical practices (médecine de ville) with the local hospitals. These Territorial Networks have been developed to meet the needs of local coordination,[240] namely the medico-social needs and home care management needs of patients. The Territorial Networks will facilitate the delivery of at-home chemotherapy and supportive care. These networks will also promote access to prevention, screening and patient education. These network will comprise *Associate Proximal Facilities* (local hospitals, general physicians (private offices), etc.) for follow-up care, general medicine and home care.

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[237] There are 20 Comprehensive Regional Cancer Centers (Centres de lutte contre le cancer, CLCC) throughout France, which are coordinated by the FNCLCC (Fédération nationale des Centres de lutte contre le cancer). Services offered by CLCCs span the entire spectrum of care from prevention to treatment, including education and research. In 2004, a formal agreement (accord-cadre) was reached between the FNCLCC and the FNCCHU (Fédération nationale de cancérologie des Centres hospitaliers universitaires) to allow for the common sharing of medical competencies, technical platforms and a cancer medical service plan in order to ensure access to specialized care and the transfer of knowledge to practice within Regional Cancer Poles.

[238] Institut National du Cancer. The 2006-2007 Strategic Action Plan. The development of cancer care networks. http://www.e-cancer.fr/v1

[239] Institute National Du Cancer (NCI). Annexe : suivi des 70 mesures du plan cancer p. 8

[240] MILCC: cancer plan. p. 8

- At present, there are 78 *Palliative Care Units*, 82 *Palliative Care Networks*, and 317 *Mobile Palliative Care Teams* that cover the 26 regions.[241,242]
- Since 2004, patients have been benefiting from receiving *Nurse Care at Home*[243] and more recently, patients have the choice of receiving *At-Home Hospital Care* via *Hospital Pharmacies* that deliver chemotherapy.[244,245]

In New Zealand, the current organizational architecture for cancer services rests on six urban-based Regional Cancer Centers with a secondary/tertiary care focus, acting as hubs in a "hub and spoke" model.[246] The establishment of *Regional Cancer Networks* as proposed in the NZ Cancer Control Strategy and NZ Cancer Control Action Plan, is intended to formalize existing collaborative initiatives on a wide-range of projects.[247,248] These Regional Cancer Networks are intended to facilitate coordination of cancer services across health providers at the primary, secondary, and tertiary levels as well as to serve as a vehicle through which organizations and stakeholders can work together to plan and coordinate services in accordance with defined national standards of treatment. These Regional Cancer Networks will take the form of managed virtual bodies linking cancer care providers (tertiary, secondary, primary), private health care providers, non governmental organization (NGO) providers, public health organizations, consumer organizations, and District Health Boards (DHBs) throughout defined geographical areas to ensure delivery of quality co-ordinated, comprehensive cancer services across the cancer control continuum.[249]. In addition, there are plans to establish: (1) *Multidisciplinary Groups* for the management of breast, rectal, head/neck, gynecology, and bone/soft tissue sarcomas; (2) *Specialized Units* for the treatment of specific cancers such as bone/soft tissue sarcoma; upper GIT; low rectal; pancreas; and bladder and specific population groups such as adolescents; and (3) a *National Intersectoral Group* responsible for identifying and addressing the resource needs of patients with cancer, their families, and whānau.[250]

Since the publication of the NZ Strategy, work is underway in a number of District Health Regions to develop models of care for cancer [251] or cancer service plans.[252] Since March 2006

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[241] MILCC (avril 2005). Ce qui a déjà changé : plan cancer à 2 ans. p.3

[242] Institute National Du Cancer (NCI) : Annexe p. 13

[243] MILCC (avril 2005). Ce qui a déjà changé : plan cancer à 2 ans. p.2

[244] MILCC (avril 2005). Ce qui a déjà changé : plan cancer à 2 ans. p.2

[245] Institute National Du Cancer (NCI). Annexe : suivi des 70 mesures du plan cancer p. 12

[246] Hub and spoke model: Any architecture that uses a central connecting point. It is the same as a star topology in a network. In this case the Regional cancer centers act as the hub and the primary and secondary services providers as the spoke. Barber J, Hewitt J, Long J. Midland DHBs Cancer Control Network.Progress to date. Presentation at the Ministry of Health seminar titled: Establishing Regional Cancer Networks in New Zealand, March 30, 2006.

[247] NZ action plan p. 7; p. 71

[248] NZ government. Regional Cancer Networks help cancer patients (2006)http://www.beehive.govt.nz/hodgson

[249] Childs, J. Establishing Regional Cancer Networks in New Zealand. Benefits and Challenges. Presentation at the Ministry of Health seminar titled: Establishing Regional Cancer Networks in New Zealand, March 30, 2006.

[250] NZ action plan p.53-55; 69

[251] Waikato District Health Board. Non surgical Cancer Treatments Haematology/Oncology Model of Care. Working document. 2004, 48p. Available at: http://www.waikatodhb.govt.nz/Media/docs/scr/MOC-ONCOLOGY.pdf#search=%22Non%20surgical%20Cancer%20Treatments%20Haematology%2FOncology%20Model%20of%20Care%22

[252] Midcentral District Health Board. Cancer service plan. August 2005, 39p. Available at: http://www.midcentral.co.nz/funding/Publications/Cancer-Service-Plan-August-2005.pdf

meetings and workshops have been held in various regions to discuss how a network would function in the respective areas, and to develop terms of reference for each network. Moreover, the Ministry of Health hosted a seminar with international and local speakers that covered issues such as: the history and experiences in establishing networks in the United Kingdom, the rationale for establishing networks in New Zealand and local experiences in establishing networks, namely in Midland, South Island, and MidCentral District Health Region.[253]

Organizational architecture of cancer services – New Zealand

Tertiary care level:

- Six *Regional Cancer Treatment Centers* (RCTCs) based in hospitals[254] and providing non-surgical cancer treatment (medical and radiation oncology, as well as heamatology services).[255] While radiotherapy is only provided in the se RCTCs, chemotherapy is also provided in peripheral clinics in addition to being provided in the six *Regional Cancer Units* within the RCTCs -- host hospitals.[256]
- Three *Pediatric Oncology Centers,* associated with *Regional Outreach Centers.*[257]

Secondary care level:

- Twenty-two *Peripheral Cancer Clinics* for chemotherapy in association with the Regional Cancer Centers.[258] These outreach clinics are generally run in the outpatient areas of secondary hospitals (about 1 – 8 times per month).[259]
- Surgical and other medical services for cancer patients are provided in tertiary and secondary hospitals.

Primary care level:

- *Public Health Units* and *non-governmental organizations* (Cancer Society) for prevention.[260]
- *Hospices* and *hospice palliative care teams* for palliative care.[261]

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[253] http://www.moh.govt.nz/moh.nsf/indexmh/cancercontrol-establishingregionalnetworks

[254] These Regional Cancer Treatment Centers are located in Auckland (Auckland hospital, Auckland DHB), Hamilton (Waikato hospital, Waikato DHB), Palmerston North (Palmerston North hospital, Midcentral DHB), Wellington (Wellington hospital, Capital & Coast DHB), Christchurch (Christchurch hospital, Canterbury DHB), and Dunedin (Dunedin hospital, Otago DHB).

[255] Improving non-surgical cancer treatment services in New Zealand, 2001

[256] Improving non-surgical cancer treatment services in New Zealand, 2001, p. 18

[257] NZ action plan p.73

[258] Improving non-surgical cancer treatment services in New Zealand., 2001, p. 18

[259] Waikato DHB. Non surgical cancer treatment in haematology/oncology. Model of Care. Working document 2004, available at : http://www.waikatodhb.govt.nz/Media/docs/scr/MOC-ONCOLOGY.pdf

[260] Childs, J. Establishing Regional Cancer Networks in New Zealand. Benefits and Challenges. Presentation at the Ministry of Health seminar titled: Establishing Regional Cancer Networks in New Zealand, March 30, 2006.

[261] Childs, J. Establishing Regional Cancer Networks in New Zealand. Benefits and Challenges. Presentation at the Ministry of Health seminar titled: Establishing Regional Cancer Networks in New Zealand, March 30, 2006.

Nova Scotia: Improving coordination while heading toward district cancer programs

In Nova Scotia, cancer services delivery is organized around three *Specialized Cancer Centers* that provide tertiary level cancer services , with regional hospitals providing primary and secondary cancer services such as surgery and chemotherapy along with supportive and usually palliative care (see shaded box below).[262] Since 2001, CCNS is working on the establishment of *District Cancer Programs* in every healthcare district in partnership with the District Health Authorities. The District Cancer Programs (DCPs) seek to offer coordinated primary and secondary cancer care, including: health promotion, education, prevention, early detection, diagnosis, staging, some elements of treatments, support rehabilitation, continuing care and palliation. These DCPs are to be "head-quartered" at regional hospitals, and services are to be provided in regional and community hospitals, community health centers, physicians' offices, and in patients homes as long as standards can be met.[263] As a first step in the development process, each DHA had to set up a *District Cancer Committee*, (DCC) to bring together providers of cancer services to meet local needs. DCCs also serve as a valuable link between districts and CCNS to ensure that CCNS meets the needs of the patients and providers in the district.[264] The creation and adoption of DCCs in every DHA in 2002 was an important first step in developing and sustaining DCPs.[265,266]

One well developed DCP is the Cancer Care Program in the QEII Health Sciences Centre, later merged into Capital District Health Authority. This Cancer Care Program was the first and for a long time the only programmatic structure in the Capital District Health Authority. At the time CCNS was created, the QEII HSC provided approximately 85% of tertiary cancer services in the province. The Cancer Care Program that was then developed has served as a good example of interprofessional collaboration and team work.[267]

In 2002, CCNS launched its *Patient Navigation System* (better known as the *Cancer Patient Navigation Program*), where trained nurses (referred to as cancer *patient navigators*) provide guidance and support to patients and families through the cancer continuum, from diagnosis to treatment and continuing care and support.[268] They also work in partnership with community health professionals and offer support to providers, especially family physicians, in the community. At present, there are *Cancer Patient Navigators* in five of the nine DHAs.

In 2005, a *Levels of Care* framework of standards was set to be developed over a timeline of 3-5 years to determine the type of cancer services that can safely and appropriately be administered in a particular location (basic, intermediate, advanced and sub-specialized). The first step focuses on chemotherapy.[269]

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[262] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

[263] Padmos A. District Cancer Program. Presentation at the Roundtable : Cancer Care in our Communities: A proposed Model for Nova Scotia

[264] CCNS. District Cancer Program. http://www.cancercare.ns.ca/media//documents/DCPFactSheet.pdf.

[265] CCNS. The District Cancer Model: A community-based system of care. August 2000.

[266] CCNS. District Cancer Programs. http://www.cancercare.ns.ca/inside.asp?cmPageID=290

[267] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.

[268] Patient Navigation: Clearing a path for patients Action Plan (2001)

[269] CCNS Newsletter September 2005.

Organizational architecture of cancer services – Nova Scotia

Tertiary care level:

- Three *Specialized Cancer Centers* that provide radiation therapy services[270] and offer tertiary care for adults with cancer:

(1) The Nova Scotia Cancer Center, part of the Queen Elizabeth II (QEII) Health Sciences Center Halifax (Capital Health District);
(2) The Cape Breton Cancer Center, part of the Cape Breton (Healthcare Complex) Regional Hospital in Sydney (Cape Breton Health District); and
(3) The IWK Grace Health Centre for Women and Children, which provides tertiary cancer services (Pediatric Oncology Program) for children in Nova Scotia and Maritime Canada. This center has its own board, administrative, and service delivery structures.[271]

Primary and secondary care levels:

- Four *Satellite Oncology Clinics* are currently oprating in New Glasgow, Yarmouth, Antigonish and Inverness for medical oncology, while radiation oncology outreach is confined to the Yarmouth clinic.[272] These outreach oncology services are provided in collaboration with the two adult tertiary cancer centers.
- 24 satellite chemotherapy sites.
- At least one well developed Cancer Care Program in the Capital District Health Authority.

Ontario: Integrating cancer services through regional cancer programs

From 1997 to 2003, Cancer Care Ontario operated and managed (in terms of staff and assets) eight *Regional Cancer Centres,* and two interim Cancer Centres. There were also plans for the construction of three additional Centres.[273] These *Regional Cancer Centres* were situated within hospitals and offered outpatient services such as radiotherapy, systemic therapy, as well as supportive and preventive programs, screening, education, and research. At that time, Regional Cancer Centres throughout the province provided 75% of radiotherapy (the remaining 25% was provided by Princess Margaret Hospital, which was not part of CCO).[274] Regional Cancer Centres also administered approximately 50% of systemic therapy.[275] In such service configuration model, CCO only governed 30% of all cancer services, the remaining 70% were provided outside CCO's facilities. Hospitals, with and without a cancer center, managed on their own the delivery of inpatient services such as surgery, diagnosis, pathology, laboratory services, and basic research.

In 2001, the Cancer Services Implementation Committee made a number of recommendations to remediate the inconsistencies in the quality and delivery of cancer services across the

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[270] CCNS. District Cancer Model (2000).
[271] Nova Scotia Department of Health. Buisness Plan 2004-2005
[272] Personnal communication, Dr. Andrew Padmos, CCNS former Commissioner, November 10, 2006 letter.
[273] CCO Annual report 2002-2003, available at : http://www.cancercare.on.ca/pdf/CCOAnnualReport0203.pdf
[274] Hudson, A. (2002)
[275] Hudson, A. (2002)

province.[276] It namely recommended that CCO no longer be directly involved in service provision, and that the relationships between *Regional Cancer Centres* and their *host hospitals* be restructured.

Over the next two years (2002-2003), CCO worked closely with the hospitals hosting those Regional Cancer Centres to establish a new *Cancer Program Integration Agreement* (CPIA). Eleven host hospital boards voluntarily signed a CPIA with the board of CCO.[277,278] Although University Health Network/Princess Margaret Hospital did not signed such CPIA, it made a collaborative agreement with CCO in regard to the integration model.[279] The goal of these agreements was to integrate CCO's cancer services provided by Regional Cancer Centres with the host hospital's cancer services through the creation of *Integrated Cancer Programs* (ICPs). The aim of the newly created ICPs was to ensure a smooth journey for cancer patients through the inpatient and outpatient components of diagnosis and treatment.[280,281] In January 2004, the cancer services of the existing eleven Regional Cancer Centres were integrated with their host hospitals. As a result, each host hospital manages the Regional Cancer Center' services, which are now part of the *Integrated Cancer Program*.

Such integration process was intended as the first step of a new service configuration model where quality and accountability for performance would be driven by CCO, according to its newly defined mandate (i.e. to plan, report and advise the Ontario government on cancer services throughout the province). In this new organizational architecture, the *Integrated Cancer Program* functions as the hub of a *Regional Cancer Program*, which is a virtual program linking cancer services of surrounding referring hospitals and healthcare facilities within a defined geographical area. [282, 283, 284] The ultimate goal of this reform involving the creation of ICPs and RCPs is to provide for seamless transition between types of cancer services and to ensure high quality standards across the province.

In the summer of 2005, the Ontario government established 14 Local Health Integration Networks (LHINs) to work with local communities and health care providers in identifying local priorities and in planning health services. The *Regional Cancer Programs* were then aligned geographically with the emerging Local Health Integration Networks. *Regional Cancer Programs* will focus on improving access to quality cancer services within their area, and simultaneously work toward maximizing opportunities for collaboration and synergy with the 14 Local Health Integrated Networks.[285] Regional Cancer Programs are expected to take shape over the next three years (2005-2008).[286] Agreements will be secured in place among those who join

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[276] Hudson A. Report of the Cancer Services Implementation Committee. December 2001.

[277] Cancer Care Ontario. Ontario Cancer Plan (2005-2008). November 2004.

[278] Sawka (2005)

[279] Cowan (2004)

[280] Hudson, A. (2002)

[281] The CPIA is a legally binding agreement that outlines the responsibilities of each hospital and CCO for the establishment, planning, and ongoing performance of the ICP in each hospital site (ICP Hospitals).

[282] Hudson, 2002

[283] Sullivan et al. 2004

[284] Cancer Care Ontario. Ontario Cancer News. March 2003; 1(1). Accessed December 9, 2004. Available at: http://www.cancercare.on.ca/OntarioCancerNewsArchives/200303/index.html.

[285] Sawka, 2005

[286] Ontario Cancer Plan 2005-2008; p. 15

as organizational partners, and these agreements will serve to solidify a commitment to regional planning for cancer services, implementation of provincial standards, and performance reporting.[287] This work will lead to the development of 14 Integrated Health Service Plans. There are now 14 ICPs throughout Ontario.

Organizational architecture of cancer services – Ontario

Tertiary and secondary care levels:

- 14 Regional Cancer Programs aligned geographically with the Province's Local Health Integration Networks (LHINs).[288]
- Two *Rapid Diagnostic Units* have been proposed to improve access to diagnostic services and reduce waiting times.[289] These projects are awaiting funding from the MOHLTC.[290]

Primary care level:

- Family doctors play a significant role in the diagnosis of cancer patients, an important supportive role during the active treatment of cancer, and a key role in their follow-up and palliative care.[291]
- As of April 2006, 150 *Family Health Teams* have been created to provide better access to primary care directly in the community.[292] Family Health Teams comprise physicians, nurses, other health care providers, dieticians, pharmacists, and other service providers may be included.
- There are 56 *Community Health Centres* across Ontario, providing primary health and health promotion programs for individuals, families and communities.
- There are 36 *Public Health Units* in Ontario, administering health promotion and disease prevention programs
- There are 42 *Community Care Access Centres* (CCACs) in Ontario, two of which are hospital-based. CCACs provide a simplified point of access to long-term care. CCACs coordinate end-of-life services and other respite care within each region.
- Regional End-of-Life Networks.[293]

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[287] OCP 2005-2008 p. 59

[288] These are the following: Windsor Regional Cancer Centre, Windsor (Erie St. Clair LHIN); London Regional Cancer Centre, London (South West LHIN); Grand River Regional Cancer Centre, Kitchener (Waterloo-Wellington LHIN); Juravinski Regional Cancer Centre, Hamilton (Hamilton Niagara Haldimand Brant LHIN); Carlo Fidani Peel Regional Cancer Centre, Mississauga (Central West LHIN and Mississauga LHIN); Toronto Sunnybrook Regional Cancer Centre (Toronto Central LHIN); University Health Network/Princess Margaret Hospital Clinics and Centres (Toronto Central LHIN); Southlake Regional Health Centre – Regional Cancer Program (Central LHIN); RS McLaughlin Durham Regional Cancer Centre, Oshawa (Central East LHIN); Kingston Regional Cancer Centre, Kingston (South East LHIN); Ottawa Regional Cancer Centre, Ottawa (Champlain LHIN); Simcoe Muskoka Regional Cancer Centre (North Simcoe Muskoka LHIN); Regional Cancer Program of the Sudbury Regional Hospital (North East LHIN); and Northwestern Ontario Regional Cancer Centre, Thunder Bay (North West LHIN). Available at: http://www.cancercare.on.ca/qualityindex2006/regions/

[289] OCP 2005-2008 p.19

[290] Personnal communication, Dr Terry Sullivan, CEO, CCO, October 23, 2006 letter.

[291] Jaakkimainen L, Upshur R, Schultz S, Maaten S. Primary Care in Ontario. Chapter 10: Physician care of cancer patients. August 2006. Available at: http://www.ices.on.ca/file/PC_atlas_Chpt10.pdf

[292] Ministry of Health and Long-Term Care. Health Results Team. http://www.health.gov.on.ca/transformation/fht/fht_work.html

[293] Ontario Cancer News, March 2006.

Summary. This overview of progress in cancer services organization across the jurisdictions suggests that they all acknowledge the need to integrate or link the various cancer services providers and facilities into coherent programs and/or networks. All jurisdictions have secured in place Cancer Networks or Programs to link cancer services of all surrounding facilities (including cancer centers, hospitals, community clinics) and to solidify commitments among all cancer providers to provincial or regional planning for cancer services, resource planning, and performance accountability. There are, however, variations across the jurisdictions in the level of integration and the extent to which delivery structures are connected at the local level, all the way up to the regional level.

Another point worth noting is the development of Patient Navigation Programs, which can be seen as an interesting alternative to important organizational reforms. This approach appears to be a hallmark of Canadian jurisdictions. In Nova Scotia, where the approach is most developed, the Navigation Program is currently in place in five of the nine health districts (for more details see shaded box of Nova Scotia's distinctive feature in this Chapter). In British Columbia, there are 2 such programs available throughout the five health regions[294] and in Alberta, plans are currently being developed.[295] Similar initiatives are being piloted in England (see England's shaded box above) or have been proposed in New Zealand.[296]

7.2 SERVICE QUALITY FACILITATORS: INITIATIVES UP AND RUNNING

As defined in our integrated framework and in the Chapter 5 on design, service quality facilitators refer to activities, tools/procedures and/or systems that enable the cancer control system to meet the growing demand for cancer services while ensuring the best quality of care possible for all cancer patients and individuals suspected of having cancer. The service quality facilitators that are examined in this report were grouped in two categories: (1) System capacity and sustainability; and (2) Quality assurance and improvement. In this section, we describe service quality facilitators initiatives that have been planned and/or implemented. More detailed information on these quality facilitators for each jurisdiction is presented in shaded boxes that can be found in Appendix 7A.[297]

Human resources management initiatives:

An overview of information provided in cancer plans or business plans and annual progress reports prepared by jurisdictions suggests that human resources management is a major priority for most. Jurisdictions are, however, at different stages in their efforts to address shortages in health care professionals and other staff. While some jurisdictions are still at the planning stage, others are already undergoing sustained investments. The need to develop strategies for the recruitment and retention of skilled individuals is clearly articulated in the cancer plans and programs of Alberta, British Columbia, Canada, England, and New Zealand. While in Alberta,

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[294] BC Cancer Agency. Patient navigation in cancer care. Final report, 2005 p. 9. Available at : http://www.bccancer.bc.ca/NR/rdonlyres/E6F649B9-761C-4C51-89E0-C2F0834B8DCC/17442/print_Final_Navigation1.pdf#search=%22patient%20navigation%20cancer%20care%20final%20report%22

[295] http://cancerboard.ab.ca/maco/initiatives_special.htm

[296] Waikato DHB. Non surgical cancer treatment in haematology/oncology. Model of Care. Working document 2004, pp. 36-37.

[297] Only SQFs that directly apply to cancer services and for which there was readily available information were included in the shaded boxes. Hence some categories may not be represented in all jurisdictions.

Canada, and New Zealand these initiatives remain mostly at the planning stage, England, France, and British Columbia report on number of new hiring as well as progress made in the creation of new levels of professional expertise. In Nova Scotia, the hiring of specialist oncologists and oncology researchers was part of initial initiatives reported by CCNS in 1998. In addition, the province is currently one of the pilot region for the Canadian Human Resources Planning Information System, driven by the Council for Canadian Strategy for Cancer Control. In Ontario, human resources issues are considered more generally at the Health Ministry level, but the cancer action plan states that innovative projects should be implemented.

Information management systems:
This category comprises a number of different tools and systems, including cancer registries, national/provincial clinical datasets, electronic health records, tissue/image collection and storage/retrieval systems, as well as service performance tracking systems. Jurisdictions vary widely in the scope of their initiatives with respect to this service quality facilitator. Our review indicates that all jurisdictions have at least a cancer registry (Canada's cancer registry is a survey based on data provided by provinces and territories). Differences between jurisdictions lie mainly in the extent of their efforts for building on the registries' foundations to develop an overall view and improved handle of cancer control services at the system level.

National/provincial clinical datasets are in operation in Alberta (surgery), British Columbia, England and Ontario (pathology). In addition, England and New Zealand have plans for developing a national dataset in primary care and in palliative care respectively. Electronic health records appear to be up and running in Alberta, British Columbia, and England, while France is at the pilot stage with its communicative file transfer system. Tumour banks have been set up in Alberta and British Columbia, but only British Columbia has an Image Distribution Network for storage and retrieval of cancer diagnostic images. British Columbia is unique among the jurisdictions for the integration of cancer information via its Cancer Agency Information System or CAIS (see shaded box on BC's distinctive feature in the following chapter section). Ontario is forging ahead with a number of recently developed tools and systems for the tracking of cancer services quality/system performance via the Cancer System Quality Index (see shaded box on Ontario's distinctive feature in the following chapter section), the iPort, a web-based tool for accessing cancer surveillance statistics and information on cancer activities such as radiation and systemic therapies, and the Data Tracking, Referral, and Analysis of Capacity for Cancer (D-TRACC), which provides management and information on cancer treatment, activity, quality, and accessibility.

Evidence-based clinical practice guidelines:
The development, dissemination, and uptake of evidence-based clinical practice guidelines is a cornerstone of the delivery of quality (and efficient) cancer control services. As noted in the design chapter, evidence-based practices constitute a central principle for ensuring the quality of cancer care service provision, a principle by which most cancer control governing organizations adhere to. Our review of the eight jurisdictions suggests that evidence-based clinical practice guidelines are being produced through basically two different ways.

In the Canadian provinces, clinical practice guidelines (CPG) are developed by designated multidisciplinary groups of experts, constituted along different cancer sites, such as breast, colorectal, lung, prostate, among others. These are called tumour groups (Alberta, British Columbia), cancer site teams (Nova Scotia) or disease site groups (CCO's Program in Evidence-Based Care, see shaded box on Ontario's distinctive feature in the following chapter section). These tumour site groups vary in number and, although their focus is on treatment protocols, some guidelines are also being developed to address other elements of care (e.g. supportive and palliative care) and/or certain health care processes (e.g. communication, waiting time).

As for the national jurisdictions reviewed, CPG in oncology are being produced by national institutions such as the NICE (England), HAS (France) and the NZGG (New Zealand). Canada's approach is to develop a CPG Adaptation Project that will evaluate the feasibility and utility of using national interdisciplinary panels to evaluate the quality, content, and currency of existing CPG's and to make recommendations about how to adapt and endorse CPG recommendations. Another approach to CPG adaptation is currently underway, via a collaboration between France's FNCLCC - Standards, Options and Recommendations (SOR) Program and Québec.[298]

7.3 DISTINCTIVE FEATURES

By highlighting one distinctive feature for each jurisdiction, we intend to demonstrate dimensions of cancer control policy development and implementation that could be considered as exemplar attributes. For a 'feature' to be viewed as distinctive, it would have to meet one or more of the following arbitrarily set criteria: (1) mentioned as a priority in the cancer action plan, (2) considered a process or a structure for quality assurance and/or improvement; (3) regarded highly by other jurisdictions and stakeholders; and (4) viewed as an innovative approach in the delivery of care. Evidently, many interesting features could easily have been listed for each jurisdiction, the selection was further based on one or all of the following criteria:

1. The distinctive feature was identified by interviewees and/or in the literature as an example of a strength or success of cancer control intervention in the jurisdiction
2. The distinctive feature is described in published documents as serving a useful mechanism to achieve certain valued outcomes associated with cancer control interventions such as to: reduce cancer incidence, reduce cancer mortality, improve quality of care, or improve patient experience
3. The distinctive feature appears to be useful in the management of chronic illnesses

We are mindful that it is possible that a selected feature may not be unique to a particular jurisdiction. We thus listed at the end of each shaded box other attributes we believed could also be characterized as unique/exemplary features.

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[298] B Fervers, JS Burgers, MC Haugh, J Latreille, N Mlika-Cabanne, L Paquet, M Coulombe, M Poirier B Burnand. Adaptation of clinical guidelines: literature review and proposition for a framework and procedure. International Journal for Quality in Health Care 2006 18(3):167-176.

Distinctive feature – Alberta

The Hospice Palliative Care Network

A distinctive feature of Alberta's cancer control system is the Hospice Palliative Care Network (HPCN), which covers the entire province. The HPCN, originally known as the Palliative Care Network Initiative, was created by ACB (currently under the guidance of ACB's Medical Affairs and Community Oncology Division) in 1998.[299] The purpose of the HPCN is "*to improve access and enhance integration of hospice palliative care in the province so that services that are needed are available timely to cancer patients and their families.*" [300] The HPCN has a rich history dating back to 1990, with the establishment of the Palliative Care Association of Alberta to advocate for equitable and accessible hospice palliative care programs or services in the province. In 1995 and 1996, the tertiary palliative care programs in Edmonton and Calgary were established.[301] Alberta has a well established hospice palliative care community, which encompasses the health, education, research, and voluntary sectors. The nine RHAs are mandated by Alberta Health and Wellness to develop palliative care programs based on the needs of their communities. For example, the Capital Health Region Regional Palliative Care Program (RPCP), which was well established by 2001, is a community-based model of care designed to increase access to exemplary palliative care services.[302] The main focus of the program is to shift the main area of care from acute care to the home and hospice.

The RPCP began as an earnest response to the need for a population-based approach in providing palliative care throughout its region. The Capital Health Region Regional Palliative Program (RPCP) has developed various clinical tools, and it acts as a key contact when requests for palliative care assessment tools are made to the HPCN.[303] It has also served an instrumental role in providing training to the East Central Health staff as part of the East Central Interface Project, an initiative sponsored by HPCN. The HPCN, therefore, formalizes linkages with all existing leaders of palliative programs, such as the RPCP and East Central Regional Health, for the purpose of ensuring equitable access to hospice palliative care. The Network also provides consultation and resources to RHAs tp assist them with the development of programs or services, as needed. Between March 2002 and March 2003, the number of interventions (this included any type of consultation services or information exchange) to RHAs totalled 379.[304] Its provincial framework is based on the national norms of hospice palliative care practice developed by the Canadian Hospice Palliative Care Association Model (CHPCA). These national norms guide the development of the Network activities such as: [305, 306]

- Addressing the expectations and needs of patients, families, and caregivers;
- Influencing the hospice palliative care program or service planning, development, implementation, and evaluation;

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[299] ACB. (October 2003). Hospice Palliative Care Network. Provincial Framework. Available on line.

[300] Hospice Palliative Care Network (2004). Annual Report 2003-2004. Edmonton, AB: Alberta Cancer Board http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

[301] MACO. Hospice palliative care in Alberta. http://www.cancerboard.ab.ca/maco/initiatives_palliative-a.htm

[302] Capital Health. Regional palliative care program. Annual report April 2002-March 2003 and April 2003 to March 2004

[303] Hospice Palliative Care Network (2004). Annual Report 2003-2004. Edmonton, AB: Alberta Cancer Board http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

[304] Hospice Palliative Care Network (2004). Annual Report 2003-2004. Edmonton, AB: Alberta Cancer Board http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

[305] Hospice Palliative Care Network (2004). Annual Report 2003-2004. Edmonton, AB: Alberta Cancer Board http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

[306] Hospice Palliative Care Network (2004). Annual Report 2003-2004. Edmonton, AB: Alberta Cancer Board http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

- Promoting the use of the National (CHPCA) norms of hospice palliative care through the delivery of workshops (between 2003 to 2004) to different groups (e.g., caregivers across all disciplines, registered nurses) across the province as well as the distribution of the training and resource manual to delegates of the Salvation Army's long-term care facilities
- Providing education via tele-education, organizing conferences, clinical rounds, and orientation sessions
- Disseminating the Alberta Palliative Care Resource Guide,[307] an educational manual to aid primary care practitioners in Alberta care for palliative patients. This resource manual offers a concise, practical, step-by-step suggestions regarding management strategies of common clinical problems; also lists for use evidence-based assessment tools for palliative care.

The HPCN is funded on an annual basis by the Alberta Cancer Board. The HPCN includes a Medical Advisor, a Provincial Coordinator, and a Program Assistant. The Provincial Coordinator's role is to provide leadership and coordination of palliative care activities for the MACO, serve as a resource for cancer centers/health regions, and other organizations; ensures that CHPCA Model is known; and encourages collaboration among the hospice palliative care stakeholders/caregivers.

Progress:
Current initiatives of the HPCN include the following:[308]

- In response to the 2003 changes to RHAs, the HPCN launched the Cancer and Rural Hospice Palliative Care Interface Projects (directed by a Committee), which are funded initiatives that aim to enhance access to palliative care for cancer patients and families living with a palliative diagnosis in Alberta. Such projects may focus on facilitating the collaboration between key stakeholders and strengthen the links between palliative care services, cancer centers, health centers, family physicians, community resources, and other providers. The East Central Interface Project is one example wherein the goal is to develop a collaborative approach between HPCN and East Central Regional Health to enhance accessibility to hospice palliative care for cancer patients and their families attending the community cancer centers within the region.[309]
- Alberta Strategic Alliance for Palliative Care reflects the collective views of over 60 stakeholders who gathered for a two-day meeting to address the critical issues of palliative care in the province and to seek proactive ways to work cooperatively to explore ways of building a strategic alliance. HPCN acts as a conveyor to making the alliance a reality.
- The ABC Oncology Hospice Palliative Care Initiative reflects the coming together of ACB and British Columbia Cancer Agency (BCCA) to enhance the quality of palliative care services delivered to patients. This venture is intended to develop activities that build on the respective cancer agencies' strengths that will focus on: clinical development; education; network development; policy development; and research.
- Integration of the Psychosocial Oncology Network with the Hospice Palliative Care Network

Other unique/exemplar features:
(1) the Integrated Cancer Care Network (electronic health record); and (2) The Web Surgical Medical Records program-WebSMR.

Distinctive feature – British Columbia

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[307] Hospice Palliative Care Network (2001). Alberta Palliative Care Resource Manual. Alberta Cancer Board. http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

[308] MACO. Current activities of the Hospice Palliative Care Network? http://www.cancerboard.ab.ca/maco/initiatives_palliative-c.htm

[309] Hospice Palliative Care Network (2004). Annual Report 2003-2004. Edmonton, AB: Alberta Cancer Board http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

Cancer Information Technology System

A distinctive feature of British Columbia's cancer control program is its enterprise-wide information technology (IT) system that enables the linking of cancer procedures to outcomes. All cancer-related activities (from prevention to palliation) within regional cancer centers, community cancer centers, and clinics are extensively linked and integrated by a number of health care technologies. The management of information on cancer patient begins with the BC Cancer Registry, which has been in existence since 1969.[310] As of 1980, the registry has been maintained by BCCA. All patients who receive a positive diagnosis for cancer must register. With the development of the cancer center in Fraser Valley came the need to update information management on cancer care. The Information Technology Group within the BCCA developed the Cancer Agency Information System (CAIS), which was initially conceived as a temporary solution to waitlist management, resource scheduling, and patient registration system, was secured in place enterprise-wide in 1994. [311, 312] The CAIS enables physicians to view information about their patients on computers located throughout the cancer centers, community centers and clinics, including their own offices. The CAIS supports:

- Patient demographic information
- Disease-site information
- Patient and resource scheduling
- Document management and workflow
- Transcription and result reporting (viewing of lab results as well)
- Diagnostic image management
- Decision support tool for health care professionals

Linked to the CAIS is a Tumor Tissue Repository (TTR)/Bioinformatic resource that tracks every patient from diagnosis, therapy, follow-up, and rehabilitation throughout BC. The components of the TTR comprise a Tumor Tissue Processing and Storage Laboratory and a Bioinformatics Clinical Research Database. At present, the focus is on the 5 most common cancers in BC: lung, breast, prostate, colorectal, and lymphoma. Health care professionals also have access to the Image Distribution Network, which is an electronic diagnostic imaging system that stores cancer-related diagnostic images of all types such as tomography, MRIs, radiography, nuclear medicine, and ultrasounds. Such images are transferred directly into a storage grid from the Picture Archive Communication System (PACS). PACS is what enables the distribution, storage, and retrieval of diagnostic.[313, 314] The PACS is linked to the CAIS. A final noteworthy IT system involves communication via the virtual private network, which enables consultation via videoconference, and a telephone system (IP telephony) that makes communication between centers and remote clinics more efficient.

Progress:
There are IT initiatives in the planning stage, which include:

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[310] BC cancer statistics. http://www.bccancer.bc.ca/HPI/CancerStatistics/default.htm

[311] British Columbia Health Industries Network Background Infomration. (2006) BCCA. http://www.hinetbc.org/database.cofull.asp?compno=921

[312] Henkelman, D. (2003).

[313] PHSA Steps forward to January 2004. http://www.phsa.ca/News/Steps-forward.htm

[314] HP. (2005). British Columbia Cancer Agency improves patient care with distributed storage grid. http://h71028.www7.hp.com/ERC/downloads/5983-2892EN.pdf

1. An electronic cancer pathology reporting system[315]
2. A translational informatics for health outcomes and evaluation capability that would incorporate economic evaluation, decision support, and performance measurement capacity[316]

Other unique/exemplar features:
(1) Web-based access to treatment protocols; and (2) translational research agenda.

Distinctive feature – Canada

CSCC Risk Management System

The Strategy is supported by a risk management system, previously known as the *Life at Cancer Risk* Approach, that is a sophisticated modeling tool to measure rewards and risk across all aspects of cancer risk and cancer interventions. This analytical tool applies quantitative techniques to measure and forecast the effects of cancer risk and the way in which cancer control can mitigate cancer risk. It has been used to model the impact (or not) of the implementation of the Strategy.[317] This instrument was developed following a review, conducted by the Council, of risk management practices used by financial institutions and their regulators. The review offered knowledge about analytical risk measurement and management techniques that could be optimized nationally to improve the fight against cancer.

A Risk Management Working Group (RMWG) is responsible for implementing and managing the risk management system.
For use by the Council, the risk management system enables:
- informed decision making about investments
- informed decision making about alignment of resources across the Action Groups
- evaluations of the impact of activities on a range of health variables such as cancer incidence and mortality as well as economic variables such as wage-based productivity (loss due to disability) and tax revenues (direct health cost, direct tax dollars)
- a systemic review of information and knowledge gaps and overlaps

For external (provinces and territories), the risk management system enables:
- informed decision making at a local level via the development of cancer profiles over a 30-year period and evaluation of the impact of cancer interventions against demographic, epidemiological, and economic factors

Progress:
- At the national level, the Council has used the risk management system to convincingly show the potential gains and losses over the next 30 years that will occur by either implementing a national cancer strategy or not implementing one, respectively. The losses translate into: an increase of 775,000 in new cancer cases; an increase of 415,000 in cancer deaths; an increase of 5.5 million potential lost years of Canadian life; an increased loss of over $43.7 billion in wage-based productivity; an increased loss of over $17.1 billion in direct health costs; and increased loss of over $7.4 billion in total government tax revenues. The gains translate into: over 1.2 million Canadians will be prevented from developing cancer; over 423,000 deaths will be avoided; 7.3 million potential years of lost life will be

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[315] PHSA Health services and design plan. From vision to reality April 2003.
[316] BCCA Strategic plan (September 2005)
[317] CSCC. Establishing the strategic framework for the Canadian strategy cancer control. 2005 and CSCC. 2006-2010 business plan for the CSCC, 2006.

prevented; a loss of over $101 billion in wage-based productivity will be prevented; over $39 billion in direct health costs will be saved; and a loss of over $34 billion in total tax revenues will be prevented.
- At the provincial and territorial levels, the risk management system has yet to be made available on line for access.

Other unique/exemplar features:
(1) The Human Resource Planning Information System (HR-PIS) developed by CAPCA; and (2) The Online Cancer Knowledge Resource for the sharing of knowledge created by the CSCC Priority Areas Action Groups.

Distinctive feature – England

NHS Cancer Services Collaborative Programme

The Cancer Services Collaborative (CSC), established in 1999, was one of the first service improvement programs in the NHS. The CSC is based on a combination of knowledge gained through the Breakthrough Series collaborative improvement model developed by the Institute for Healthcare Improvement in Boston (USA) and through the National Patients' Access Team experience of service redesign initiatives.[318] By examining possible improvements to the patient journey using redesign tools such as mapping the patient journey, measuring capacity and demand, and involving patients and their caregivers, the goal of the CSC was to: "*improve the experience and outcomes for patients with suspected or diagnosed cancer by optimizing care delivery systems across the whole pathway of care.*"[319] The five aims of the CSC are to: [320]
1. Reduce the number of days from referral to first definitive treatment
2. Increase the percentage of patients with a booked admission/appointment (key stages of the patient journey by providing certainty and choice)
3. Increase the proportion of patients who are reviewed by a multidisciplinary team;
4. Improve patient and caregiver (carer) experience
5. Ensure that the patient receives the best care, in the best place, by the best person/team

There were three phases to the CSC program:
CSC Phase 1: In Phase I, the improvement methodology was piloted in 9 of the 34 Cancer Networks, and focused on the process of care in five cancer tumour groups-namely, breast, lung, colorectal, prostate, and ovarian. The gains achieved through this first phase were noted as: [321] (1) significantly reduced waiting times for prostate cancer; (2) increase in booking for first specialist appointments; (3) the adoption of the patient perspective as in the use of patient mapping; (4) the formation and facilitation of multidisciplinary team working; and (5) the opportunities for networking with peers. As a result of the first 6000 changes tested and the subsequent 1000 implemented changes, 14 initial Service Improvement Guides were produced.[322] At present, there are 11 Service Improvement Guides for: colorectal; primary care; gynaecology; lung; multidisciplinary; breast; chemotherapy; radiotherapy; upper GI; urology; and patient and caregiver (carer) experience.

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[318] Health Service Management Centre, School of Public Policy CSC Phase 1 Evaluation.
[319] Cancer Services Collaborative. page 1. http://www.cancerimprovement.nhs.uk/App_Includes/PrintPreview/PrintFriendly.htm
[320] Cancer Services Collaborative. Background. http://www.cancerimprovement.nhs.uk
[321] Robert, G., McLeod, H., & Ham, C. (2003). Summary lessons from phase 1 of the Cancer Services Collaborative. School of Public Policy. Health Services Management Centre. Full reports available at: www.bham.ac.uk/hsmc.
[322] NHS Modernization Agency. Cancer Services Collaborative. A quick guide. http://www.modern.nhs.uk/cancer

CSC Phase II: In April 2001, the methodology was rolled out to all Cancer Networks as part of the CSC Phase II. In addition to the five key cancer sites, improvements were sought in all gynaecology cancers, all urological cancers, and upper GI cancers.[323]There were also projects addressing cross tumour sites: palliative care, primary care interface, radiotherapy, radiology, chemotherapy, endoscopy, and patient carer experience. Also part of Phase II was the development of a new approach to involve patients and their caregivers in the process of setting the agenda for change. Changes in cancer services were found across the Networks with improvements in waiting times for bowel, urology, lung, as well as communication to GP following a positive diagnosis for breast cancer, pre-booking for radiology and X-ray slots, and informing patient about treatment.

CSC Phase III: By March-April 2003, and Phase III of the program, the service improvement methodology was embedded at the level of all Networks as a new Cancer Services Collaborative 'Improvement Partnership' (CSC 'IP').[324] The CSC 'IP' program is about solidifying implementation and having impact. The focus is now on all cancers and in aligning service improvements to lead priorities. New clinical and managerial roles have emerged, with every network appointing a clinical and managerial Service Improvement Lead to lead modernization locally. This has moved the service improvement program from being centrally driven to being locally owned and driven, albeit with the remaining support of the NHS Institute for Innovation and Improvement (formerly the NHS Modernization Agency).

The CSC 'IP" is set within an integrated service improvement strategy system wherein commissioners and providers of services can obtain clinical information, managerial information, and patient information. Clinical Information system includes service improvement case studies for each tumour group, and cross-tumour services, treatment, and diagnostic services. The Managerial Information system includes How to Guides and Service Improvement Guides, and performance management resources. The Patients Information system includes patient information pathways, network resources, publications and useful links on the patient journey.

Progress:

- Phase III work resulted in the cancer High Impact Changes, which sets out a number of practical steps that can be taken to reduce cancer waiting times and improve the patients' experience of care (regarding referral, diagnosis, treatment planning, follow-up).[325] Providers and managers responsible for cancer services will now be focusing on redesigning the patient pathway involving the multidisciplinary teams and implementing the cancer High Impact Changes
- Updates on the CSC 'IP' How to Guide to support commissioners (PCTs, SHAs, Trusts) and providers (Networks) to maintain their achievements of cancer waiting times standards
- Information on factors essential for sustained and continuous service improvement and achievement of targets for cancer waiting times
- Self-assessment questionnaires to determine the sustainability of delivery for all NHS organizations-namely, SHAs, Cancer Networks, PCTs, and hospital care service providers. Assessment templates for each type of organization (SHAs, Networks, PCTs, providers) have been developed
- The Benefits' Realisation Tool enables Networks to report details of their local service improvement priorities, financial flows, and progress in cancer and related services

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[323] Cancer Services Collaborative. history. http://www.cancerimprovement.nhs.uk

[324] NHS Modernization Agency. (2003). An overview of the impact of the Cancer Services Collaborative in Modernisation in the the NHS. http://www.modern.nhs.uk/cancer/5622/Overview of CSC response2.doc

[325] NHS Cancer Services Collaborative Improvement Partnership. (2005). Applying high impact changes to cancer care. Excellence in cancer care. www.modern.nhs.uk.

- The Recovery Support Unit for Primary Care Trusts (PCTs), Hospital Trusts, Strategic Health Authorities (SHAs) and Networks to assess themselves on what mechanisms their organization have in place to assist in sustaining their cancer wait times

In 2005, the NHS Modernization Agency that was operating this program was superseded by the NHS Institute for Innovation and Improvement.

Other unique/exemplar features:
(1) Rigorous performance monitoring through the National Surveys of the NHS Patients' program, which provide information about cancer services from the patients' perspective over time, and independent performance assessments through National Audit Office and Healthcare Commission; and (2) NICE Improving Outcomes Guidance Program for cancer services.

Distinctive feature – France

Cancer Plan measure #40: le *dispositif d'annonce*. A structured approach for breaking the bad news and providing support

A distinctive feature of France's 2003-2007 cancer plan is its clear initiatives to ensure a more humane and comprehensive approach to caring for cancer patients, such as providing patients with improved "breaking the bad news" consultations and other forms of individual and social support. The inclusion of breaking the bad news consultations as a central measure of the cancer plan is the result of demands made by patients at the first *États généraux sur le cancer* organized by the League against cancer in 1998.[326] Measure 40 reads as follows:Pproviding patients with improved "breaking the bad news" consultations [by] defining the conditions to be met for imp[roved information of patients being handed a diagnosis of cancer, including the possible provision of psychological support and additional information (specifications); [and by] introducing flat free remuneration for these special consultations, to be paid to the health care institution, so as to collect funding for patient support structures, and for physician pay.[327]

Expected to be available nation-wide in 2005, implementation of these consultations began in 2004 with pilot projects. The original concept was broadened into a « *dispositif d'annonce* », a two-step procedure to announce cancer to the patient based on optimal conditions defined by the League against cancer. On the fist visit, which is to take place in the physician's cabinet and should involve a face-to-face encounter, without disrupting conditions, that should last at least 30 minutes, the doctor tells the patient about his disease, his treatment options and indicates that the patients case will be discussed in a multidisciplinary consultation meeting. On the second visit, the doctor elaborates the treatment strategy and proposes an individualized treatment plan for each patient. The objective of this plan is to offer to patients and caregivers an accurate, precise and personalized treatment schedule.

The medical aspects of the *dispositif d'annonce* includes the following steps:[328]
The breaking the bad news consultation
The multidisciplinary consultation meeting

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[326] Ligue national contre le cancer. Le dispositif d'annonce. Information destinée aux patients atteints de cancer. November 2006, p. 1.

[327] Cancer: A nation-wide mobilization plan, 2003, p. 26.

[328] Ligue national contre le cancer. Le dispositif d'annonce. Information destinée aux patients atteints de cancer. November 2006, pp. 3-7.

The personalized care plan
Information on rights and the possibility of getting a second opinion
Information on and the possibility of participation to clinical trials

In addition to this medical timeframe for information, the *dispositif d'annonce* also stipulates three other timeframes to provide adapted, progressive and respectful information and explanations on the disease and treatments, which are the following:[329]
Temps d'accompagnement soignant (nurse accompaniement timeframe) : allowing patients and their families to complete the information about the disease, to receive information about patients' rights and to obtain information on existing patient associations that may provide assistance;
Temps de soutien (support timeframe): entailing the proposal of socail accompaniement and access to physical, psychological and social support services; and
Temps d'articulation avec la medicine de ville (coordination of care timeframe) : is intended to optimise the coordination of care between the health facility, services available within the local/regional cancer network and the patient's treating physician.

Such *dispositif d'annonce* provides a unique opportunity to also implement some of the social support measures , which reflect the more general human aspect of the French cancer plan distinctive feature. The cancer plan also comprises a Social Issues priority (measures 54 to 60) that stipulates specific actions directed at keeping the patient's work and family life as normal as possible. They recognize that family and social networks are important to help patients cope with cancer (as well as to help parents of children with cancer). During such a difficult time, social problems need not compound physical hardships and psychological vulnerability. Initiatives to ensure that patients do not feel isolated from their families and social network, as well as burdened by social problems include:

- Ensuring that mechanisms are in place to help patients remain in their job, if they chose to, to return to the workforce, as well as to take a leave to support a friend or relative
- Increasing at-home health care and service provision to allow patients to remain at home, if they chose to
- Making it easier for parents to stay with their sick child through improved support mechanisms (such as through special grant for parental presence)
- Broadening patient's access to loans and insurance, deriving from the Insurance convention (known as the Belorgey Convention
- Improving coverage for specific medical or cosmetic expenditure by involving compulsory health care insurance bodies and personal insurance schemes
- Increasing access to patient and user support groups, which can provide entertainment and psychological help when in hospital

Progress:[330]

- Between June 2004 and May 2005, 18,500 patients (from 58 facilities) benefited from breaking the bad news consultations, and 90% of the patients' case were reviewed in a multidisciplinary consultation meeting, among which 35% of those patients benefited from supportive care.
- Between 2004 and 2005, close to 1300 new staff were hired, including 250 doctors, 324 nurses and 127 psycho-oncologists.
- INCa is planning a conference on work and cancer, scheduled to take place in June 2006. It will also be launching a call for research initiatives that take a interdisciplinary perspective on the subject of cancer

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[329] Ligue national contre le cancer. Le dispositif d'annonce. Information destinée aux patients atteints de cancer. November 2006, pp. 8-18.
[330] INCa. Plan Cancer 2003-2006. Ce qui a changé April 2006. See the Appendix: Suivi des 70 mesures du plan cancer. http://www.e-cancer.fr/les-actions/Presentation-Plan-cancer/op_1-it_112-la_1-ve_1.html

and work. There are currently several experimental projects taking place within a funded project – "EQUAL."

- Nursing at-home care has been expanded for patients younger than 60 years of age who are living with a chronic and long-term condition, such as cancer. There are currently experimental projects underway in two regions that aim to examine the setting up of information and coordination units to disseminate information on existing at-home support structures and other forms of support available to patients.
- As of May 2006, financial and social security law supports the allocation of support to parents.
- An information working group on the Belorgey Convention was held in 2004: The outcome of this working group is available on line (www.lesclesdelabanque.com). Ways in which the convention could be improved are currently being considered.
- As of February 2005, a first prosthetic model for breast is included on the list of products. Other prosthetic models are currently being considered.
- A model has been proposed that outlines the conditions of interventions that volunteer associations can take in health care settings in their efforts to offer support to patients and their families.

Other unique/exemplar features:
(1) Public accountability of cancer plan implementation through organized progress monitoring and regular public reporting; and (2) The Standards, Options and Recommentations for patients prepared by the Fédération nationale des centres de lutte contre le cancer.

Distinctive feature – New Zealand

NGOs' leadership in cancer strategy development

A distinctive feature of the New Zealand's cancer control action plan is the level of involvement and initiative of nongovernmental organizations (NGOs) in the development of the cancer strategy. NGOs initiated and significantly contributed to the policy development process in close partnership with the Ministry, beyond the usual collaboration, consultation, and/or partnership among different stakeholder[331]. The Cancer Society, its division, and the Child Cancer Foundation provided significant funding to head-start the New Zealand Cancer Control Trust, as well as to enable the Trust to continue its work in partnership with the Ministry of Health. There is clear recognition by the Trust that without the support ($676,000 between February 2001- April 2004) of these NGOs, very limited action would have been possible[332]. The Trust then served as a mechanism through which the non-governmental sector could facilitate the development of a cancer control strategy. Indeed, this collaboration represents a unique commitment of both government and NGOs to work together to fight cancer in NZ. Achievements made possible by the support of these three NGOs, including others (appropriately indicated below) are summarized as follows:

- In response to the overwhelming support for the development of a strategy by a network of organizations committed to cancer control (following the 1999 Cancer Control Workshop), the Cancer Society of New Zealand and the Child Cancer Foundation provided funding to establish the New Zealand Cancer Control Trust. The Trust was a consortium of organizations who worked together to develop a national plan for cancer control.

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[331] This distinctive feature has been indisputably recognized by the selected group of stakeholders interviewed during the course of this project.

[332] NZ Cancer Control Trust. 2003 annual report of the NZ Cancer Control Trust. http://www.cancercontrol.org.nz/update09.html

- The development of the NZ cancer control strategy was funded by the Ministry of Health and the Trust (the Cancer Society, its Division, and the Child Cancer Foundation).
- The national workshop (held in September 2003) entitled "*From Policy to Action: Working together to implement the Cancer Control Strategy,*"[333] which aimed to increase acceptance and involvement of a wide range of organizations and individuals responsible for the implementation of the cancer control strategy was made possible by a grant of $50,000 from the Genesis Oncology Trust (as premier sponsor), including the Cancer Society, the Child Cancer Foundation, and the Ministry of Health. This workshop marked the transition from policy development to planning the implementation of the strategy.[334,335]

Progress:

- The Cancer Society of New Zealand is identified as a key stakeholder in many initiatives stipulated in the Cancer Control Action Plan. It has established the Cancer Control Action Group, comprising of some of its Divisional CEOs. This group (within the past 6 months, as of June 2006) has led a comprehensive planning process to establish a common mission, vision, and set of values across the organization and to identify strategic priorities related to the cancer control strategy[336]. In addition, divisional CEOs have also been working with government-funded services and others to establish the Regional Cancer Control Networks.

Other unique/exemplar feature:

(1) Strong focus on reducing health inequalities for Maori and Pacific Island populations in all aspects of cancer control (prevention, screening, treatment, support and palliative care), as well as more generally via the *Reducing Inequalities Intervention Framework* and the *Health Equity Assessment Tool* that provide assistance in developing interventions with an equity focus.

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[333] Report of the 2003 Cancer Control Workshop: from policy to action- working together to implement the New Zealand Cancer Control Strategy. Wellington. September 2003.

[334] NZ Cancer Control Trust. 2003 annual report of the NZ Cancer Control Trust. http://www.cancercontrol.org.nz/update09.html

[335] NZ Cancer Control Trust. Significant step in the control of cancer. http://www.cancercontrol.org.nz/update07.html

[336] Personal communication with Ms. Betsy Marshall, Policy Advisor of Cancer Screening & Cancer Control of the Cancer Society of NZ. June 19, 2006

Distinctive feature – Nova Scotia

Patient Navigation Program

A distinctive feature of Nova Scotia's cancer control intervention is the Patient Navigation (PN) Program developed and implemented by CCNS.[337] The PN program, introduced in 2001 and currently running in five of the nine District Health Authorities aims to support health professionals, patients and their families in navigating through the cancer system. The PN program is the result of extensive consultation with cancer patients, family members, health professionals, community organizations and volunteers throughout Nova Scotia.[338,339] PN program is led by trained patient navigators whose work includes providing patients and their families with emotional and instrumental support as well as information and education about cancer and the cancer journey through the system. Patient navigators also collaborate with health care professionals serving as linkages throughout the different components of the system, as well as educating the cancer team about services and actions other team members are providing. A database was also developed to track referrals made to navigators-namely; information on reasons for referrals, referral source, date of referral and diagnosis, cancer site, ICD oncology diagnostic code, patient characteristics, family physician, and specialist; issues to be resolved; and length of time to resolve issue. The PN program has three goals:

- Ensure cancer patients and their families have information, knowledge, and support they need as they journey through the cancer system
- Assist family physicians, surgeons, community-based specialists, oncologists, and other health professionals to provide optimal cancer care
- Enhance district health authorities capacity to care for and support people with cancer

Progress:
A formal PN evaluation in the three initial districts was conducted in 2003 (findings published in 2004). Multiple stakeholder groups participated in the evaluation process: patients and families; the Canadian Cancer Society staff/volunteers; physicians; other health professionals within the districts and at cancer centers; patient navigators; senior leaders in the original three districts; and key CCNS staff. The evaluation integrated information from 16 focus groups, 57 one-on-one interviews, 162 patient surveys, and a review of 808 records in the patient navigation database. The findings confirmed that:[340]

- Patient navigators possess significant knowledge and awareness of the provincial cancer system, community supports, and resources.
- Use of this knowledge has resulted in improvements in the cancer care system itself by addressing problems related to integration, coordination, and continuity of care in the district-namely: improved coordination between community services and tertiary centers, more consistency in cancer care, earlier referrals to oncologists; and offering a new source of oncology expertise to the community.
- The program is meeting the expectations of health professionals, community partners, and senior leaders in the district in that the patient navigators are providing consistency in care, patients are better prepared and have more support; and there is improved patient collaboration.
- Benefits of the program for patients and families included receiving emotional support, being better prepared for their cancer journey, being referred to appropriate health professionals, having more knowledge about cancer, getting help with coordinating appointments, being referred to supports in the

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[337] Cancer Patient Navigation. Evaluation findings. March 2004.
[338] CCNS. Patient Navigation: Clearing a path for patients: Action Plan (April 2001)
[339] CCNS. Patient Navigation- background. http://www.cancercare.ns.ca/inside.asp?cmPageID=89
[340] CCNS. Cancer Patient Navigation. Evaluation findings. March 2004.

community, getting assistance with the logistics of getting to a cancer center, and getting help with finding sources of funding for medications and supplies.

- Remaining challenges of the PN program include: encouraging a greater number of referrals; increasing the timeliness of the referrals received; more continuous communication about navigation with health professionals; strategies to ensure equal access to the navigator in districts with larger geographical areas; careful and consistent monitoring of the roles and priorities of the patient navigators, along with their workload.
- CCNS initially funded patient navigation and piloted it in three DHAs: Yarmouth, New Glasgow, and Antigonish. In 2004-05, funding responsibility was transferred to the DHAs.[341] Bridgewater and Kentville have since implemented the role in their respective DHAs. DHAs are free to fund and provide this role/service from within their approved budgets. Department of Health funding for any new positions/ programs must be approved through the New and Expanded Program and business planning processes.

Other unique/exemplar features:
(1) Excellence in Cancer Care initiative, comprising continuing education programs for health professionals such as the Interprofessional Core Curriculum; Communication Skills; and Palliative Care Front-Line Education program; and (2) Action in your Community against Tocacco (ACT), a collaborative initiative (Canadian cancer Society and CCNS) developed to enhance capacity at the community level to implement the tobacco control strategy.

Distinctive feature – Ontario

Quality improvement/assurance through the Cancer System Quality Index and Program in Evidence-Based Care

A distinctive feature of the Ontario cancer control system is the establishment of an innovative platform for ensuring system quality improvement and assurance through initiatives stemming from the Program of Evidence-Based Care (PEBC)[342] and the Cancer Quality Council of Ontario (CQCO) .[343]

The Program in Evidence-Based Care (PEBC), established by CCO,[344] aims to ensure the transfer of high-quality cancer care research into informed clinical care by (1) developing evidence-based care information for providers and the public; (2) maintaining the quality and currency of resources; (3) ensuring the availability and accessibility of resources; and (4) disseminating and evaluating resources.[345] There are three *Guideline Development Groups* for cancer screening, supportive care, and therapeutic radiopharmaceutical as well as 11 *Disease Site Cancer Groups*: breast, gastrointestinal, genitourinary, gynecology, head/neck, hematology, lung, melanoma, neuron-oncology, sarcoma, and systemic treatment. All 14 groups are responsible for ensuring the production, dissemination,

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[341] DH Annual Accountability Report 2004-2005, p. 52. Available at: http://www.gov.ns.ca/health/downloads/2004-2005_Annual_Accountability_Report.pdf

[342] Cancer Care Ontario. About the Program in Evidence-Based Care. http://www.cancercare.on.ca/index_ AboutthePEBC.htm

[343] Cancer Quality Council of Ontario. (2004). Gaining Access to Appropriate Cancer Services: A Four-Point Strategy to Reduce Waiting Times in Ontario.

[344] Ontario Cancer Plan p.50

[345] Cancer Care Ontario. About the Program in Evidence-Based Care. http://www.cancercare.on.ca/index_ AboutthePEBC.htm

implementation, evaluation, and updating of guidelines, standards, and planning tools.[346] CPG development includes surveys of oncologists' opinions, using a structured questionnaire, about draft recommendations that were developed by the expert panels. The work on clinical practice guidelines has now been expanded to include standards. Implementation of the guidelines and standards is led by the clinicians and staff of the clinical programs division of CCO working with the 14 regional cancer programs.

The CQCO was established in 2003[347] following the recommendation put forth by the Cancer Services Implementation Committee. The CQCO is considered to be the first council of its kind in Canada. The Council monitors, assesses, and offers tools for improving the quality of cancer services throughout Ontario. One of its first task was to produce the book entitled *Strengthening the Quality of Cancer Services in Ontario* (2003) which is an assessment of the quality of cancer services in Ontario and which identifies existing gaps in the ability to measure quality. In 2004, the CQCO put forth a 4-point strategy for reducing wait times for cancer services, which made reference to: (1) reducing demand for services by lowering the risk of developing cancer and by promoting detection; (2) increasing supply of cancer resources; (3) coordinating access to cancer services; and (4) increasing efficient use of existing cancer resources. The restructuring of CCO led to a performance management perspective as an add-on to its existing evidence-based foundation (enforced through PEBC). Apart from the surveillance data from the Ontario Cancer Registry, the performance tracking measures in place tended to focus only on those services delivered by CCO. There was thus a need to develop and secure in place a comprehensive and system-wide performance measurement system that would track cancer service delivery across the spectrum of cancer care. CCO currently hosts the secretariat for the Quality Council and holds financial accountability for the work of the Council. The Council nevertheless operates with an independent voice and is expected to function impartially with respect to CCO.[348]

In 2005, the CQCO launched the Cancer System Quality Index (CSQI).[349] The CSQI provides a framework for measuring the success of the strategy for the cancer system. The Index tracks progress against the 5 goals of the Ontario's cancer system: (1) improve access to services and reduce wait times; (2) improve outcomes as in survival rates; (3) increase use of evidence when treating cancer; (4) improve efficiency of cancer care resources; and (5) improve measurement and reporting of cancer of data across all aspects of cancer care.[350] The CSQI is a publicly available website that uses 25 key indicators to monitor the performance of the cancer system, in terms of services delivered across the spectrum of cancer care (from prevention to palliation). The indicators were selected on the basis of sufficient evidence. The Index is considered to be the first of its kind in Canada.[351] It was developed in partnership with CCO, the Institute for Clinical Evaluative Sciences, and the University of Toronto, and more than 60 cancer experts.

Progress:

- With the 2005 creation of the Local Health Integration Networks (LHIN) , the Cancer System Quality Index data for 2006 are collected according to the 14 LHIN.

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[346] CCO. About the Program in Evidence-Based Care. http://www.cancercare.on.ca/index_AboutthePEBC.html.

[347] Cancer Care Ontario. Ontario Cancer News. Canada's first cancer quality council. http://www.cancercare.on.ca/OntarioCancerNewsArchives/200304/0304story4.html

[348] See *Strengthening the Quality of Cancer Services in Ontario*, 2003, p. xviii.

[349] Cancer Care Ontario. Cancer System Quality Index. http://www.cancercare.on.ca/qualityindex

[350] http://www.cancercare.on.ca/qualityindex2006/

[351] Cancer Care Ontario. Ontario Cancer News. Web report evaluates Ontario's cancer system. April 2006; vol. 4. http://www.cancercare.on.ca/OntarioCancerNewsArchives/200604/index_534.html

Other unique/exemplar features:
(1) Pathology Information Management System, which automates the capture and reporting of cancer pathology data across Ontario; and (2) Computerized Physician Order Entry for Drugs, which integrates clinical practice guidelines for ordering drugs.

8. IMPACT

As described in Chapter 5, most cancer control programs and action plans have stated targets and/or indicators that can be used to evaluate progress. *Progress* may be related to either (1) monitoring the implementation process; or (2) determining the impact of the program or action plan. A review focusing on monitoring the implementation process can examine the program or action plan's major accomplishments, and how these accomplishments are contributing to meeting established goals and targets; it can also examine whether the cancer control program or action plan is on track with regard to stated timelines, as well as whether it has the monetary commitment or investment to reach stated goals and targets. A review focusing on assessing the *Impact* of the cancer control program or action plan will examine the effects the program or plan on the problem at hand (e.g., high cancer mortality rates, variations in the quality of care etc.). Those effects are usually characterized in relation to intended outcomes. Outcomes may be classified as process outcomes and health outcomes. A process outcome may include, for example, reduction in waiting time, increased participation rate to a screening program, raising awareness about cancer care and treatment, and patient satisfaction with service delivery. A health outcome may include reduction in smoking prevalence rates, reduction in cancer incidence and mortality rates, as well as increases in survival rates.

In this Chapter, we endeavor to provide a succinct, yet informative descriptive review of the progress of each jurisdiction's cancer control program or action plan in meeting program or action plan goals and targets, as well as measurable indicators of outcome. To facilitate this review of the existing literature, we distinguish between reports that have focused on monitoring the implementation process from those that have focused on determining impact. Included are reports stemming from independent bodies or organizations that do not have the mandate to monitor or implement the cancer program or action plan. However, not all jurisdictions have published such independent assessments. Therefore, in the absence of literature from independent bodies, we included publicly available information regarding progress as published by the governing organization responsible for overseeing implementation. As a result, this descriptive review will vary in depth and thoroughness depending on the availability of information.

8.1 HIGHLIGHTS OF THE JURISDICTIONS

Jurisdictions can be distinguished according to whether or not they have stipulated specific timelines for the achievement of their plan's goals and targets. The ones with clear timelines are the following:

- CSCC Business Plan (2006-2010)
- New Zealand Cancer Control Action Plan (2005-2010)
- France Nation-wide Cancer Mobilization Plan (2003-2007)
- England NHS Cancer Plan (2000-2010)
- Ontario Cancer Plan (2005-2008)

The remaining three jurisdictions (Nova Scotia, British Columbia, and Alberta) have ongoing program activities that are subject to annual planning and reporting. The Cancer Care Nova Scotia: A Plan for Action, published in 1996, the BC Cancer Agency Strategic Plan, published in

2003, and the Alberta Cancer Control Action Plan, published in 2004 do not specify a timeline for implementation. For those last three jurisdictions, the review will examine available assessments of the Cancer Care Nova Scotia, the BC Cancer Agency, and the Alberta Cancer Board program activities, in addition to their action plans. Summary tables, for each jurisdiction, juxtaposing cancer programs and/or action plans' measurable targets/indicators of outcome with published information on progress are included in Appendix 8A. Our review begins with Canada, and follows the order provided above.

8.1.1 Canadian strategy for cancer control

Although the CSCC was drafted and adopted in 2002, it is in 2006 that the Canadian government committed substantial funds to begin its implementation. The Strategy is meant to provide evidence-based knowledge and tools needed for Canadian provinces/territories to independently build cancer management strategies tailored to their own needs. The CSCC is not a strategy for imposing specific programs, initiatives, services, or targets on any jurisdictions. Provinces and territories have the freedom to opt in and out of the Strategy, as resources and priorities dictate. The CSCC approach can therefore been seen as establishing a mechanism that enables comparability, transparency, consistency, and portability of evidence in cancer care and services across all provinces/territories. To this end, then, there is no specific independent evaluation of each province as it relates to implementing CSCC aims and targets.

All activities undertaken by the CSCC Council and its progress in (1) engaging provinces/territories to use the strategy in building their cancer plan, and (2) meeting its established goals and targets are ongoing. A newly created (2006) Quality and Performance Assurance Working Group will assess and ensure the appropriateness of the targets stipulated by the Priority Area Action Working Groups, and will evaluate their performance using a set of key performance indicators.

Given that no evaluation has yet been conducted on the impact of CSCC targets (*impact* in terms of process and health outcomes), we report on CSCC efforts in raising awareness about the importance of implementing the CSCC strategy across the four provinces/territories reviewed in this report. We also provide some general information on the status of Canada's fight against cancer, based on relevant data from Canadian organizations.

In February 2006, a report by the Conference Board of Canada[352] compared Canada to 23 other OECD countries on 19 indicators including cancer incidence and mortality rates. The report also examined the performance of Canadian provinces on 70 health indicators grouped into the three categories of health status, health outcomes and health-care utilization and performance, using Health Canada's health indicator data, released in December 2004.[353] Relevant results pertaining to Canada are presented herein, while provincial data will be presented under the provincial jurisdictions.

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[352] Hamilton C. Healthy Provinces, Healthy Canadians: A Provincial Benchmarking Report. Conference Board of Canada, February 2006. Available at: http://www.conferenceboard.ca/documents.asp?rnext=1533

[353] Much of this data can be found in the Health Canada publication Healthy Canadians: A Federal Report on Comparable Health Indicators, December 2004.

Also in February 2006, the Health Council of Canada issued an annual report to Canadians on the quality of health care in 2005 across the provinces/territories.[354] A focus of their review was gathering information on the actual wait times for selected treatments, among which included radiation therapy as of December 2005. Results pertaining to the provinces selected in our review will be presented under the provincial jurisdictions unless more recent data is available.

In April 2006, the Canadian Cancer Society and the National Cancer Institute of Canada published the 2006 Canadian Cancer Statistics.[355] Such compilation provides health status data that, once analysed and put in perspective, could be relevant to examine progress, overall (Canada) and by provinces.

Monitoring the implementation process

January 2005: A second stakeholder forum[356] was held to provide an opportunity for all involved cancer stakeholders to review and renew commitments to the CSCC, and to plan implementation at both the national and provincial/territorial levels. Approximately 125 stakeholders attended the Forum, representing individuals with expertise and experience from across Canada, including not-for-profit, federal/provincial governments, patient/support/advocacy, and healthcare professional groups. The input, advice, expert opinions, and recommendations for direction supplied by Forum stakeholders undoubtedly influenced the Council's decisions regarding their new business plan, as well as informed the mandate of Priority Area Action Groups.

April 2005: In the CSCC news bulletin,[357] the Council provided an update on its activities, as well as an update on provincial cancer control activities based on provincial reports submitted to the CSCC. As of March 2005:

- Alberta published the Alberta Cancer Control Action Plan in September 2004, which is a call for an action plan that mirrors the CSCC's priority areas.
- British Columbia established a BC and Yukon Council of the CSCC in the fall of 2004 to promote and coordinate a provincial/territorial strategy based on the CSCC.
- Nova Scotia described Cancer Care Nova Scotia Program achievements along the seven CSCC Priority Areas. Nova Scotia is one of the pilot provinces for the Human Resource Planning Information System.
- Ontario's described the development process and priorities associated with the Ontario's Cancer Plan 2005-2008. The development of a broad range of practice guidelines, as well as quality and performance indicators to monitor the cancer system that comes with the new action plan addresses some of the CSCC Priority Areas.

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[354] Health Council of Canada (February 2006). Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005. Available at: http://www.healthcouncilcanada.ca/en/index.php?option=com_content&task=view&id=70&Itemid=72

[355] Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada, 2006. Available at: http://129.33.170.32/vgn/images/portal/cit_86751114/31/21/935505792cw_2006stats_en.pdf.pdf

[356] The first Forum was held in 2001. CSCC (2005). Outlook 2005: Stakeholders Forum II: Report. March 9, 2005

[357] CSCC (2005). Bulletin April, vol. 8: 1-7

Impact: Process and health outcomes

Regarding the impact of CSCC implementation, no data is available yet. See Appendix 8A for stated targets/indicators and summary of progress.

December 2005: The latest report from the Canadian Tobacco Use Monitoring Survey indicates a steady decline in the rate of cigarette smoking among Canadians aged 15 and over, from 35% in 1999, to 20% in 2004, to 19% in 2005.[358] However, when considering all Canadians (aged 12 and over) the rates of current smokers fell from 26% in 2000/01 to 23% in 2003 to 22% in 2005.

February 2006: In an international comparison of health system performance presented by the Conference Board of Canada, Canada‘s performance on several cancer indicators suggest the need for improvement. Of particular concern are the following:

- Canadian females have the second highest incidence rate for lung cancer among the 24 countries. Canada’s incidence rate for breast cancer is very similar to the rates of the comparator countries with the lowest performances on this indicator.
- Canada’s mortality rate for female breast cancer is just above that of France, which stands just above the comparator countries with the lowest performances.
- Canada’s mortality rate for colorectal cancer in females is low, however Canadian incidence rates for both sexes are high.

April 2006: The 2006 Canadian Cancer Statistics Report indicated that by 2003, every province had an organized program offering biennial mammography screening to asymptomatic women between the ages of 50-69 with no previous history of breast cancer. Although none of the organized programs have achieved the nationally established target of 70% participation, the proportion of women in organized screening has increased over time, reaching 34% nationally by 2002. In 2003, about 61% of women aged 50-69 reported having screening mammography in the last two years, a considerable increase from the 53% reported in 2000/01.

April 2006: The CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that Canada had an 18 % increase in new cancer cases between 1996 and 2006.[359]

8.1.2 New Zealand cancer control strategy and action plan

The New Zealand Cancer Control Action Plan (2005-2010) outlines in detail how the NZ cancer Control Strategy’s objectives can be achieved. The Action Plan incorporates and builds upon existing government health strategies and activities that contribute to cancer control. The plan has an initial five year timeframe for implementation: it is expected that by the end of its fifth year (2010), considerable progress will have been made. Targeted actions that are expected to have a greater impact will take longer to initiate (usually 3 to 5 years) and are thus designated as Phase 2 activities. Phase 1 activities are those targeted actions that will, in general, take 1 to 2 years to implement.

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[358] Health Canada. Canadian Tobacco Use Monitoring Survey 2005. Available at: http://www.hc-sc.gc.ca/hl-vs/tobac-tabac/research-recherche/stat/ctums-esutc/2005/ann_summary-sommaire_e.html

[359] Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

The Action Plan indicates that ongoing monitoring and periodic independent review will be the primary mechanisms for evaluation. The Cancer Control Council is assigned the role of monitoring the overall progress toward achieving the main goals of the Action Plan. Results of monitoring will be disseminated through annual progress reports to the Minister of Health and Parliament, and will provide the basis for periodic review. Although milestones have been described for each specific action linked to each objective associated with the 6 goals, no independent review of overall progress (in terms of implementation according to priorities and impact of the action plan) has been conducted so far. However, the Ministry of Health has published its annual report on tobacco,[360] with the latest information available for 2004. In addition, the Independent Monitoring Group[361] published its internal analysis report of the BreastScreen Aotearoa program. We report on these findings in terms of impact.

Monitoring the implementation process

No information is publicly available on the NZ Cancer Control Council's activities, on the progress of the Cancer Control Work Programme, nor on the progress in meeting the NZ Cancer Control Action Plan milestones and targets, except for the progress reported in establishing regional cancer networks as described in Chapter 7.

Impact: Process outcomes

June 2005: The internal analysis report published in 2005 by the Independent Monitoring Group[362] revealed that the biennial participation rate for women aged 50-64 years to the BreastScreen Aotearoa (BSA) program was 64%. BSA is a population-based mammography screening program offered tor all NZ women aged 50-64 years since 1999. In July, 2004 the target age group was extended to include women aged 45-49 years and 65-69 years.

May 2006: Waiting times for radiation treatment have been collected since December 1998 when a shortage of medical radiation technologists led to increased waiting times for some cancer patients. Radiotherapy waiting times are reported monthly to the Ministry of Health from each of the six Cancer Centres.[363] Since March 2005, more than 80% of all patients (and more than 90% of Priority C patients) waited less than 8 weeks between the first specialist assessment and the start of radiation treatment in all 6 cancer centres.[364] (See Appendix 8A for definition of Priority C patients).

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[360] Ministry of Health. 2005. *Tobacco Facts 2005*. Wellington: Ministry of Health

[361] Andrew Page & Richard Taylor. INDEPENDENT MONITORING REPORT BreastScreen Aotearoa January-June, 2005

[362] Andrew Page & Richard Taylor. INDEPENDENT MONITORING REPORT BreastScreen Aotearoa January-June, 2005, p. 3

[363] http://www.moh.govt.nz/cancerwaitingtimes

[364] Graphs of monthly trends from September 2002 to May 2006. Available at: http://www.moh.govt.nz/moh.nsf/pagesmh/4685/$File/radiation-waitingtimes-may06.pdf

Impact: Health outcomes

October 2005: The Ministry of Health published data from the 2004 AC Nielson (NZ) Ltd Survey, as part of its tobacco control initiatives.[365] In that report, we learn that the percentage of smokers in the general population has dropped from 25% in 2001 to 23.4% in 2004. Although the prevalence of smoking among Māori and Pacific people remains high, there are noted decreases in smoking prevalence. For the Māori population, the prevalence has dropped from 52% in 2001 to 47% in 2004; and for the Pacific population, the prevalence has dropped from 32% in 2001 to 29%.

8.1.3 France nation-wide cancer mobilization plan

France's Nation-wide Cancer Mobilization Plan (2003-2007) was presented to the public in 2003 by the President of the Republic. The plan comprises 70 measures, and identifies a number of key indicators, for prevention, screening, health care, support, and research to be achieved within a 5-year time frame (2007). At present, France does not have any independent reviews of progress. Numerous periodic reports of progress toward implementation of the plan have been made public, namely at 6, 10, and 12 months and then on a yearly basis (see Appendix 4A for details). These reports were prepared by the Interministerial Taskforce (2003-2005) [366,367] ,and since 2005, by the National Cancer Institute (INCa).[368] INCa activities and progress toward implementation are also presented in its newsletters.[369]

Progress of implementation has been monitored on a yearly basis by the governing organization, with a focus on guaranteeing strict compliance with agreed targets and timelines for achieving them. Moreover, in 2005, INCa was expected to put forth a template for an evaluation system that would be used to monitor the fight against cancer in France.[370] The Institute was also scheduled to carry out its first assessment in 2006.[371] Once the full term of the Cancer Plan has been met, INCa is expected to initiate new programs in line with national, European, and international action against cancer.

Monitoring the implementation process

April 2006: The Cancer Plan three-year progress report prepared by INCa provides information on the progress achieved in implementing the plan's 70 measures.[372] Progress is described

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[365] Ministry of Health. 2005. *Tobacco Facts 2005*. Wellington: Ministry of Health

[366] Mission interministérielle de lutte contre le cancer. Rapport annuel 2003-2004. La dynamique du plan cancer. Un an d'actions et de résultats, May 2004. Available at: http://www.plancancer.fr

[367] Mission interministérielle de lutte contre le cancer. Rapport annuel 2004-2005. La dynamique du plan cancer. Actions et résultats, April 2005. Available at: http://www.plancancer.fr

[368] Institut national du cancer. Plan Cancer 2003-2006. Ce qui a changé April 2006. Available at: http://www.e-cancer.fr/les-actions/Presentation-Plan-cancer/op_1-it_112-la_1-ve_1.html

[369] La lettre de l'Institut national du cancer. No 1, November 2005, No 2, May 2006 and No 3, July 2006. Available at: www.e-cancer.fr

[370] INCa website. Evaluating cancer care conditions in France. http://www.e-cancer.fr/v1

[371] INCa website. The 2005-2007 Strategic Action Plan. http://www.e-cancer.fr/v1

[372] INCa. Plan Cancer 2003-2006. Ce qui a changé April 2006. See the Appendix: Suivi des 70 mesures du plan cancer. http://www.e-cancer.fr/les-actions/Presentation-Plan-cancer/op_1-it_112-la_1-ve_1.html

according to the 200 actions, along the 6 priorities- prevention, screening, care, social support, training and research. The first INCa newsletter[373] shows that by the end of 2005, 32 measures had been met, which included 15 of the 20 measures outlined for prevention; 4 of the 8 measures stipulated for screening; 2 of the 25 measures associated with care; 5 of the 7 measures linked to social support; 1 of the 5 measures associated with training; and 2 of the 5 measures outlined for research. These accomplishments closely follow the priority established in the Cancer Plan implementation timeline, where years 1and 2 were to be focused on improving prevention and screening, and years 2-5 would focus on the organization of health care.[374]

Impact: Process outcomes

April 2006: INCa three-year progress report[375] also shows that:

- Between June 2004 and May 2005, 18,500 patients (from 58 facilities) benefited from a new approach to “breacking the bad news” (dispositif d’annonce), and 90% of the patients’ case were reviewed in a multidisciplinary consultation meeting, among which 35% of those patients benefited from supportive care.
- Between 2004 and 2005, close to 1300 new staff were hired, including 250 doctors, 324 nurses and 127 psycho-oncologists.
- By the end of 2005, 80 PET scanners were authorized and 53 were in operation; 467 MRIs were authorized and 351 were in operation; 801 scanners were authorized and 728 were in operation.
- Genetic testing increased by 22.3% in 2004 (compared to 2003)
- Genetic counseling increased by 40.6% in 2004 (compared to 2003)

May 2006: A study by the Institut National de Veille Sanitaire (INVS)[376] shows that participation rates of women between 50-74 years of age to organized breast cancer screening program (which was generalized to all regions in 2005) increased gradually from 2003 to 2005: from 33 % in 2003, to 40 % in 2004 to 45 % in 2005. There were regional variations ranging from 32% to 59% (2004-2005). However, the *Baromètre santé 2005* survey indicated that 65% of women 50-74 surveyed said they underwent a mammography in the last 2 years.

Impact: Health outcomes

April 2006: INCa three-year progress report[377] indicates that:

- Between 1990 and 2002, the rate of cancer death increased by 7.2% with significant differences (1 to 1.3 fold) between regions.
- Between 2000 and 2005, 1.4 million people stopped smoking. The prevalence of smoking (12-75 years of age) has dropped to 29.9% in 2005 (compared to 33.1% in 2000). A reduced

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[373] La lettre de l’Institut National du Cancer. No 1, November 2005. Available at: www.e-cancer.fr

[374] MILC. Cancer : A nation-wide mobilization plan, 2003, p. 13.

[375] INCa. Plan Cancer 2003-2006. Ce qui a changé April 2006. See the Appendix: Suivi des 70 mesures du plan cancer. http://www.e-cancer.fr/les-actions/Presentation-Plan-cancer/op_1-it_112-la_1-ve_1.html

[376] Taux de participation des femmes au programme de dépistage organisé du cancer du sein en France, 2003-2005. Available at: http://www.invs.sante.fr/presse/2006/le_point_sur/cancer_sein_2003_2005/index.html

[377] INCa. Plan Cancer 2003-2006. Ce qui a changé April 2006. See the Appendix: Suivi des 70 mesures du plan cancer. http://www.e-cancer.fr/les-actions/Presentation-Plan-cancer/op_1-it_112-la_1-ve_1.html

prevalence is observed in both men and women of all age group: e.g., the prevalence of smoking among teens (15-19 years of age) has dropped to 31.3% in 2005 (from 40.9% in 2000).

8.1.4 Ontario cancer plan

The Ontario Cancer Plan (2005-2008) is a provincial plan based on the input of 11 regional plans, and incorporating previous policy documents such as Ontario's Cancer Prevention and Screening Action Plan (Cancer 2020) and the Aboriginal Cancer Strategy. The Cancer 2020 Prevention and Screening Action Plan includes 20 measurable targets, including five for tobacco use and five for screening. In the *Ontario Cancer Plan 2005-2008*, the six priorities are each associated with a number of actions (termed action plans). Each action plan is in turn characterized by a description, deliverables and a list of outcomes. Those outcomes are not quantifiable outcomes but more like expected results.

Progress of implementation has been reported in *Ontario Cancer Plan: 2005 progress report*. In addition, the *Cancer System Quality Index* (CSQI) developed by the Cancer Quality Council of Ontario supports the assessment of the Action Plan's impact through the development of relevant quality and performance measures. The CSQI includes performance indicators that measure progress made in five areas: access, improving outcomes, evidence, efficiency, and measurement. The measurable targets stipulated in the Cancer 2020 document are also captured in this index. In this review we report on the 2006 CSQI, which demonstrates activity in 2005.

The Ontario government also tracks and reports on wait times for radiation and systemic therapy by cancer sites and regional cancer centers. This information is accessible via the Cancer Care Ontario website. Moreover, Ontario hospitals have been measuring patient satisfaction since 1998 as part of series of reports known as Hospital Report, which uses a balanced score card approach to assess activities and outcomes in four dimensions of hospital performance: (1) financial performance; (2) clinical utilization and outcomes; (3) system integration and change; and (4) patient satisfaction.[378] In addition to the measurement of inpatient satisfaction by the Hospital Report, Cancer Care Ontario also measures patient satisfaction in ambulatory oncology in the regional cancer centres. These data, using a similar tool as the Hospital Report, are reported in the Cancer System Quality Index.[379]

Monitoring the implementation process

Ontario Cancer Plan 2005 Progress Report describes major achievements in 2005, some of which were presented in Chapter 7 on Main Accomplishments. Data related to meeting stated targets and indicators of outcome are provided below.

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[378] These reports are published by the Hospital Report Research Collaborative, an independent team of investigators consisting of professors and researchers drawn from many organisations. Among the organisations that play key roles in the development of those reports are the Ontario Hospital Association, the Department of Health Policy, Management and Evaluation of the University of Toronto, the Canadian Institute for Health Information, and the Ontario Government. There are Hospital Reports for: acute care, complex continuing care, emergency department care, mental health, and rehabilitation. Available at: http://www.oha.com/oha/reprt5.nsf

[379] Personnal communication, Dr Terry Sullivan, CEO, CCO, October 23, 2006 letter.

Impact: Process outcomes

2005: Ontario Cancer Plan Progress Report indicates that 27% of the target population (women aged 50-69) is being screened through the Ontario Breast Screening Program. Other women in this age group are being screened through stand-alone programs with inconsistent quality standards. CSQI 2006 indicates that breast cancer screening (including organized) increased to 56.4% in 2005, up from 52.5% in 2004. The CSQI 2006 also revealed that less than 10% of the Ontario population aged 50-74 undergoes colorectal cancer screening.

2006: The Hospital Report 2006 showed that 95 % of survey respondents rated the overall quality of their care as excellent, very good or good.[380] The Report also examined the proportion of hospitals that reported collaboration with Cancer Centres. In 2005, 40.4% of hospitals reported developing standardized protocols with Cancer Centres that spanned patient care in the hospital and community. In 2006, the proportion increased to 60.6%.[381]

September 2006: A Press release by the Ontario Government[382] indicated that radiation wait times have steadily improved because of investments in cancer centres, new equipment and better planning. Median radiation wait times have dropped from 6.6 weeks in 2003 to 4.1 weeks in 2006 – a 38% reduction. From spring 2005 to spring 2006, wait times for radiation treatment were reduced by 11%. Results from the 2005 Cancer System Quality Index revealed the average wait for radiation treatment was 4.7 weeks, down from 7.0 in 2002.

Impact: Health outcomes

December 2005: The latest report from the Canadian Tobacco Use Monitoring Survey indicates a steady decline in the rate of cigarette smoking among Ontarians aged 12 and over, from 24.5% in 2000/01 to 22.3% in 2003 to 21.9% in 2005.[383]

February 2006: A Conference Board of Canada Report[384] concluded that among the 10 Canadian provinces, Ontario ranked fourth in overall health performance and fifth in health care outcomes.

April 2006: The CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that Ontario witnessed a 14% increase in new cancer cases from 1996-2006.[385]

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[380] http://www.hospitalreport.ca/downloads/year.html

[381] Hospital Report – Acute Care, p. 25. Available at: http://www.hospitalreport.ca/downloads/2006/AC/acute_report_2006.pdf

[382] McGuinty Government Strengthening Cancer Treatment in Ontario. Funding will provide leading edge radiation treatment equipment. September 15, 2006. Available at: http://www.health.gov.on.ca/english/media/news_releases/archives/nr_06/sep/nr_091506_2.html

[383] Health Canada. Canadian Tobacco Use Monitoring Survey 2005. Available at: http://www.hc-sc.gc.ca/hl-vs/tobac-tabac/research-recherche/stat/ctums-esutc/2005/ann_summary-sommaire_e.html

[384] Hamilton C. Healthy Provinces, Healthy Canadians: A Provincial Benchmarking Report. Conference Board of Canada, February 2006. Available at: http://www.conferenceboard.ca/documents.asp?rnext=1533

[385] Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

2006: The CSQI revealed that the five-year survival rates for patients with one of the four most common cancers now exceeds 50%, albeit survival for lung cancer remains low.

8.1.5 England NHS cancer plan

England's NHS Cancer Plan (2000-2010), published in 2000, is the first-ever comprehensive strategy for tackling cancer from prevention to palliative care, at a national level in England. England is also the jurisdiction with the most comprehensive knowledge base regarding available assessments.

In 2002, the results from the National Surveys of NHS patients was released that provided an assessment of the quality of care as seen by hospital patients with one of six types of cancer-breast, colorectal, lung, ovarian, prostate, and non-Hodgkin's lymphoma.[386] Because the period of reference for the survey was prior to launch of the Cancer Plan, the data offer a benchmark from which the implementation of the cancer plan can be monitored. Since the publication of the NHS Cancer Plan, there have been several reviews put forth by NHS and the Department of Health, as part of the government's endeavor to improve services by considering the patient's perspective. In addition, several external reviews from bodies or organizations independent of government have monitored and reported on the progress made in cancer control. These include reports by the National Audit Office, the MacMillan Cancer Relief in partnership with the Department of Health, and the All-Parlimentary Group on Cancer. All of these reports stipulate timely recommendations, which will not be the focus of our review.

Moreover, it should also be noted that in December 2001, the former Commission for Health Improvement (CHI) and the Audit Commission[387] published an evaluation on the progress made in implementing recommendations stipulated in the 1995 Calman-Hine Report.[388] Given that the Cancer Plan was published in 2000, the information presented in the CHI report may be seen as a baseline review against which progress can be measured. Also worth noting is a report released in 2005 by the Reform non-party think tank,[389] which recommended that within a two year period, 30% of diagnostics, radiotherapy, and chemotherapy become outsourced to the independent sector.

Monitoring the implementation process

May 2003: The Department of Health[390] launched an internal evaluation into how money allocated to NHS trusts through the NHS Cancer Plan was spent. The evaluation revealed a slower start to Cancer Plan investment in 2001/2002, with some cancer centers receiving less than 60% of the money earmarked to pay for better services.

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[386] Department of Health (2002). National Surveys of NHS patients. Cancer National Overview 1999/2000

[387] Commission for Health Improvement (2001). National Service Framework Assessments No. 1: NHS cancer care in England and Wales.

[388] The NHS Cancer Plan built on those recommendations, along with introducing a comprehensive strategy (from prevention to palliation) to tackle cancer in England.

[389] Sikora, K/. Slevin, M., & Bosanquet, N. (2005). Cancer care in the NHS. Reform. http://www.reform.co.uk

[390] Richards. M., (May, 2003). Investment in cancer 2001/02 and 2002/03. Department of Health. see also http://www.newsvote.bbc.co.uk/mpapps/pageto.../newsbbc.co.uk/2/hi/health/3046297.stm

October 2004: The All-Party Parliamentary Group on Cancer[391] inquiry focused on the implications of introducing national standards and guidance for cancer services while also encouraging local NHS bodies such as Primary Care Trusts (PCTs) to make decisions on the basis of local priorities. Oral evidence from cancer networks, PCTs, the pharmaceutical industry, the National Audit Office, the National Cancer Director, the parliamentary under-secretary of state, and the Department of Health officials informed the inquiry. Conclusions reached included high degree of variation in the extent to which cancer networks were driving change across England in part due to their dependency on investment decisions made by PCTs. When cancer networks were able to effectively engage PCTs to invest in changes that were needed in local practice to ensure that the network complies with national guidance, the results were positive: Cancer networks were capable of delivering change by working across the primary-secondary care divide and across professional disciplines as well as identifying and addressing gaps in service provision. Aside from a focus on cancer networks' capacity to drive improvements, the report also underscored the need to train general practitioners to recognize cancer symptoms sooner and to make timely referrals for diagnosis.

March 2005: The third of three reports produced by the National Audit Office[392] focused on the NHS Cancer Plan, its implementation and progress against targets and commitments in the Plan.[393] The report concluded that there has been a number of major achievements, which included: boosting the downward trend in smoking; extending breast screening program; speeding access to cancer diagnosis and treatment; establishing specialist cancer teams; reducing variation in access to drugs; boosting specialist palliative care services; getting more cancer specialists in place and faster than planned; modernizing and expanding cancer diagnostic and treatment facilities; and increasing the pace of research. Specific progress include the following: Targets set for waits for diagnosis and treatment are within expectations, for example, 99.9% of patients with suspected cancer are seen by a specialist within 2 weeks; 99.3% of patients diagnosed with cancer are treated within 31 days. Smoking among manual groups has been reduced to 31% from 33,5 in 1998. Investing in staff, as stipulated in Plan such as hiring extra consultants has been met ahead of schedule, the number of cancer nurses hired has increased, new roles were introduced for diagnostic and other staff and new skill mix models were implemented. Investing in facilities has been met as planned; however, some potential gaps have been identified in imaging. And, in terms of investing in research and genetics, the National Cancer Research Institute was established, and research into cancer genetics is one of its mandates.

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[391] All-Party Parlimentary Group on Cancer (2004). Meeting national targets, setting local priorities: the future of cancer services in England. In total 12 recommendations were made; We focus on two which we were able to link directly to the cancer plan priorities. Available at: http://www.cancerbackup.org.uk/News/Press/Pressreleasesstatements/2004/99640897/CSCReport.pdf

[392] The National Audit Office. (March, 2005). The NHS Cancer Plan: A progress report. Report by the Comptroller and Auditor General, HC 343, Session 2004-2005.

[393] The NHS did publish an earlier report in 2003 that covered the first three years of the Cancer Plan. The information provided in that report is similar to what has been covered in the NAO progress report published in 2005.

Impact: Process outcomes

December 2001: The Commission for Health Improvement and the Audit Commission evaluation of key recommendations put forth in the 1995 Calman-Hine report was conducted in 1999/2000 using information gleaned from 15 focus groups (involving 85 patients with cancer). The data revealed poor communication and a failure to plan cancer care in a systematic way between different professionals; lack of access to someone who could provide information, support, and guidance; as well as variations in the provision of care and treatment across geographical areas and between patients with different types of cancer.

May 2003: Health Services Management Centre, School of Public Policy conducted an evaluation of the Cancer Services Collaborative, Phase 1 (that ran from November 1999 to March 2001), which aimed to improve national cancer waiting times in five cancer groups (breast, lung, colorectal, prostate, and ovarian- see Distinctive Features section for more information on Phase 1).[394] The evaluation was funded by the Department of Health. Among the outcomes achieved included a reduction in the median waiting times for prostate cancer from 140 to 63 days (a 55% decrease); a reduction in median waiting times for colorectal cancer from 64.5 to 57 days (an 11.6% decrease); and increases in the proportion of patients being booked at each of the three stages of cancer care: first specialist appointment; first diagnostic test; and first definitive treatment.

May 2004: The Macmillan Cancer Relief, in partnership with the Department of Health conducted an independent evaluation of the Cancer Partnership Project (CPP).[395] The CPP was a three-year initiative to support the development of service user involvement (includes patients, families, and other caregivers) in the 34 Cancer Networks throughout England. This initiative was in response to the 1995 Calman-Hine report, which stressed the need for NHS decision makers at all levels to take account of patients' views and preferences. Among the achievements identified by the review, the Partnership groups often felt that one very important accomplishment was their planning and development of initiatives that focused on advances in access to sources of patient information and involvement in policies regarding communication skills for staff.

June 2004: The Centre for Research in Primary Care conducted an independent evaluation of the Primary Cancer Care Lead Clinician Initiative (PCCL).[396] The PCCL was an initiative to enable each Primary Care Trust (PCT) to have a primary care cancer clinician for at least once a week to provide strategic leadership within the PCT, to contribute to the development of Cancer Networks, as well as to improve partnerships and communications across all sectors (primary to tertiary) and levels of cancer care (communication to ensuring services are responsive to the

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[394] Robert, G., McLeod, H., & Ham, C. (2003). Summary lessons from phase 1 of the Cancer Services Collaborative. Health Services Management Centre, School of Public Policy. It is important to note that the findings are based on available information provided by the participating health regions. In most cases, health regions found it difficult to comply with the requirements agreed between the evaluation team and those responsible for leading the CSC at the national level.

[395] Sitzia, J., Cotterell, P., & Richardson, A. (2004). Formative Evaluation of the Cancer Partnership Project. London: Macmillan Cancer Relief.

[396] Leese, B., Din, I., Darr, A., Walker, R., Heywood, P., & Allgar, V. (2004). 'Early days yet'. The primary care cancer lead clinician (PCCL) initiative. Final report. Centre for Research in Primary Care, University of Leeds.

needs of those affected by cancer). This initiative was funded and supported by the Macmillan Cancer Relief, in partnership with the Department of Health. Key achievements noted by PCCL were in the areas of improving communication and early diagnosis and referral, establishing relationships across all sectors, contributing to service improvements by means of raising the profile of primary cancer, as well as improving adherence to baseline assessments and established standards.

February 2005: The second of three studies conducted by the National Audit Office[397] included a national follow-up survey on patients' experiences and opinions of the quality of cancer services. The survey focused on the experiences of patients diagnosed with one of the four commonest cancers (breast, lung, bowel, and prostate), and tracked changes since 2000 when the first national survey on cancer services was conducted by the Department of Health (in 1999-2000).[398] The survey was carried out in 2004 and involved responses from 4300 patients with the four commonest cancers in 49 NHS Trusts. The report concluded that patients were broadly positive about their experience with GPs, those referred urgently by their GPs were seen almost universally by a specialist within two weeks, albeit a minority of patients diagnosed with cancer were not referred urgently. The majority of patients considered that they were told bad news with suitable sensitivity, and more verbal/written information about diagnosis was communicated to patients. Patients' experience of care given by hospital improved, but gaps remained in supportive and palliative care. Most were content with the support received after discharge and as outpatients, albeit hospice provision and end of choices could be enhanced. Examining responses by cancer type revealed that prostate patients tended to report less positive experiences. Patients' experiences of services in London remained less positive than elsewhere in England. No differences in response pattern were noted between patients living in deprived versus affluent areas.

2005: The annual review of the NHS Breast Screening Programme indicates that the attendance rate at first invitation for breast screening was 72.8% among eligible women of 50-64 years of age and 72.4% when considering eligible women of 50-70 years of age.[399] In 2003 the rate was 76% in women aged 50-64. This high participation rate has been consistently observed since 1999.[400] This program, initially opened to women of 50-64 years of age, was extended to the 50-70 age group in 2001. Extending the program to include all women from 50 to 70, and combined with the introduction of two-view mammography, resulted in substantial rise in the number of cancer detected.[401]

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[397] National Audit Office. (February 2005). Tackling cancer: Improving the patient journey. Report by the Comptroller and Audit General. HC 288 Session 2004-2005.

[398] Department of Health. National Surveys of NHS patients. Cancer National Overview 1999/2000

[399] NHS Breast Screening Programme. Annual Review 2005. One Vision. Available at: http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp-annualreview2005.pdf

[400] For summary information on breast and cervical screening take-up rates and other informations see: Department of Health -- Publications and Statistics -- Screening and Immunization. Available at: http://www.dh.gov.uk/PublicationsAndStatistics/Statistics/StatisticalWorkAreas/StatisticalHealthCare/StatisticalHealthCareArticle/fs/en?CONTENT_ID=4086491&chk=LUyYGS

[401] The Information Center. More breast cancers detected in 2004-05. February 28 2006. Available at: http://www.ic.nhs.uk/news/press/pr280206b

<u>Impact: Health outcomes</u>

March 2004: The first of three report produced by NAO[402] focused on determining whether the NHS cancer services were leading to lower incidence and mortality rates from cancer, as well as better survival rates. The results revealed that between 1971 and 2000, the overall cancer incidence overall increased by 31%. Explanations provided for this increase included a more comprehensive collection of data on the occurrence of cancer and increases in several different cancer types such as prostate cancer in men, lung, and breast cancer in women, and melanoma in men and women. Although the overall cancer incidence increased, there was a reduction in incidence in certain cancers such as stomach cancer, a reduction in mortality rates falling 12% between 1971 and 2002, and improvement in the five-year survival rates for all cancers diagnosed in the early 1990s. However, the degree of improvement in survival and mortality rates has not been uniform- improved more for the better off compared to those less well off or in areas with high levels of deprivation. England's position in terms of mortality relative to other comparable countries (such as France, Germany, Spain) was reported to be better, albeit only among men. The report goes further in describing areas of cancer services that might be delaying early diagnosis and treatment of cancer such as patient delay in coming forward, difficulties for GPs in identifying symptoms early enough, waits for diagnostic tests, and treatment within hospitals.

December 2005: The 2004/05 General Household Survey on Smoking and drinking among adults, 2004[403] indicated that 25% of adults aged 16 or over in England were current cigarette smokers. In 2003, it was 26% (28% of men and 24% of women).Between 1998/99 and 2004/05, the proportion of smokers fell from 28 to 25%.

8.1.6 Cancer Care Nova Scotia program

CCNS was created in 1998 following the publication in 1996 of the first comprehensive cancer management strategy in Nova Scotia. Since then, CCNS has been working toward implementing recommendations put forth in the 1996 Cancer Action Plan. CCNS has put a major emphasis on evaluation, with several independent reviews published on its various programs (e.g., Cancer Patient Navigation Program). CCNS Cancer Surveillance and Epidemiology Unit compiles statistics based on the operations of the provincial registry. The latest available data are for the period of 1995-1999.[404]

In 2001, three years after the creation of CCNS, an external peer review of its plan of implementation was carried out. A number of recommendations were stipulated pertaining to governance and leadership, cancer site teams, information management and patient registry, prevention, screening, managed systemic therapy program, standards of care, research, patient navigation, evaluation of performance and planning of resource needs, education, and human resources. Since then, a handful of evaluation reports have been published particularly in the area

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[402] National Audit Office. (March, 2004). Tackling cancer in England: saving more lives. Report by the Comptroller and Audit General HC 364 Session 2003-2004.

[403] Office for National Statistics. General Household Survey, 2004. Smoking and drinking among adults 2004. December 2005.

[404] Cancer Statistics in Nova Scotia. A focus on 1995-1999. Available at : http://cancercare.ns.ca/media/documents/CCNS_ReportSEU.pdf

of prevention, patient navigation, and evaluation of performance as it relates to patient satisfaction with care received and quality of screening for cervical cancer.

Monitoring the implementation process

March 2004: Results from the Cancer Patient Navigation Evaluation[405] revealed that the program itself contributed to overall improvements in the cancer system by ensuring integration, coordination, and continuity of care. Multiple stakeholder groups participated in the evaluation, which took place during the summer of 2003. Patients and families, community partners (Home Care Nova Scotia, the Canadian Cancer Society), physicians, and other health professionals, patient navigators, senior leaders in the *early adopter* districts, and key CCNS staff participated. Data collection included focus groups, one-one-interviews, patient surveys, and a review of records in patient navigation database. Results are further highlighted below in terms of impact on outcomes.

March 2006: During the fall of 2004, personal specimen adequacy report cards were sent to more than 900 doctors who performed Pap tests.[406] This is the second year that CCNS monitors the quality of screening for cervical cancer, as part of its CCNS' Cervical Cancer Prevention Program (CCPP). The results indicated an average satisfactory rate of 99% in cervical cytology specimens, a satisfaction rate similar to that of 2003.

Impact: Process outcomes

March 2004: There were a number of key findings from the Cancer Patient Navigation (CPN): First, according to community partners, district service providers, senior leaders, health professionals, patient navigators, and CCNS staff CPN improved consistency and quality of cancer care in the districts, according to. Second, senior leaders and health professionals in all districts viewed CPN as an integral component of cancer services. Third, health professionals stated that CPN fostered collaboration and communication, as well as reduced duplication of services. Fourth, patients and families came to view patient navigators as an important source of support in dealing with emotional turmoil, informational needs, and logistical challenges associated with cancer. Fifth, patient navigators reported the referral process to be open and flexible, allowing contact with patients. Sixth, health professionals felt that communication initiatives about patient navigators must be continuous and hard-hitting to ensure all are aware about the service. Seventh, navigators felt that comprehensive orientation and ongoing educational opportunities are necessary for the continued success of the CPN. Eight, there was consensus among all district personnel that the CPN was one of the most effectively implemented programs, and that a network of patient navigators coordinated by CCNS is collectively a strong asset to the cancer system.

March 2005: From April 2002 through November 2004, the Palliative Care Front-Line Education Program was delivered to more than 1, 400 practicing health professionals in Nova Scotia. It was offered 19 times, and in each District Health Authority at least once. The three-day

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[405] CCNS (March 2004). Cancer patient navigation evaluation findings. Province of Nova Scotia.

[406] CCNS (March, 2006). Newsletter, vol. VII (Issue 1). News and Notes (CCNS' Cervical Cancer Prevention Program-report cards)

program is an interdisciplinary education course designed to provide front-line health care workers with the education they need to ensure delivery of high quality palliative and supportive care. It was developed following a needs assessment and a Palliative Care Roundtable hosted by CCNS. Participants were asked to complete a satisfaction survey at the end of each training day. An evaluation of the program was conducted among 710 participants who completed the course between April and November 2003.[407] The results of a satisfaction survey with the program indicated that patients were highly satisfied with the content, the facilitators who delivered the program, and with the overall set-up and structure for each of the three days. The results regarding the measurement of change in participants' knowledge on palliative care indicated an increase following the completion of the three day course test (pre- and post test scores), and a retention of knowledge at the 5-month follow-up period (post and 5-month test scores). Measurement of change in knowledge was determined by the Palliative Care Quiz for Nursing, which covers the philosophy and principles of palliative care, pain and symptom management, and psychosocial and spiritual care of individuals and families.

2005: The Canadian Cancer Society and CCNS have been helping communities become smoke-free through Action in Your Community against Tobacco (ACT), a collaborative initiative that engages individuals to implement effective activities that address the high rates of tobacco use in Nova Scotia. The ACT consists of two components: a toolkit for local initiators with practical evidence-based tobacco control activity ideas that can be used in their communities; and an orientation and ongoing support for ACT initiators based on a train-the-trainer model, which encourages the use of the toolkit and contributes to enhancement of the toolkit over time. ACT exists through networks of tobacco awareness champions (individuals who want to further the program's goals), community groups, health promotion agencies, youth groups, and educators, as well as all organizations involved in its Steering Committee and funding agencies who want to work together to reduce the harm caused by tobacco. An interim evaluation of ACT was conducted in 2005.[408] Telephone interviews were conducted with 32 ACT participants (including trained coaches, volunteers, members of the ACT Steering Committee) during July and August 2005, four focus group meetings (comprising a total of 15 participants) throughout the province between July and September, one telephone conference open to all regions; and a confidential on-line questionnaire Results from the evaluation revealed that the ACT initiative has been successful in achieving its goal of increasing capacity of people to take effective action against tobacco in their communities. ACT has been firmly embedded in the provincial tobacco strategy, and it is regarded highly for the quality of information, community mobilization materials, and networks to which it provides access by participants. ACT's relevance was not as much in network expansion (that is, through its train-the-trainer approach), but rather as addressing a professional need in making available community-oriented tobacco related resources.

July 2005 and May 2006: CCNS, in partnership with the Cape Breton District Health Authority and the Capital Health District Authority contracted NRC Picker to conduct a national satisfaction survey among cancer patients in 2004 and 2005.[409,410] The survey results were

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[407] CCNS. (March 2005). Palliative Care Front-Line Education Evaluation Report

[408] Action in Your Community Against Tobacco: A formative evaluation. Shedding light on community capacity. Produced by Stylus Consulting Inc. for the ACT Initiative, 2005.

[409] CCNS (July, 2005). Newsletter, vol. VI (Issue 3). Cancer patients in Nova Scotia report highest quality of care.

[410] CCNS (May, 2006). Newsletter, vol. VII (Issue 2). Nova Scotians report high quality cancer care.

compared to the Canadian average (which comprises other cancer agencies across Canada). The survey targeted all patients of 18 years and older who had received outpatient treatment at either the Cape Breton Cancer Centre in Sydney or the Nova Scotia Cancer Center in Halifax. In 2005, 445 patients completed the survey (the number of patients who participated in the survey for 2004 was not available). The 2004 survey shows that 96.9 per cent of Nova Scotia cancer patients consider their overall quality of care to be excellent, very good or good. This compares with the Canadian average of 96.7 per cent. The 2004 survey also shows that 79 per cent of respondents from the Cape Breton Cancer Centre and 61 per cent of patients from the Nova Scotia Cancer Centre reported their overall care as excellent. The Canadian average was 50 per cent. However, the 2005 survey shows that 78 per cent of respondents from the Cape Breton Cancer Centre and 71 per cent of patients from the Nova Scotia Cancer Centre reported their experience as excellent, very good or good. The Canadian average was 68.5 per cent.

February 2006: According to the Health Council of Canada 2006 report to Canadians on the quality of health care in 2005 across the provinces/territories,[411] Nova Scotia reported radiation therapy average wait times for emergency cases within 1 day; urgent cases in 5 to 7 days; semi-urgent cases in 20 to 21 days; and less urgent cases in 32 to 36 days.

April 2006: The 2006 Canadian Cancer Statistics Report indicated that participation rate of asymptomatic women between the ages of 50-69 with no previous history of breast cancer to organized biennial mammography screening was over 30% by 2002.[412] In 2003, about 50% of women aged 50-69 reported having screening mammography in the last two years, from 45% in 2000/01.

Impact: Health outcomes

2002: CCNS Statistics provide age-specific incidence rate for all tumour sites combined, Nova Scotian males and females 1999-2003. Statistics show that age-standardised incidence rates (all cancer sites combined) have been consistently high in Nova Scotia relative to other Canadian provinces, over the past 15 years.[413] CCNS Statistics also provide age-specific relative survival rates at one, three and five years, by gender, common invasive cancers, for 1992-1996. This may serve as baseline for measuring progress since the publication of the 1996 Action Plan. During that period, five-year relative survival rates were highest for patients diagnosed with prostate (93%) or breast cancer (82%), but were low for colorectal cancer (61% in males, 57% in females) and lower still for lung cancer (13% in males, 15% in females).[414]

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[411] Health Council of Canada (February 2006). Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005. Available at: http://www.healthcouncilcanada.ca/en/index.php?option=com_content&task=view&id=70&Itemid=72

[412] See p. 82 In: Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada, 2006. Available at: http://129.33.170.32/vgn/images/portal/cit_86751114/31/21/935505792cw_2006stats_en.pdf.pdf

[413] Saint-Jacques N, MacIntyre M, Dewar R, Johnston G. Cancer Statistics in Nova Scotia: A Focus on 1995-1999. Surveillance and Epidemiology Unit, *Cancer Care Nova Scotia*; 2002. Available at: http://cancercare.ns.ca/media/documents/CCNS_ReportSEU.pdf

[414] Cancer statistics in Nova Scotia. An Overview 1995-1999. Available at: http://cancercare.ns.ca/media/documents/CancerinNS_Overview.pdf

December 2005: The latest report from the Canadian Tobacco Use Monitoring Survey indicates a steady decline in the rate of cigarette smoking among Nova Scotians aged 12 and over, from 28.2% in 2000/01 to 23.6% in 2003 to 22.7% in 2005.[415] However, among adults the smoking rate fell from 30% in 2000 to 20% in 2004.[416]

February 2006: The Conference Board of Canada Report concluded that among the 10 Canadian provinces, Nova Scotia ranked ninth in overall health performance and seventh in health care outcomes.

April 2006: The CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that Nova Scotia had an 8% increase in new cancer cases between 1996 and 2006.[417]

October 2006: Evaluation of the Tobacco Control Strategy by an independent consulting firm for the Department of Health Promotion and Protection showed that most planned indicators of outcomes were achieved.[418]

8.1.7 British Columbia Cancer Agency program

There is no specific independent evaluation of the cancer control program in British Columbia. Since 2002, information about progress in cancer control is found in reports published by the Provincial Health Services Authority (PHSA), which is responsible for overseeing cancer control activities of the BCCA. The BC Cancer Agency produces statistics on cancer survival, mortality, and incidence rates using data from the BC cancer registry and BC Vital Statistics Agency. This information is made available through BCCA website.[419]

Outcome assessment is integrated in the BC Cancer Agency operations.[420] The BCCA provides data on its performance to the PHSA, which in turn is bound by a Multi-year Performance Agreement with the BC Ministry of Health Services. Specific targets for screening mammography are included in this agreement. Moreover, specific targets for smoking prevalence, physical activity, and cancer services waiting times and end-of-life care can be found in the BC Ministry of Health 2006/07-2008/09 service plan[421] (see Appendix 8A for details).

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[415] Health Canada. Canadian Tobacco Use Monitoring Survey 2005. Available at: http://www.hc-sc.gc.ca/hl-vs/tobac-tabac/research-recherche/stat/ctums-esutc/2005/ann_summary-sommaire_e.html

[416] Smoking rates continue to decline.August 11, 2005. Available at: http://www.gov.ns.ca/news/details.asp?id=20050811001

[417] Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

[418] Nova Scotia Tobacco Control Strategy Evaluation, October 2006, p. iii

[419] The latest *Facts and Figures* Report is for year 2003. http://www.bccancer.bc.ca/HPI/CancerStatistics/FF/default.htm#factsfigures

[420] According to a literature review and environmental scan for cancer control indicators conducted in 2004 by the Canadian Council for Health Services Accreditation (p. 11), BCCA has a list of performance indicators to help measure the agency's effectiveness in achieving its mission, in addition to program specific indicators. These indicators are not publicly available.

[421] Ministry of Health. 2006/07-2008/09 Service Plan. www.gov.bc.ca

Monitoring the implementation process

April 2003: The PHSA published a thorough plan on its strategic initiatives that would ensure that evidence-based policies and best practice standards lead to optimal results.[422] Within the report, information is provided regarding major accomplishments for 2002-2003 of each provincial agency. Major investments were targeted to BCCA to ensure a competitive research platform. It further reported that BCCA was on target for the implementation of its digital imaging technology in the clinical environment. A strategy was being developed to respond to the population growth and need for screening.

April 2005: The PHSA reported on its three year progress since its inception in 2001.[423] BCCA invested in developing strategies such as the Radiation Therapy System, the construction of a new cancer center, and prevention initiatives.

Impact: Process outcomes

July 2006: The BC Health Ministry published waiting time data for radiotherapy, chemotherapy and 5 year age-standardized mortality rates for all cancers for the period of 1999-2004.[424] The Ministry indicated that in 2004/05, over 95% of British Columbians requiring radiotherapy started treatment within four weeks of being medically able to receive it. Regarding chemotherapy, there is no significant wait for British Columbians. The webpage also indicates that 5 year age-standardized mortality rates for all cancers fell from 16.9 per 10,000 in 1999 to 15.9 per 10,000 in 2004.

February 2006: According to the Health Council of Canada 2006 report to Canadians on the quality of health care in 2005 across the provinces/territories,[425] British Columbia reported a median wait time of 0.9 weeks for radiation therapy.

February 2006: The Conference Board of Canada Report[426] concluded that, among the 10 Canadian provinces, British Columbia had the lowest female patient satisfaction rate for overall health-care services, and second lowest male rate. However, when surveying patients in hospitals on acute care services only, a BC Health Ministry Report based on a 2005 survey of BC acute care hospitals indicated that 91.8 per cent rated the overall quality of their care as good, very good or excellent.[427]

April 2006: The 2006 Canadian Cancer Statistics Report indicated that participation rate of asymptomatic women between the ages of 50-69 with no previous history of breast cancer to

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[422] PHSA (April 2003). Health services design plan: From vision to reality.

[423] PHSA. Three years of progress- PHSA accomplishments (2002-2005).

[424] Ministry of Health. National priorities. July 26, 2006. Available at: www.health.gov.bc.ca/cpa/mediasite/waitlist/priorities.html

[425] Health Council of Canada (February 2006). Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005. Available at: http://www.healthcouncilcanada.ca/en/index.php?option=com_content&task=view&id=70&Itemid=72

[426] http://www.conferenceboard.ca/documents.asp?rnext=1533

[427] Acute Care Inpatient Experiences in British Columbia. Available at: http://www.health.gov.bc.ca/socsec/pdf/ac_survey.pdf#search=%22patient%20satisfaction%20British%20Columbia%22

organized biennial mammography screening reached 50% by 2002.[428] In 2003, about 60% of women aged 50-69 reported having screening mammography in the last two years, from 50% in 2000/01.

Impact: Health outcomes

December 2005: The latest report from the Canadian Tobacco Use Monitoring Survey indicates a steady decline in the rate of cigarette smoking among British Columbians aged 12 and over, from 20.6% in 2000/01 to 18.8% in 2003 to 17.8% in 2005.[429]

February 2006: The Conference Board of Canada Report[430] concluded that, among the 10 Canadian provinces, British Columbia ranked first in overall health performance and first in health care outcomes.

April 2006: The CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that British Columbia had a 16% increase in new cancer cases between 1996 and 2006.[431]

8.1.8 Alberta Cancer Board program

There is no specific independent evaluation of cancer control programs and policies in Alberta. At the end of each year, the Alberta Cancer Board makes available a self-assessment of its performance against the agreement established with the Alberta Health and Wellness in its Multi-year Performance Agreement (MYPA).[432] The Alberta Cancer Board's Division of Population Health and Information publishes data on the cancer burden by regional health authority. The information is based on all cancer cases and deaths captured by the Alberta Cancer Registry.[433] Most recent information on cancer is compiled using data from 2003.

The Alberta Health Ministry also stipulates specific targets for cancer control, and the Alberta government monitors and reports on wait times periodically. The Implementation of the Alberta Tobacco Reduction Strategy is under the responsibility of the Alcohol and Drug Abuse Commission. The overall health of Albertans is also monitored by the Health Quality Council of Alberta (HQCA).[434] In addition, the HQCA reports on Albertans' perception of the quality of the health care system as well as their level of satisfaction with services received.[435]

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[428] See p. 82 In: Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada, 2006. Available at: http://129.33.170.32/vgn/images/portal/cit_86751114/31/21/935505792cw_2006stats_en.pdf.pdf

[429] Health Canada. Canadian Tobacco Use Monitoring Survey 2005. Available at: http://www.hc-sc.gc.ca/hl-vs/tobac-tabac/research-recherche/stat/ctums-esutc/2005/ann_summary-sommaire_e.html

[430] http://www.conferenceboard.ca/documents.asp?rnext=1533

[431] Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

[432] ACB. Annual report: Patient care, research, prevention: 2004-2005. http://www.cancerboard.ab.ca/pdf/about_acb/ar_2004-05.pdf

[433] ACB. (2006). Cancer in Alberta: A regional picture 2006. Available at: http://www.cancerboard.ab.ca/pdf/cancer_prevention/regionalpicture_2006.pdf

[434] HQCA (2005). Health report to Albertans 2004: Measuring up

[435] Health Quality Council of Alberta (November 2004). Satisfaction with the health care system. A survey of Albertans 2004: Final report.

Monitoring the implementation process

August 2005: The latest available ACB Annual report (2005-2006)[436] reproduced part of ACB self-assessment for the second year (2004-2005) of the 2003-2005 MYPA,[437] which addressed measures in the following areas: information management and technology, cost of services, access to services, quality of services, comprehensive cancer care, workforce, government relationships, partnerships and collaborations, and service delivery research.[438] One of the expected achievements was to begin the implementation of the ACCAP. Reported performance was as follows: (1) The RHA's were in the process of reviewing the ACCAP for possible integration into their local activities and plans; and (2) Joint Regional/ACB meetings were being planned for 2005/2006 to discuss areas of collaboration and joint planning for cancer servioces based on ACCAP.[439]

Impact: Process outcomes

November 2004: The HQCA report the findings of the 2004 survey on Albertans' perception of the overall quality of the health care system as well as their level of satisfaction with the services received.[440] A total of 4,608 telephone interviews were conducted among a random stratified sample of adult Albertans between May and June 2004. The findings were then compared to the 2003 survey wherein a similar methodology was used to gauge the perceptions and levels of satisfaction of 4,004 Albertans. The results revealed that their perception of the overall quality of the health care system and medical services significantly improved compared to 2003. In 2004, 73% rated the quality of the health care system as excellent, very good or good compared to 69% in 2003. In terms of Albertans' level of satisfaction with the quality of the services actually received, 81% rated the quality as excellent, very good or good in 2004 compared to 74% in 2003. Of interest to note is that the gap between their perception of the quality of services and their actual experiences has widened to 8% in 2004 compared to 5% in 2003.

August 2005: ACB's annual report for 2004-2005 reports that their patient feedback survey conducted in 2004 indicated that over 90% rated the quality of services and satisfaction as high. By 2005, the Alberta Cervical screening program was implemented in two health regions and the Alberta Breast screening program was launched by the end of 2005.[441] The self-assessment also revealed that family physicians of breast cancer patients had readily access to information from specialists. Palliative care programs across all regions received a boost through interface program initiatives, with reconfiguration of staff to meet service demands. Investments were also directed toward hiring specialists and the development of research space and projects.

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[436] ACB Annual Report 2004-05. Patient Care, research, Prevention., 2005. Available at: http://www.cancerboard.ab.ca/pdf/about_acb/ar_2004-05.pdf

[437] The most recent MYPA is for 2005/06-2006/07. See Appendix 5C for the measurable targets.

[438] ACB Annual Report 2004-05. Patient Care, Research, Prevention., 2005, pp. 11-26. Available at: http://www.cancerboard.ab.ca/pdf/about_acb/ar_2004-05.pdf

[439] ACB Annual Report 2004-05. Patient Care, Research, Prevention., 2005, p. 20.

[440] Health Quality Council of Alberta (November 2004).Satisfaction with the health care system. A survey of Albertans 2004: Final report

[441] ACB. Annual Report 2004-2005. Patient care, Research, Prevention, 2005, pp. 17, 20-21.

February 2006: According to the Health Council of Canada 2006 report to Canadians on the quality of health care in 2005 across the provinces/territories,[442]Alberta reported wait times for breast and prostate cancer of 2-5 weeks from referral to appointment with oncologist, and <2-3.5 weeks from appointment to therapy.

April 2006: The 2006 Canadian Cancer Statistics Report indicated that participation rate of asymptomatic women between the ages of 50-69 with no previous history of breast cancer to organized biennial mammography screening was just over 10% by 2002.[443] In 2003, about 62% of women aged 50-69 reported having screening mammography in the last two years, from 50% in 2000/01.

Impact: Health outcomes

January 2005: The HQCA released its second annual report on the overall health of Albertans and the quality of the health care system. It reported that cancer incidence rates are on the rise and expected to double between 2000 and 2020.

December 2005: The latest report from the Canadian Tobacco Use Monitoring Survey indicates a decline in the rate of cigarette smoking among Albertans aged 12 and over, from 27.7% in 2000/01 to 23% in 2003 to 22.8% in 2005.[444] However, the Alberta Tobacco Reduction Strategy Highlights 2005-2006 reports that the rate of cigarette smoking among Albertans aged 15 and over was 20% in 2003 and in 2004, but increased to 21% in 2005. Rate among 15-19 years was 18% in 2003, 16% in 2004, but increased to 19% in 2005.

June 2006: The Cancer in Alberta: A regional picture 2006, which is based on data from 2003, revealed that the cancer incidence rate is on the rise, and that the mortality rate has remained relatively stable since 1987.[445] The five-year relative survival rate for those diagnosed with cancer in 2000-2002 is expected to be better than for those diagnosed in earlier years (1984-86; 1993-95). Cancer incidence rates, mortality rates, and survival rates tended to vary by site and regional health authority. Focusing exclusively on the targets set by the Alberta government in its *Framework for a Healthy Alberta*,[446] the age-standardized incidence rate for lung cancer in 2003 was approxiamtely 61 per 100,000 and 42 per 100,000 for men and women, respectively. In that same year, the age-standardized mortality rates for breast and prostate cancer were approximately 25 per 100,000 and 27 per 100,000 respectively.

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[442] Health Council of Canada (February 2006). Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005. Available at: http://www.healthcouncilcanada.ca/en/index.php?option=com_content&task=view&id=70&Itemid=72

[443] See p. 82 In: Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada, 2006. Available at: http://129.33.170.32/vgn/images/portal/cit_86751114/31/21/935505792cw_2006stats_en.pdf.pdf

[444] Health Canada. Canadian Tobacco Use Monitoring Survey 2005. Available at: http://www.hc-sc.gc.ca/hl-vs/tobac-tabac/research-recherche/stat/ctums-esutc/2005/ann_summary-sommaire_e.html

[445] ACB Cancer in Alberta: A regional picture 2006.

[446] Government of Alberta. Framework for a Healthy Alberta: highlights.

February 2006: The Conference Board of Canada Report[447] concluded that, among the 10 Canadian provinces, Alberta ranked second in overall health performance and second in health care outcomes.

April 2006: The CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that Alberta had a 48% increase in new cancer cases between 1996 and 2006.[448]

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[447] http://www.conferenceboard.ca/documents.asp?rnext=1533
[448] Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

9. CANCER CONTROL IN QUÉBEC

9.1 HISTORY OF POLICY/PROGRAM DEVELOPMENT

The need to develop a structured approach to fight cancer was first recognized by the Rochon Commission in the late eighties. The Rochon Report proposed to establish prevention and screening programs for cancer sites for which there was scientific evidence of efficient interventions.[449] Following these recommendations, the Minister of Health and Social Services began to lay the groundworks to develop a coherent cancer control strategy. First, a *Comité ministériel* (Ministerial Committee) was set up to make recommendations on cancer services organization. The Ministerial Committee was composed of 16 members representing the Ministry of Health and Social Services, regional authorities, the *Fondation québécoise du cancer* and the *Société canadienne du cancer* (Canadian Cancer Society). The 1992 report comprised 23 recommendations covering the many facets of cancer control, including the need to develop an integrated network of cancer services.[450]

Then, in November 1993, the Minister of Health and Social Services made several public announcements regarding the fight against cancer. These included the publication of a *Plan d'action ministériel en radiothérapie et en cancérologie*[451] and a *Plan d'action pour le dépistage du cancer du sein* that included a proposal for an organized breast cancer screening program.[452] The *Plan d'action ministériel en radiothérapie et en cancérologie* was accompanied by a budget of 124 million dollars over four years (1993-1997),[453] while seven million dollars were committed over three years for implementing the breast cancer plan and screening program.[454] The screening program was launched in October 1998.

Following up on the 1992 report from the *Comité ministériel*, the Minister of Health and Social Services also established a *Comité consultatif sur le cancer* (Cancer Advisory Committee) to examine ways to organize cancer control services more efficiently. The Cancer Advisory Committee was mandated to: (1) Develop a program based on the whole continuum of cancer control activities; (2) Define the parameters for program operations and assessment; and (3) Coordinate cancer control activities within the Ministry of Health and Social Services.[455] The Cancer Advisory Committee comprised thirty individuals and was part of the *Direction générale de la santé physique* within the Ministry of Health and Social Services. It was supported by five sub-committees covering the entire cancer control continuum. The Committee's final report, which resulted from the collaboration of more than a hundred stakeholders, was published in

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[449] Commission d'enquête sur les services de santé et les services sociaux (Commission Rochon). Rapport de la Commission d'enquête sur les services de santé et les services sociaux. Québec, Qc : Publications du Québec ; 1988, pp. 457-8.

[450] Comité ministériel sur l'organisation des services en cancérologie au Québec. Rapport du Comité ministériel sur l'organisation des services en cancérologie au Québec. Québec, Qc : 1992. Details of the recommendations are provided in Appendix 9B.

[451] Ministère de la Santé et des Services Sociaux (MSSS). Plan d'action ministériel en radiothérapie et en cancérologie. Québec, Qc : MSSS ; 1993a.

[452] MSSS. Plan d'action pour le dépistage du cancer du sein. Québec, Qc : MSSS ; 1993b.

[453] MSSS. Plan d'action ministériel en radiothérapie et en cancérologie, 1993a, p 26.

[454] MSSS. Plan d'action pour le dépistage du cancer du sein, 1993b, p. 20.

[455] MSSS. Plan d'action ministériel en radiothérapie et en cancérologie, 1993a, p. 21.

October 1997. This Report, adopted by the government in April 1998 as the *Programme québécois de lutte contre le cancer* (PQLC), is Québec's first comprehensive cancer control strategy to prevent cancer and improve care for those affected.[456] Also in 1998, the government established a *Conseil québécois de lutte contre le cancer* (CQLC) with the mandate to: (1) advise the Minister of Health and Social Services on cancer control issues and priorities; and (2) promote cancer control by facilitating knowledge transfer to the cancer control community. Though it was recommended by the Cancer Advisory Committee that CQLC should lead implementation of the cancer control program, such role was not included in its mandate. Another important milestone occurred, in the summer of 1998, with the adoption of the *Loi sur le tabac* (tobacco control law) that prohibited smoking in the workplace.[457]

By the year 2000, cancer had become the first cause of death in Québec.[458] Early that year, the Ministry of Health and Social Services released an action plan in radio-oncology for 2000-2008, which included the acquisition of equipment and the building of new radio-oncology centers.[459] This radio-oncology action plan was developped to follow up on a report, prepared by the *Comité radio-oncologie* of the CQLC,[460] stressing the important shortage of manpower and equipment in radio-oncology. This shortage created undue access delays for cancer patients, and forced the transfer of some patients to the US for treatment.[461]

In March 2001, a *Centre de coordination de la lutte contre le cancer au Québec* (CCLCQ) was created within the Ministry of Health and Social Services to better coordinate existing resources toward cancer control and to provide leadership for the implementation of the PQLC by the regional authorities. In a 2003 report produced by the CCLCQ[462] describing the regional accomplishments in the fight against cancer it was noted that, despite existing efforts, important changes still needed to occur to reduce the important cancer burden in Québec and to improve Québec's performance in cancer control. Indeed, Québec ranked 20th among 21 OECD countries for overall cancer mortality.

These findings would give support to the *Coalition Priorité Cancer au Québec*, a group of voluntary, community, and professional organizations, created in May 2001 to mobilize all stakeholders and the government in advancing cancer control in Québec. Since its creation, the

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[456] Comité consultatif sur le cancer. Programme québécois de lutte contre le cancer : pour lutter efficacement contre le cancer, formons équipe. Québec, Qc : MSSS; 1998. Thereafter cited as PQLC, 1998. Details of the recommendations are provided in Appendix 9B.

[457] Gouvernement du Québec. Loi sur le tabac, L.R.Q., Chapitre T-0.01. See also « La loi québécoise sur le tabac est adoptée à l'unanimité ». Info-tabac, no 20, July-August 1998. Available at: http://www.info-tabac.ca/bull20/adopt.html.

[458] In Québec, deaths from cancers surpassed deaths from cardiovascular diseases in 2000. See Institut national de santé publique (INSPQ) et MSSS. Portrait de santé du Québec et de ses régions 2006 : les analyses. Deuxième rapport national sur l'état de santé de la population du Québec. Québec, Qc : Gouvernement du Québec ; 2006. p. 47.

[459] Comité de radio-oncologie. La radio-oncologie au Québec : plan d'action 2000-2008. Québec, Qc : Ministère de la Santé et des Services sociaux (MSSS); 2000.

[460] Conseil québécois de lutte contre le cancer (CQLC). Rapport du Comité radio-oncologie. Québec, Qc : CQLC; 1999.

[461] Freeman, C. Radiotherapy in Québec: An update. CARO-ACRO Enews, Vol. 2, no 1, February 2001.

[462] Centre de coordination de la lutte contre le cancer (CCLCQ). La lutte contre le cancer dans les régions du Québec : Un premier bilan. Québec, Qc : MSSS; 2003.

Coalition had asked the Québec government to make cancer control a priority, to set up a more coherent leadership and management, and to provide the necessary means to implement the PQLC.[463]

In April 2003, the Minister of Health and Social Services established cancer as one of his top priorities. Immediate actions included the establishment of a *Groupe de travail ministériel en cancer* (Ministerial Cancer Working Group) to make recommendations on how to improve the management and impact of the PQLC. Based on the Working group report,[464] the Minister of Health and Social Services presented a three-year (2004-2007) working plan at the first annual forum of the *Coalition Priorité Cancer* in April 2004.[465] Ten million dollars would be invested annually to implement this working plan. The Minister also announced that a *Direction de la lutte contre le cancer* (DLCC) had been created within the Ministry of Health and Social services (the CQLC and CCLCQ were abolished) and that a Cancer Control Director would be appointed.

Moreover, the provision of a continuum of cancer services, a cornerstone of the PQLC, was then reaffirmed and included among the seventeen goals of the *Plan stratégique 2005-2010* of the Ministry of Health and Social Services.[466] In 2006, amendments to the tobacco control law, prohibiting smoking in all public indoor spaces and on schoolgrounds were put into effect. In 2007, the DLCC released its *Orientations prioritaires 2007-2012*,[467] an action plan with 60 measures to further improve the quality, accessibility and continuity of cancer control services.

9.2 DESIGN

This section first provides a brief overview of the policies, programs, and action plans that are relevant for cancer control, with a focus on their underlying goals, priorities, as well as values and principles. Then it describes the main features of the remaining components of design, namely the spectrum of cancer services, the organizational architecture, service quality facilitators, as well as stated targets and indicators of outcome.

In Québec, the actual cancer control intervention rests on the following cancer specific strategic documents (details of which can be found in Appendix 9B):

1. The *Programme québécois de lutte contre le cancer : pour lutter efficacement contre le cancer, formons équipe* (PQLC, 1998)
2. *La radio-oncologie au Québec. Plan d'action 2000-2008.*

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[463] Cri d'alarme de la Coalition Priorité Cancer au Québec – Le Québec est en retard dans la lutte contre le cancer : la population est pénalisée. Fondation québécoise du cancer, 25 février 2003.

[464] Groupe de travail ministériel en cancer. Unifier notre action contre le cancer. Rapport de la démarche ministérielle visant l'amélioration de la gestion et de l'impact du Programme québécois de lutte contre le cancer. Québec, Qc : MSSS; 2004.

[465] Couillard P. Notes pour une allocution du ministre de la Santé et des Services sociaux, monsieur Philippe Couillard, à l'occasion du Forum sur le cancer. Montréal, le 23 avril 2004. Available at: http://msssa4.msss.gouv.qc.ca/fr/document/dossierpresse.nsf/9990d07f20130db985256dce00553853/457a96acec118aa185256e7f00629782?OpenDocument.

[466] Ministère de la Santé et des Services Sociaux (MSSS). Plan stratégique 2005-2010. Québec, Qc : MSSS; 2005.

[467] Direction de la lutte contre le cancer (DLCC). Orientations prioritaires 2007-2012 du Programme québécois de lutte contre le cancer. Québec, Qc : MSSS; 2007.

3. *Unifier notre action contre le cancer. Rapport de la démarche ministérielle visant l'amélioration de la gestion et de l'impact du programme québécois de lutte contre le cancer*. The 2004 Ministerial Cancer Working Group report which formed the basis for the Health Minister's three-year working plan (2004-2007).
4. The *Orientations prioritaires 2007-2012 du PQLC.* The DLCC five-year action plan.

More generally, the following policies and programs contribute to the overall design of the cancer control intervention and will be briefly discussed:

- The *Programme national de santé publique 2003-2012.* The public health program.
- The *Politique de soins palliatifs en fin de vie, 2004*. The policy on end-of-life palliative care, whose implementation is under the responsibility of the DLCC.
- The *Plan québécois de lutte contre le tabagisme 2006-2010*. The tobacco control plan.
- *Investir pour l'avenir 2006-2012.* The action plan for healthy eating and healthy living.

Programme québécois de lutte contre le cancer (PQLC, 1998):

The PQLC is Québec's first comprehensive cancer control strategy directed at preventing, detecting and managing cancer. Most importantly, it is centered on the caring for those affected (patients, their family and close relatives).[468] The design of the program is more akin to a strategy than to an action plan. It provides a vision of optimal cancer services organization through an integrated cancer services network that focuses on the available resources to ensure more efficient care, as well as supports the sharing of information and expertise on best practices among all cancer providers.[469] The main goals of the strategy are to improve access, continuity and the quality of care.[470] The program also embraces the continuum of cancer control, as reflected in the structure of the report, which comprises nine chapters: (1) Cancer burden and current service provision in Québec; (2) Strategic approach and goals; (3) The cancer control integrated network; (4) Prevention; (5) Early detection; (6) Diagnostic, investigation-treatment-rehabilitation; (7) End-of-life palliative care; (8) Supportive care (beginning at diagnosis); and (9) Framework for program monitoring and impact assessment.

Three *orientations* (principles) guided the development of the PQLC (a detailed description of its values and guiding principles is provided in Appendix 9C):[471]

1. *A global approach to cancer control.* A perspective that: (1) combines population-based and individual-based approaches to health policy planning; (2) acknowledges the importance of considering cancer control as a continuum of services in the organization of health care services; and (3) advocates a concerted effort to meeting the multiple needs of cancer patients and their family.
2. *Patient-centeredness* as a guide to the organization, management and provision of health care services.
3. *Quality* as the priority criteria for decision-making. A perspective that rests on the use of scientific evidence about relevance, effectiveness, efficiency, as well as quality of life and

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[468] Mot du Ministre in: PQLC, 1998.
[469] PQLC, 1998, p. 41.
[470] As presented in: Direction de la lutte contre le cancer (DLCC). Rapport d'activité 2005-2006, p. 7.
[471] PQLC, 1998, pp. 39-40.

satisfaction of cancer patients and the population. These elements are used as main criteria for defining the required services at each phase of the cancer control continuum, and for each type of cancer. Balanced against the available resources in a particular region, these criteria are intended to serve as guides for defining access to services at the local, regional and supraregional levels.

The PQLC stipulates a number of recommendations which are grouped under the following three main headings: (1) Organizational means to be put in place to structure the fight against cancer and to promote an integrated approach to organized service delivery; (2) Proposed objectives in terms of health, quality of life or organization of services to be used as targets for monitoring and assessing the implementation of the program; and (3) Evidence-based quality criteria of relevance, effectiveness, and efficiency to guide the regional organization of service delivery so that the quality of services is maintained and levels of access (local, regional, provincial) are clearly defined.

Radio-oncology 2000-2008 Action Plan (Comité de radio-oncologie, 2000):

The 2000-2008 Action Plan for radio-oncology was developed, based on the report by the *Comité radio-oncologie* of the CQLC, to achieve a balance between service capacity and demand, as well as to facilitate access of cancer patients to the quality services they are entilted to. It stipulates four recommendations:

1. Increase the effectiveness of existing radio-oncology centers in Québec by replacing outdated equipment, adding 16 new machines by 2008, using new technologies, hiring medical and professional staff and allocating the necessary resources for operating the equipment.
2. Build 4 new radio-oncology centers.
3. Implement the recommendations on human resources planning made by the three radio-oncology human resources planning committees (technologists, medical physicists, aand radio-oncologists).
4. Mandate a Radio-oncology Coordination Center with the responsibility to implement and monitor the action plan, as well as to involve the CQLC Radio-oncology Committee in the follow up of the action plan and in an updating of the planning.

Ministerial Cancer Working Group Report and 2004-2007 Working Plan:

The 2004 Ministerial Cancer Working Group report[472] reiterates the relevance of the PQLC and advocates that the "modernization" of cancer control in Québec should be based on the integration and hierarchical organization of services, as well as on an accountability management framework.[473] In doing so, it reaffirms the goals, values and principles of the PQLC, albeit with an additional focus on the values of accountability, leadership, action, and transparency (see appendix 9C for the complete list of the report's explicit values).

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[472] Groupe de travail ministériel en cancer. Unifier notre action contre le cancer. 2004.

[473] DLCC. Rapport d'activité 2005-2006, p. 11.

The report proposed concrete actions structured along four axes, and for each of those axes, the Minister of Health and Social Services identified a number of priorities:[474]

1. *Implement an integrated service delivery organization:* The priority is to set up, or strengthen, interdisciplinary cancer care teams in every region.
2. *Optimize clinical practices:* The priorities are to: (1) establish clear norms regarding cancer care services delivery, organization and operations for the most common cancer sites, and for those cancers that are associated with inadequate practice variations; and (2) establish care protocols involving radiation therapy.
3. *Act on continuous quality improvement:* The priority is to introduce an outcome-based management of the PQLC.
4. *Establish united governance:* The priority is to nominate a Cancer Director.

In addition, a number of priorities were established by the Cancer Director for the year 2005-2006:[475]

1. Designate (through a qualification process) interdisciplinary cancer teams
2. Establish a Sectorial Table on Cancer with representatives from the four networks of university-designated health facilities
3. Promote the setting up of local cancer registries and the migration of the *Fichier des tumeurs* toward a provincial cancer registry
4. Plan for human resources
5. Make a list of existing community resources
6. Improve palliative care by: (a) increasing the number of dedicated beds; (b) improving access to home care; (c) training; and (d) integrating palliative care to regional planning
7. Improve access to radio-oncology
8. Increase capacity for surgical oncology and hence provide access within 4 weeks

Orientations prioritaires 2007-2012 du PQLC:

The *orientations prioritaires 2007-2012* can be considered as the DLCC five-year action plan to further improve the quality, accessibility and continuity of cancer services. Such plan is congruent with the strategy layed out in the PQLC, while coming within the scope of the 2003 reform in health system governance and organisation and the 2005-2010 strategic plan of the Ministry of Health. The *orientations prioritaires* also builds on the recommendations made by the Ministerial cancer working group in 2004 and on the priorities set forth by the Minister of Health and Social services for 2003-2007. The *orientations* contain 60 measures that specifically focus on strengthening collaborative efforts towards improving cancer services organisation and quality along the following five priority areas for intervention and their associated objectives:

1) Consolidate the foundations for an integrated and hierarchical organization of services:

- Ensure cancer control is a priority within the health services and social care system;
- Continue the implementation of a functional cancer control network; and

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[474] These most immediate priorities correspond to the specific elements that were communicated regarding the Ministry Cancer Working Group Report by the Minister of Health and Social Services on April 23 2004, at the First Forum of the Coalition Priorité Cancer au Québec.

[475] Loutfi A. Bilan de la réorganisation de la lutte contre le cancer au MSSS. Powerpoint presentation at the second Annual Forum of the Coalition Priorité Cancer au Québec, April 22, 2005. Available at: http://www.fqc.qc.ca/coalition/forum2005.asp

- Consolidate a hierarchical organisation of cancer care and control services.

2) Promote health as well as prevention and early detection of cancer:
- Promote a healthy lifestyle (healthy diet, active living, avoid tobacco use) and create environments that sustain this healthy lifestyle;
- Reduce exposure to environmental and work-related carcinogenic agents;
- Facilitate acces to organized screening programs for certain cancers when proven effective and feasible, and ensure quality standards are met; and
- Optimize existing capacity for cancer-related health surveillance.

3) Facilitate cancer patient's journey through the continuum of care and services;
- Improve accessibility and quality of cancer care and services through optimal use of resources;
- Facilitate home care and follow-up for all cancer patients, by ensuring access to a general physician;
- Provide quality end-of-life palliative care for all patients in need and their close relatives, irrespective of age or type of illness;
- Consider the perspectives of the patients and that of their close relatives providing care; and
- Further continuity and complementarity of health services provided by Québec health system facilities and local aboriginal facilities.

4) Support evidence-based practice in cancer control:
- Promote general physician's role in cancer control (prevention, screening and care);
- Promote best practices at the regional level;
- Encourage RUIS involvement in cancer control;
- Further the use of evidenced-based practice;
- Ensure cancer control issues are prioritized by cancer research organisations; and
- Further knowledge exchange with cancer control partners in Canada and abroad.

5) Assess achievements against outcomes:
- Establish Ministerial outcome targets to be focused especially on access as a dimension of quality and efficacy; and
- Get the necessary information for proper management of cancer control interventions.

<u>Other relevant policies, programs and plans:</u>

Public Health Program (2003-2012)

This 10-year program is the first comprehensive public health program in Québec and comprises six fields of intervention, among which two are highly relevant for cancer control, namely chronic illnesses and lifestyle and environmental health. Cancers of the lung, skin, breast, prostate, colon/rectum and cervix were selected as a focus since their incidence can be decreased with health promotion, prevention and early detection activities.[476] A number of the program's

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[476] MSSS. Programme national de santé publique 2003-2012. Québec, Qc : MSSS; 2003, p. 42.

activities are directly taken from the PQLC and the 2005-2010 Tobacco Control plan.[477] In addition, the program states many targets regarding cancer control to be achieved by 2012 (details on those targets are presented in the sub-section on targets and indicators of outcome).

Policy on End-of-life Palliative Care (2004)

This Policy provides a formal recognition of palliative care services in the network of health and social services in Québec.[478] The policy first defines the scope for end-of-life palliative care services and then presents three guiding principles: (1) patients' needs and choices must be at the center of service planning, organization and provision; (2) inasmuch as it is their choice, service users must stay as long as possible in their own *milieu de vie* (habitat); and (3) close relatives and friends of the patient must be supported. The policy also states four main goals: (1) equitable access to services anywhere in the province; (2) continuity of services; (3) quality services provided by interdisciplinary teams; and (4) awareness of health providers to the inescapability of death. Based on these pillars, the policy proposes a vision for an optimal service configuration given the current organizational context.[479] Finally, the policy defines the accountability, resources allocation and the sharing of responsibility among the relevant actors within the health system, as well as a framework for monitoring progress and assessment.

Tobacco Control Plan (2006-2010)

This Plan[480] is in continuity with the 2001-2005 Tobacco Control Plan and hence, reaffirms the need for a global and integrated approach to tobacco control to reduce morbidity and mortality associated with tobacco use.[481] The plan has three main goals: (1) preventing initiation of tobacco use; (2) promoting and supporting cessation; and (3) ensuring the protection of non-smokers against second-hand smoke. Its approach rests on the "denormalization" of tobacco use among the population, especially among the youth, young adults, pregnant women and the aboriginals. The tobacco control intervention comprises three axes: (1) policy and laws; (2) information, awareness, education, and support; and (3) mobilization. It also stipulates activities regarding knowledge-surveillance, monitoring, research as well as the assessment of the plan. The plan reaffirms the target set forth in the Public Health Program regarding tobacco use reduction.[482]

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[477] Programme national de santé publique, 2003, p. 45.

[478] MSSS. Politique en soins palliatifs de fin de vie. Québec, Qc : MSSS; 2004. Available at : http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2004/04-828-02.pdf

[479] Marcoux H and Roy L. La politique en soins palliatifs de fin de vie : est-ce que cela va changer le monde? Les cahiers de soins palliatifs, vol. 6, no. 1, 2005, pp. 71-72.

[480] MSSS. Plan québécois de lutte contre le tabagisme 2006-2010. Québec, Qc : MSSS; 2006. Available at: http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-006-17.pdf

[481] MSSS. Service de lutte contre le tabagisme. Available at : http://msssa4.msss.gouv.qc.ca/fr/document/publication.nsf/4b1768b3f849519c852568fd0061480d/947e4c5373fbb3e785257179005b2104?OpenDocument

[482] Hamelin J. Plan de lutte contre le tabagisme. Québec veut réduire la prévalence à 18% d'ici 2012. Info-tabac, no 65, septembre 2006. Available at: http://www.info-tabac.ca/bull65/pqlt.htm

Action Plan on Healthy Eating and Healthy Living (2006-2012)

This Action Plan[483] is designed to improve the quality of life of the population in Québec by facilitating the adoption of a healthier lifestyle that includes more exercice and healthy eating. It was developed namely to address the obesity problem, especially among the youth, and does not have any specific focus on cancer. However, it is included here as a policy relevant for cancer control since healthy eating and lifestyle are important in the prevention of chronic diseases, including cancers.

9.2.1 Spectrum of cancer services

The following shaded box displays Québec's spectrum of cancer control services as revealed by the analysis of the preceding policies, strategies and programs, as well as by research on available services on the website of the Ministry of health and Social Services.

Spectrum of cancer services -- Québec

Prevention:[484]

- Ministère de la Santé et des Services Sociaux – Direction Générale de la Santé Publique (MSSS-DGSP): *Loi sur le tabac dans les milieux scolaires*: Prohibits tobacco smoking on school property as of September, 2006
- MSSS-DGSP: *Loi sur le tabac à l'usage du tabac dans les endroits publics*. Prohibits smoking in all public indoor spaces as of May 31, 2006
- Modifications in June 2005 to the 1998 Tobacco law prohibited smoking in all public places.[485]
- MSSS-DGSP: *Plan québécois de lutte contre le tabagisme 2006-2010*
- MSSS-DGSP: *Investir pour l'avenir 2006-2012*. Plan d'action gouvernemental de promotion des saines habitudes de vie et de prévention des problèmes de poids.
- Beginning January 2007, physicians will be remunerated for providing smoking cessation counseling services, which include informing patients about smoking cessation programs, referring patients to the appropriate resources, prescribing pharmacological aids, etc.[486]

Screening:

- MSSS - DGSP: *Programme québécois de dépistage du cancer du sein* (PQDCS). Organized breast cancer screening program since 1998.
- o Québec has no organized screening program for cancer of the uterine cervix. However, women can undergo regular PAP tests according to practice guidelines on visits to their general physician or gynecologist.[487]
- o Québec has no organized screening program for colon and rectal cancers, but access to FOBT-based screening for the general population aged between 50 and 74 will be ensured should its feasibility be

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[483] MSSS. Direction générale de la santé publique. Plan d'action gouvernemental de promotion des saines habitudes de vie et de prévention des problèmes reliés au poids 2006-2012 – Investir pour l'avenir, 2006. Available at: http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-289-01.pdf

[484] http://www.msss.gouv.qc.ca/sujets/santepub/tabac/index.php?accueil

[485] http://www.info-tabac.ca/bull63/Loi-tabac-2006.pdf

[486] Leduc S. (Direction de la santé publique) La santé publique et la lutte contre le cancer des actions sur le terrain. Powerpoint presentation, Congrès de la Direction de la lutte contre le cancer, December 1, 2006.

[487] See MSSS webpage on Access to specialized medical services / cervical cancer. Available at: http://wpp01.msss.gouv.qc.ca/appl/g74web/cancerducol.asp

demonstrated.[488] Screening is now available on an individual basis according to existing clinical practice guidelines.
- Opportunistic screening is available for multiple cancers.

Diagnosis and treatment:

- Radiation therapy services are available in 10 centers, located in seven sociosanitary regions: Four centers in the Montreal area and six in other regions (see shaded box on organizational architecture for details). Formal referral pathways (*corridors de service*) between regional institutions are being established.[489]
- Surgery and chemotherapy for the most common forms of cancer are provided in the vast majority of hospitals distributed across the Province.
- Treatment of rare and complex cancers is available mainly in the University affiliated hospitals.

Supportive care:

- *Infirmières pivot en oncologie* ("enhanced" patient navigators) are available across the Province, with the exception of the northern regions.[490] These oncology nurses with a special training are integrated to interdisciplinary cancer teams at the local, regional and supraregional levels. Their role was defined as comprising the following activities: (1) to assess the cancer patient's needs and see to it that these needs are answered; (2) to provide information to the cancer patient and his/her family; (3) to support and accompany the cancer patient and his/her family, and (4) to ensure the coordination and continuity of actions between health professionals and between settings.[491]
- Physical and psycho-social support services are provided by professionals within hospitals and are available via interdisciplinary cancer teams.
- Various volontary and community initiatives are providing support services for cancer patients and their families.
- Initiated in 1988 by the Fondation québécoise du cancer,[492] there is a network of hotel accomodation for cancer patients (réseau d'hôtellerie), which includes four hotels in the Montreal, Estrie (Sherbrooke), Mauricie (Trois-Rivières), and Outaouais (Gatineau) regions.

Palliative care:

- Palliative care services are provided in four different settings: (1) home; (2) hospital; (3) long-term care and lodging facilities (CHSLD); and (4) hospices. The vast majority of palliative care services is provided in the hospital setting.[493] A survey of regional Agencies in August 2006 (updated October 2006), showed there were 120 palliative care beds in 18 hospices distributed across 12 sociosanitary regions.[494]
- A *Comité sur l'agrément ministériel des maisons de soins palliatifs* (hospice palliative care ministerial approval committee) is in place to define guidelines and a reference framework for the standardized approval of palliative care hospices across the Province.[495]

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[488] See measure 24 of DLCC Orientation prioritaires 2007-2012.

[489] See MSSS webpage on Access to specialized medical services / radio-oncology. Available at: http://wpp01.msss.gouv.qc.ca/appl/g74web/carte.asp

[490] Direction de la lutte contre le cancer. Rapport d'activité 2005-2006, p. 12.

[491] Conseil québécois de lutte contre le cancer. L'intervenant pivot en oncologie. Un rôle d'évaluation, d'information et de soutien pour le mieux-être des personnes atteintes de cancer. 2000, pp. 15-16.

[492] La Fondation québécoise du cancer donne le coup d'envoi officiel à l'important projet de construction de son Hôtellerie de l'Outaouais à Gatineau ! FQC press release, 31 janvier 2005.

[493] MSSS. Politique en soins palliatifs de fin de vie. 2004, 93 p.

[494] Personnal communication, Dr. Antoine Loutfi, Québec Cancer Director, March 1, 2007.

[495] Personnal communication, Dr. Antoine Loutfi, Québec Cancer Director, March 1, 2007.

9.2.2 Organizational architecture

The vision set forth in the PQLC for service organisation rests on a provincial network of integrated cancer control services, composed of local and regional cancer control networks. Such integrated network was proposed to improve the continuity and the complementarity of cancer expertise and ressources, while considering patients' preferences for having care delivered closer to home. It was based on the following main pillars:

1) Local, regional and supraregional interdisciplinary cancer teams whose mandates are complementary;
2) *Infirmières pivots en oncologie* (IPO, which are "enhanced" patient navigators);
3) Formal referral pathways, and a cancer patient file, as means to improve communications and service coordination;
4) Quality assurance and improvement initiatives, including *Comités des thérapies du cancer* (cancer treatment committees), with general (at regional level) or site-specific (supraregional level) expertise in cancer treatment to support interdisciplinary cancer teams.

This initial vision was progressively enriched by numerous advisory reports produced for or by the Ministry of Health and Social Services.[496] In 2003, the Ministry spelled out what would be the cancer teams' mandate, catchment area, and criteria for team composition at the local, regional and supraregional levels.[497] Some adjustments were also made to align the originally planned service configuration with the 2003 health system reform that created four levels of service accessibility: local, regional, and two supraregional levels, namely the RUIS, and the provincial (or inter RUIS). The current organisational architecture still rests on the complementarity of interdisciplinary cancer teams, a prominent role played by the IPO, and on establishing formal referral pathways. Ultimately, the goal is to set up integrated local and regional cancer networks. Significant steps along this process are the development by CSSS of local clinical and organizational projects that will include a cancer program, and the development of regional cancer networks by the regional Agencies.

The fundamental architecture for the organization of cancer services in Québec is thus based on interdisciplinary cancer teams that have earned a specific designation for either a local, regional or supraregional level of care. It is not based on comprehensive cancer care centers. There are specialized radio-oncology centers, located within hospitals, but most cancer treatment (chemotherapy and surgery) and care services are provided by hospital facilities that also offer

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[496] These reports included the following: CQLC. L'intervenant pivot en oncologie – un rôle d'évaluation, d'information et de soutien pour le mieux être des personnes atteintes de cancer, 2000; CQLC. Cancer de l'appareil digestif. Critères d'organisation par niveau de services, 2001 ; MSSS. Le médecin de famille et la lutte contre le cancer, 2005; DLCC. Les équipes interdisciplinaires en oncologie, 2005; MSSS. Pour optimiser la contribution des infirmières à la lutte contre le cancer, 2005; MSSS. Le soutien, l'adaptation et la réadaptation en oncologie au Québec, 2005; MSSS. Besoins des personnes atteintes de cancer et de leurs proches, 2005. See appendix 9A for complete references.

[497] MSSS. Direction générale des services de santé et médecine universitaire. Comité aviseur (Nicole Lefebvre, chair). Le continuum de services pour les personnes atteintes de cancer et leurs proches : paramètres d'organisation. Programme québécois de lutte contre le cancer. April 2004, 41 p.

general and specialized health and social services. However, a number of hospital facilities have developed specific expertise related to different tumour sites.

9.2.3 Service quality facilitators

A number of initiatives related to service quality facilitators have been planned in the various strategy and action plans that make up the cancer control intervention. First, the PQLC made recommendations related to establishing a standardized patient cancer file and norms of practice according to local, regional and supraregional levels of service delivery (see Appendix 9B for details). It also comprised a number of propositions regarding human resources development, including training and continuous education of health professionals, as well as promoting research. Second, human resource needs and capital equipment investments related to radio-oncology were addressed in a specific action plan. Third, the 2004 Ministerial Cancer Working Group report included recommendations such as: (1) clinical practice guidelines and practice standards; (2) *comités des thérapies du cancer* (; (3) optimum use of cancer drugs; (4) cancer registry; and (5) information management system. The DLCC five-year action plan (*orientations prioritaires 2007-2012*) is in continuity with the 2004 report, as reflected by two of its five priority areas, namely to support evidence-based practice in cancer control and to assess achievements against stipulated outcomes. It also conatins specific measures related to developing tools and systems for the management of access to treatments. Finally, the general health system reform that was initiated in 2003 includes the setting up of information management systems to improve integration, access, continuity and quality of health and social services.

9.2.4 Targets and indicators of outcome

Existing targets and indicators of outcome that have relevance for cancer control address three domains: 1) health outcomes (mortality); 2) dimensions of cancer control, beginning with prevention and screening and ending with palliative care; and 3) the implementation of the PQLC. The annual measurable targets that are included in the performance agreements between the Health Ministry and the Agencies (regional authorities) and facilities can subsequently be found in the Health Ministry's annual management reports, along with results achieved by March 31 of the relevant year (for details, see Appendix 9D). The existing and current measurable targets and indicators of outcomes are the following:

Health outcomes:
- Reduce breast cancer mortality rate by 25% among women aged 50-69 by 2012

Prevention and health promotion:
- Reduce rate of tobacco use among 15+ from 24% to 18% by 2012
- Number of smokers having received smoking cessation services (2005-06 target was 4937)
- 80% of adults eating 5 servings of fruits and vegetables a day by 2012
- A 2% decrease of obesity prevalence among youth and young adults by 2012
- A 5% decrease in the prevalence of overweight youth and adults by 2012
- A 5% increase in the proportion of 15+ doing adequate exercice (reduce sedentarity from 53% to 48%) by 2012

Screening:

- 70% participation rate of eligible women aged between 50-69 to biennial mammography (since 1996)
- Breast cancer screening participation rate (2004-05 target was a 5% increase from 43,6 to 48,6%)
- Proportion of designated breast cancer screening centers having implemented quality assurance measures (2004-05 target was a decrease in the investigation reference rate of 1% at initial screening and of 0,5% at subsequent screenings)

Diagnosis and treatment:

- Radiotherapy: the actual waiting time target is that 90% of patients will be treated within a period of four weeks (since 2006).[498] Number of "ready to treat" patients having waited for more than 8 weeks before beginning radiation therapy must be 0 (since 2004)
- Surgical oncology: the following waiting time target for elective cancer surgery for all types of cancer will be under development/assessment in 2007: 90% of "ready to treat" patients will be treated in less than four weeks (such target would become a performance indicator within service performance and accountability agreements between the Ministry and regional agencies)[499]

Supportive and palliative care:

- Number of people receiving palliative care at home : (2004-05 target was 19 000; 2005-06 target was 20 484)
- Mean number of palliative care interventions at home (2004-05 target was 13,4; 2005-06 target was 14)

Implementation of the PQLC:

- Number of interdisciplinary teams at local, regional and supraregional levels (2005-06 targets were 28 for local teams and 5 for regional teams)

The DLCC five-year action plan has one objective related to the establishment of indicators for access to be included in performance agreements between the Health Ministry and the Agencies by December 2009.[500]

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[498] Personnal communication, Dr. Antoine Loutfi, Québec Cancer Director, April 11, 2007.
[499] Personnal communication, Dr. Antoine Loutfi, Québec Cancer Director, April 11, 2007.
[500] DLCC. Orientations prioritaires 2007-2012, p. 35.

9.3 GOVERNANCE

9.3.1 Central governing organization

In Québec, the Health Ministry plays a central and direct role in the governance of cancer control. In 2004, the Minister of Health and Social Services created a *Direction de la lutte contre le cancer* (DLCC) within the Health Ministry, and appointed a Cancer Director in 2005, to drive the implementation of the PQLC and the policy on end-of-life palliative care. The following shaded box highlights the main features of this central governing organization (See Appendix 9F for a description of the various forms taken by the cancer control central governing structure since 1998, and Appendix 9 G for DLCC's position within the Health Ministry organizational chart). Activities related to health promotion, tobacco control, the breast cancer screening program and the *Fichier des tumeurs* (a provincial cancer database) is under the responsibility of the Public Health Branch (see Health Ministry organizational chart in Appendix 9G).

Direction de la lutte contre le cancer (DLCC)

Legal status:
The *Direction de la lutte contre le cancer* (DLCC) is a division, created in April 2004, within the Health Services and Academic Affairs Branch of the Ministry for Health and Social Services. The Director is a physician appointed in 2005 by the Minister of Health and Social Services. The Cancer Director position was not established through law.

Mission:
To steer and support cancer control interventions in Québec, in order to adequately respond to the needs of the population as well as the needs of cancer patients and their close relatives or friends.[501]

Vision:
In dialogue and in collaboration with DLCC partners, to implement an integrated and functional network that ensures excellence in cancer care and services for individuals suffering from, or suspected with cancer, as well as their close relatives or friends.[502]

Accountability:
The Director and DLCC are accountable to the Minister of Health through the Director of the Health Services and Academic Affairs Branch. The DLCC must produce an annual activity report.

Responsibilities and mandates:
The DLCC is responsible for cancer services organisation and for ensuring the quality of cancer care and services for individuals suffering from, or suspected with cancer. Its mandates are the following:[503]

- Identify needs to make accessible a full continuum of cancer services.
- Develop existing collaborations and act as a ministerial representative toward cancer stakeholder groups
- Develop expertise and take advantage of scientific evidence and best practices to improve access, organization and quality of cancer services
- Adopt and implement clinical governance mechanisms to increase adherence to highest clinical practice standards Ensure the provincial coordination of radio-oncology, hostels services, supportive and palliative care services, as well as the coordination of the network, including the designation of cancer teams
- Monitor the application of the PQLC by the Regional authorities

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[501] DLCC. Orientation prioritaires 2007-2012, p. 13.
[502] Idem
[503] Plan d'organisation administrative du Ministère de la santé et des services sociaux, March 2006, p. 53.

- Contribute to solving punctual problems linked to quality and accessibility of cancer services
- Measure quality of service provided and assess the degree of implementaton of the regional action plans
- Participate in data analysis regarding contractual arrangements and performance agreements.

Executive team:
The executive team comprises a deputy director and a dozen staff members.

Steering committee:
The DLCC is supported by a *Comité directeur* (steering committee) to assist and advise the Director on clinical governance and outcome-based management.[504]

Advisory groups:
A *Groupe conseil de lutte contre le cancer* (GCLC) was set up in September 2004 with the mandate to develop a framework and process for the assessment and designation of local, regional and supraregional interdisciplinary cancer teams and their respective host facility. The DLCC is also assisted by the following advisory bodies: (1) RUIS sectorial table in oncology; (2) *Comité d'évolution de la pratique en encologie* (CEPO); (3) Working group on access to innovative cancer drugs; and (4) several advisory committees on the following topics: cancer registry, hemato-oncology, nursing oncology, palliative care hospice accreditation, radio-oncology, and regional leaders in cancer control.

Annual expenditures related to cancer:
The 2006-2007 entire budget for health and social services in Québec was 22,1 billion dollars.[505] Total expenditures related to cancer are not available. More than 115 million dollars were invested in 2005-06 for capital equipment acquisition, hospital upgrade and for the construction of new cancer centers.
The costs of the cancer burden in Québec was estimated to be 210 billion dollars over the next 25 years: 61,6 billion in directs health care costs; 104 billion in lost productivity; 44,5 billion in salary loss.[506]

Additional funding for service improvement and reform implementation:
In 2007, the Health Minister commited 75 million dollars over 5 years to implement the orientations prioritaires 2007-2012 of the PQLC.[507] In 2004, 10 million dollars were committed annually for implementing the Health Minister's 2004-2007 working plan related to the PQLC.[508] In 2006, this budget was raised to 20 million annually.[509] Between 2001 and 2003, each Regional Health Board received 60,000$ to review cancer control services and to develop a cancer plan in their region.[510]

9.3.2 Other key actors within the health system

Governance of cancer control services is also closely linked to the general governing arrangements within the health system. Beginning in 2003, an important reform in the organization and governance of health and social services was enacted by law to improve

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[504] Loutfi A. (Cancer Director) Bilan de la réorganisation de la lutte contre le cancer au MSSS. Powerpoint presentation at the second Annual Forum of the Coalition Priorité Cancer au Québec, April 22, 2005. Available at: http://www.fqc.qc.ca/coalition/forum2005.asp

[505] Gouvernement du Québec. Budget 2006-2007. Budget en bref, mars 2006, p. 5. Available at: http://www.budget.finances.gouv.qc.ca/budget/2006-2007/fr/pdf/BudgetBref.pdf

[506] Pierre Boucher (économiste principal, Marcon-DDM) Les impacts du cancer sur la collectivité. Presentation, Forum of the Coalition priorité cancer, April 21, 2006. Available at: http://www.fqc.qc.ca/coalition/images/forum2006/Presentation_Pierre_Boucher_economiste.pdf

[507] De nouveaux investissements de près de 75 millions de dollars – Le minister philippe Couillard dévoile les orientations prioritaires en matière de lutte contre le cancer 2007-2012. MSSS press release # 4264, September 24, 2007. Available at: http : www. Communiques.gouv.qc.ca/gouvqc/communiques/GPQF/Septem

[508] See Dr. Philippe Couillard speech, Forum de la Coalition Priorité Cancer, April 23 2004.

[509] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, March 21, 2007.

[510] MSSS. Rapport annuel de gestion 2002-2003, p. 49.

accessibility, continuity and the quality of care.[511] Such reform rests on a population-based approach, and is guided by the principles of integration, hierarchical organization and complementarity of services, as well as interdisciplinarity of actors.

Local level:

At the local level, this reform involved: 1) the merging of the Province's existing health and social services facilities[512] into 95 local entities called CSSS (*Centres de santé et de services sociaux*); and 2) the creation of 95 *Réseaux locaux de santé et de services sociaux* or RLS (local health and social services networks), to which the 95 CSSS are the heads. Each CSSS is now responsible for the coordinated provision of a comprehensive basket of general, specialized, and ultraspecialised services to the population within their local network catchment area.[513] This comprehensive basket of services, established on a population health basis and on the complementarity of existing services within the CSSS catchment area, is called the *projet clinique et organisationnel* (clinical project). As a result, all institutions and service providers will be accountable (through the CSSS) for the coordinated provision of a comprehensive basket of services to the population within the CSSS/RLS catchment area.[514] To do so, CSSS are to establish service agreements with all relevant institutions and service providers within or outside the service network. In turn, CSSS are accountable to their respective regional Health Agency through management (performance) agreements.[515]

Each *projet clinique et organisationnel* is to include a cancer control program that spans the entire cancer control continuum, from prevention to palliative care services. In support of this process, the Health Ministry produced a guide that sums up the government's existing reference documents that are relevant for the organization of cancer control services in Québec.[516] The DLCC's *orientations prioritaires* stipulate that 90% of CSSS must include such cancer control program in their clinical project by December 2008, and that the same is required from all hospitals centers involved in canvcer control.[517]

Regional level:

At the regional level, the reform involved the transformation of the 18 existing Regional Health Boards into Health and Social Services Agencies.[518] Each Agency has a board of directors, whose members are nominated by, and are accountable to, the Minister for Health and Social

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[511] Projet de loi 83 modifiant la Loi sur les services de santé et les services sociaux (LSSSS) et d'autres dispositions législatives. This bill was introduced in December 2004 and adopted in November 2005. LRQ, c. S-4.2 ; 2005 c. 32. Thereafter referenced as LSSSS.

[512] The merged facilities were the existing CLSCs (Centres locaux de services communautaires), the CHSLDs (Centres d'hébergement et de soins de longes durée) and, in the case of 78/95 CSSS, it also included a hospital.

[513] See Health Ministry website at: http://www.msss.gouv.qc.ca/reseau/rls/

[514] See Health Ministry website at: http://www.msss.gouv.qc.ca/reseau/rls/

[515] LSSSS, art 99.7

[516] MSSS. Les documents ministériels en appui aux projets cliniques. Projet clinique santé physique – La lutte contre le cancer. Document de travail, août 2006.

[517] DLCC. Orientations prioritaires 2007-2012, p. 25.

[518] Loi sur les agences de développement des réseaux locaux de services de santé et de services sociaux, adopted in December 2003. L.R.Q., c.A-8.1. There are 15 such Agencies and, in the Northern regions, health and social services are managed by different regional organizations. See MSSS. Rapport annuel de gestion 2005-06, p. 20.

Services. The Agencies' mandate[519] includes the following responsibilities : 1) ensuring public participation to the management of the health system, as well as the safeguard of users' rights and the safe provision of health and social services, including the assessment of patient satisfaction; 2) facilitating the development and management of the local networks (RLS) within their respective region ; 3) overseeing and supporting the CSSS within their catchment area in developing population health-based and coordinated local service plans; 4) ensuring agreements are made between the CSSS and any other facilities or providers to allow for the coordinated provision of required health and social services; 5) allocating financial resources for the provision of health and social services within their region; 6) planning human resources within their region; 7) preparing a multi-year regional strategic plan that is consistent with the Health Ministry's goals; and 8) assessing results from its strategic plan as well as being accountable for its management against provincial and regional targets and established standards for access, integration, quality, and efficiency.

The Health Ministry has management and accountability agreements with the Agencies that define the parties commitments, based on the performance indicators identified for the various service programs. The Agencies are accountable for achieving targets set in Ministry's 2005-2010 Strategic Plan and in turn have performance agreements with the regional hospitals and CSSS included in their region. For its part, the Health Ministry has an obligation to support the Agencies and institutions through the required financial, technological and human resources.

The governance of cancer control at the regional level is evolving since the 2003 reform. No longer at the forefront of service organization -- a responsibility now devoted to the CSSS – the Agencies remain nonetheless responsible for the production of a regional cancer control action plan (or program), the implementation of a regional cancer control network, the official designation of local and regional interdisciplinary cancer control teams, and for the regional coordination of cancer control services, through defined referral pathways. The regional cancer control networks (and plan or program) are likely to be implemented through the collaboration between a regional cancer committee within the Agency, a regional interdisciplinary cancer team and its affiliated regional facility, and the multiple CSSS within the region.[520]

The DLCC's *orientations prioritaires*[521] stipulate that by December 2008, Agencies must update their cancer control action plan and program and ensure CSSS have access to a regional cancer team/facility. Agencies must also finalize the structure of their cancer control network by March 2010.

Provincial and territorial (RUIS) levels:

An equally important change was the creation of four RUIS *(Réseaux Universitaires Intégrés de Santé et de services sociaux*) which are territorial networks linking one university and university-teaching hospital with facilities that have a "university" designation.[522] The RUIS have a four-part mission: (1) to provide tertiary and quaternary health care; (2) to provide medical education;

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[519] LSSSS, art 340

[520] Personal communication, Dr Antoine Loutfi, Cancer Control Director, March 21, 2007.

[521] DLCC. Orientations prioritaires 2007-2012, p. 25

[522] LSSSS Chapitre I.1, art. 436.1

(3) to conduct research; and (4) to conduct health technology assessment. As a partner of one or more CSSS in one or more RLS, the RUIS must make a significant contribution to the clinical projects initiated by these CSSS. RUIS must propose to the Regional Agencies within their territories the basket of services that the RUIS will make available at the local, regional and supraregional levels. They are also to assist the Agencies in achieving better coordination of care, namely by agreeing on formal referral pathways in order to avoid fragmentation of services.[523] The RUIS are coordinated by a National Coordinating Table.[524] RUIS Sectorial Tables were also created in telehealth, mother-infant care, health technology assessment, oncology, tertiary cardiology, and genetics.[525]

The *RUIS Sectorial Table in oncology* was created in January 2005 to foster the complementarity of existing expertise, namely by contributing to define the responsibilities of supraregional interdisciplinary cancer teams affiliated with each RUIS.[526] It is headed by the Cancer Director and is accountable to the National Coordinating Table.[527] Its mandate comprises the following goals:[528]

- Facilitate RUIS excellence in achieving their four-part mission related to health services, education, research and health technology assessment
- Define the responsibilities of RUIS members, and to see to it that cancer control services being offered within the RUIS are complementary.
- Ensure the complementarity between RUIS in cancer control, according to each RUIS' existing expertise in highly specialized care
- Facilitate evidence-based continuous quality improvement by disseminating and adopting practice guidelines.

Some of its priorities for 2005-2006 were two-fold: (1) to facilitate knowledge transfer and evidence-based practices; and (2) to facilitate networking and improved access to expertise by supporting the implementation of cancer site teams (or tumour boards). It is assisted by two working groups (*sous-tables*). The first one (*sous-table radio-oncologie*) is mandated to make recommendations to the DLCC on strategies to ensure access and quality of radiation therapy services.[529] The second (*sous-table registre*) is devoted to the creation of a provincial cancer registry. Its mandate includes identifying the necessary data that should be part of a central registry, as well as describing the process of registry implementation.[530]

One main objective of the DLCC is to incite RUIS commitment toward cacner control. In this regard, the DLCC's *orientations prioritaires* stipulate that cancer site-specific community of practice networks supporting supraregional cancer teams should be set up by 2009 in order to improve the quality of oncology practice.

Non-governmental organizations:

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[523] LSSSS Chapitre I.1, art 436. 6.
[524] LSSSS Chapitre I.1, art 436. 8.
[525] MSSS, DGSSMU - Direction des affaires universitaires. Tables sectorielles – RUIS, January 2007.
[526] Health Minister speech, Forum Coalition priorité cancer, April 22, 2005.
[527] MSSS, DGSSMU - Direction des affaires universitaires. Tables sectorielles – RUIS January 2007.
[528] DLCC. Rapport d'activité 2005-2006, p. 16.
[529] This sous-table replaces the national radio-oncology coordinating center that was created in 1999.
[530] DLCC. Rapport d'activité 2005-06, p. 16.

Non-governmental organizations (NGOs) are an umbrella term referring to charitable, voluntary, community and/or advocacy organizations (see appendix 9D for a selected list) playing significant roles in one or more of the following tasks: (1) fundraising and financing research; (2) providing information to patients and the public; (3) contributing to cancer prevention; (4) providing home care and support services; and (5) doing advocacy. For example, the *Fondation québécoise du cancer*, a provincial organization providing information to cancer patients and to the public, is also offering accommodation services for patients travelling to major health centers to receive treatments. The *Canadian Cancer Society - Québec chapter* is mainly involved in raising funds for research and in providing information to cancer patients and to the public.

Community organizations are mostly involved in the care of cancer patients and their family by providing information and support, as well as home care and community services. Some are specifically involved in palliative care. Services provided by these community organizations are to be included in the clinical projects being developed by the CSSS and their partners. The DLCC is in the process of establishing a list of these organizations mandated by the government to provide support services in oncology and in palliative care.[531] Such list is to be posted on the Health Ministry and Agencies' websites.[532]

Many organizations are also involved in advocacy through the *Coalition Priorité Cancer au Québec*. This coalition was created in 2001 to incite the Québec government to prioritize the fight against cancer and to intensify the implementation of the PQLC. Since 2001, activities of the Coalition included the following:

- Submitting a petition to the national assembly of Québec in 2002, asking the government to recognize cancer as a priority and to improve cancer control services;[533]
- Establishing annual forums, which were held in 2004, 2005 and in 2006; and
- Holding a cancer summit (*États généraux sur le cancer*) in 2007.

9.4 MAIN ACCOMPLISHMENTS

This section first provides a summary of progress toward the implementation of the PQLC, and then describes some of the main accomplishments, focusing on the achievements in organizational architecture reform and service quality facilitators. The section also highlights what is perceived to be a distinctive feature of the province regarding its cancer control program.

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[531] Loutfi A. Bilan de la réorganisation de la lutte contre le cancer au MSSS (2005).

[532] Personnal communication, Dr. Antoine Loutfi, Québec Cancer Director, March 1, 2007.

[533] « 40 000 personnes réclament l'amélioration des services pour les personnes atteintes de cancer. » Press release, Fondation québécoise du cancer, 25 février 2003.

9.4.1 Summary of progress

9.4.1.1 The first five years (1998-2003)

From 1998 to 2003, the following accomplishments related to the implementation of the PQLC and in cancer control more generally could be highlighted:

- The CQLC was set up in 1998 as an arm's length advisory body to the Minister of Health and Social services. CQLC activities and productions by its various committees included numerous guidance reports and an annual conference to promote the PQLC. The CQLC was abolished in 2004 (see appendix 9E).
- The 1998 tobacco control law, and 2001-2005 tobacco control plan, provided a comprehensive approach based on prevention, cessation, protection and surveillance.
- The breast cancer screening program (PQDCS) was implemented in 16 out of 18 regions,[534] and the 2003-2012 Public Health Program reiterated the Government's priority to reducing breast cancer mortality.[535]
- Significant investments and measures were taken to reduce waiting for radio-oncology treatments, a problem that reached a critical level in 1999.[536] First, a *Comité d'experts en radio-oncologie* was set up in 1999 to evaluate Québec's capacity in radio-oncology and to propose solutions to reduce waiting time for cancer patients. The *Comité* report noted that there was an important shortage of manpower and an insufficient number of treatment machines among others.[537] It recommended as a short-term solution the sending of patients to the United States for treatment, a program that began in June 1999.[538] Second, a *Centre de coordination nationale de radio-oncologie* was set up to manage the operations, coordinate short-term measures, and plan for future needs in radio-oncology. Investments were made to acquire new linear accelerators, planning exercises were conducted regarding human resources and capital equipment, and an action plan was developed to increase treatment capacity. The resulting *Plan d'action en radio-oncologie (2000-2008)* was released in 2000.[539] The transfer of patients to the United States ended in January 2002.[540] From then on, patients waiting for more than 8 weeks were being dispatched among the various Québec radio-oncology centers, and agreements were reached for centers to remain opened after-hours for treatment.[541]
- In 1999, regional health boards were instructed by the Ministry of Health and Social Services to begin the implementation of the PQLC, and to establish regional cancer control networks.[542] Regional health boards were given a three-fold mandate: (1) create a regional

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[534] PQDCS. Bilan 1998-2003, p. 12.
[535] Programme national de santé publique 2003-2012, p. 45.
[536] Based on MSSS. Rapport annuel de gestion for years 2001-2002 to 2005-2006.
[537] Conseil québécois de lutte contre le cancer (CQLC). Comité radio-oncologie – Rapport du Comité radio-oncologie, 1999.
[538] C. Freeman. Radiotherapy in Quebec : An update. CARO-ACRO E-news, vol 2, issue 1, February 2001. Available at: http://www.caro-acro.ca/caro/comm/newsletters/Newsletter_Feb2001.pdf
[539] Gouvernement du Québec, Ministère de la Santé et des Services Sociaux. La radio-oncologie au Québec -- Plan d'action 2000-2008. Plan adopté par le Comité de radio-oncologie, 4 février 2000.
[540] Gouvernement du Québec. MSSS. Rapport annuel de gestion 2004-2005, page 54.
[541] MSSS. La lutte contre le cancer dans les régions du Québec. Un premier bilan, 2003, p. 82-83.
[542] Le relais. Bulletin d'information de la Régie régionale de la santé et des services sociaux - Montérégie, vol. 4, no. 1 janvier 2002. Available at : http://www.bibliotheque.assnat.qc.ca/01/PER/824582/2002/Vol_4_no_1_(janv_2002).pdf

cancer committee; (2) review existing cancer control services; and (3) develop a three-year regional cancer action plan.[543] In November 2000, the Minister of Health announced that a body would be created within the Ministry to better coordinate existing resources toward cancer control and strenghten leadership.[544] A *Centre de coordination de la lutte contre le cancer au Québec* (CCLCQ) was set up in Spring 2001. CCLCQ activities included logistic and financial support to regional health authorities, and the production of a *Bilan* (2003), which was based on regional pictures of existing (2001-2002) cancer control services and accomplishments toward the implementation of the PQLC.

Five years after the launch of the PQLC, only a few recommendations of the PQLC had been implemented across all the regions.[545] Regional Cancer Committees had been established in 13 out of 18 regions; *infirmières pivots* (enhanced patient navigators) were operational in some regions, and few regions had local or regional interdisciplinary cancer teams.[546] While the regional services reviews were completed in 2002-2003, [547] the development of three-year regional cancer plans that began in 2003 was only completed in 2005.[548]
There were however notorious local efforts, including the setting up of a regional cancer control network in the Montérégie.[549]

The problems associated with the organization of cancer control services that were described in the 2003 CCLCQ Bilan[550] were comparable to the ones documented in the early nineties by the Cancer Advisory Committee.[551] Existing gaps in the organization of cancer services still related mainly to:

1. **Fragmentation of care**, as documented by: (a) the lack of formal protocols for referral (referral patterns depending on providers' personnal networks); (b) Lack of agreements between facilities for clinical follow-up; and (c) reduced effectiveness of existing follow-up care mechanisms due to lack of communication between health care providers and lack of systematic procedure for the transmission of information. This situation was worse when many health care facilities were involved, and/or when patients required services available in a different region.
2. **Reduced access** to specific services in certain regions and significant differences in waiting time for certain services among different facilities.

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[543] MSSS. Rapport annuel de gestion, 2001-2002, p. 35 and Rapport annuel de gestion 2002-2003, p. 49.

[544] Gouvernement du Québec, Ministère de la Santé et des Services Sociaux. Direction générale des affaires médicales et universitaires (Authors: Lacroix L, Côté-Brisson L, Turgeon L.). Un centre de coordination nationale de lutte contre le cancer, 2001, p. 3. Available at: http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2001/01-902-01.pdf

[545] See Mot du Président In: CQLC. Stratégie et plan d'action 2003-2005.

[546] Based on our analysis of the regional status reports included in the CCLCQ Bilan on existing cancer control services. See : MSSS. CCLCQ. La lutte contre le cancer dans les régions du Québec : Un premier bilan. Bibliothèque nationale du Québec, 2003.

[547] By March 2004, 10 out of 18 regions had submitted their cancer control regional plan to the Ministry. See MSSS. Rapport annuel de gestion 2003-2004, p. 77.

[548] Bound by new performance agreements, Regional authorities had to develop a regional cancer plan by March 31, 2005. See MSSS. Rapport annuel de gestion 2004-2005, p. 52.

[549] See Roberge D, Denis J-L, Cazale L,Comtois E, Pineault R, Touati N, Tremblay D. Évaluation du réseau intégré de soins et de services en oncologie : l'expérience de la Montérégie. Fondation canadienne de la recherche sur les services de santé, December 2004.

[550] MSSS. CCLCQ. La lutte contre le cancer dans les régions du Québec : Un premier bilan. Bibliothèque nationale du Québec, 2003.

[551] PQLC p. 34

3. **Lack of supportive care** right from the beginning of diagnosis
4. **Suboptimal use of primary care physicians** as specialist consultation time was being used for follow-up care which could be done by the patient's family doctor.

Moreover, important challenges regarding health promotion, prevention and early detection remained. Tobacco use was elevated; there was no policy on healthy eating; and there was significant potential for mortality reduction to be gained from increased participation to breast, cervical and colorectal screening.[552]

9.4.1.2 Progress since April 2004

Following recommendations of the 2004 Ministerial cancer working group report, renewed efforts toward the implementation of the PQLC focused on: (a) the setting up of interdisciplinary cancer teams; (b) the hiring of *infirmières pivots* and psycho-social care providers; (c) the setting up of mechanisms to improve access to specialized care; and (d) the improvement of palliative care.[553] Most recent initiatives and accomplishements in cancer control can be found in the DLCC annual activity reports.

9.4.2 Progress in organizational architecture reform

In concordance with the priority announced by the Minister of Health and Social Services in 2004, a systematic process began toward the setting up of interdisciplinary cancer teams at the local, regional and supraregional levels. To this end, the DLCC mandated the *Groupe Conseil de lutte contre le cancer* to develop and conduct an assessment process for the subsequent designation of interdisciplinary cancer teams at the local, regional and supraregional levels (see vshaded box on distinctive feature for more details).[554] By December 2006, 42 teams had been designated for a local cancer services mandate and 8 for a regional mandate.[555]

The following shaded box highlights the mandates of local, regional and supraregional interdisciplinary cancer teams and lists existing structures and facilities where cancer services are provided, according to their local, regional, and supraregional missions.

Organizational architecture of cancer services – Québec

Local level:

Local interdisciplinary cancer teams (and their host facilities) will be responsible for providing general and cancer specific services (primary care level), including cancer prevention and health promotion, diagnostic services, care coordination, supportive care and end-of-life palliative care.

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[552] See summary of challenges noted in the CCLCQ 2003 Bilan as cited in the Ministry Cancer Working Group Report, 2004, page 15.

[553] De meilleurs services en vue – Phillippe Couillard annonce ses prioritiés d'action pour la lutte contre le cancer. Fondation Québécoise du Cancer, 23 avril 2004.

[554] Latreille J. (Chair, Groupe conseil de lutte contre le cancer). Évaluation des équipes interdisciplinaires et des établissements. Processus et impact. Powerpoint presentation, Congrès annuel de la Direction de la lutte contre le cancer, Décembre 2006.

[555] Ibid

The following local structures may be linked to local, regional or supraregional cancer teams:

- *95 local health networks*: each network includes a CSSS (which results from the fusion of specific primary care facilities and the local hospital), general physician practices, other health and social service providers, as well as community resources in the network catchment area. Such network offers primary care services, but also in some case secondary care through the CSSS-associated hospital.
- *Public Health Units* involved in cancer prevention
- *86 Designated Screening Centers* providing mammography for the organized breast cancer screening program (PQDCS).[556] There is also a mobile mammography service operating in remote regions.
- *14 Hospices* and *home care community resources* involved in palliative care.

Regional level:

Regional interdisciplinary cancer teams (and their host facilities) will provide general and specialized cancer services (secondary care), as well as advice and expertise to local teams for the most common tumour sites (breast, lung, colorectal and prostate) and for hemato-oncology. They are also to provide screening services, diagnostic confirmation, specific treatments (surgery, chemotherapy, radio-oncology), and specialized supportive and palliative care.

The following structures with a local and/or regional mission may be linked to local, regional or supraregional cancer teams:

- *38 Designated Referral Centres* (centres régionaux d'investigation désignés, CRID) providing complementary examinations following an abnormal mammogram. The screening program services are managed regionally by *eighteen regional coordinating centers*.
- *Nine University affiliated hospitals* (Centre hospitalier affilié universitaire, CAU) with major expertise in various cancers, among which five are located in Montréal, including Hôpital Maisonneuve-Rosemont with major expertise in hemato-oncology, and four in other regions: (1) CSSS Chicoutimi ; (2) CSSS de la Vieille capitale (Québec) ; (3) Hotel-Dieu de Lévis; and (4) hôpital Charles-Lemoyne (Greenfield Park, south bank of Montréal).[557]
- *Five University Health Institutes*[558] (Instituts universitaires de santé), including Hôpital Laval in the Québec area, with major expertise in lung cancers.
- *Ten radio-oncology centers* based in hospitals and providing radiation oncology. There are four centers in the Montreal area and six in other regions: (1) CHUM (hôpital Notre-Dame and Hotel-Dieu de Montréal); (2) CUSM (hôpital Royal Victoria and hôpital général de Montréal); (3) Hôpital général Juif de Montréal; (4) Hôpital Maisonneuve-Rosemont (Montréal); (5) CHUQ (Hotel-Dieu de Québec); (6) CHUS (Hôpital Fleurimont de Sherbrooke); (7) CRSSS de Rimouski; (8) CH Régional de Trois-Rivières; (9) CSSS de Chicoutimi; and (10) CSSS de Gatineau. The *Centre intégré de lutte contre le cancer de la Montérégie* of the hôpital Charles-Lemoyne (to be constructed) will also provide expanded radio-oncology capacity and substantially upgrade the existing cancer center located in the external clinic of the hospital.[559]

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[556] http://www.msss.gouv.qc.ca/sujets/santepub/pqdcs/index.php?aid=66
[557] http://wpp01.msss.gouv.qc.ca/appl/m02/M02ResultRechEtabInst.asp
[558] http://wpp01.msss.gouv.qc.ca/appl/m02/M02ResultRechEtabInst.asp
[559] http://www.hclm.qc.ca/fr/lutte_cancer/index.jsp?id=699

Supraregional (RUIS and inter RUIS) level:

Supraregional interdisciplinary cancer teams (at RUIS level) and their host facilities will be responsible for providing, upon referral, highly specialized and complex care (tertiary care) for specific tumour sites. This will include consulting diagnostic services and highly specialized and complex treatments for most tumour sites. *Provincial interdisciplinary cancer teams* will be responsible for providing tertiary care for rare cancers (diagnostic and treatments) upon referral.[560]

The following structures with a supraregional mission [561] may be linked to local, regional or supraregional cancer teams:

- *Four University Health Centers* and *one Pediatric University Health Center* involved in the treatment of rare and complex cancers as well as more common forms of cancers: (1) CHUQ (Centre hospitalier universitaire de Québec, including the Centre mère-enfant du Centre hospitalier de l'Université Laval); (2) CHUS (Centre hospitalier universitaire de Sherbrooke, which has a pediatric department); (3) CUSM (Centre universitaire de santé McGill, which includes the Montreal Children Hospital); (4) CHUM (Centre hospitalier de l'université de Montréal); and (5) Centre mère-enfant du Centre hospitalier universitaire Ste-Justine in Montréal.
- *Two University Affiliated Hospital Centres with a supraregional mission* and major expertise in various cancers: (1) Centre universitaire affilié de Québec (this CAU includes two hospitals (Enfant-Jésus and Saint-Sacrement, with major expertise in brain and breast cancers respectively); and (2) Hôpital du Sacré-Coeur de Montréal with major expertise in lung cancers and hemato-oncology.

9.4.3 Service quality facilitators: Initiatives up and running

The shaded box below displays Québec's ongoing initiatives related to service quality facilitators. Such inventory indicates that there are increasing efforts committed to improve the collection and management of clinical and administrative data, which will facilitate cancer surveillance and clinical governance.

Service quality facilitators – Québec

1. System capacity and sustainability:

Cancer drugs management systems:

- The *Comité d'évolution de la pratique en oncologie* (CEPO), a permanent Committee that was established in 2001 by the CQLC, is an interdisciplinary group of oncology experts including a majority of physicians (specialists) and pharmacists, as well as representatives from the *Groupe d'étude en oncologie* (GEOQ), the *Programme de gestion thérapeutique des médicaments* (PGTM), the *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) and from the *Conseil du médicament*. CEPO's role is to assess the therapeutic value of cancer drugs and its mandate comprises the following tasks among others: (1) Develop, adopt (or adapt if needed) clinical practice guidelines on the screening and treatment of cancer (radiation therapy, chemotherapy,

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[560] Direction de lutte contre le cancer (DLCC). Le réseau de services intégrés de lutte contre le cancer. Internal document, March 28, 2006, 4 p.

[561] The supraregional mission is linked to the following ministerial designations: Centre hospiptalier universitaire or Centre affilié universitaire à vocation suprarégionale. See http://wpp01.msss.gouv.qc.ca/appl/m02/M02Rech EtabInstall.asp

surgery) and related investigative examinations; (2) Develop protocols and patient information sheets for chemotherapy drug administration; and (3) Propose mechanisms to facilitate the uptake and use of clinical practice guidelines.[562]

- The *Conseil du médicament* is responsible for assisting the Minister of Health and Social Services in updating the list of drugs covered by the *Régie d'assurance maladie du Québec* (RAMQ).[563] It makes recommendations regarding the registration of anti-cancer drugs on the lists of insured drugs. The list is available on the RAMQ website and includes a whole section on anti-cancer drugs.[564] In 2006, following a ministerial order,[565] the Conseil set up a Committee to examine the pharmacoeconomic dimension of anti-cancer drugs, with the ultimate aim to develop a framework to facilitate decision-making and improve its transparency. The mandate of this Committee is three-fold: (1) make recommendations regarding pharmacoeconomic guidance based on scientific literature and international experience; (2) develop a rationale for dealing with the ethical questions raised by the registration of anti-cancer drugs on the lists of insured drugs; and (3) examine the possibility of implementing a framework for social debate if needed.
- The 2007 *Politique du médicament* (public policy on medications) includes four specific directions: (1) improved access; (2) fair pricing; (3) optimal use of medications, as well as (4) to support the pharmaceutical industry.[566]
- The DLCC set up a Working group on access to innovative cancer drugs, as part of the RUIS sectorial table in oncology, to develop specific rules for fair and optimal access to new anti-cancer drugs.[567]
- A *Programme de gestion thérapeutique des médicaments* (University hospitals' drug assessment program)[568] was set up in 2004 by the five university hospitals (CHUM, CUSM, CHUS, CHUQ and CHUSJ) to foster optimal (safe, effective, and efficient) drug use in these facilities through the systematic assessments, care protocols, and educational activities. The Program was also put in place to prevent the duplication that may occur in the various steps that are involved in the decision-making process regarding drug use in these facilities. Results from the Program's research, assessments and other activities are, however, not binding; the pharmacological comittee of each CHU retain full power to make decisions regarding drug use for its facility.
- A *Service québécois d'information sur les médicaments* (SQIM) is among the various projects to result from the ongoing *Plan d'informatisation du réseau de la santé et des services sociaux* (see information management systems below). The SQIM will allow physicians to have rapid access to the pharmacological profile of their patients.[569]

<u>*Capital investments:*</u>

- Since 2004, substantial investment was committed in radio-oncology, namely for capital equipment acquisition (linear accelerators), the creation of new radio-oncology centers as well as for the upgrade and/or expansion of, and financial support to, existing radio-oncology centers.[570, 571, 572, 573, 574, 575, 576,

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[562] DLCC. Rapport d'activité 2005-2006, p. 19.

[563] http://www.cdm.gouv.qc.ca/site/index.php?fr_le_conseil

[564] http://www.ramq.gouv.qc.ca/fr/professionnels/resant/listmed/listmed_eta_ajour.shtml

[565] Letter of Dr Juan Roberta Iglesias, Deputy Health Minister, to the Conseil du Médicament, 5 juin 2006.

[566] Une première en Amérique du Nord – Lancement de la politique québécoise du médicament. 1er février 2007, Available at : http://communiques.gouv.qc.ca/gouvqc/communiques/GPQF/Fevrier2007/01/c3690.html

[567] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, March 21, 2007.

[568] http://www.pgtm.qc.ca/faq.asp

[569] See MSSS webpage on Dossier santé at: http://msssa4.msss.gouv.qc.ca/fr/reseau/dossante.nsf/b3c58543cc0dc4af85256db3004f34ae/9d3237445075289f852571fb006c7485?OpenDocument

[570] Notes pour une allocution du ministre de la Santé et des Services sociaux, monsieur Philippe Couillard, à l'occasion du deuxième Forum sur le cancer au Québec, le 22 avril 2005.

[577, 578, 579] Significant investments were also made to improve medical imaging capacities, including the installation of PET scanners in each RUIS and according to a population-based approach.[580, 581] Other notable investments were made for setting up research-based external oncology clinics[582, 583] and for the expansion of the Fondation québécoise du cancer network of hotel accommodations.[584]

Human resources management initiatives:

- The 2004 *Ministerial cancer working group* Report stipulated that all human resources needs in oncology (medical, professional, technical) be considered a priority by the relevant Ministry branches, in close collaboration with the educational and training sectors.
- Human resource planning is a priority of the DLCC (see design section). Current initiatives are focusing on the hiring and training of the following cancer professionals: (1) Infirmières pivots en oncologie (enhanced cancer patient navigators); and (2) cancer registrars. DLCC also set up an advisory committee to examine the issue of specialists in hemato-oncology.[585]

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[571] MSSS. Report on the progress made regarding the bilateral agreement entered into during the federal-provincial-territorial meeting of the first ministers on health, September 2004. Released in October 2005. Available at: http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2005/05-720-01F

[572] Un quatrième accélérateur linéaire pour le traitement du cancer - La ministre Monique Gagnon-Tremblay annonce des investissements de 5,5 millions de dollars au centre hospitalier de l'université de Sherbrooke pour de l'équipement de haute technologie médicale, October 7, 2005. Available at: http://communiques.gouv.qc.ca/gouvqc/communiques/GPQF/Octobre2005/07/c8877.html

[573] Québec rend des comptes à sa population - Le ministre Philippe Couillard rend public un bilan des progrès accomplis en santé. Press release, October 21, 2005. Available at: http://communiques.gouv.qc.ca/gouvqc/communiques/GPQF/Octobre2005/21/c4315.html.

[574] Investissements de 3,3 millions de dollars pour de l'équipement médical spécialisé - Le centre hospitalier universitaire de Montréal accentue son rôle de chef de file dans le traitement du cancer. November 14, 2005. Available at: http://communiques.gouv.qc.ca/gouvqc/communiques/GPQF/Novembre2005/14/c4605.html

[575] Le gouvernement annonce la construction du centre intégré de lutte contre le cancer de l'Hôpital Charles LeMoyne. February 17, 2006. Available at: http://www.premier.gouv.qc.ca/salle-de-presse/communiques/2006/fevrier/com20060217.shtml

[576] Centre de santé et de services sociaux de Chicoutimi – Le gouvernement annonce un important agrandissement du service de radio-oncologie, au coût de 19,2 millions de dollars. FQC Press release, February 20, 2006.

[577] Investissement de 36 millions de dollars en radio-oncologie à l'hôpital Maisonneuve-Rosemont de Montréal. April 27 2006. Available at : http://www.msss.gouv.qc.ca/sujets/prob_sante/cancer/index.php?communiques_de_presse

[578] Services de cancérologie - Le ministre Benoit Pelletier confirme un projet d'agrandissement de 29,5 millions de dollars à l'hôpital de Gatineau. December 19, 2006. Available at: http://communiques.gouv.qc.ca/gouvqc/communiques/GPQF/Decembre2006/19/c8768.html

[579] Le premier ministre annonce que la Cité de la santé sera dotée d'un centre de radio-oncologie. January 29 2007. Available at: http://www.premier.gouv.qc.ca/salle-de-presse/communiques/2007/janvier/2007-01-29.shtml

[580] Déploiement d'une technologie de pointe en imagerie médicale à l'Hôtel-Dieu de Québec. May 10 2006. Available at : http://www.msss.gouv.qc.ca/sujets/prob_sante/cancer/index.php?communiques_de_presse

[581] See MSSS webpage on Access to specialized services / medical imaging. Available at: http://wpp01.msss.gouv.qc.ca/appl/g74web/imageriemedicale.asp

[582] Le ministre Couillard inaugure le centre du cancer Segal de l'hôpital général Juif. August 28 2006. Available at: http://communiques.gouv.qc.ca/gouvqc/communiques/GPQF/Aout2006/28/c8783.html

[583] Un nouveau centre pour les patients atteints de cancer. CHUQ Press release, November 7, 2006. http://www.chuq.qc.ca/fr/actualites/communiques/nouveau_centre.htm

[584] Un million de dollars à la Fondation québécoise du cancer - Québec soutient le réseau d'hôtellerie pour les personnes atteintes de cancer. FQC Press release, April 26 2004.

[585] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, April 11, 2007.

- Recommendations on human resources planning, as stipulated in the *Plan d'action en radio-oncologie 2000-2008,* were implemented. The number of technologists, physicists and radio-oncologists more than doubled during that period.[586]

Information management systems:

- The *Fichier des tumeurs du Québec* is a computerized database gathering, processing, and storing all newly diagnosed cases of cancer. The Fichier uses the MedÉcho file that includes data for all day surgeries and hospitalisations in acute care hospitals in Québec. In 2003, INSPQ conducted an assessment of the completeness of the *Fichier des tumeurs* with respect to the registration of new cancer cases confirmed by histology in 1996. The assessment demonstrated that completeness is high, reaching more than 95% for most cancers in adults, with however, lower completeness for prostate cancers and melanomas, which can be diagnosed and treated without hospitalization or day surgery.[587] While a useful data source for surveillance, cancer prevention, and public health prioritisation activities, the Fichier does not support all the functions to be expected from a central cancer registry.[588]
- A *Registre québécois des cancers* (provincial cancer registry) is under development in collaboration with the DLCC and the Direction de la santé publique. As a first step toward the creation of a central cancer registry, the Minister of Health and Social Services announced in April 2005, the importance of implementing local cancer registries.[589] Half a million dollars was provided in 2005 to fund a number of local projects aimed at analysing the feasibility of implementing and operating local cancer registries to better understand the implications of such implementation.[590, 591] Moreover, to obtain complete, precise, valid and timely information on cancer incidence, mortality and survival in the province of Québec, the RUIS Sectorial Table in oncology created a working group to: (1) define the main goals of a provincial cancer registry; (2) determine the scope of data (and cancer sites) to be collected in relevant facilities; (3) assess the feasibility of merging the existing *Fichier des tumeurs* with the proposed central cancer registry; and (4) analyse the opportunity, determine the steps, and detect the barriers to overcome in order to implement such a cancer registry.[592] A report is forthcoming. Ultimately, the new registry will include the date of diagnosis and stage of cancer and will be based on the *Fichier des tumeurs*, and data drawn from local cancer registries in existing health care facilities.[593] This will require the standardization of pathological specimens in order to ensure comparable data, as was recommended in the PQLC.[594]
- The *Système de gestion de l'accès aux services* (SGAS), which was initiated in 1998, and developed by the Health Ministry, is a system built to support physicians and facilities in the day-to-day management of waiting lists for medical and surgery procedures.[595] The system is based on the notion of maximum tolerable delays which are defined by Advisory Committees composed of the relevant medical specialists. After completing a phase of experimentation, the system was first implemented in 2003 in tertiary cardiology (fully deployed in January 2004) and was then adapted to be used in radio-oncology.[596] A Radio-oncology Advisory Committee was set up in 2002 that established a framework

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[586] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, April 11, 2007.
[587] INSPQ. Evaluation of the completeness of the Fichier des tumeurs du Québec. June 2003.
[588] DLCC. Rapport d'activité 2005-2006, p. 20.
[589] Health minister speech, Forum Coalition priorité cancer, April 22 2005.
[590] Health minister speech, Forum Coalition priorité cancer, April 22 2005.
[591] DLCC. Rapport d'activité 2005-2006, p. 21.
[592] DLCC. Rapport d'activité 2005-2006, pp. 20-21.
[593] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, April 11, 2007.
[594] PQLC, 1998, p. 99.
[595] Bulletin SGAS Fall 2001.
[596] Bulletin SGAS Spring 2004.

for defining waiting time intervals and for defining medically acceptable waiting times.[597] This classification scheme was approved by the Government's Radio-oncology Expert Committee, and validated by the College of Physicians. The system allows the Health Ministry to assess the impact of measures to reduce waiting times, and offers valid data for planning.[598] The SGAS system now compiles a weekly list of medically ready to treat patients awaiting radiotherapy treatment, which provides the necessary data to the Health Ministry for the public posting of waiting time (see service performance tracking below).

- The *système d'information sur le mécanisme d'accès aux services spécialisés* (SIMASS) is similar to SGAS, without the clinical information part. Such system will be progressively implemented to harmonize the management of hospitals' elective surgery waiting lists. It is planned that the management of elective cancer surgeries (according to a waiting time target under assessment) will be part of this system.[599]
- The ongoing *Plan d'informatisation du réseau de la santé et des services sociaux* (2004) aims to improve the quality, accessibility and continuity of health and social services provided to the population in every region.[600] The plan is to be implemented over 2005-2010 and includes a number of projects seeking to better integrate available health information or to improve accessibility and continuity of available services.[601]
- The *dossier santé* (electronic health record) is a central aspect of the *Plan d'informatisation*. This electronic health record will comprise main health information on Québec residents who have given their consent, to be used only by authorized health professionals.[602] The following applications will result from this electronic health record: (1) The service québécois d'information sur les médicaments (SQIM); (2) Systèmes d'information sur les résultats de laboratoire; and (3) The répertoire d'imagerie diagnostique (RID/PACS).
- The *Systèmes d'information sur les résultats de laboratoire* is among the various projects to result from the *Plan d'informatisation du réseau de la santé et des services sociaux*. This project seeks to develop a provincial strategy for collecting, storing and retrieving laboratory information by health professionals.[603]
- *Répertoire d'imagerie diagnostique (RID/PACS)* is also among the various projects to result from the *Plan d'informatisation du réseau de la santé et des services sociaux*. This project will first allow health professionals to access results from diagnostic imaging stored in regional conservation sites with the consent of the patient. Ultimately, all relevant imaging data should be accessible and be part of the electronic health record.[604]

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[597] La gestion de l'accès aux services en radio-oncologie : pour une approche systématique. Énoncé de position du Collège des médecins du Québec. Novembre 2004

[598] Turgeon L and Gagnon M. Utilisation du logiciel SGAS pour la gestion des files d'attente en radio oncologie au Québec. March 31, 2005. Powerpoint presentation at the Canadian Policy research network symposium on the management of waiting lists. Available at:

[599] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, April 11, 2007.

[600] MSSS. Plan d'informatisation du réseau de santé et des services sociaux. Présentation générale, March 2004. Available at: http://msssa4.msss.gouv.qc.ca/extranet/ri.nsf/49dd266bd183416e852566e2005c98b6/7d0dabe970f8b1188525714e0067bb91/$FILE/Plan%20informatisation%20-%20Presentation%20generale_V1.1.pdf

[601] See MSSS webpage on Dossier santé at: http://msssa4.msss.gouv.qc.ca/fr/reseau/dossante.nsf/64497ed9fafde57b852569650051fb70/e47eec7f50a69328852571fb0067e140?OpenDocument

[602] MSSS. La circulation des renseignements de santé dans le contexte du plan d'informatisation du réseau de la santé et des services sociaux. Document d'information. Avril 2006.

[603] See MSSS webpage on Dossier santé at: http://msssa4.msss.gouv.qc.ca/fr/reseau/dossante.nsf/64497ed9fafde57b852569650051fb70/e47eec7f50a69328852571fb0067e140?OpenDocument

[604] See MSSS webpage on Dossier santé at: http://msssa4.msss.gouv.qc.ca/fr/reseau/dossante.nsf/64497ed9fafde57b852569650051fb70/e47eec7f50a69328852571fb0067e140?OpenDocument

2. Quality assurance and improvement:

Accountability agreements and performance contracts:

- Since 2000, a new management framework (Public Administration Act, 2000) obliges the Health Ministry to produce a multi-annual strategic plan, an annual expense management plan and an annual management report (*rapport annuel de gestion*). In 2001, important changes to the *Act respecting Health Services and Social Services* were made to institute results-oriented management within the health and social services network. These legislative changes oblige the regional authorities to prepare management and accountability agreements with the Health Ministry and to produce an annual management report. For their part, institutions must enter into a management and accountability agreement and produce an annual report.[605]

Accreditation procedures:

- All health facilities had until December 2005 to be registered to an accreditation program as stipulated since 2002 by the *Loi sur les services de santé et les services sociaux* (LSSSS). Such accreditation will have to be renewed every three-year. A sihgnificant number of health facilities are accreditated through CCHSA whose accreditation program includes oncology and palliative care.
- A ministerial accreditation process for palliative care hospices is being developed to foster a more homogeneous framework and process on the one hand and, on the other, so as to enable the resulting accredited community organizations to request financial resources from their regional health Agency for service provision as stipulated in LSSSS, art. 454.[606]
- A "designation" process for the formal recognition of local, regional and supraregional interdisciplinary cancer teams was undertaken in 2004 by the Ministry of Health and piloted by the *Groupe conseil de lutte contre le cancer* (GCLC). [607] The resulting designation is made by the relevant regional health authority (for local and regional teams) or the ministry (for supraregional teams) based on assessment reports produced by the GCLC following peer-review visits of teams and their host facilities. See shaded box on distinctive feature for more details.

Evidence-based clinical guidelines:

- *Comité de l'évolution de la pratique en oncologie* (CEPO): During 2005-2006, the CEPO published 10 clinical practice guidelines.[608] In addition, there is an ongoing project conducted in partnership with France's FNCLC (*Fédération nationale des centres de lutte contre le cancer*) to adapt evidenced-based guidelines to the Québec context.
- *Comités de thérapie du cancer* (CTC): Groups of oncology specialists responsible for the continuing education of interdisciplinary cancer teams and the promotion of evidence-based pratice. [609] These groups, which will be closely linked to regional and supraregional interdisciplinary cancer teams, are being progressively put in place. At the regional level, a minimum of one CTC per region must be set up in order to provide continuing cancer care education to local interdisciplinary teams and other

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[605] MSSS. Report on the progress made regarding the bilateral agreement entered into during the federal-provincial-territorial meeting of the first ministers on health, September 2004. Released in October 2005, p. 27. Available at: http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2005/05-720-01F

[606] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, March 1, 2007.

[607] DLCC. Rapport d'activité 2005-2006, pp. 11-12.

[608] DLCC. Rapport d'activité 2005-2006, p. 19.

[609] DLCC. Le réseau de services intégrés de lutte contre le cancer (internal document), 2006. See also MSSS. Direction générale des services de santé et médecine universitaire. Comité aviseur (N. Lefebvre, chair). Le continuum de services pour les personnes atteintes de cancer et leurs proches : paramètres d'organisation. Programme québécois de lutte contre le cancer. April 2004, p. 37.

primary care professionals.[610] At the supraregional level, CTC must be organized along cancer sites and should be viewed as a tool for quality assurance.

- Following a recommendation stipulated in the 2004 Ministerial Cancer Working Group Report, an oncology assessment unit was created at the *Agence d'évaluation des technologies et des modes d'intervention en santé* to consolidate existing and new assessment activites in this field, and to strenghten collaborations with health professionals in the health and social services network.[611]

Patient participation:

- The 2004 report on the continuum of services for cancer patients and their family recommended that mechanisms be set up to promote cancer patients' involvement in cancer services improvements. Mechanisms proposed included forum and representation of cancer patients in Regional cancer committees.[612]
- Some health facilities have patient committees, but there is no formalisation of patient participation linked to the above-mentionned recommendation. Patients' experience along the cancer care trajectory will be taken into consideration through a survey designed for quality improvement (in development).[613]

Professional training and certification:

- In 2005, the DLCC, in collaboration with a group of expert nurses, created a training program providing the minimal requirements for nurses working within a cancer interdisciplinary team. Regional Agencies and facilities are responsible for ensuring that all *infirmières pivots en oncologie* ("enhanced" patient navigators) are meeting these requirements. The 84-hour training program covers three modules: (1) The role of the "enhanced" patient navigator within the cancer interdisciplinary team, (2) Clinical and practical knowledge for patient information and symptom assessment, and (3) The intervention in the context of loss, bereavement and palliative care. Four training sessions were organized by the Health Ministry in 2005-2006, which resulted in the creation of 84 new "enhanced" patient navigators.[614]
- Annual meetings and forums organized by the cancer governing bodies (CQLC, CCLCQ and DLCC) serve as continuous medical education for health professionals.

Service delivery standards:

- The PQLC, CQLC guidances, and 2004 Advisory Committee report on the Continuum of Cancer Services included multiple recommendations relating to service delivery standards, including levels of services and team composition, according to the local, regional and supraregional mandates.
- The government White Paper, entitled *Garantir l'accès : un défi d'équité, d'efficience et de qualité,* which is now part of the *Loi sur les services de santé et les services sociaux,* stipulates waiting times targets for radiation therapy.
- Norms for peadiatric palliative care were published in 2006 by the DLCC.
- INSPQ conducted a review of palliative care services and resources in Québec. The first part of this project was published in 2006 and comprised a series of indicators for the adult population, among

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[610] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, April 11, 2007.

[611] AETMIS. Rapport annuel de gestion 2005-2006. p. 9.

[612] MSSS. Direction générale des services de santé et médecine universitaire. Comité aviseur (N. Lefebvre, chair). Le continuum de services pour les personnes atteintes de cancer et leurs proches : paramètres d'organisation. Programme québécois de lutte contre le cancer. April 2004, p. 33.

[613] Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, April 11, 2007.

[614] DLCC. Rapport d'activité 2005-2006, p. 12.

which some could be used to track progress regarding the coordination and continuity of palliative care services.[615]
- Optimal access trajectories are being defined for specific cancer sites by the DLCC and waiting times for access to services will be defined by the DLCC in 2006-2007, including emergency criteria.[616]

Service redesign initiatives:

- There are ongoing initiatives in some regions to map cancer patients' trajectories of care in order to identify service improvement opportunities. For example, the regional Agency for the Mauricie et Centre-du-Québec region is conducting *suivi systématique de clientèle* projects (follow-up of patient care episodes within the context of an integrated care pathway) for breast cancer patients among others.[617] The regional Agency for the Montérégie region published regional guidelines based on an analysis of a typical cancer control trajectory that includes prevention, treatment and support. The analysis included the identification of strenghts and weaknesses in the quality and accessibility of services, as well as gaps in service continuity, to allow for the identification of action items associated with significant health impact.[618]

Service performance tracking:

- Waiting times for radiation therapy are being tracked by the SGAS system and posted on the government's website. For each of the 11 centers providing radio-oncology services, the following information is posted: a) the number of patients waiting for more than 4 weeks; b) the proportion of patients that began their treatment within 4 weeks; c) the number of patients who received treatments over the last two fiscal years.[619]
- INSPQ is examining the relevance, performance and viability of organized screening programs in a variety of fields including cancers. Three types of cancers are included in their assessments: cervical, colorectal and prostate cancers. INSPQ is assisting the Health Ministry on various aspects of cancer early detection and cancer care trajectories including: (1) strategies to improve the percentage of women undergoing a PAP test; (2) clinical approaches, information needs, costs, and quality assurance to support an organized colorectal screening program; (3) assessment of care trajectories and adherence to clinical practice guidelines regarding prostate cancer.[620]
- Precise information concerning patient waiting times for access to oncology surgeries will be obtained from most institutions in Québec through the new SIMASS system, to be deployed in 2007. The waiting time has been defined as the period between the date the patient is deemed medically ready to undergo surgery and the actual date of surgical treatment. The proposed waiting time target for elective surgery is that 90% of ready to treat patients will be treated within four weeks for all types of cancer.[621]

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[615] INSPQ. Soins palliatifs de fin de vie au Québec : définition et mesure d'indicateurs. Partie 1 : Population adulte (20 ans et plus), March 2006.

[616] DLCC. Rapport d'activité 2005-2006, p. 27.

[617] Danièle Hubert (ADRLSSSS de la Mauricie et Centre-du-Québec). Le SSC : De la théorie à la pratique en GMF. Powerpoint presentation. 2007. Available at: http://www.agencesss04.qc.ca/autre/journee%20gmf/Suivi%20systematique.pdf

[618] ADRLSSSS de la Montérégie, Direction de la gestion de l'information et des connaissances. Le Continuum d'intervention « Lutte contre le cancer » June 2005, 30 pages. Available at : http://www.rrsss16.gouv.qc.ca/continuums/continuum7.htm

[619] See MSSS webpage on Access to specialized medical services / cancer/ radio-oncology/ health region where the service is provided. Available at: http://wpp01.msss.gouv.qc.ca/appl/g74web/Resultats.asp

[620] INSPQ. Programmation 2005-2008. pp. 96-97.

[621] See MSSS webpage on Access to specialized medical services / cancer/ oncology surgeries. Available at: http://wpp01.msss.gouv.qc.ca/appl/g74web/Oncologie.asp

9.4.4 Distinctive feature

The selected distinctive feature of Québec cancer control system is the designation process for interdisciplinary cancer teams and their host facility, which serves both as an educational/training process for service providers/health facility administrators, and as an incentive for the implementation of the PQLC throughout Québec.

Distinctive feature – Québec

Designation of interdisciplinary cancer teams

In November 2004, the *Direction de lutte contre le cancer* (DLCC) mandated the *Groupe conseil de lutte contre le cancer* (GCLC) to : 1) assess the state of development of the cancer control program in all facilities throughout Québec ; (2) to develop an assessment questionanire and process for the designation of local, regional and supraregional interdisciplinary cancer teams/host facility ; and (3) to set up a number of oncology expert groups that would conduct the peer-review visits and assessments of candidate teams/facility as a prerequisite for a formal "cancer control" designation, to be delivered by the relevant regional Health Agency (for local and regional teams) or by the Ministry (for supraregional teams). [622,623, 624]

The assessment questionnaire (*matrice d'évaluation des équipes interdisciplinaires/établissement*) was the tool developed by the GCLC to foster the adoption of the organisational model and quality criteria set forth in the PQLC.[625] Candidate teams and their host facility that had been proposed by their respective regional Health Agency were given the assessment questionnaire to fill in to prepare for their peer-review assessment visit. Assessment visits of local and regional teams/host facility began in April 2005, while visits of supraregional teams and their host facilities began in October 2006.

The assessment visit, which would last a whole day, includes the following: (1) a review of the assessment questionnaire and relevant documentation by the visiting independent expert group along with the candidate team; (2) a visit of the relevant clinics and informal exchanges; (3) a patient pathway analysis exercise; and (4) the write up in camera, by the visiting independent expert group, of an assessment report that summarizes the main findings, team/facility strengths and weaknesses, and experts' recommendations. Based on this report, the GCLC then recommends a designation status for the visited team/facility to the regional health agency.[626]

Four types of designation status could be attributed depending on the resulting assessment: [627, 628]

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[622] DLCC. Rapport d'activité 2005-2006, p. 11.

[623] Jean Latreille (GCLC) Évaluation des équipes interdisciplinaires et des établissements – Processus et impact. Powerpoint presentation, DLCC meeting. December 2006.

[624] MSSS. PQLC – Matrice d'évaluation des équipes interdisciplinaires /établissement (internal document) September 2005. See annexe I for the exact terms of the mandate.

[625] MSSS. PQLC – Matrice d'évaluation des équipes interdisciplinaires /établissement (internal document) September 2005. The framework was based on the PQLC (1998) and on the MSSS report on the continuum of cancer services (2004), which form the cornerstone of the organizational vision and quality criteria for cancer control services.

[626] Jean Latreille (GCLC) Évaluation des équipes interdisciplinaires et des établissements – Processus et impact. Powerpoint presentation, DLCC meeting. December 2006.

[627] Jean Latreille (GCLC) Évaluation des équipes interdisciplinaires et des établissements – Processus et impact. Powerpoint presentation, DLCC meeting. December 2006.

[628] DLCC. Rapport d'activité 2005-2006, p. 11.

(1) ***Designated*** (the regional health agency is then responsible for following up on the team that should, within a year, meet the assessors' recommendations);
(2) ***Designated with conditional standing*** (the regional health agency is then responsible for following up on the team that should, within a year, meet the assessors' recommendations, and for deciding after that year if designation should be maintained);
(3) ***Designation to be determined*** (a designation status (either 1 or 2 above) will be granted provided the assessors' recommendations are met by the team/facility within a year); and
(4) ***Not designated*** (the team must follow up on the assessors' recommendations prior to resubmitting its proposal).

As of December 2006, 60 teams/facilities had been visited for a local designation, 8 for a regional designation, and 6 for a supraregional designation. As a result of the peer-review visit process and assessment reports, the GCLC recommended to the regional health agencies that the following number of teams be granted the following statuses: (1) Designated (local n=21; regional n=3); (2) Designated with conditional standing (local n=21; regional n=5); (3) Designation to be determined (local n=8); and (4) Not designated (local n=10).[629]

The assessment of interdisciplinary cancer teams is conceived as an evolving process that entails two main phases. The first phase focuses on the the setting up of the required structures (cancer committees, cancer teams, clinical and management leaderships, dedicated resources, referring protocols, quality assurance initiatives, etc.), while the second phase (to begin three years after the first designation round) will focus on the functioning of designated cancer teams and the impact of interdisciplinary work on the quality of cancer services (access, continuity of care, etc.) in each facility.[630]

The assessment of interdisciplinary cancer teams and their host facility is the strategy chosen to motivate change toward the development of the cancer control program in all health facilities throughout Québec. Such strategy must be conceived as the first step for the local implementation of the PQLC, along with the setting up of local (territorial) and regional cancer programs, such as the *projets-cliniques* devoted to cancer control (local network cancer control programs) being developed in each of the 95 *Réseaux Locaux de Santé*.

Other unique/exemplar features:
(1) *Infirmière pivot en oncologie* ("enhanced" patient navigator); (2) SGAS; (3) Network of hotel accomodation.

9.5 IMPACT

In this Section, we endeavor to provide a descriptive overview of the existing literature that has either examined the progress of Québec in meeting program goals and targets, or assessed program impact. By that we mean available documents that provide information on the effects of cancer control programs, which are usually characterized in relation to intended outcomes. Outcomes may be classified as process outcomes and health outcomes. A process outcome may include, for example, reduction in waiting time, increased participation rate to a screening program, raising awareness about cancer care and treatment, and patient satisfaction with service

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[629] Jean Latreille (GCLC) Évaluation des équipes interdisciplinaires et des établissements – Processus et impact. Powerpoint presentation, DLCC meeting. December 2006.
DLCC. See also Rapport d'activité 2005-2006, p. 12.

[630] MSSS. PQLC – Matrice d'évaluation des équipes interdisciplinaires /établissement (internal document) September 2005.

delivery. A health outcome may include reduction in smoking prevalence rates, reduction in cancer incidence and mortality rates, as well as increases in survival rates. Included in this overview are reports stemming from independent bodies (when available) and from organizations that have the mandate to monitor or implement the cancer program or action plan.

Jurisdictions can be distinguished according to whether or not they have stipulated specific timelines for the achievement of their cancer plan's goals and targets. In Québec, while the PQLC does not specify a timeline for implementation, the most recent DLCC five-year action plan (2007-2012) does.

For now, no independent assessment of the PQLC is available at the provincial level, whether in terms of its implementation progress or in terms of its effects on the quality of services and health outcomes. A proposal was submitted by the DLCC to the Ministry of Health and Social Services in December 2004 to mandate INSPQ for assessing the implementation of the PQLC.[631] INSPQ has conducted a number of assessments related to cancer control, namely regarding the breast cancer screening program and the *Fichier des tumeurs* (see appendix 9A for a list of relevant INSPQ documents).

Monitoring the implementation process

Progress in cancer control at the provincial and regional levels are documented in the *Rapports annuels de gestion* produced by the Ministry of Health and Social services, as well as in the annual activity report of the DLCC (since 2005). A detailed description of all the regional initiatives in cancer control was produced by the CCLCQ in 2003, and one study assessed the development of an integrated regional cancer network.[632] Additionnal information can also be found in the following reports:

1. INSPQ et MSSS. Portrait de santé du Québec et de ses régions 2006.
2. Canadian Cancer Statistics 2006
3. MSSS. Report on the progress made regarding the bilateral agreement entered into during the federal-provincial-territorial meeting of the First Ministers on health, September 2004 (October 2005).

Ongoing projects, mandated by the DLCC in 2005, include: (1) an assessment, by the *Direction de l'évaluation*, of the interdisciplinary cancer teams designation process; and (2) the development, by the *Direction des études et des analyses*,[633] of a national survey of cancer patients to assess the quality of cancer services along the cancer control continuum.[634]

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[631] See INSPQ webpage titled: Nos activités en…/ habitudes de vie et maladies chroniques/ lutte au cancer. Available at: http://www.inspq.qc.ca/domaines/index.asp?Dom=40&Axe=45

[632] Roberge D, Denis J-L, Cazale L, Comtois E, Pineault R, Touati N, Tremblay D. Évaluation du réseau intégré de soins et de services en oncologie : l'expérience de la Montérégie. Fondation canadienne de la recherche sur les services de santé, 2004.

[633] This ministerial branch as well as the Direction de l'évaluation are both part of the Direction générale de la planification stratégique, de l'évaluation et de la gestion de l'information.

[634] DLCC. Rapport d'activité 2005-2006, p. 21 ; Personnal communication, Dr Antoine Loutfi, Québec Cancer Director, April 11 2007.

Impact: Process outcomes

Since 1998, important efforts were made to reduce tobacco use, yielding a significant decline in tobacco smoking rates, from 30 % among 15+ in 1999 to 25 % in 2003 and to 22% in 2005.[635] Compared to the Canadian average of 19%, the actual rate in Québec is the highest in Canada, along with three other provinces (New Brunswick, Manitoba and Saskatchewan).[636] The goal is to decrease the proportion to 18% by 2012.[637]

As regards screening, the government's *rapport annuel de gestion* 2005-06 indicates that by March 31st 2006, the participation rate to organized breast cancer screening program was 49,4%, a slight increase from 47,9 in 2004-05.[638] The year 2005 was the first time where the PQDCS had been available for 24 months in the Terres-Cries de la Baie James and hence in all 18 sociosanitary regions. Since the launch of the PQLC in 1998 there were always important variations in the participation rate among the regions. In 2005 the lowest rate was 36% in the Montréal region, while the highest rate was 81,2% in the Terre-Cries de la Baie James region.[639] The mean rate of 49,4% is lower than the internationally advocated rate of 70%, which is also the PQDCS set target. The PQDCS has still many challenges to face, including a high rate of referral for investigation and a long time interval between the screening exam and the diagnosis. These concerns have called for the strenghtening of quality assurance measures.[640] As for cervical cancer, there is no organized screening program in Québec. The proportion of women that underwent a PAP test in the last three years fell from 76% (1999) to 71% (2003) to 68.5% (2005).[641]

In February 2006, Québec Prime Minister and the Minister of Health and Social Services announced wait time targets for radiation therapy (90% of cancer patients to wait less than 4 weeks).[642]Although this target does not reflect a direct alignment with the 2005 pan-canadian benchmark that resulted from the 2004 federal-provincial-territorial meeting of the first ministers on health, [643] it underscores the Québec strong commitment to deal with the issue. Indeed, concerted efforts were made over the least few years to curb delays in radio-oncology. Hence, as

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[635] According to the Canadian Tobacco Use Monitoring Survey, Annual results 1999-2005. Available at: http://www.hc-sc.gc.ca/hl-vs/tobac-tabac/research-recherche/stat/ctums-esutc/prevalence/prevalence_e.html

[636] According to the Canadian Tobacco Use Monitoring Survey for February-December 2005.

[637] Leduc S. (Direction de la santé publique) La santé publique et la lutte contre le cancer des actions sur le terrain. Powerpoint presentation at the Congrès annuel de la Direction de la lutte contre le cancer, December 1, 2006.

[638] MSSS rapport annuel de gestion 2005-2006 du ministère de la santé et des services sociaux, p. 49. Available at : http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-102-01.pdf

[639] PQDCS rapport d'activité 2004-2005. Available at: http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-204-04.pdf

[640] See Avant-propos p, 3. In : PQDCS rapport d'activité 2004-2005. Available at: http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-204-04.pdf

[641] Leduc S. (Direction de la santé publique) La santé publique et la lutte contre le cancer des actions sur le terrain. Powerpoint presentation at the Congrès annuel de la Direction de la lutte contre le cancer, December 1, 2006

[642] Garantir l'accès: un défi d'équité, d'efficience et de qualité. Le premier ministre Jean Charest et le ministre Philippe Couillard annoncent des cibles d'accès aux services médicaux spécialisés. Fondation québécoise du cancer. 16 février 2006.

[643] In contrast to the other Canadian provinces which must conform to the pan-canadian benchmark in order to receive the associated federal funding, Québec is under an asymetrical federalism clause that allows the province to get its share of the funds while retaining autonomy in the setting of its own priorities in health.

of March 31 2006, there were 721 patients waiting for radiation therapy, among which 59 had been waiting for more than 4 weeks and only 1 for more than 8 weeks.[644]

Impact: Health outcomes

In 2006, Canadian Cancer Statistics estimated that in 2006, more than 38 300 Québecers will be diagnosed with cancer, and 19 000 will die from it. Since 2000, cancer is the first cause of death in Québec.[645] According to the latest statistics, at least 1 person in 3 will develop cancer in their lifetime and 1 in 4 will die from it.[646] The CSCC business plan estimated, based on the 2006 Canadian Cancer Statistics Report, that Québec had a 23% increase in new cancer cases between 1996 and 2006.[647]

In comparison with 21 OECD countries for overall cancer mortality rates in 1996-1998, Québec ranked 20th among men (286/100,000) and 17th among women (171/100,000).[648] A similar comparison in 2001 with 15 OECD countries showed that Québec ranked below the US (169/100,000), France (174/100,000), Canada (174/100,000) and the UK (183/100,000) with a rate of 192/100,000.[649] The Conference Board of Canada Report[650] concluded that among the 10 Canadian Provinces, Québec had:

- The highest male incidence rate for lung cancer and highest female rate, tied with Manitoba
- The highest incidence rate for female breast cancer
- The highest male mortality rate for lung cancer, and second highest female rate after Nova Scotia
- The highest female mortality rate for colorectal cancer and second highest male mortality rate after Newfoundland and Labrador
- The lowest share of women who have had at least one Pap smear test in the past three years.

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[644] DLCC. Rapport d'activité 2005-2006, p. 13.

[645] INSPQ. Portrait de santé du Québec et de ses régions 2006. Deuxième rapport national sur l'état de santé de la population du Québec. Les analyses, p. 47.

[646] Canadian Cancer Society – Québec division. Annual Report 2005-2006, p.2. Available at: http://www.cancer.ca/vgn/images/portal/cit_86751114/1/45/1053331764qc_rapportannuel2006-en.pdf

[647] Canadian Strategy for Cancer Control. 2006-2010 Business Plan for the CSCC, p. 7.

[648] CCLCQ 2003 assessment, p. 21.

[649] INSPQ. Portrait de santé 2006, p. 48.

[650] Conference Board of Canada. Healthy Provinces, Healthy Canadians. A Provincial Benchmarking Report, February 2006. Available at: http://www.conferenceboard.ca/documents.asp?rnext=1533

Appendix 2A -- Interview guide

PART A: Organization and financing of cancer program

Purpose: to describe key organizational features, governance, extent of integration and method of designating specialist teams/institutions.

1. What were the key dates/milestones in the development or evolution of the cancer program in your jurisdiction?
    - *significant events*
    - *obstacles and enabling factors*

2. Do you believe that there is a clear and common vision for the cancer program?
    - *developed by whom?*
    - *underlying values/principles – articulated?*
    - *examples of how manifested in practice?*

3. Describe the governance structure for cancer care.
    - *overall governance structure; accountability – e.g. national strategy/coordinating council*
    - *who makes strategic decisions; are these decisions binding?*

4. Describe the main organizational features of the cancer program:
    - *institutions and professionals providing cancer care*
    - *role of community-based organizations*
    - *prevention and screening activities*
    - *links between primary-secondary-tertiary care*
    - *mechanisms for including patient 'voice'*
    - *any unique distinguishing features – examples of best practice?*
    - *what proportion covered by: public vs private insurance, out-of pocket elements?*

5. To what extent is delivery of care integrated ?
    - within organizations – *case management; multidisciplinary teams*
    - between organizations – *referral guidelines/protocols; care/case manage-ment*
    - amongst professionals – *team work, nurses role*
    - between specialities – *paediatrics vs. adult services; prevention vs. care*

6. How is the budget for cancer care allocated in your jurisdiction?
    - *global budget from MoH?*
    - *contributions from other ministries, sources?*
    - *how are changes in operating/capital expenditures approved and financed?*
    - *comparability with other programs of similar size?*
    - *relative priority with other health care programs?*

7. To what extent do patients have choices about their care in terms of:
    - *place of care (hospital; community; home)*
    - *providers of care (individual physician, local vs. specialist hospital)*
    - *time of care (waiting lists?)*

8. Are there (explicit or implicit) criteria for the designation of institutions and professionals as specialist cancer care providers?

- *if yes, what has been the experience of implementing these criteria?*
- *consideration of volume-outcome relationship in designating specialist providers?*
- *written documentation?*

9. To summarize, would you describe the organization of care in your jurisdiction as:

- *highly organized - medium/average - low or disorganized ?*

PART B: Evidence base and knowledge transfer

Purpose: to understand the scientific basis for decision-making, particular initiatives in quality assurance and research, the development and dissemination of clinical guidelines.

10. What do you think are the key sources of 'evidence' that influence policy-makers regarding the organization and delivery of cancer care?

- *scientific evidence; professional consensus; public preferences; lobby groups; opinions leaders*
- *academic institutions, research agencies, professional advice/consensus, public input*
- *relative strength of influence*
- *evidence of performance against objectives – any systematic evaluation of adopted model of care?*
- *assessment of impact of strategy/policy*

11. What mechanisms are in place to monitor and evaluate system performance and the quality of care?

- *routine and ad hoc mechanisms*
- *involvement in clinical audit ;measurement of outcome?*
- *accreditation processes*
- *routine information systems (e.g. registers, audit)*
- *involvement in other forms of program evaluation*

12. Is there a coordinated (national) cancer care research program; identified priorities?

- *leadership?; relationship to program delivery*
- *dissemination mechanisms to influence policy and practice?*

13. Who is responsible for developing clinical guidelines for cancer care and how are they developed?

- *e.g. tumour groups*
- *use of information systems/clinical database*
- *statistics/audit mechanisms?*

14. How are guidelines disseminated to clinicians?

- *key mechanisms for knowledge transfer – e.g. CME, opinion leaders, decision aids*
- *evidence of what works in your area?*

PART C: Perceptions regarding current issues

Purpose: to obtain leaders' perceptions about examples of good practice, major achievements, key challenges, and areas for improvement .

15. From your perspective, what is working particularly well in the organization and delivery of cancer care services in your jurisdiction?
    - *patient care (quality, integration, continuity of care)*
    - *professional roles/relationships*
    - *overall organisation and management – major achievements?*
    - *assessing quality of care (information/evaluation)*

16. With respect to the organization of care, what could be improved?
    - *major challenges*
    - *issues of access, distribution, efficiency of service delivery*
    - *waiting times – are there published standards; rationale; copy of written guidance*

PART D: Plans for development and implementing change

Purpose: to describe priorities for development, relative importance of national vs. local priorities, key constraints and facilitators in implementing change, and lessons for others.

17. From your perspective, what are the top 3-4 priorities for development/reform?
    - *why .. related objectives?*
    - *extent to which vision/strategy has been implemented*
    - *relative priorities(national VS local);role of national strategy in supporting for local/regional strategies*
    - *for Canadian jurisdictions only: progress on Canadian strategy (governance, prevention, rebalancing resources, human resources development, research);*

18. What have been the key constraints or barriers to implementing change?
    - *strategies adopted to reduce/manage barriers*

19. What have been key facilitators for implementing change?
    - *major achievements and facilitating factors?*
    - *examples of effective levers for change*
    - *role of national/regional strategy – role as an instrument in supporting change?*

20. From the experience in your jurisdiction, what lessons would you offer to others in implementing an effective cancer care program?

21. Can we contact you again to obtain further details on anything we discussed? Y / N

- Further contacts suggested for follow-up:
- Supporting documents and materials:

Appendix 3A -- Frameworks in the literature

1. Donabedian's Structure-Process-Outcome (SPO) framework[651,652,653]

The S-P-O framework is informative insofar as it focuses attention on how care is delivered in health care settings and the interrelatedness among the structure, process, and outcomes of care. These three indicators provide the evidence one needs to determine whether what is known or accepted to be the best care is being implemented in the most skillful way.

The structure indicator refers to attributes of settings wherein care is delivered. This includes: (1) material resources such as facilities, equipment, and money; (2) human resources such as the number and qualifications of personnel involved in the delivery of care; and (3) organizational structure such as medical staff organization, methods of peer review, and methods of reimbursement. The process indicator denotes evidence of what is being done for the patient. It includes those activities carried out by the providers of care such as making diagnosis, recommending, and implementing treatment. It also makes reference to the receiving end of care by the patient. It therefore includes those activities sought and carried out by the patient. The outcome indicator refers to the effects of care on the patients' health status as well as satisfaction with the care received. This would also include improvements in the patient's knowledge and lifestyle.

Good structure is expected to increase good process, which in turn increases good outcomes. Indicators of structure, process, and outcome ought to be considered when undertaking an assessment of a particular care strategy. This would then allow compensation of weaknesses in one indicator by the strengths in the others. It further helps one interpret the findings. For example, confidence in the validity of inferences drawn about a particular care strategy is increased when there if agreement in the inferences drawn from several types of indicators. If there is disagreement, this may indicate the presence of problems such as data were incomplete or inaccurately measured as well as the possibility that outcomes were measured at the inappropriate time frame or in an insufficient number of cases[654].

Attributes of quality that should be considered when the S-P-O framework is applied to improve care include:

- *Efficacy*: ability of the health care to bring about improvements. It signifies the best that an intervention can do, under the most favorable condition, given the patient's condition, and unalterable circumstances
- *Effectiveness*: degree to which the care whose quality is being assessed attains the level of health improvement that studies of efficacy have established as attainable.
- *Efficiency*: measure of cost at which any given improvement in health is achieved
- *Optimality* refers to the effects of care relative to the cost of delivering such care

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[651] Donabedian A. Evaluating the quality of medical care. 1966. Milbank Quarterly, 2005; 83(4):691-729; Donabedian A. The quality of care. How can it be assessed? JAMA, 1988;260(12):1743-8.

[652] Donabedian A. The seven pillars of quality. Arch Pathol Lab Med 1990;114:1115-1118.

[653] Donabedian A. The role of outcomes in quality assessment and assurance. QRB 1992:356-360.

[654] Donabedian A. (1992); p. 360

- *Acceptability*: adapting care to the wishes, expectations, and values of patients and their families
- *Accessibility*: ability of care to be easily and conveniently obtained by patients when needed
- *Legitimacy*: acceptability of care to the community and to the society at large
- *Equity*: what is just or fair in the distribution of care and its benefits

2. WHO Innovative Care for Chronic Conditions (WHO-ICCC) framework[655]

The WHO-ICCC framework is advanced as a comprehensive approach to updating health care to meet the needs of individuals living with chronic conditions. Innovative care refers to the need to re-orient health care systems so that the outcomes valued by the system are those that are more in line with the needs of patient with chronic conditions. Patients with a chronic condition[656] need broader support than the type of care that is necessary for acute problems. Such patients need more than biomedical interventions: They need integrated care that cuts across time, settings, and providers. Patients, along with their family further need support within their communities and support from boarder policies to effectively manage their condition. Patients, communities, and health care organizations each play a vital role in improving outcomes in chronic conditions.

The WHO-ICCC framework is therefore founded on the notion that optimal outcomes occur when a health care triad is formed. This triad is represented by a partnership among patients and families, health care teams, and community supporters. The triad is influenced and supported by the larger health care organizations, the broader community, and the policy environment. Patients and families as well as the health care teams and community supporters are at the micro-level of health care systems. The health care organization and the boarder community are at the meso-level, with the policy environment at the macro-level. Each of these levels interacts with and is influenced by the other two. Although the WHO_ICCC framework delineates between these components of the health care system that feed into outcomes, it is clear that in reality the lines are often blurred. An example offered by the WHO illustrates this point: Lack of efficient training could be considered a micro-level problem because it affects patients. It could also be viewed as a problem at the meso-level because it lies with the health care organization to ensure providers have proper training. Alternatively, one can conceive this problem to stem from the macro-level as policies could be instated to affect medical training or encourage continued training to meet population demands.

The WHO-ICCC framework is an expansion of the Chronic Care Model (CCM),[657] which was developed to offer a structure for managing health care for chronic conditions. Within the CCM, greater attention was placed upon those indicators within the health care setting as well as the actions of patients to bring about desired outcomes, and less upon the boarder community and political setting. Within the WHO-ICCC framework, the policy environment is recognized for its role in legislation, leadership, policy integration, partnerships, financing, and allocation of human

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[655] World Health Organization. Innovative Care for Chronic Conditions: building blocks for action; global report. WHO Geneva, 2002.

[656] Through this report the term ‘condition’ is used interchangeably with either ‘disease’ or ‘illness’

[657] Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. Milbank Quarterly. 1996;74(4):511-44

resources. These indicators are what allow communities and health care organizations to help patients and families optimally manage chronic conditions.

The components within each of the levels are viewed as building blocks that can be used to create or redesign a health care system that can more effectively manage chronic conditions Decision makers and other leaders in health care are viewed as being able to initiate changes; albeit the involvement of individuals within each level of the triad would be beneficial. Changes should be implemented where feasible among the levels of the system, with changes being supported with the addition of more targeted components within the triad over time. The WHO-ICCC framework is guided by the following principles, which are viewed as fundamental to the different levels of the health care system:

- *Evidence-based decision-making*: use of evidence-based information to guide decision making, thereby optimizing the care for chronic conditions
- *Population focused*: prioritizing the health of a defined population rather than the single unit of a patient seeking care, thereby reducing the need for high cost, high intensity resources
- *Prevention focus*: include prevention support in every health care interaction, which would include promoting prevention in health care, the commitment and action of the health care organization, community, and government
- *Quality focus*: proper use of resources, the accountability for providing effective and efficient care, and ensuring the best possible patient outcomes given any limitations.
- *Integration*: merging of multiple perspectives emulating from the different levels of the health care system-micro, meso, and macro- thereby ensuring that all individuals work together and share in the goal of better care for chronic conditions
- *Flexibility/adaptability*: ability of a health care system to tolerate transitions as in political leaders, respond flexibly to changing health care demands, and remain robust in the facing of unexpected economic downturns

3. WHO framework for a National Cancer Control Program (WHO-NCCP) [658]

The WHO-NCCP framework emphasizes a systemic and a comprehensive approach by governmental and nongovernmental bodies acting in partnership. The framework is designed to reduce the incidence of cancer, reduce the mortality of cancer, and improve the quality of life of cancer patients. This purpose is accomplished through a systematic and equitable implementation of key evidence-based strategies targeting prevention, early detection, treatment, and palliative care. The framework posits that a cancer control program must be integrated with other health programs, which are linked to the health system and are tailored to the board social (political and medical) context.

Juxtaposed onto this framework is a ‘systems’ view of the program implementation with attention to the inputs, processes, outputs, and outcomes. The input refers to the resources needed to run the program. The term resources is used in a board sense, implying people, staff, finance, facilities, techniques, methods, among others. The process aspect of implementation refers to the means by which the services will be delivered, whereas the output refers to the direct products of

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[658] Available in: WHO. National Cancer Control Programmes. Policies and Managerial Guidelines, 2nd Edition, WHO Geneva, 2002, 203p. Available at: http://www.who.int/cancer/media/en/408.pdf

the activities implemented. Finally, outcomes refer to the actual measured impacts of the services on individuals who have received the services or who have participated in the program.

The planning and implementation processes advocated within this framework is adopted from the USA Division of Cancer Prevention and Control's framework (later described) and involves a series of planning stages or phases that involve the active participation of all stakeholders. The phases are presented in a circular fashion to underscore the continuous exchange of information for adequate decision making. Effective decision making, as described by the WHO, involves making the best use of available resources to guarantee sustained progress. Decision making therefore rests with competent management, comprising a strong leadership team, guided by a program coordinator; a board of the cancer control program; and a network of local coordinators, backed up by local leaders.

The WHO-NCCP framework further posits that a quality management approach, shared by all stakeholders, is essential to improving the performance of a cancer control program. This approach is guided by 7 principles:

- *Goal orientation*: the process involved in continual improvement in health and quality of life of those targeted by the program
- *Focused on the needs of the people*: focus on the target population, while addressing the needs of all stakeholders to ensure their continued involvement
- *Systematic decision-making process*: the use of evidence, attention to social values that apply to the majority of the target population as well as the efficient use of available resources
- *Systemic and comprehensive approach*: linking a cancer control program to other health programs, both of which are subsequently linked to the broad health system and tailored to the social context
- *Leadership*: creating a clear and united purpose, encouraging team building and participation, ownership of process, acknowledging continuous learning, and celebrating efforts
- *Partnership*: enhancement of effectiveness through mutually beneficial relationships among various partners from different disciplines and sectors
- *Continual improvement, innovation, and creativity*: maximizing performance to address social and cultural diversity, attention to new emerging needs and remaining responsive to the challenges brought on by a changing environment.

4. The Quality in the Continuum of Cancer Care (QCCC) framework[659]

The QCCC framework offers an understanding of how organizational strategies can impact the process of cancer care across the continuum in health care setting. The unique feature about this model is that it underscores the reality that the patient may enter the continuum of care at different points and at different times in the nature history of a cancer. The continuum of care, divided into 7 phases, includes: risk assessment; primary prevention; detection; diagnosis; treatment; recurrence surveillance; end-of-life care (palliation and bereavement support). Proper care is dependent on the decisions and actions of both patients and health care professionals during any of the phases of care. Poor outcomes can occur from failures in transitions from one type of care (e.g., detection) to another (e.g., diagnosis) and from failures in the health care

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[659] Zapka JG, Taplin SH, Solberg LI, Manos MM. A framework for improving the quality of cancer care: The case of breast and cervical cancer screening. Cancer Epidemiology, Biomarkers, & Prevention, 2003;12: 4-13.

system or practice care teams to deliver the service optimally. To improve the quality of cancer care, attention must be directed to both transitions and actual services delivered.

The QCCC view of program implementation for ensuring optimal delivery of care begins by identifying high priority areas for improvement. Strategies advocated to improve the system of care are organized into 4 categories: delivery system design; clinical decision support; clinical information systems; and patient self-management support. These strategies were adopted from the CCM.[660,661] The delivery system design category draws attention to those aspects that will define the practice setting such as: service arrangements and contracts; capacity/demand management; centralized versus decentralized programs; development of teams/task designation; quality control/improvement functions that touch on management and clinical practice; and coordination with community resources. The clinical decision support category includes strategies that address gaps in clinician information and skill. These include establishing a structure and a process to develop, update, and disseminate clinical practice guidelines. Also included are strategies to promote continuing education, improve access to specialists, and ensure adherence to guidelines by implementing protocols/prompts. The clinical information systems category includes measures that will facilitate and improve the delivery of proactive care and follow-up such as: a registry or tracking system; computerized medical record and reminder systems; and the use of performance measures and feedback. The final category, patient self-management support, draws attention to implementing strategies that will encourage patient participation in their care such as: telephone or mail reminders regarding upcoming appointments; conducting risk assessment surveys; tracking and follow-up of incomplete adherence; and informing patients about service arrangements/system navigation programs.

Expanding on these organizational strategies, the QCCC includes the importance of leadership as a fifth category. Leadership is seen as responsible for establishing a system of care that capitalizes on the aforementioned organizational strategies. Leadership stems from within the organizational setting and is responsible for making delivery of excellent care across the natural history of cancer a priority, espousing a collaborative philosophy that engages all key stakeholders, willing to commit resources to realize the vision of optimal care, and able to effectively lead the process of change. The leadership role also includes advocating for public policy change, encouraging self-evaluation, research, and quality improvement.

Within the framework, the external community plays a role insofar as it affects the efficiency, equity, and effectiveness of care through interactions among health professionals, legislators, and community activists. Implicit principles advocated by the framework include:

- *Patient involvement*: patients being informed and activated
- *Productive interactions/encounters between patients and providers*: encouraging patient activation by providing them with relevant information about their health and medical care needs
- *Accountability*: clear responsibilities for all involved in ensuring optimal care

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[660] Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. Milbank Quarterly, 1996;74(4):511-44.

[661] Glasgow RE, Orleans CT, Wagner EH. Does the chronic care model serve also as a template for improving prevention? The Milbank Quarterly, 2001;79(4):579-612.

5. USA Division of Cancer Prevention and Control framework for Comprehensive Cancer Prevention and Control (DCPC-CCPC) [662]

The DCPC-CCPC framework is based on a vision of comprehensive cancer control as expressed by participants in the DCPC comprehensive cancer control initiative, existing cancer control models in the literature, as well as actual experiences of stakeholders involved in the data-based cancer control planning (Date-Based Intervention Research Program) in 22 states. The framework formalizes the cancer control planning and implementation process by depicting four phases that are linked in a cycle running from the setting of objectives (Phase 1) to implementing of strategies (Phase 4). Although the framework was originally proposed to guide the process of planning and implementation at the local and/or state level, it can serve as a useful framework for efforts directed at a national level (as adopted by the WHO[663]). Schematically, the four phases follow a circular path and there is a continuous flow of knowledge for adequate decision making, which serves as the core to the framework. All phases involve the active participation of state and local stakeholders.

Phase 1 involves setting optimal objectives driven by available data on cancer burden in the population and the capacity to respond (e.g., facilities, programs, and services). Sub-steps include establishing coalitions and work groups, identifying and assessing the quality and the usefulness of available data. Such data is then used to address the needs and gaps in knowledge. Phase 2 draws attention to the importance of determining the best possible strategies to achieve the objectives. Sub-steps include reviewing fundamental research data as well as data related to the effectiveness, relevance, and efficaciousness of intervention strategies. Efforts at building infrastructure, developing data and reporting procedures would also take place within this phase. Phase 3 involves the planning of feasible strategies to address the objectives. Sub-steps include setting realistic priorities, reviewing existing programs and their coverage, identifying and advocating for additional resources outside the invested stakeholder partnership, defining roles, and determining networking approaches. Attention to societal, political, and economic considerations is necessary during this planning phase. Phase 4 consists of implementing the strategies reviewed during Phase 2 and selected during Phase 3 to meet the objectives set out in Phase 1. Sub-steps during this final phase include selecting relevant and affordable intervention strategies, tailoring intervention strategies to target populations, conducting, monitoring, and evaluating interventions.

Central to the framework is a collection of knowledge that feeds into the decision making process, an element adopted from the national cancer control framework advanced by the National Cancer Institute of Canada. The different phases can draw from this collection of knowledge and continue to contribute to it. This exchange is represented by arrows feeding into the decision making process as well as arrow generating outward from this to inform the phases of planning. Through its circular approach to cancer control planning, the DCPC-CCPC framework encourages the view of decision-making as being flexible and responsive to fluctuations in resources, changing in public health needs, new scientific discoveries, and shifts in political priorities. By all accounts this means that after the planning and implementation cycle is

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[662] Abed J, Reilley B, Butler MO, Kean T, Wong F, Hohman, K. Journal of Public Health Management Practice, 2000;6(2):67-78.

[663] WHO-NCCP framework (2002)

completed, efforts begin again this time building on the information and experience gained from the previous cycle. New priorities may be set as more information about risk factors and interventions are known. Reduced or increased funding may also set the tone for planning. In essence, then, the approach to cancer control planning and implementation must be circular, flexible, and practical in light of new discoveries and resource allocations.

Although a circular process to planning and implementation is schematically represented, the authors of the DCPC-CCPC model acknowledge that in reality knowledge assembled during Phase 2 may be needed to define objectives in Phase 1. In addition, monitoring and evaluating the implemented strategies are explicitly mentioned in Phase 4. However, both activities take place at every step of planning. Implicit principles inherent within the DCPC model include:

- *Partnerships* as it relates to cancer control staff forming board-based coalitions early on in the planning process and maintaining the active participation of coalition members and other stakeholders throughout.
- *Flexibility* as it relates to the outputs of the planning process, reflected in individual and coalition preferences, differences in data availability, analysis capacity, and resources
- *Practicality* as it relates to scaling down optimal objectives to what is feasible to implement given the available resources.

6. Advisory Committee on Cancer Control, National Cancer Institute of Canada (NCIC) framework[664,665]

The NCIC framework provides an overarching view of a cancer control strategy, which goes beyond the inclusion of program delivery mechanisms and implementation strategies. It incorporates Greenwald and Cullen's approach to cancer control,[666,667] which emphasized the importance of adequate research efforts before wide-scale implementation of interventions. The NCIC framework expands upon their initial approach by also incorporating research on interventions. It offers a systematic approach to assessing the efficacy and effectiveness of interventions across the full range of cancer activities and places considerable importance on how programs should be delivered.

The NCIC framework stipulates a central core of knowledge synthesis and decision making in the development of any cancer control initiative. The conclusions and recommendations that emerge from this decision making synthesis process informs and is informed by activities in the following four cancer control categories: (1) fundamental research; (2) intervention research; (3) program delivery; and (4) surveillance and monitoring. Fundamental research aims to answer the question of what is known in cancer control. As such, it encompasses biomedical science as well as all disciplines on whose theories and findings in areas such as interventions, programs, and policies can be based. Intervention research, on the other hand, is designed to address the question of what works. This type of research aims to assess the efficaciousness and effectiveness

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[664] Advisory Committee on Cancer Control, National Cancer Institute of Canada. Canadian Medical Association Journal, 1994;151(8):1141-1146.

[665] Best A., Hiatt RA., Cameron R, Rimer BK, & Abrams DB. The evolution of cancer control research: an international perspective from Canada and the United States. Cancer Epidemiology, Biomarkers & Prevention, 2003;12:705-712.

[666] Greenwald P & Cullen, JW. The scientific approach to cancer control. Cancer J. Clini, 1984;34:328-332.

[667] Greenwald, P & Cullen, JW. The new emphasis in cancer control. J. Natl. Cancer Inst, 1985:74;543-551

of interventions in cancer prevention, screening, diagnosis, treatment, rehabilitation, palliation as well as activities such as fund-raising, public education, and advocacy. Research into any of these interventions should proceed sequentially through a proposed 6-stage process, an extension of the 5-stage process originally described by Greenwald and Cullen. Program delivery makes reference to the specific design and delivery of cancer control interventions, thereby addressing the issue of how programs should be delivered. A 6-stage approach to program delivery is also described that ought to proceed in concert with the stages for intervention research. Surveillance and monitoring includes the collection, analysis, and review of data to address the question of where we are in the process of controlling cancer.

The use of the knowledge synthesis and decision-making element is posited as an iterative process that aims to answer the question of what comes next based on new information provided by the activities within the four categories. In so doing, it regulates the process of decision making by ensuring that evidence from all areas be critically evaluated before new research or program initiatives are implemented. All key stakeholders must participate in this decision making process such as those who conduct fundamental and intervention research, are responsible for surveillance and monitoring, as well as providers, policymakers, administrators, educators, volunteers, fund-raisers, and epidemiologists. The decision making element and the four categories are embedded within a context of key principles that are advanced as essential to guiding all cancer control activities-namely:

- *Accountability*: acceptance of responsibility for one’s actions, which includes reporting, explaining, and justifying actions or behaviors.
- *Empowerment*: acquisition by individuals or groups regarding their capacity to participate fully in the decision-making process in a fair and equitable manner. It also encompasses the recognition that such participation is legitimate.
- *Efficiency*: extent to which the benefits achieved explain the cost and benefits expended.
- *Ethics*: rules and principles that govern proper conduct, including those relevant to scientific merit.

Appendix 4A -- List of main policy documents by jurisdictions

Alberta

Stages of policy process	**Documents/events**
I. Strategic development	1999: Creation of the Alberta Coordinating Council for Cancer Control (ACCCC) 2002: ACCCC Steering commitee formed and planning forum held
II. Formal strategy, action plan and/or program	1993: Alberta Health and Wellness – Palliative care: A policy framework 2001: Alberta Health and Wellness – Reducing tobacco use in Alberta: A comprehensive strategy 2002: ACB Business plan 2002-03 to 2004-05 2003: Alberta Health and Wellness – Framework for a healthy Alberta 2004: ACB Business plan 2004-2005 2004: ACB - Alberta Cancer Control Action plan 2005: ACB Business plan 2005-2006
III. Program operations and/or progress of reform implementation	2002: ACB annual report 2001-02 2003: ACB annual report 2002-03 2003: Alberta Alcohol and Drug Abuse Commission (AADAC) – Alberta Tobacco Reduction Strategy - Highlights 2002-2003 2004: ACB annual report 2003-04 2004: AADAC – Alberta Tobacco Reduction Strategy - Highlights 2003-2004 2005: ACB annual report 2004-05 2005: AADAC – Alberta Tobacco Reduction Strategy - Highlights 2004-2005 2006: ACB annual report 2005-06 2006: AADAC – Alberta Tobacco Reduction Strategy - Highlights 2005-2006 2006: ACB and Foundation -- Possible. Alberta’s cancer free future. Alberta Cancer Board and Foundation Annual review 2005/2006. 2025 Milestones. Prevent cancers. Saves lives. Eliminate suffering.
IV. Evaluation of program/action plan implementation	2003: Alberta Health and Wellness and ACB - Multiyear performance agreement 2003-2005 2004: Health Quality Council of Alberta (HQCA) - Program Evaluation Committee for Breast Cancer Screening Program
V. Outcome assessment	2004: Alberta government - 2004 Public survey conducted by the Population Research Laboratory, University of Alberta (since 1995) 2004: Health Quality Council of Alberta (HQCA) – Satisfaction with the health care system. A survey of Albertans 2005: HQCA – Health report to Albertans 2004 2006: ACB – Cancer in Alberta: A regional picture 2006

	2006: Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada 2006: Hamilton C. Healthy Provinces, Healthy Canadians: A Provincial Benchmarking Report. Conference Board of Canada 2006: Health Council of Canada – Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005

British Columbia

Stages of policy process	**Documents/events**
I. Strategic development	2000: BCCA – Partners in Cancer Care 2000 Conference: Strategic Planning for Provincial Cancer Services 2001: BCCA – Partners in Cancer Care 2001 Conference: Continuing Professional Education and Development. Satellite meeting with Ministry of Health and Regional Authorities/Hospitals: Challenges and Critical Issues for cancer Control in BC 2002: BCCA – Annual Cancer Conference 2002 included Partners in Care Conference on: Implementing the Canadian strategy for Cancer Control in BC and Yukon 2003: BCCA – Partners in Cancer Care 2003 Conference: The Evolving Regional, Provincial and BC Cancer agency Collaboration in Planning and Delivery of Cancer Care 2004: BCCA – Annual Cancer Conference: Management of Cancer in the Community 2005: BCCA – Annual Cancer Conference: Patients and Families 2005: BCCA and Northern Health – Northern Cancer Control Strategy Final Report. 2005: BCCA and Northern Health – Radiation therapy review. Final Report 2006: A Northern Vision. Cancer Care in Northern BC: A Discussion Paper 2006: Premier's Consultation for improved cancer care in Northern BC 2006: Annual Cancer Conference: Partners in Research and Care: BC and the world
II. Formal strategy, action plan and/or program	2002: Provincial Health Services Authority (PHSA) – Clinical plan. Directions for the Future. 2003: BCCA Strategic Plan 2004-2010. 2005: BCCA and PHSA - BCCA Strategic Plan 2004-2010. Updated September 2005 2005: PHSA – Leveraging Strenghts... Transforming Health Care. PHSA Strategic Plan. Updated September 2005

III. Program operations and/or progress of reform implementation	Annual Reports/website – Cervical Cytology Screening Program of BC Annual Reports/website – Screening Mammography Program of BC 1997- : News releases 2001: BCCA Annual report 2003: Provincial Health Services Authority (PHSA) – PHSA health services design plan. From vision to reality. 2005: BC Cancer Foundation – 2005 Report to donors. Then and now: 70 years of supporting cancer research and care 2005: PHSA – Three years of progress. PHSA Accomplishments. April 2002-2005. 2005: PHSA – Three year service plan 2005/06 to 2007/08. 2005: BC Ministry of Health -- 2005/06-2007/08 Performance agreement between the PHSA and the BC Ministry of Health. 2006: BCCA - Cervical Cancer Screening Program – 2005 annual report 2006: BCCA – Screening Mammography Program of BC – 2005/2006 annual report 2006: BC Ministry of Health -- BC Ministry of Health 2006/07-2008/09 service plan
IV. Evaluation of program/action plan implementation	Integrated in BCCA operations
V. Outcome assessment	Integrated in BCCA operations 2005: BC Ministry of Health -- Acute Care Inpatient Experiences in British Columbia. 2006: Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada 2006: Hamilton C. Healthy Provinces, Healthy Canadians: A Provincial Benchmarking Report. Conference Board of Canada 2006: Health Council of Canada – Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005

Canada

Stages of policy process	**Documents/events**
I. Strategic development	1990 : Cancer 2000 Task Force Report 2001: Canadian Strategy for Cancer Control (CSCC) - Draft Synthesis Report 2003: CSCC - Draft Business Plan consolidating existing work of the action groups 2005: CSCC - Stakeholder Forum II: Outlook
II. Formal strategy, action plan and/or program	2002: CSCC Action Plan: Priorities for action. 2002: CSCC - Gouvernance Model for the Canadian Strategy for Cancer Control. 2005: CSCC - Establishing the strategic framework for the Canadian Strategy for Cancer Control. 2006: CSCC - 2006-2010 Business Plan for the CSCC

	2006: CSCC - The Canadian Strategy for Cancer Control: A cancer plan for Canada
III. Program operations and/or progress of reform implementation	2000: S. Luciani and N. Berman – Status Reports. Canadian Strategy for Cancer Control. Chronic Diseases in Canada, vol. 21, no. 1 2001- : CSCC Bulletins (Vol. 1, May 2001 to vol. 8, April 2005)
IV. Evaluation of program/action plan implementation	2002: Health Canada - Report from the Evaluation Indicators Working Group: Guidelines for Monitoring Breast Screening Program Performance 2004: Canadian Council on Health Services Accreditation – Literature review and environmental scan for cancer control indicators. Submitted to the CSCC Standards Action Group 2004: Evaluation framework developed for CSCC Council by Technology Management Associates 2006: CSCC Business Plan 2006-2010
V. Outcome assessment	2005: Canadian community health survey (latest smoking rates) 2005: Canadian tobacco use monitoring survey 2006: Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada 2006: Hamilton C. Healthy Provinces, Healthy Canadians: A Provincial Benchmarking Report. Conference Board of Canada 2006: Health Council of Canada – Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005

England

Stages of policy process	**Documents/events**
I. Strategic development	1984: Bagshawe KD on behalf of the Standing Medical Advisory Committee. Acute services for cancer: report of a Working Group.
II. Formal strategy, action plan and/or program	1995: Department of Health (DH) – A policy framework for commissionning cancer services : a report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales (Calman-Hine Report) 2000: DH - The NHS Cancer Plan : A Plan for Investment, a Plan for Reform 2000: NHS Executive, DH – Cancer Information Strategy

III. Program operations and/or progress of reform implementation	1996- : DH, then NICE - Service Guidance on Improving Outcomes for specific tumor sites 2001: NHS executive, DH - Manual of Cancer Services Standards (first edition) 2001: DH – The NHS Cancer Plan – Making progress 2003: DH - NHS Cancer Plan. Three-year Progress Report: Maintaining the Momentum 2003: DH – Investments in Cancer in 2001/02 and 2002/03 2004: NHS executive, DH - Manual of Cancer Services Standards (second edition) 2004: All-Party Parlimentary Group on Cancer – Meeting National Targets, Setting Local Priorities: the Future of Cancer Services in England 2004: DH – The NHS Cancer Plan and the New NHS: Providing a Patient-Centred Service
IV. Evaluation of program/action plan implementation	2001: Commission for Health Improvement (CHI) and Audit Commission - National Service Framework Assessments No.1 NHS Cancer Care in England and Wales 2003: Health Services Management Centre - CSC Phase I Evaluation
V. Outcome assessment	2002: DH – Cancer. National overview 1999/2000 2004: House of Commons Committee of Public accounts, National Audit Office (NAO) - Tackling cancer in England: Saving more lives 2005: NAO –Tackling cancer: Improving the Patient Journey 2005: NAO – NHS Cancer Plan – A Progress report 2005: Office for National Statistics – 2004/05 *General Household Survey. Smoking and drinking among adults, 2004.* *2006: DH, Health and social care information centre – Statistics on screening and immunization (includes annual statistics and information on breast and cervical screening)*

France

Stages of policy process	Documents/events
I. Strategic development	2003: Rapport de la Commission d'orientation sur le cancer
II. Formal strategy, action plan and/or program	2000: Programme national de lutte contre le cancer 2000-2005 2003: Cancer. Une mobilisation nationale. Tous ensemble (Cancer. A nation-wide mobilization plan) 2005: Institut national du cancer -- The 2005-2007 Strategic action plan

III. Program operations and/or progress of reform implementation	2003: Health Minister – Plan cancer : la situation 6 mois après le lancement (conférence de presse) 2004: Health Minister – Le plan cancer a 10 mois (conférence de presse) 2004: Mission interministérielle de lutte contre le cancer (MILC) – Rapport annuel 2003-2004. La dynamique du plan cancer. Un an d'actions et de résultats 2004 : Health Ministry (DHOS) – L'organisation des soins en cancérologie en application du plan cancer 2003-2007. 2005: MILC – Rapport annuel 2004-2005. La dynamique du plan cancer. Actions et résultats 2006 : Institut national du cancer – Plan cancer 2003-2006. Ce qui a changé.
IV. Evaluation of program/action plan implementation	2006 : Institut national du cancer – Plan cancer 2003-2006. Ce qui a changé. INCa to carry out its first assessment in 2006 (taken for INCa strategic plan 2005-07).
V. Outcome assessment	2006 : Institut national du cancer – Plan cancer 2003-2006. Ce qui a changé. 2006: Institut national de veille sanitaire (INVS) – Taux de participation des femmes au programme de dépistage organisé du cancer du sein en France, 2003-2005

New Zealand

Stages of policy process	Documents/events
I. Strategic development	1996-1999: NZ Treament Working Party (working party's productions) 2001: NZ Cancer Control Trust – The development of a New Zealand cancer control strategy 2001: NZ Cancer Control Trust – Progress towards a New Zealand cancer control strategy 2001: NZ Treament Working Party - Improving Non-Surgical Cancer Treatment Services 2002: NZ Cancer Control Steering Group – Experts working groups' reports 2002: NZ Cancer Control Steering Group – Toward a Cancer Control Strategy for New Zealand Marihi Tauporo (public consultation)
II. Formal strategy, action plan and/or program	2001: NZ Health Strategy – DHB Toolkit: Cancer Control. Edition 1 2001: Ministry of Health – NZ Palliative Care Strategy 2003: Ministry of Health – NZ Cancer Control Strategy 2003: From Policy to Action: Working Together to Implement the Cancer Control Strategy (Workshop report) 2004: Ministry of Health – Clearing the Smoke. A five-year plan for tobacco control in New Zealand (2004-2009) 2005: Ministry of Health and Cancer Control Taskforce - The NZ Cancer Control Strategy: Action Plan 2005-2010 2005-: Some DHBs have produced cancer services plans. E.g. MidCentral DHB – Cancer service plan, August 2005.

III. Program operations and/or progress of reform implementation	2006: Setting up of a *Cancer Control Work Programme and Steering Group.*
IV. Evaluation of program/action plan implementation	
V. Outcome assessment	2005: Ministry of Health -- Tobacco Facts 2005. 2005: INDEPENDENT MONITORING REPORT -- BreastScreen Aotearoa January-June, 2005

Nova Scotia

Stages of policy process	**Documents/events**
I. Strategic development	1993: Metropolitan Hospital Advisory Committee – Oncology services. A strategy for comprehensive cancer control in Nova Scotia (report to the Department of Health) 1996: Government appointed Committee report to Deputy Minister of Health: “Cancer Care Nova Scotia: A plan for Action”
II. Formal strategy, action plan and/or program	1996: Department of Health (DH) - Cancer Care Nova Scotia: A plan for action 1998: DH – Appendix to the contract for the Commissioner 2000: Cancer Care Nova Scotia (CCNS) - The District Cancer Model: A Community-based System of Care 2001: CCNS – Patient navigation. Clearing a path for patients. Action plan. 2001: DH – A Comprehensive Tobacco Control Strategy for Nova Scotia
III. Program operations and/or progress of reform implementation	2000: CCNS - Report to the Community 1998-2000 2001- : CCNS - Many hearts, many minds, one goal. CCNS Newsletters 2003: CCNS - Report to the community. Cancer Care News volume 1 april 2003. 2006: CCNS – We’re Here. Summary progress report tot the community
IV. Evaluation of program/action plan implementation	2001: Evaluation Committee (Eldon R. Smith, Chair) -- Evaluation of Cancer Care Nova Scotia 2002: DH – Tobacco Control Strategy Evaluation Framework (planned indicators of outcome for Strategy) 2004: Corporate Research Associates Inc. – Cancer Patient Navigation. Evaluation findings 2005: Hampton and Hampton Stylus consulting -- Action in your Community against Tobacco: 2005 Formative evaluation. Shedding light on community capacity. 2005: CCNS -- Palliative Care Front-Line Education Evaluation Report
V. Outcome assessment	1999: CCNS -- Cancer statistics in Nova Scotia. An Overview 1995-1999. 2002: DH – Reporting to Nova Scotians on comparable health and health system indicators 2004: Cancer patient satisfaction survey conducted by NRC Picker

	2005: Cancer patient satisfaction survey conducted by NRC Picker 2005: Canadian community health survey (latest smoking rates) 2005: Canadian tobacco use monitoring survey 2006: CCNS – Understanding Cancer in Nova Scotia 2006: Pyra Management Consulting Services – Nova Scotia Tobacco Control Strategy Evaluation 2006: Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada 2006: Hamilton C. Healthy Provinces, Healthy Canadians: A Provincial Benchmarking Report. Conference Board of Canada 2006: Health Council of Canada – Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005

Ontario

Stages of policy process	**Documents/events**
I. Strategic development	1994: Establishment of Provincial Cancer Network and consultation processes *Phase II:* 2001: Cancer Services Implementation Committee Report 2003: Sullivan T, Evans W, Angus H, and Hudson A (eds.). Strengthening the Quality of Cancer Services in Ontario, Ottawa, ON: Canadian Healthcare Association Press.
II. Formal strategy, action plan and/or program	1994: Ministry of Health -- Life to gain: a cancer strategy for Ontario 1998: Cancer Care Ontario - Strategic Plan 1998-2000 *Phase II:* 2002: Cancer Care Ontario (CCO) – Partners in Care : Building a Quality Improvement Coalition- 2002-2007. Information Management Strategic Plan 2002-2007 2003: CCO and Canadian Cancer Society - Cancer 2020. Targeting Cancer: An action plan for cancer prevention and early detection 2004: CCO – Greater Toronto Area 2014 Cancer Report. 2004: Cancer Quality Council of Ontario (CQCO) - Gaining access to appropriate cancer services: A four-point strategy to reduce waiting times in Ontario 2004: Aboriginal Cancer Control Unit - Action plan 2004-2009 2004: CCO – Ontario Cancer Plan 2005-2008 2006: CCO – Improving the quality of palliative care services for cancer patients in Ontario

III. Program operations and/or progress of reform implementation	1997-2003: CCO Annual reports *Phase II:* 2004: CCO Annual report 2003-04 2006: CCO – Ontario Cancer Plan 2005 Progress Report 2006: Report on Cancer 2020: A Call for Renewed Action on Cancer Prevention and Detection in Ontario
IV. Evaluation of program/action plan Implementation	2005: Cancer System Quality index (QSQI) developed by CQCO
V. Outcome assessment	2003: Sullivan T, Evans W, Angus H, and Hudson A (eds.). Strengthening the Quality of Cancer Services in Ontario, Ottawa, ON: Canadian Healthcare Association Press. 2005: Canadian community health survey (latest smoking rates) 2005: Canadian tobacco use monitoring survey 2006: Canadian Cancer Society/National Cancer Institute of Canada: Canadian Cancer Statistics 2006, Toronto, Canada 2006: Hamilton C. Healthy Provinces, Healthy Canadians: A Provincial Benchmarking Report. Conference Board of Canada 2006: Health Council of Canada – Health care renewal in Canada. Clearing the road to quality. Annual report to Canadians 2005 2006: QSQI 2006 report (data from 2005) 2006: Ontario Women's Health Council, CCO and CQCO – The Quality of cancer services for women in ontario. Summary report. 2006: Hospital Report Research Collaborative – Hospital Report 2006 Series.

Note: I. *Strategic Development*, refers to the policy initiation process, involving identifying, recognizing, and characterizing the problem(s) or issue(s) to be addressed, including carrying out a needs assessment. The assessment often involves establishing working groups or advisory committees comprised of experts and other key stakeholders to formulate recommendations that usually serve as the starting point for the government's policy, action plan or program. II. *Formal Strategy, Action Plan and/or Program* refers to the official documents that summarize the work from Stage I and set the goals and means to achieve the stated goals. These documents are usually focused on justifying why cancer is such a burden, describing the jurisdiction's vision of a performing approach to tackle the problem, stating the objectives sought and presenting the chosen actions (priorities), and means to realize the stated objectives. Our review of the selected jurisdictions has shown that cancer control policy in New Zealand includes a "strategy" document accompanied by an "action plan", while in England and France, the "action plan" constitutes the policy. III. *Program operations and/or progress of reform implementation* refers to publicly available reports presenting main accomplishments of the cancer control program or action plan. IV. *Evaluation of program/action plan implementation* and V. *Outcome assessment* pertain to the activities undertaken toward achieving the intended reforms and the expected accomplishments and mechanisms put in place to carefully monitor and evaluate strategies, services, activities, as well as the intended outcomes. Such classification is an adaptation of key stages in the policy process, as defined in: Cabinet Office. Government's Center for Management and Policy Studies. Beyond the Horizon: Workbook -- A Framework for Policy Comparison, p. 7. Those stages are: Agenda-setting, Objective-setting, Choosing policy instruments, Implementation, and Evaluation. (Available at: www.policyhub.gov.uk/docs/workbook.pdf).

Appendix 4B – Barriers and facilitators of change according to key informants

Barriers	***Facilitators***
• **Unachieved commitment**: (1) Lack of awareness and of knowledge at the government and public levels (cancer not seen as a crisis, inadequate communication to politicians), which leads to (2) Lack of government's commitment.	• **Achieving political commitment**: (1) Getting policy-makers attention via media coverage; and (2) Solid relationships with, and access to key decision-makers within government.
• **Funding/resources**: (1) Lack of funding; (2) Inadequate funding mechanism; (3) Lack of time; (4) Lack of space; and (5) Lack of human resources and inadequate workforce.	• **Adequate resources**
• **Weak leadership**: (1) Absence of a clear mandate; (2) No clear lines of authority; and (3) Lack of consensus around the vision.	• **Strong leadership**: (1) Willingness to take risks; (2) Sharing common vision and mission; (3) Having a good plan; (4) Displaying a public image of credibility, integrity and impartiality; and (5) Continuity of people's involvement.
• **People**: (1) Fear of change (not wanting to change; resistance from unions; insecurity about change); (2) Difficulties in engaging people to begin new activities (beliefs/habits that people maintain based on perceptions of what different organizations are or are not doing); and (3) Lack of commitment to work as partners.	• **Involvement of clinical specialists**: (1) Clinicians' participation/ implication of specialists; (2) Specialist clinical team meetings for care improvement; and (3) Cancer site teams for guidelines.
• **Organizations**: (1) Bureaucracy; (2) Difficulties in getting organizations to work coherently together; and (3) Difficulties in working across organizations.	• **Collaborative and transparent processes**: (1) Structures/events for multidisciplinary collaboration; and (2) Consultative processes: e.g. listening to practitioners or administrators' experiences.
• **Concurrent health system reforms**	• **Promoting performance**: (1) Set targets; (2) Information technology systems: clinical and financial; (3) Performance-based reporting; (4) Measuring and reporting on progress; (5) Strategies for quality improvement; and (6) Rewards for good performance.
• **Culture**: (1) Sectorial thinking about health, i.e., health is not viewed as a responsiblity of other Ministries (e.g. education or labor); (2) Decision-making is too much medically-centered; and (3) Absence of statutory target-driven goal to improve the entire cancer control continuum.	• **Increased focus and funding for primary care**
	• **User involvement**: (1) Informed and empowered public; (2) Involvement of patients; and (3) Patient-centered approach.

Note: Barriers and facilitators are not listed according to frequency of responses. The order of presentation is to facilitate the identification of distinct factors.

Appendix 5A -- Stated goals to intended actions by jurisdictions

Alberta

Alberta Cancer Board and Foundation 2025 Milestones (2006)

By the year 2025, The Alberta Cancer Board is charged with ensuring that instead of projected rates of cancer, Alberta has

- **35 per cent fewer people developing cancer**
- **50 per cent fewer people dying of cancers**
- **Support for every Albertan living with cancer that eliminates or reduces their suffering**

Alberta's Cancer Control Action Plan (2004)	Alberta Cancer Board Business Plan 2005-06
Goals 1. Reduce the number of Albertans diagnosed with cancer or the severity of their illness 2. Enhance the quality of life for those living with or affected by cancer 3. Provide reasonable and affordable access to evidence-based cancer control activities 4. Balance investment in, and integration of, cancer control efforts across the spectrum, from primary prevention to palliative care 5. Enhance Alberta's cancer research capabilities and contributions 6. Create a supportive environment to help Albertans make healthy lifestyle choices that will reduce the number of preventable cancers 7. Empower patients and families to make informed decisions regarding care 8. Link the goals, plans and strategies of the federal and provincial governments, Alberta Cancer Board, health regions, and the many other organizations involved in cancer control **Priority 1: Standards and guidelines** • Establish a provincial coordinating infrastructure/body supported with human and financial resources that will coordinate all Clinical Practice Guideline (CPG) development efforts and liaise with the national CPG Action Group • Establish formal linkages with provincial, national, and international	**Goal 1: Effective delivery of quality cancer programs and services** Priority 1.1: Patient access • Reduce wait times for cancer diagnosis and treatment • Consult and collaborate with community and inter-provincial partners to Implement and coordinate cancer services • Improve availability and access to full spectrum of cancer services as appropriate across the province ➢ *Ten actions planned to meet this priority* Priority 1.2: Improving quality of care • Enhance evidence-based decision-making in the development and delivery of services and programs • Improve cancer surgery coordination and practice • Positive feedback from patients rating quality of services and satisfaction with services • Effective response to all patient complaints and concerns • Enhance provincial management through quality assurance and quality improvement activities ➢ *Nine actions planned to meet this priority and its associated objectives*

groups or organizations involved in the development and/or dissemination of standards and guidelines related to cancer control
- Develop an integrated and coordinated strategy for the dissemination, implementation, and evaluation of the standards and guidelines related to cancer control, in order to enhance quality cancer care
    - ➢ *Eleven initial steps planned to meet this priority and its associated objectives*

Priority 2: Primary prevention

- Increase our provincial capacity to deliver primary prevention by supporting implementation of a province-wide system for integrated chronic disease prevention through the Alberta Healthy Living Network
- Support the establishment of a surveillance system that captures risk factor information on disease incidence related to primary prevention – Data collection, Analysis, and Timely dissemination
- Improve stability for primary prevention by securing protected funding for long-range strategies (5+ years) for chronic disease prevention in government, cancer agencies, and health regions
- Advocate for healthy public policies for health living under the Alberta Healthy Living Network framework and facilitate a coordinated approach to creating a supportive environment for healthy public policy
    - ➢ *Seven initial steps planned to meet this priority and its associated objectives*

Priority 3: Integration and access to psychosocial, supportive, rehabilitative, and palliative care (PSRP)

- Establish a provincial cancer control strategic framework for PSRP
- Establish a coordinated and balanced cancer control system that addresses the expectations and needs of patients/families (physical, social, emotional, nutritional, informational, psychological, spiritual and practical) throughout the spectrum of care/services
- Strengthen nationwide communication related to PSRP priority
    - ➢ *Four initial steps planned to meet this priority and its associated objectives*

Priority 1.3: Planning for tomorrow’s care

- Adequate ACB facilities for patient care
- Programs and services are available closer to patient’s home
    - ➢ *Six actions planned to meet this priority and its associated objectives*

Ten performance measures to achieve this goal

Goal 2: Healthy Albertans through the provision of effective strategies for health promotion, prevention, early detection and screening

Priority 2.1: Provincial screening program

- Coordinate and operate the Alberta Cervical Cancer and Alberta Breast Cancer Screening Programs
- Lead development of additional cancer screening programs
    - ➢ *Three actions planned to meet this priority and its associated objectives*

Priority 2.2: Reduce future morbidity and mortality (from cancer and other chronic diseases) while improving wellness through primary prevention and health education

- Provide leadership to coordinate cancer prevention programs within the mandate of the Cancer programs Act and according to the framework for a Healthy Alberta
- Create programs, policies and environments that support healthy lifestyle choices for prevention of major chronic illnesses through collaboration with stakeholders
- Develop intersectorial partnerships to implement programs and initiatives that address the underlying determinants of health
- Conduct relevant surveillance, evaluation, and research programs to build knowledge in best practices
- Communicate accurate, timely and relevant information about cancer prevention.
    - ➢ *Two actions planned to meet this priority and its associated objectives*

Priority 4: Human resource planning

- Develop a workforce planning capability that allows planners to: (a) anticipate trends, in the workforce including changes in the roles of various cancer service providers; (b) look at changing health needs in the population, and build plans based on service delivery structures and on appropriate assignments of work in relation to the qualifications, skills and training of various cancer service providers; (c) evaluate the influence of cancer workforce planning decisions on service outcomes
- Ensure appropriate numbers of personnel are educated, recruited and retained to meet service requirements, based on a clearly defined staffing model, so that there will be an adequate supply of cancer service providers to deliver the cancer health services that Albertans need
- Make effective and efficient use of cancer personnel in the delivery of first class clinical, research and educational programs, so that cancer care staff are able to provide competent services
- Create workplace environments that help staff contribute fully in the delivery of effective services, with resulting benefits in recruitment, retention, and personnal health, so that there will be a satisfied, healthy, stable and productive cancer service workforce
    - ➢ *Eleven initial steps planned to meet this priority and its associated objectives*

Priority 5: Research

- Establish a single cancer research institute to coordinate cancer research in Alberta
    - ➢ *Five initial steps planned to meet this priority and its associated objective*

Six performance measures to achieve this goal

Goal 3: Support cancer control in Alberta through high quality cancer research

Priority 3.1: Coordinate cancer research inAlberta to generate the best possible improvement and progress in cancer research with the most effective utilization of ressources

- Promote research collaboration across Alberta
- Enhance capacity and quality of the full spectrum of cancer research (discovery research in cancer biology; translational research; clinical research; population-based research; palliative care research and supportive care research).
    - ➢ *Five actions planned to meet this priority and its associated objectives*

Five performance measures to achieve this goal

Goal 4: Financial health and organizational effectiveness

Priority 4.1: Enhancing human resources and financial management

- Utilize staff skills appropriately
- Enhance staff working environment
- ACB and health authorities collaborate on staff recruitment and retention
- Programs and services align with available resources
    - ➢ *Four actions planned to meet this priority and its associated objectives*

Priority 4.2: Manage drug costs

- Strengthen provincial process for approval, management and evaluation of cancer drugs
- Obtain lowest possible cancer drug purchase price
    - ➢ *Four actions planned to meet this priority and its associated objectives*

	Priority 4.3: Information management and capital equipment • Maximize information management and technology capabilities to support the secure exchange and warehousing of timely, accurate information to support decision-making • Implement a capital equipment enhancement and replacement strategy ➢ *Seven actions planned to meet this priority and its associated objectives* **Eight performance measures to achieve this goal**

British Columbia

BCCA and Northern Health – Northern Cancer Control Strategy Final Report (march 2005)	**British Columbia Cancer Agency Strategic Plan (2003, updated 2005)**
The proposed strategy is part of the **Premier's consultation for improved cancer care in Northern BC.** The above mentioned strategy is focused on reviewing and expanding cancer care services in Northern BC in a coordinated way. It addresses both short term improvements and the need to find models of cancer care appropriate to rural and northern centers. Also worth noting is the most recent vision proposal : **A Northern Vision. Cancer Care in Northern BC. A discussion paper (2006)** **Purpose (priorities for action around four outcomes):** 1. reduce cancer incidence 2. inprove survival rates among people affected by cancer 3. improve quality of life for those living with cancer 4. Improve access to cancer care services for northerners **Recommendations for Building a Northern Cancer program:** **A- Develop a Regional Cancer Program for Northern Health**	**Mission:** 1. To reduce the incidence of cancer 2. To reduce the mortality from cancer 3. To improve the quality of life of people experiencing cancer **Key Direction 1: Sustain and advance the BCCA's system of cancer control** *(to sustain and enhance BCCA's ability to effect the provincial cancer control program)* • Deliver the clinical programs and program enhancements as defined in operational plans 03-04, 04-05 and 05-06 to the degree possible with resources allocated • Meet the requirements of PHSA-MoH Service contracts, or at the highest level achievement within resource allocations • Develop the physician/oncologist recruitment and retention plan with the health authorities in accordance with the need for regional and community oncology services • Ensure continuous attention to all of the "hard to recruit" oncology professional disciplines through recruitment, retention, and competitive remuneration considerations

B- Short Term Priorities:

1. *Prevention, promotion and screening*

- Develop a comprehensive tobacco control strategy
- Support the Women's health program to increase screening rates
- Investigate known programs and best practices to reduce the incidence of cancers amenable to preventive action

2. *Detection and diagnosis*

- Complete a retrospective staging study to better understand where resources and effort should be focused to improve survival
- Link diagnostic testing processes with primary care practitioners to develop a coordinated system from first encounter to screening, detection, treament and follow up. This priority will see the establishement of clear clinical guidelines and will decrease the time required of patients for investigation in circumstances where multiple studies are required

3. *Treatment and care*

- Develop travel assistance strategies to reduce the burden of travel for cancer patients.
- Ensure that surgeons in the North have access to timely outcomes information and an opportunity to participate in a surgical oncology best practices program.
- Increase capacity in systemic/chemotherapy services in the immediate future. An external assessment will be completed to provide guidance with respect to clinic services and the integration of these services into a region wide program.
- The burden of travel for care planning, treatment and follow-up is very significant for patients requiring treatments such as radiotherapy. In addition to improvements in transportation, the following short term actions will reduce the very significant burden of travel for patients:
    - Enhance navigation services across NH to support patients in the planning and organization of their treatment to minimize travel requirements.
    - Increase the accessibility of consultation for specialist care

- Ensure alignment of health professional staff levels with standards for clinical care as defined by program and professional standards
- Develop community partnerships/networks to create capacity for clinical, education, supportive care and research activities
- Enhance effective succession planning for leadership and management positions across the BCCA
- Develop a responsive and effective administrative and organizational structure to support the strategic and operational requirements of the BCCA's strategic plan/key directions
- Establish the Centre for Functional Imaging in Cancer Medicine and recruit a program leader for functional imaging

Key Direction 2: Establish the knowledge generation and application paradigm within the provincial cancer control platform *(establishing the "intellectual" engine to enhance cancer control outcomes)*

- Establish teams across the discovery-clinical-population application spectrum to plan interdisciplinary, translational-research projects, both within the BCCA system and with partner organizations in academic, community and private sector settings
- Develop additional capacity to support competitive fund acquisition
- Realign clinical environment to foster translational research
- Establish a phase I/II clinical trials unit capability within selected BCCA Centers
- Develop the knowledge transfer environments, forums, process, and supports for innovation and adoption
- Improve population-based cancer control planning and policy through the coordination and management of knowledge and information resources across the organization
- Establish academic Chairs as a focus for integration of discovery-clinical-population application research

Key Direction 3: Support regional centres, regions and communities with the implementation of provincial cancer control programs and the integration of knowledge across the discovery-clinical-practice population application continuum *(enhancing population-based cancer control across tertiary – community –*

through the application of telehealth.

- Explore how consultative services to Northern family practitioners from BCCA tumor site specific specialists in radiation, medical, and surgical oncology could be enhanced.
- Develop and implement a comprehensive Palliative Care Program that has linkages with Home Care, Hospice Services and the BCCA Palliative Care Network.

C- Additional Considerations and Enablers

1. *Research and education*

Work in this area will be ongoing and will be an essential enabler of the Northern Cancer Program by **improving recruitment and retention** as well as through **evidenced based improvements to care.** The BCCA is engaged in all aspects of research at the provincial, national and international levels. Northern Health has an opportunity to build relationships with BCCA, UNBC, UBC and the Northern Medical Program to **work collaboratively to expand research and teaching in the area of cancer control.**

2. *Information technology*

Having the appropriate technical infrastructure will enable the Northern Cancer Program to improve patient care as well as monitor and share clinical information. There are several initiatives underway that will be essential enablers of the priorities. For example:

The Clinical Information System (CIS) will interface with PHSA-BCCA, Cancer Information System (CAIS).

Telehealth is well established in the North and opportunities exist to link through PHSA for the provision of diagnostic reports and interpretations.

The Physician Connectivity Project will connect all doctors across the North.

The BC Bycast Diagnostic Imaging Network will allow for effective, fast and efficient access to electronic diagnostic images to and from PHSA,

primary care continuum)

- Collaborate with regions and communities to implement the CSCC in BC and the Yukon
- Provide leadership, analytical and administrative support, and coordination for provincial networks, facilitate the deployment of network activity to other chronic disease conditions, and provide linkage of provincial networks to other national cancer initiatives
- Provide leadership, analytical, and administrative support to health authorities to assist their management of cancer control within their communities
- Provide leadership and administrative support to advisory committees in partnership with health authorities

Key Direction 4: Ensure the provision and deployment of resources to achieve maximal organizational effectiveness
(ensuring the ability of BCCA to effect its cancer control mandate)

- Develop novel approaches and partnerships to secure new and incremental resources to pursue the BCCA vision
- Ensure the human resources availability necessary to implement the provincial cancer control strategy
- Build and manage knowledge assets
- Provide the expertise and information to obtain the operational funding necessary to sustain the provincial cancer control program at agreed levels and/or as defined by the performance contract
- Ensure the provision of space adequate to host the BCCA provincial cancer control program.

BCCA's operational planning for years 2003-2005 is included in the following Provincial Health Services Authority (PHSA) strategic documents:

- PHSA Health Services Design Plan (2003), that includes BCCA major accomplishements for 2002/03 and planned strategic initiatives for 2003/04, 2004/05 and 2005/06
- PHSA Three-year service plan 2005/06-2007/08 (2005), that

other Health Authorities, and Northern Health. The Private Network Gateway (PNG) initiative will provide a fully integrated and secure network for Health Authorities to access electronic clinical data. 3. *Linkages with Yukon and Alberta* Areas with rural and remote populations often share similar characteristics in that they have low population density, greater unemployment, income inequality and a higher proportion of Aboriginal persons. It will be important for the leadership of the Program to **engage jurisdictions with similar populations such as the Yukon to determine areas for collaboration and shared learning.** It will also be important to **develop ties with the Alberta Cancer Board to explore border issues around referral patterns.**	includes BCCA planned strategic initiatives for 2005-2006 **British Columbia Cancer Agency – Annual Report (2001)** **Goals:** Goal 1: Plan and fund cancer control program to meet a growing need for: • existing services • infrastructure and equipment • new programs in cancer control Goal 2: Improve cancer control by generating new knowledge through research Goal 3: Develop a cancer control strategy for the entire population of BC, shared by the BC Cancer Agency, the provincial government, and our community partners Goal 4: Plan the human resources necessary to implement our cancer control strategy

Canada

Canadian Strategy for Cancer Control (2002, 2005)	2006-2010 Business Plan for the CSCC (2006)
Priority Goals: 1. **Reduce mortality, morbidity, and incidence** through tobacco control, physical activity, health nutrition, reduced exposure to occupational and environmental carcinogens, appropriate sun exposure, decreasing mortality for lung, breast, prostate, cervical, colorectal cancer, etc, focusing on improved diagnosis for lung, breast, prostate, colorectal cancer, etc; reducing mortality and improving survivorship through surveillance 2. **Increase access to care** through decreasing waiting times, improving access to specific treatments at various stages 3. **Increase quality of life of Canadians and their families living with cancer** through reducing physical discomfort and emotional distress, improving pain and symptom control **Priority Area 1: Primary prevention** *(nationwide cancer prevention strategy)* • Develop a system that enables the implementation and sharing of knowledge for best practices in noncommunicable disease prevention • Increase awareness and practice of primary prevention measures and lifestyle changes at a national, provincial/territorial and regional level • Develop a system which would capture what interventions are being implemented assess the impacts of particular interventions, and determine the required level or dose of intervention to create the desired change • Collaborate at the municipal, provincial and national levels to facilitate and support action at the local community level. **Priority Area 2: Rebalancing the focus** *(system-change for greater investment in supportive and palliative care)* • Develop and promote action plans, strategies, projects, tools, objectives, targets that address the urgent need for adequate resources (program, qualified staff, and more) • Integrate supportive care, psychosocial care, rehabilitative care, and palliative care expertise into the existing cancer control system • Develop a prioritized implementation plan and budget with products and milestones for the assessment and integration of the fifth and sixth vital signs: pain and emotional	**Purpose:** (1)To maximize the translation, transfer and sharing of knowledge across Canada's cancer system to reduce fragmentation in cancer knowledge and service delivery, and (2) make improvements in the health of Canadians, including: • Reducing the expected number of Canadians diagnosed with cancer • Enhancing the quality of life of those living with and through cancer • Lessening the likelihood of dying from this disease **Measurable Outcomes:** 1) Health outcomes: • 45% reduction in the projected number of new cases in 2033 • 51% reduction in the projected number of cancer deaths in 2033 2) Economic outcomes: • Save over $39 billion in direct health care costs • Prevent the loss of over $34 billion in total government tax revenues • Prevent the loss of over $101 billion in wage-based productivity **System-related Targets and Performance Objectives:** The CSCC Council and its Priority Area Action Groups have established system-related targets and performance objectives for each CSCC Priority Area Action Group.

distress, respectively into the Canadian cancer control system **Priority Area 3: Improving surveillance and analysis** • Address the challenge of balancing the development of information systems (user perspective and a collector’s perspective) while monitoring, planning and evaluating the Canadian cancer control system. • Identify the opportunity to link together a vast series of information silos across Canada- Record Linkage Capacity • Build on the progress and successes of the previous Canadian surveillance coalition, including the capture of data on incidence, prevalence, mortality, stage, risk factors, treatment interventions and outcomes **Priority Area 4: Standards** *(common data and technology system to promote and facilitate national standards)* • Establish a process to identify national standards, ensure uptake of national standards, and the development of performance indicators for cancer control • Co-develop an online information resource containing a comprehensive list of standards • Undertake a gap analysis and develop other tools to facilitate standards development • Continuously identify and monitor a core set of national indicators for cancer control for the purposes of quality improvement **Priority Area 5: Clinical Practice Guidelines** *(centralized national database of clinical practice guidelines)* • Develop tools to reduce duplication and improve processes for guidelines development and use- development of a Guideline Adaptation Tool • Contribute to the development of a cancer knowledge resource to effectively synthesize and disseminate improvements to consumers and providers • Mobilize effective partnerships for optimal use of evidence in cancer control **Priority Area 6: Human Resources** *(national human resource database)* • Develop a human resources planning information system (HR-PIS)- already designed and being piloted with data from Nova Scotia, New Brunswick, Newfoundland, and British Columbia. The HR-PIS provides an objective standards-based tool to support provincial and national needs-based planning strategies for cancer control human resources and capital equipment • Create a platform that can monitor, analyze and track human resources in the	Those systemic objectives (action groups’ targets) are the following: • To address a range of risk factors from tobacco use to occupational and environmental carcinogens (*Primary prevention Action Group (AG))* • To produce and publish a consensus-built cancer control standards database (*Standards AG)* • To develop, implement, share, and use regionally relevant evidence-based clinical practice guidelines for cancer control (*Clinical practice guideline AG)* • 100% of cancer patients will have access to supportive and palliative care services by 2010 (*Rebalance focus AG)* • Over the next 10 years, implement the Planning Information System and identify gaps in human resources across the cancer care continuum (*Human resources AG)* • To formalize the collection of relevant cancer staging data. Over the next three years, link and standardize surveillance and data collection systems across Canada (*Surveillance AG)* • To increase funding to academic and cancer agency researchers (*Research AG)*

Canadian cancer system.

Priority Area 7: Research *(long-term research agenda)*

- Seek out and acquire the funds needed to conduct research that will make a difference in diagnosis, prevention, treatment
- Focus on translational research initiatives by enhancing a series of basic research platforms that will facilitate the development of new methods of diagnosis and treatment.
- Focus on the development of an appropriate national population study to evaluate factors that need to be targeted to better prevent cancer in future generations

Create a process for the development of a funds-generating action plan

England

Department of Health. The NHS Cancer Plan: A Plan for Investment, a Plan for Reform (2000)

Aims:

1. Save more lives
2. Ensure people with cancer get the right professional support and care as well as the best treatment
3. Tackle the inequalities in health that means unskilled workers are twice as likely to die from cancer as professionals
4. Build for the future through investments in the cancer workforce, through strong research and through preparation for the genetics revolution, so that the NHS never falls behind in cancer care again

Implicit priorities extracted from chapter headings:

“Improving prevention” (chapter 2)

- New national and local targets to reduce smoking in disadvantaged groups
- New local alliances for action on smoking
- Support in primary care to help people quit smoking
- 2.5 million pounds for research into smoking cessation
- National five-a-day programme to improve fruit and vegetable consumption
- National School Fruit Scheme
- Development of a cancer public awareness programme
    - ➢ *Thirteen action and milestones planned to meet this priority*

“Improving screening” (chapter 3)

- Routine breast screening to be extended up to age of 70 and available on request to women over 70
- Improved breast screening technique to increase detection rate
- New ways of working to meet staffing requirements of breast screening programme
- Improved cervical screening techniques
- Colorectal screening pilots
- The National Screening Committee to introduce a prostate cancer risk management programme
- Tackling inequalities in cervical screening
- Information to patients for better understanding of screening
    - ➢ *Fourteen action and milestones planned to meet this priority*

“Improving cancer services in the community” (chapter 4)

- A central role for primary care in new cancer networks
- 3 million pounds in partnership with MacMillan for a lead cancer clinician in every Primary Care Trust
- 2 million pounds for palliative care training for district nurses
- New primary care clinical dataset for cancer patients
    - ➢ *Six action and milestones planned to meet this priority*

“Cutting waiting times for diagnosis and treatment” (chapter 5)

- Maximum one month wait from urgent GP referral to treatment garanteed for children’s and testicular cancer and acute leukaemia by 2001
- Maximum one month wait from diagnosis to treatment for breast cancer by 2001
- Maximum one month wait from diagnosis to treatment for all cancers by 2005
- Maximum two month wait from urgent GP referral to treatment for breast cancer by 2002
- Maximum one month wait from urgent GP referral to treatment for all cancers by 2005
- Roll out of Cancer Services Collaborative to streamline services in all networks
- Cancer the first priority for roll out of booked appointments
- By 2004 every patient diagnosed with cancer will benefit from pre-planned and pre-booked care
    - ➢ *Twelve action and milestones planned to meet this priority*

“Improving treatment” (chapter 6)

- Extension of guidance programmes for all cancers (e.g. “Improving Outcomes” guidance)
- NICE appraisals of cancer drugs to end postcode prescribing lottery
- Establishment of specialist teams
- Care of all patients to be reviewed by specialist teams
- Monitoring progress to achieve standards
- National cancer datasets (support for collection and analysis of cancer data through *Local Information Strategy* and support audit database

development for cancer within the *Information for Health* programme)
- Strengthening cancer registries (government to set out its plan in the fall of 2000)
  - ➢ *Seven action and milestones planned to meet this priority*

“Improving care” (chapter 7)
- New supportive cancer strategy
- NICE to develop guidance for supportive and palliative care
- New training in communication skills
- Improved information for patients
- New Cancer Information Advisory Group
- Internet resources for patients
- 50 million pounds extra for hospices and specialist palliative care services
- New *Opportunities Fund* money for palliative care in deprived communities
  - ➢ *Eight action and milestones planned to meet this priority*

“Investing in staff” (chapter 8)
- Nearly 1,000 extra cancer consultants,
- Increases in the number of specialist trainees
- More cancer nurses, radiographers, and other professionals
- New skills and new roles for cancer staff
- Better deal for staff (improve working lives of cancer staff and develop the workforce through targeted training initiatives)
- Better planning for the future (e.g. cancer networks to develop workforce plans)
  - ➢ *Five action and milestones planned to meet this priority*

“Investing in facilities” (chapter 9)
- Substantial investment from New Opportunities Fund
- Additional funding in NHS Plan for 50 MRI scanners, 200 CT scanners, and 45 linear accelerators
- Modernisation of pathology services
- First ever cancer facilities strategy
- National audit of major cancer diagnostic facilities
- New partnerships with the private sector
  - ➢ *Three action and milestones planned to meet this priority*

“Investing in the future: research and genetics” (chapter 10)
- New National Cancer Research Institute (NCRI)
- Additional investment in clinical research infrastructure (funds to develop a National Cancer Research Network to be part of NCRI)

- Additional investment in high priority cancer research ares (prostate)
- Partnership with cancer charities for new genetics research
- Partnerships with MacMillan Cancer relief on genetic counselling
    - *Three action and milestones planned to meet this priority*

“Implementing the NHS Cancer Plan” (chapter 11)

- Additional 570 million pounds by 2003-04 for cancer services
- Implementation of cancer service improvements by cancer networks
- Cancer networks develop strategic service delivery plans
- Network workforce, education, and training and facilities strategies to underpin service delivery plans
- Cancer networks commissioning pilots to be established
    - *Four action and milestones planned to meet this priority*

Specific targets/outcomes:

- Since 1997, the government has pledged that it will cut the death rate from cancer in people under 75 by at least 20% by 2010.
- By 2010, our five-year survival rates for cancer will compare with the best in Europe
- In addition to the existing *Smoking Kills* targets of reducing smoking in adults from 28% to 24% by 2010, the cancer plan shall reduce smoking rates among manual groups from 32% in 1998 to 26% by 2010
- The new goals and targets to reduce waiting times for diagnosis and treatment listed above

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Department of Health. A policy Framework for Commissioning Cancer Services: A report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales (1995) “Calman-Hine Report”

Includes seven general principles for the provision of cancer care (see appendix % B for details) as well as recommendations regarding the structure of cancer services, children with cancer, palliative care and the relationship of cancer services with primary care and the development of the purchasing process.

France

Cancer: A Nation-wide Mobilization Plan (2003)

Goal:
To bring cancer-caused mortality down by 20% in the next five years.

Aim:
To impact the entire health care system with a renewed vision where the fight against cancer is fought by patients, their families and friends, and the medical and nursing teams alike.

Outcome goals (key indicators):
1. Smoking should drop by 30% among the young; by 20% in the adult population, and there should be a 20% drop as well in the number of alcohol dependent adults
2. Consistent screening strategies shall be deployed throughout the country
3. 100% of all patients must gain access to customized care programs
4. All patient must have access to quality information on support structures
5. Develop a cancer monitoring system which truly covers the whole population. Ensure that at least 10% of all patients are included in clinical trials in reference centers. French research in oncology must achieve levels of international excellence.

Priority Area 1: "Prevention: Making up for lost time"
(Taking what steps are necessary to significantly reduce high risk behavior among the general population, so as to avoid those cancers which are indeed avoidable)
- Gaining better knowledge of disease development (measures 1-3)
- Developing a comprehensive anti-smoking strategy (measures 4-12)
- Strengthening the fight against work-and environment-related cancers (measures 13-14)
- Strengthening the fight against alcohol abuse (measures 15-17)
- Developing the prevention of other risks and promoting pro-health attitudes (measures 18-20)
  - ➢ *Twenty measures (1-20) planned to meet this priority area*

Priority Area 2: "Improving screening"
(Setting up early screening mechanisms for the most frequently occurring cancers)
- Generalizing nation-wide systematic breast cancer screening by the end of 2003 and ensuring access to genetic testing for hereditary forms of cancer (measures 21-23)
- Fostering the development of colon cancer screening (measures 24-25)
- Encouraging individual, non-compulsory screening for cervical cancer (measure 26)
- Improving conditions for early detection of melanoma (measures 27-28)
  - ➢ *Eight measures (21-28) planned to meet this priority area*

Priority Area 3: “Improving quality of care and focusing care on patients”

(Very deliberately enforcing change in patient care: making the health care system more transparent, coordinating health care institutions and departments, providing equal access to information, therapeutic innovation, and general and customized health care)

- Developing conditions for systematic coordination of all health care players (hospital-based or not) through the generalization of oncology networks, and through regulated grading of health care institutions (measures 29-38)
- Meeting the expectations of patients and their families through more humane therapies and support structures, providing improved information, so that patients who wish to play an active role in their own care may do so (measures 39-41)
- Ensuring that patients get support as individuals by providing not only for technical protocols, but also for additional and palliative care development (measures 42-43)
- Helping health care centres provide patients with innovative diagnostic and therapeutic tools, by overhauling funding mechanisms and deliberating increasing investment (measures 44-53)
  - ➢ *Twenty-five measures (29-53) planned to meet this priority area*

Priority Area 4: “Providing more humane and more comprehensive social support structures”

(Providing patients with all they need to lead as normal a life as possible, so as not to compound the trials of cancer with those of social exclusion)

- Improving patient access to loans and insurance (measure 54)
- Improving mechanisms allowing patients to retain their jobs, to recover their jobs, and to take leave to support a friend or relative (measures 55-57)
- Improving coverage for specific medical or cosmetic expenditure (measure 58)
- Encouraging patients and user groups to participate in hospital life by defining the scope of such participation (measures 59-60)
  - ➢ *Seven measures (54-60) planned to meet this priority area*

Priority Area 5: “Adapting training”

(Within the framework of basic or ongoing training schemes, implementing reform so as to train more professionals with expertise in cancer care)

- Strengthening basic training in oncology so as to increase the potential number of physicians with expertise in cancer care (measures 61-63)
- Strengthening paramedical training schemes for cancer care staff through more focused training (measures 64-65)
  - ➢ *Five measures (61-65) planned to meet this priority area*

Priority Area 6: “Developing research and the hope for a cure”

(Providing oncology research with new impetus and improved coordination. Ensuring it meets the highest international standards, in particular in new fields stemmimg from the genomic revolution as well as in social sciences and economics)

- Identifying *cancéropôles* at the regional or inter-regional level, to ensure a cancer-to-research continuum from patient back to patient, linking reference hospitals to certified research units (measure 66)
- Developing, in particular through the National Cancer Institute, a program-based research policy encouraging partnerships between public and private sector research (measures 67-68)
- Fostering the emergence of world class sites and developing international cooperation, in particular within Europe (measures 69-70)
  - ➢ *Five measures (66-70) planned to meet this priority area*

New Zealand

NZ Cancer Control Strategy (2003)	NZ Cancer Control Action Plan 2005-2010
Overall purposes: 1. To reduce the incidence and impact of cancer 2. To reduce inequalities with respect to cancer **Goal 1: Reduce the incidence of cancer through primary prevention** (*with the seven following objectives*) • Reduce the number of people who develop cancers due to tobacco use and second-hand smoke • Reduce the number of people developing physical inactivity and obesity-related cancers • Reduce the number of people developing nutrition-related cancers • Reduce the number of people developing skin cancer due to UV radiation exposure • Reduce the number of people developing infectious disease-related cancers • Reduce the number of people developing alcohol-related cancers • Reduce the number of people developing occupational-related cancers **Goal 2: Ensure effective screening and early detection to reduce cancer incidence and mortality** (*with the two following objectives*) • At a national level, provide a strategic approach to cancer screening, and the assessment and surveillance of those with familial risk, to ensure quality, acceptability and effectiveness • Establish a process to access the value of early detection of cancer other than that obtained through organized screening **Goal 3: Ensure effective diagnosis and treatment of cancer to reduce cancer morbidity and mortality** (*with the four following objectives*) • Provide optimal treatment for those with cancer	**Goals:** "The Action Plan incorporates and builds upon existing activities which contribute to cancer control. In many cases the recommended actions are designed to: 1. Close existing gaps in services, or reduce duplication 2. Ensure greater coordination of services being developed 3. Ensure that scarce and finite resources are used efficiently and effectively" **For each objective of the NZ Cancer Control Strategy, the Action Plan provides a template which identifies desired outcomes/results, specific actions, key stakeholders, and milestones and/or measures and/or timeframes. Highlights of those measures include:** • Reduction in adult smoking prevalence to 20% or less by the end of phase 2 (2010) • Accreditation programme in operation for defining and monitoring service quality • DHB to ensure local/regional guidelines/protocols are in place for all major cancers • National minimum palliative care data set being used to monitor outcomes in DHB's and cancer networks (phase 2 = years 3-5) • Cancer control workforce development plan completed (phase 1 = years 1 and 2) • All cancer control groups and related activities will have informed consumer representatives and linked to a consumer organization or network (phase 2) • A five-year rolling plan for cancer control research adopted and reviewed two-yearly thereafter (phases 1 and 2) **Overall priorities for phase 1 (year 1-2) implementation** 1. Establish regional cancer networks.

- Develop defined standards for diagnosis, treatment and care for those with cancer
- Ensure patient-centered and integrated care for those with cancer, their family and whānau
- Improve the quality of care delivered to adolescents with cancer, their family and whānau

Goal 4: Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care
(*with the seven following objectives*)

- Establish integrated programs of supportive care and rehabilitation with defined leadership
- Ensure all people with cancer and their families and whānau are able to access the appropriate resources for support and rehabilitation that they need
- Ensure all survivors of childhood and adolescent cancer receive timely and ongoing support and rehabilitation, including early identification of, and intervention in, late effects
- Ensure that those with cancer and their family and whānau have access to high-quality information on treatment and care, including complementary and alternative medicine
- Ensure optimal independence and function for those with cancer through systematic assessment and appropriate multidisciplinary intervention for their social and vocational needs
- Continue to improve access to essential palliative care services that provide appropriate symptom relief and emotional, spiritual, cultural and social support for those with cancer and their family and whānau
- Ensure an integrated and comprehensive service is provided to all those with cancer who require palliative care and their family and whānau

Goal 5: Improve the delivery of services across the continuum of cancer control, through effective planning, coordination and integration of resources and activity, monitoring and evaluation
(*with the three following objectives*)

2. Expand smoking cessation services and programmes for Mäori women.
3. Implement Healthy Eating – Healthy Action.
4. Implement strategies to improve coverage of BreastScreen Aotearoa in areas where the need for increased coverage has been identified.
5. Ensure timely and acceptable access to cancer services by establishing standards.
6. Establish multidisciplinary care for cancer patients.
7. Pilot studies to map and analyse cancer patients' journey and clinical pathway.
8. Establish groups to develop guidance for children, adolescents and adults.
9. Implement and evaluate pilot survivorship programmes for children and adolescents.
10. Implement the New Zealand Palliative Care Strategy.
11. Develop a workforce plan for cancer control, ensuring consideration of cancer workforce shortages for Mäori and Pacific peoples.
12. Plan for capital expenditure on cancer control, including equipment, drugs and new initiatives.
13. Apply the Health Equity Assessment Tool (HEAT) to policy and funding decisions regarding cancer control.
14. Support Mäori-led cancer services where possible and ensure that all mainstream cancer services have a cultural framework for Mäori that aligns with He Korowai Oranga.
15. Develop a five-year rolling plan for research relating to cancer control.
16. Develop a nationalised, standardised clinical cancer data set.

Ministry of Health -- Cancer Control Work Programme (2006-)

This programme will help implement the Action Plan through a series of interrelated projects that align with the six goals of the Strategy/Action Plan. Priorities for the programme are influenced by the phasing in the Action Plan. The national projects in the programme are:

• Develop a coordinated national cancer workforce strategy • Ensure appropriate programs and services are accessible to Māori across the cancer control continuum • Ensure the active involvement of consumer representatives across the spectrum of cancer control **Goal 6: Improve the effectiveness of cancer control in New Zealand through research and surveillance** (*with the two following objectives*) • Extend and enhance research across the continuum of cancer control • Improve the use, efficiency and scope of national data collection and reporting	• Guidance to improve cancer care • Integrating care for cancer patients (cancer networks) • Improving care provided to adolescents with cancer • Improving palliative care • Supporting workforce planning • Reducing inequalities • Coordinating development of cancer data management *** Available at:** http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/f05b456f0b979a0bcc257139000749be?OpenDocument

Nova Scotia

Appendix to contract for Commissioner for Cancer Care Nova Scotia – Goals of Cancer Care Nova Scotia (1998)

1. Facilitate, develop and support divisions consisting of departments and services which will operate programs of cancer control and care…
2. Encourage, facilitate, develop and support the activities of Tumour Groups composed of specialists and health professionals with common interests in treating patients with concerns of the same or related anatomic sites…
3. Operate the provincial cancer registry and ensure that it meets national, provincial and international standards.
4. Develop and operate a cancer control/epidemiology research program in collaboration with the Dalhousie University Department of community health and Epidemiology
5. Develop a multi-disciplinary team to evaluate and accredit Nova Scotia cancer programs and services and assist health care facilities in achieving full accreditation status with national programs such as those operated by the Canadian Council on Health Services Accreditation or the Royal college of Physicians and Surgeaons of Canada.
6. Ensure that cancer services are delivered by medical practitioners and health professionals who are qualified, experienced and credentialed to hold active privileges in health acre facilities.
7. Ensure that cancer prevention and risk reduction programs are given early emphasis and high priority.
8. Develop and enhance surgical oncology programs and cancer supportive care and palliation programs.
9. Ensure that cancer facilities, services and personnel meet or exceed relevant provincial or national standards.
10. Ensure that all cancer patients are registered and have access to specialty consultation and care within an appropriate time frame.
11. Work to ensure that cancer patients have co-ordinated and integrated follow-up care and treatment of intercurrent medical problems close to

patients' homes and in concert with family physicians, local health care facilities and agencies.

12. Establish a communication and advisory network of patients, survivors, family members and volunteers to provide advice and support for program activities.
13. Strive to develop and maintain a comprehensive, co-ordinated cancer system focusing on excellence and quality improvement in personnel, programs, and facilities while maintaining consideration of individual patients' needs and helping patients navigate through the system.
14. Foster cancer program research activities based in the Faculty of Medicine at Dalhousie University, including basic, applied and health services research and clinical trials in order to sustain and continuously improve cancer programs and the education and development of professional staff in all cancer activites.
15. Improve access to and navigation through the cancer system by: requiring and facilitating immediate registration of all cancer cases in the province; assuring that health care facilities provide for responsive patient triage, consultation and treatment services; developing and providing patients with appropriate orientation and informational materials to improve their understanding and decision making; assisting patients identify family physicians to assist in system navigation and follow-up; supporting the development and operation of peer support groups in co-operation with other agencies, organizations and volunteer groups.
16. Ensure the development and operation of a provincial cancer formulary to supervise and evaluate the use of systemic therapy in cancer patients in all health care facilities in the province.

Cancer Care Nova Scotia: A Plan for Action (1996) **A comprehensive, integrated, and accountable cancer management strategy.**	**Cancer Care Nova Scotia Program Activities (1998-)**
Goals: 1. Promote the physical, psychological, social and spiritual well being of people living with cancer 2. Reduce the incidence of cancer 3. Reduce the cancer mortality rate 4. Improve the quality of life for people living with cancer 5. Focus on outcomes 6. Develop standards for cancer care providers and facilities 7. Enhance compliance with evidence-based protocols 8. Strengthen all cancer control components 9. Develop a central role for family physicians 10. Develop the cancer registry and a cancer epidemiology unit as a more complete health system resource. **Recommendation #1: Establishing CCNS** That *Cancer Care Nova Scotia (CCNS)* be established as a body corporate by a Legislative Act and be independent of any one facility. Its mandate will be to: 1. implement a comprehensive, integrated, province wide patient centred cancer management plan;	**CCNS Goals:** 1) To have high quality cancer care across the province 2) To reduce the number of people diagnosed with cancer, and dying from cancer 3) To enhance cancer research in Nova Scotia 4) To bring reliable and helpful information to Nova Scotian **Priorities:** (not explicitly stated as such, based on our review of available documentation*) **Priority #1: Quality and delivery of care** • Support Cancer Site Team (13 in total) responsible for writing clinical practice guidelines to ensure that patients receive treatments based on up-to-date information, under the leadership and support of CCNS • CCNS will disseminate clinical practice guidelines

2. act as the catalyst and leader for the complete continuum of cancer care programs: prevention, screening/detection, education, research, treatment, support rehabilitation and palliation; 3. establish multi-disciplinary clinical planning teams (tumour groups) to develop practice guidelines, standards and multi-disciplinary research initiatives; 4. develop linkages with regional and community health services to ensure continuing development of regional programs and support services for cancer patients and their families; 5. develop an integrated cancer informatics service; 6. develop standards and processes to accredit/credential cancer providers and facilities; 7. evaluate cancer care and services throughout the province; 8. co-ordinate strategic planning for all cancer care components; 9. participate in the development of a funding methodology to support cancer care; and 10. advise on the location and specific types of cancer services to be offered within the province. **Recommendation #2: CCNS Governance** That CCNS will be governed by a Board of Directors.There will a maximum of 15 members initially appointed by Order- In- Council. The membership should reflect major stakeholder groups and consumer representatives from persons who have experienced cancer. Representation should achieve balance among the stakeholders and reflect the geographic diversity of the Nova Scotia population. The inaugural board will serve for three years and will be replaced by a nomination process to be developed by the Board. The Board will report to the Minister of Health. **Recommendation #3: Hiring CCNS CEO** That the Board of Directors hire a Chief Executive Officer and establish an appropriate administrative structure necessary to develop and implement CCNS. All positions must be filled through open competition. That a search committee be charged with finding a suitable candidate for Chief Executive Officer of CCNS. This committee should include representatives from Dalhousie University Faculty of Medicine, Department of Health, and the Cancer Action Committee**.** **Recommendation #4: IT support for reseach and surveillance** That CCNS should have appropriate information technology to support cancer research and planning, and the surveillance and analysis of cancer information for all stakeholders. **Recommendation #5: Prevention**	across Nova Scotia, ensure that these are adhered to, and provide education to professionals, patients, families, and the public about the guidelines • Establish a patient navigation system throughout the province that involves trained nurses working as navigators to help patients and family doctors obtain information on the disease and treatment options; keep all providers abreast with patient progress; connect patient to support services • CCNS to work with district health authorities to help develop and sustain a District Cancer Program; a quality coordinator will work with district health authorities (DHBs) to develop a framework of standard known as levels of care, which will define the type of cancer services that can safely and appropriately be provided in a particular location • Ensure that care in terms of monitoring, assessment, and planning takes place closer to the patient’s home through outreach oncology clinics in communities • Develop two new programs to improve the delivery of palliative care: (1) CCNS will work with Canadian Palliative Care Association Nurses Interest Group to achieve a new speciality designation for palliative care nurses; and (2) CCNS will work with the Nova Scotia Hospice Palliative Care Association to provide training/support for palliative care volunteers across the province **Priority #2: Primary prevention** • Develop, in collaboration with the Nova Scotia Department of Health, a tobacco control strategy. • Collaborate with the Canadian Cancer Society-Nova Scotia Division, and other partners to create

That CCNS lead the development of intersectoral cancer prevention strategies by including relevant government ministries, health professions, advocacy groups and non-government organizations. **Recommendation #6: Screening** That the planning, standard setting, and evaluation of cancer screening programs be facilitated through CCNS. **Recommendation #7: Tumor groups** That cancer treatment policies and clinical practice guidelines be developed through interdisciplinary teams known as tumour groups. **Recommendation #8: Teleconferencing** That the Department of Health make available to CCNS Tele-medicine facilities to allow province wide electronic conferencing for tumour groups and other activities. **Recommendation # 9: Cancer drug formulary** That CCNS assume responsibility for a provincial cancer formulary service in order to: • ensure consistent drug availability across the province; • develop, communicate, and maintain appropriate guidelines for the preparation of cancer pharmaceuticals; • monitor the use of cancer pharmaceuticals, including adherence to treatment guidelines; • integrate the use of cancer pharmaceuticals into a provincial cancer information system; and • advise the Department of Health on new cancer agents in a timely fashion. That the cost of cancer pharmaceuticals, (excluding antiemetics, colony stimulating agents and other treatment enhancers), established by clinical guidelines and provided on an ambulatory basis, be borne by the Department of Health, consistent with prevailing terms, conditions and the policy of insurer of last resort. **Recommendation #10: Supportive care** That all cancer patients should have access to professionals who can appropriately address their physical, social, emotional and spiritual needs. **Recommendation #11: Rehabilitation** That there be uniform and timely access to cancer rehabilitative/restorative services throughout the province.	"A Joint Initiative to Build Community Capacity to Take Action on Tabacco • Co-lead and support individuals and groups in taking action against tobacco in their own community through the Action in your Community against Tobacco (ACT) program. • Partner with the Canadian Cancer Society-Nova Scotia Division to develop a tobacco community tool kit and training plan. **Priority #3: Research** • Provide leadership and vision to ensure a coordinated approach to cancer research in Nova Scotia through the Dalhousie Cancer Research Program • Be a funding partner of the Cancer Research Training Program, which provides students at all levels of their education with the opportunity to train and work with leaders of Nova Scotia's research community to hone their research skills. • Establish the Norah Stephen Oncology Scholar Award to foster interest in cancer research among students **Priority #4: Dissemination of information on cancer and community outreach** • Hold round table discussions on how patients can shape cancer services through the Cancer Patient Family Network, which serves as a formal communication channel for cancer patients, survivors, and family members. • Develop the Reef Knot Kit, a prostate cancer information kit made available to all Nova Scotian men newly diagnosed with prostate cancer. • Establish Patient Navigation Community Liaison to work with people in diverse communities to provide education on how health services can

Recommendation #12: Palliative care
That a province wide palliative care component be fully developed and implemented.

Recommendation #13: Oncology training
That Dalhousie University be encouraged to develop an interdisciplinary academic Department of Oncology.

Recommendation #14: Research
That CCNS promote, facilitate and foster a full spectrum of cancer research from behavioural and outcomes research to research into basic mechanisms of disease. That CCNS develop the proposal “To establish A Cancer Control Research Council in Nova Scotia” submitted by the Nova Scotia Regional Research Development Plan Working Group, October 1995, to the National Cancer Institute of Canada (Appendix C).

Recommendation #15: Clinical practice guidelines
That cancer treatment policies and clinical practice guidelines, known as tumour groups, be developed through interdisciplinary experts drawn from across the province. That patient focus groups should be available to each tumour group. That consistent nursing policies and procedures, approved by CCNS, be used by all agencies.

Recommendation #16: Cancer facilities approval and review
That all facilities, (hospitals, clinics, etc.), wishing to provide cancer care services, be required to undergo an approval process developed by CCNS, which endorses the facility’s ability to meet standards of care. That all individuals who institute, direct, or provide cancer care services be reviewed and approved according to standards developed by CCNS. That CCNS, when established, be given legislated authority to conduct reviews and audits of individuals and facilities providing cancer care within the province and to conduct appropriate follow up reviews. That material gathered during the course of such reviews and audits be protected under the Evidence Act as a "Peer Review Function". That those persons conducting such audits be indemnified by CCNS. That CCNS direct tumour groups to establish review and audit programs for their specialty so that such reviews commence within one year of the formation of the tumour group. That CCNS provide tumour groups with the necessary support to carry out this review and audit function.

Recommendation #17: Nova Scotia Cancer Network

better meet their needs; working with health providers to become aware of cultural values/beliefs
- Provide patients with information on drugs used in cancer treatment and care

***Based on CCNS website and on the following reports:**

CCNS. Many Hearts. Many Minds. One Goal. Report to the community 1998-2000

CCNS. The District cancer model: A community-based system of care (2000)

CCNS Cancer News. Report to the community (2003)

Cancer Care Nova Scotia: Patient Navigation. Action Plan (2001)

Outcomes:
1. The development of a provincial Patient Navigation system
2. The provision of timely reports from cancer specialists to the referring physician
3. The development of a Patient Passport to accompany the patient on their journey through the cancer system
4. The provision of information about the cancer journey for patients and health professionals
5. The enhancement of educational opportunities for health professionals working with cancer patients and their families

That CCNS develop a Nova Scotia Cancer Network to foster the broad exchange of cancer information.That CCNS provide necessary operational support.That the Nova Scotia Cancer Network be open to all groups or organizations involved in any aspect of cancer care. That CCNS and the Department of Health participate in this network.That the Nova Scotia Cancer Network hold regular public meetings at least once a year. **Recommendation #18: General Physician** That the family physician role in cancer care coordination be strengthened to become a key communicator with patients/family. To do so, they must be kept fully informed of the diagnosis and ongoing care of the patient. **Recommendation #19: Program approval** That Regional Health Boards and facilities wishing to expand or establish new programs in cancer care, must be endorsed by CCNS. Only approved programs will be funded. **Recommendation #20: Accountability** That CCNS, in its annual report to the Minister of Health, provide evidence on how the changes in management of cancer care have contributed to improved cancer outcomes.	6. The development of an advocacy position to ensure a provincial health information technology system to improve communication between health professionals 7. The support of quality patient community care through Clinical Sites Teams 8. The establishment of Outreach Cancer Clinics throughout Nova Scotia 9. The development of a plan for disseminating information to health professionals in relation to access and ways to improve access 10. The removal of barriers to family physicians spending adequate time with their patients, i.e. remuneration practices 11. The resolution of issues related to the recruitment and retention of health professionals in Nova Scotia.

Ontario

Targeting Cancer. An action plan for cancer prevention and detection. (Cancer 2020) (2003)	**Ontario Cancer Plan 2005-2008 (2004)**
Goals: 1. to reduce cancer incidence 2. to reduce cancer mortality **Cancer 2020 Targets:** ➢ *Twenty measurable Prevention and Screening Targets planned to achieve these goals, including 5 for tobacco use and 5 for cancer screening.* **Action plan for Ontario: 2003-2008:**	**Goals:** (not stated eplicitely in the plan, but mentioned in both the 2005 Progress Report and a backgrounder document available at: www.cancercare.on.ca/documents/OCPBackgrounder.pdf.) 1. Enhancing prevention and screening to detect cancer earlier 2. Improving the diagnosis of cancer 3. Providing the highest quality care using the best available evidence. 4. Improving access to care by closing the gap between demand for treatment and our capacity to treat, reducing wait times and ensuring services are available close to home. **Provincial priorities** (and their associated planned actions**):**

To create a *Provincial Cancer Prevention and Screening Council* to report to Cancer Care Ontario with a mandate for strategy development, planning and public reporting, surveillance of risk factors and leadership for the implementation of the cancer 2020 action plan. **A- Immediate priorities:** • Implementation of a comprehensive tobacco control strategy • Funding and implementation of a colorectal screening pilot program • Strengthening breast and cervical screening programs • Developing and implementing an Aboriginal tobacco strategy as part of an overall provincial Aboriginal cancer strategy **Longer-term priorities:** • Develop a comprehensive provincial strategy for nutrition and healthy body weight • Invest more in the Healthy Living strategy • Develop an Alcohol strategy • Develop an occupational carcinogens surveillance strategy • Develop an environmental carcinogens reduction strategy • Develop a Sun safety strategy • Develop an overall provincial screening strategy **Priorities for infrastructure development:** • Integrate the *Cancer 2020 Targets* into the Public health mandatory core programs • Invest in prevention research	**Priority 1: Provincial standards and guidelines** *The following three actions are respectively associated with deliverables and outcomes* • CCO will promote an evidence-based culture in the cancer care community and facilitate continuing professional development and rapid incorporation of new knowledge into practice • CCO will broaden the scope of program standards and guidelines across the continuum of care, addressing known needs and opportunities in cancer-related imaging, pathology, and palliative care • Expand the use of organizational standards to ensure that a consistent level of quality of cancer services is available throughout Ontario **Priority 2: Regional cancer programs** *The following two actions are respectively associated with deliverables and outcomes* • Implement patient-focused regional cancer programs in every area of the province • Develop regional palliative care services in collaboration with the Ministry End-of-Life Provincial Advisory Committee **Priority 3: Closing the gap between demand and capacity** *Several of the following actions are respectively associated with deliverables and expected outcomes* • Increase effort to ensure successful achievement of ***Cancer 2020*** prevention targets • Increase screening activities in high impact areas of breast, cervix, and colorectal cancer, coordinated with the necessary diagnostic assessment activities • Implement components of the *Aboriginal cancer strategy* that will reduce preventable cancer rates. • Secure Post-Construction Operating Plan funding for eight centers under construction, or anticipated to open, to maximize results from capital investments • Fund new capital construction requirements in seven areas of the province • Capital investments in equipment (investment in radiation treatment machines) • Increase operating dollars to support increased volumes of surgery, systemic and radiation treatment to meet predicted demand projections • Implement a new approach to funding new and expensive anti-cancer drug • Implement new approaches to funding cancer services by (1) developing and testing new rate-complexity-volume funding methodologies for cancer services in Ontario, and (2) developing alternate funding plans as required

• Enhance risk factor surveillance activities • Estqblish a screening panel to review and assess new screening methods and approaches • Establish mechanisms to coordinate and plan regional cancer prevention and screening activities	**Priority 4: Rapid access strategies** *The following five actions are respectively associated with deliverables and expected outcomes* • Understand, monitor, and reduce waiting times • Optimize access and point of diagnosis, by implementing, funding, and evaluating two rapid access diagnostic units in Ottawa and Sudbury • Implement innovative health human resources, such as nurse endoscopists and oncology nurse practitioner projects • Fund high-impact process improvement projects that increase throughput across the cancer system • Implement innovative new technologies to promote access **Priority 5: Invest in performance measurement and accountability** *The following four actions are respectively associated with deliverables and expected outcomes* • Implement a framework for indicator reporting at the program, organizational and systems levels to improve quality • Expand the scope and quality of data collected for performance monitoring and system planning • Accelerate data extraction, analysis and reporting cycles for ongoing performance improvement that includes data management, warehouse, intelligence tools, and analytic capacity • Implement new performance reporting systems associated with accountability agreements and implementation of the Ontario Cancer Plan **Priority 6: Cancer research** *The following action is associated with deliverables and outcomes* • Coordinate cancer research initiatives across Ontario by implementing a Cancer Research Council for Ontario and establishing networks that address CCO’s priorities

Appendix 5B – Values and guiding principles by jurisdictions

Alberta

Alberta Cancer Board* Guiding Principles for provision of cancer services:

(1) **Cancer research is the foundation** upon which high quality programs in cancer treatment, prevention and education continue to be built. Cancer research programs will continue to be conducted in accordance with the highest ethical and scientific standards.

(2) Cancer care programs will be conducted to achieve **continuous improvement in patient outcomes and efficient resource utilization**. Patients and their loved ones will be active, informed participants in holistic care in an atmosphere of compassion and respect for human dignity.

(3) With the **prevention of cancer as the ultimate goal**, the Alberta Cancer Board is committed to work in **collaboration with others** to ensure that Albertans receive consistent and accurate messages which empower them to minimize their own risks for developing cancer.

(4) **Effective communication and consultation** between the Alberta Cancer Board, Regional Health Authorities and other major stakeholders underpins the optimal delivery of cancer control programs.

Guiding principles and values of the Alberta Cancer Control Action Plan (2004):

(1) **Research to policy to practice**: Our plan will support research to develop evidence-based policy to guide practice, continuous enhancements in cancer control, and improved outcomes. We are committed to rapid adoption of research findings.

(2) **Population health based**: Our plan will address both the patient-oriented and population components of cancer control. We will further refine and act on our understanding of the "determinants of health."

(3) **Accessibility**: Our plan will promote reasonable and equitable access to appropriate and effective care, regardless of where an Albertan lives.

(4) **Creative, Flexible, Adaptable Framework**: Our plan will be a blueprint that allows the Alberta Cancer Board, health regions, voluntary organizations and communities the flexibility to customize according to local circumstances, resources and opportunities.

(5) **Action oriented**: Our plan will keep stakeholders together to work on complementary long and short-term action plans. The benefits of the strategy will increase progressively over time.

(6) **Sustainability**: Our plan will support the long-term sustainability of the health system by helping it deal effectively with and ultimately reduce the rising number of cancer cases.

(7) **Collaboration**: Our plan will bring together and motivate collaboration among the general public, service providers from all sectors, and our provincial/territorial counterparts; from territorialism to partnerships dedicated to common outcomes; from duplication to synergy.

(8) **Integration**: Our plan will recognize common risk factors and opportunities for collaborative, integrative action to reduce the incidence of chronic diseases.

(9) **Accountability**: Our plan will focus on outcomes, regularly report on related progress, and be ultimately accountable to the persons living with cancer or at risk of developing cancer. We will develop accountability mechanisms to ensure that evidence-based standards are met.

Core organizational values identified through ACB's executive and management leadership development and strategic planning activity (in no priority rank order):

(1) Collaboration
(2) Compassion
(3) Courage
(4) Innovation
(5) Integrity

*****: *ACB guiding principles taken from ACB's website at: http://www.cancerboard.ab.ca/about/index.html; Core organizational values were communicated by Dr. Anthony Fields, February 1, 2007.*

British Columbia

Characteristics of the British Columbia Cancer Agency*:

(1) **Population-based**

(2) **Outcome-focused**

(3) **Patient-centered**

(4) **Equity of services**: Provincial standards for access and quality of care and provincial guidelines for cancer management.

(5) **Evidence-based care**: The use of proven effective approaches demonstrated from peer reviewed

clinical studies, i.e. established through rigorous, methodically sound research. Such evidence-based approaches are provided in the context of efficient (measures of process and quality) and accountable care (measures of outcome/performance).

(6) **Integrated across sectors**: Organized to ensure service across primary care, community, tertiary and quaternary levels through a co-ordinated system of cancer centres, community centres and clinics, and a series of provincial networks.

(7) **Technology-enabled**: Active deployment of established and innovative health care technologies for clinical services, research and development, e.g. electronic health record, diagnostic and therapeutic equipment, research and development interfaces with cancer imaging and pathology and lab medicine.

(8) **Research driven**: Invested in cancer research across the biomedical, clinical, sociobehavioural and health systems domains as part of the principal "business" of the BC Cancer Agency.

(9) **Fiscally responsible**: Fiscally stable, deficit-free, balanced budgets prior to, and through fiscal 2002/03 to 2004/05.

*****: *"BCCA characteristics" taken fromBCCA Strategic Plan 2003*

Canada

Values of the Canadian Strategy for Cancer Control*:

(1) **Inclusiveness**: Membership incorporates federal, provincial and territorial representatives, health professionals, key NGOs and cancer patient/survivor groups.

(2) **Person-centered**: A person-centred focus is used when setting priorities and developing plans for implementation.

(3) **Scientific rigour**: Only evidence-based interventions are recommended, and the CSCC advises when existing, ongoing interventions for cancer control in Canada do not have an adequate evidence base.

(4) **Comprehensiveness**: All aspects of cancer control (prevention, early detection and screening, treatment, rehabilitation and palliative care) are considered in order to set priorities for cost-effective cancer control interventions and advise on the appropriate allocation of funds.

(5) **Respectful of jurisdictions**: The policy framework is clearly defined and respectful of existing federal, provincial and territorial jurisdictions in health care.

(6) **Engagement of experts from the cancer control community**: The CSCC promotes awareness and fostering of pan-Canadian networks of experts addressing priority areas, developing information about Canadian and international proven interventions and best practices, and coordinating feasibility studies. It recognizes that patients and their families are experts in the experience of cancer.

(7) **Integrative**: The activities of CSCC are integrated with other federal, provincial and territorial government investments in cancer control to maximize cancer control effort, including promoting and supporting multidisciplinary action where relevant.

(8)**Transparency**: Reports of activities of the group and its recommendations are made available to the cancer control stakeholder community and to the public at large.

(9) **Accountability**: The CSCC is accountable to cancer stakeholders and the Canadian public through development and monitoring of performance against specified targets and indicators.

*****: *"CSCC values" taken from CSCC 2006-2010 Business Plan*

England

Calman-Hine Report (1995): General principles which should govern the provision of health care services*:

(1) **All patients should have access** to a uniformly high quality of care in the community or hospital wherever they may live to ensure the maximum possible cure rates and best quality of life. Care should be provided as close to the patient's home as is compatible with high quality, safe and effective treatment.

(2) **Public and professional education** to help early recognition of symptoms of cancer and the availability of national screening programmes are vital parts of any comprehensive programme for cancer care.

(3) **Patients, families and carers should be given clear information** and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards.

(4) The development of **cancer services should be patient centred** and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional. Good communication between professionals and patients is especially important.

(5) The **primary care team is a central and continuing element in cancer care** for both the patient and his or her family from primary prevention, presymptomatic screening, initial diagnosis, through to care and follow up or, in some cases, death and bereavement. Effective communication between sectors is imperative in achieving the best possible care.

(6) In recognition of the impact that screening, diagnosis and treatment of cancer have on patients, families and their carers, **psychosocial aspects of cancer care should be considered at all stages.**

(7) Cancer registration and careful **monitoring of treatment and outcomes** are essential.

Implicit values and guiding principles from the NHS plan (2000)*:

(1) Evidence-based practice (national standards)
(2) Integration of health and social care
(3) Continuity of care
(4) Faster access to treatment
(5) Reshaping health services around the needs and aspirations of patients
(6) Better conditions for health care professionals (expanded role for nurses, incentives for general physicians)
(7) Performance evaluation
(8) Decentralisation (more power to local community and creation of local trusts for commissioning services)
(9) Patient empowerment
(10) Institutional autonomy linked to good performance
(11) Partnership with the private sector

Implicit additional values and guiding principles from the NHS cancer plan (2000)*:

(1) Equality
(2) Patient-centered care
(3) Evidence-based care
(4) Continuity of care
(5) Faster access to treatment
(6) Reshaping health services around the needs and aspirations of patients
(7) Population health
(8) Patient empowerment/ User involvement in service planning
(9) Partnerships at the national level
(10) Performance evaluation

*****: *Values and guiding principles are not explicitely stated and have been inferred from: Calman-Hine report, NHS Plan, and NHS Cancer Plan..*

France*

(1) Humanism
(2) Expertise
(3) Hope
(4) Proximity (better home care as a result of better integration of public private sectors, hospitals and general physicians, etc.)
(5) Fairness: garanteeing acces to good quality care that meet existing clinical practice standards and to innovations for all, throughout France and whereever care is given.
(6) Patient-centered care
(7) Research and innovation driven
(8) Multidisciplinary and comprehensive approach to cancer: from the research lab, to the hospital bed, and to social reintegration.
(9) Coordination of all health professionals
(10) Federation: to coordinate cooperation between private and public stakeholders.
(11) International cooperation
(12) Transparency

*****: *Values and guiding principles are not explicitely stated in the cancer Plan and have been inferred from: 2003 Cancer Plan, INCa strategic plan and mission as well as from a presentation given in Montreal by a INCa representative in april 2006. See for example: http://www.e-cancer.fr/Institut-National-Cancer/Plan-action-strategique-2005-2007/Patient-action/op_1-it_110-la_1-ve_1.html*

New Zealand

Principles from the New Zealand Cancer Control Strategy:

All activities undertaken to meet New Zealand Cancer Control Strategy’s two overall purposes should be guided by the following principles. They should:

(1) **Work within the framework of the Treaty of Waitangi**: The New Zealand’s founding document is fundamental to the relationship between Maori and the Crown and should underpin actions to address the diverse needs of Maori. Within the context of cancer control, these actions should reflect the Treaty which is based on the following three principles: *partnership* in service delivery; *participation* at all levels of the health sector; as well as the *protection* and improvement of Maori health status and the safeguarding of Maori cultural concepts, values and practices.

(2) **Reduce health inequalities**: Significant health inequalities exist among different groups in New Zealand and can be seen in the distribution of the cancer burden: cancer mortality rates for Maori are higher than for others in New Zealand. Pacific peoples also have higher cancer mortality rates than non-Maori. Gender and geographic inequalities are other important areas for action.

(3) **Ensure timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay**: This principle acknowledges the need to address, in a fair way, factors that impact on the ability of people to access services across the continuum of cancer control in sufficient time to be of benefit.

(4) **Be of high quality**: This principle identifies the importance of developing standards and guidelines, monitoring performance, and evaluating outcome to ensure high quality.

(5) **Be sustainable**: This principle identifies the importance of having the adequate resources, including human resources, required over a period of time to ensure a high standard of performance.

(6) **Use an evidence-based approach**: This principle acknowledges the need for actions to be based on best practice, which is supported by a systematic review of scientific knowledge and includes ongoing research and development.

(7) **Reflect a person-centered approach**: This principle recognises a person’s total wellbeing, including her or his physical, emotional, spiritual, social and practical needs within the context of family and whanau. For Maori, this means recognising and responding appropriately to a Maori holistic view of health. It also recognises people’s autonomy and dignity and their right to make informed choices.

(8) **Actively involve consumers and communities**: This principle identifies the need to have consumers and communities involved in the decisions that affect them and to provide opportunities for consumer participation. It also means that services should reflect the needs of individuals and communities.

(9) **Recognize and respect cultural diversity**: This principle recognises the importance of actions being culturally appropriate; that is, responsive to, and respectful of, the history, traditions and cultural values of the different ethnic groups in New Zealand.

(10) **Be undertaken within the context of planned, coordinated, and integrated approach**: This principle underscores the importance of adopting a systematic and coordinated approach to ensure effectiveness and that resources are used efficiently.

(11) **Population-based approach**: The previous principle also acknowledges that activities to control cancer should be part of a population-based approach to health. The New Zealand Public Health and Disability Act (2000), which governs the structure of the New Zealand health care system, mandates a population-based approach to health.

Nova Scotia

From Cancer Care Nova Scotia Vision statement*:

(1) Population health based
(2) Coordination
(3) Integration
(4) Comprehensiveness
(5) Consideration to patients
(6) Responsiveness
(7) Quality

From CCNS Values*:

(1) Display leadership
(2) Be centered on patients/families
(3) Support caregivers
(4) Demonstrate compassion, and integrity
(5) Value privacy, dignity and diversity
(6) Collaborate with others
(7) Build on existing strengths
(8) Use resources responsibly

Value statement for Cancer Care Nova Scotia based on Appendix to contract for Commissioner for Cancer Care Nova Scotia

(1) Excellence, integrity, reliability
(2) Consideration, compassion, beneficience
(3) Confidentiality, privacy, dignity and autonomy for every patient.

*****: *CCNS "values" and vision statement taken from CCNS website at: http://www.cancercare.ns.ca/inside.asp?cmPageID=9*

Ontario

Cancer Care Ontario Mission*:
“Quality, accountability, Innovation”

CCO Guiding Principles*:

(1) **Transparency**: We will adopt a transparent approach to sharing performance-related information and foster a culture of open communication with colleagues, partners and the public.
(2) **Equity**: We will ensure fairness across regions in the development of a strong provincial cancer system.
(3) **Evidence-based**: We will make decisions and provide policy advice based on the best available evidence.
(4) **Performance oriented**: We will advance new ideas, promote change and take action toward quality improvements in the cancer system.
(5) **Active engagement**: We will consult widely and collaborate with other organizations and service providers in order to achieve our goals.
(6) **Value for money**: We will use public resources wisely and promote the efficient use of these resources throughout the cancer system

Guiding principles of the Cancer 2020 prevention and screening action plan (2003):

(1) **Optimism**: We believe that innovative planning and responsiveness to technological developments can dramatically reduce the burden of cancer.

(2) **Accountability**: The plan establishes a five-year framework that can be used to develop measures for progress in cancer prevention and screening and identifies key actions including who is responsible for carrying them out.

(3) **A focus on population health**: A population-based focus would utilize a variety of targeted strategies to increase knowledge among the public and health professionals and create a supportive public policy environment that reinforces behaviour change across the entire population.

(4) **Evidence-based**: Cancer 2020’s research priorities are based on emerging evidence of cancer risk, public concern and prevention research that is currently underway.We will respond quickly to new evidence in cancer prevention and screening and adapt proposed policies, programs and media campaign components accordingly.

(5) **The precautionary principle**: Cancer 2020 is also guided by precaution in the avoidance of cancer risk. Even if some cause-and-effect relationships are not fully established scientifically it is desirable to reduce and/or eliminate exposure.

(6) **Integration and collaboration**: Many risk factors for cancer such as tobacco use, poor diet and physical inactivity are common to other chronic diseases. Collaborative action among organizations involved in chronic disease prevention is cost-effective and increases the chance of successful behaviour change.

(7) **Strategic use of resources**: It is crucial to make the best use of prevention resources and therefore, Cancer 2020's overall priorities for action are based on factors that put the population at the highest risk for cancer. For example, *Aboriginal communities in Ontario have slightly different high-risk categories* of cancer than the rest of the population and therefore, the best use of prevention resources would probably be different for this group.

*****: *CCO mission and guiding principles taken from CCO's website at: http://www.cancercare.on.ca/index_vision.htm*

Appendix 5C -- Selected targets and indicators of outcome by jurisdictions

Alberta

The *Alberta Cancer Prevention Legacy Act*, which was introduced by the government to help meet two of ACB measurable goals by 2025:

- Reduce the 2025 projected incidence rate of cancer by 35 percent;
- Reduce the 2025 projected mortality rate from cancer by 50 percent.

Tobacco use reduction targets are the following:[668]

- Reduce the consumption of tobacco products in Alberta by 50% from 2001 to 2011
- Reduce the percentage of Albertans age 15+ who smoke from 25% in 2001 to 17.5% in 2011
- Reduce the percentage of youth age 15 -19 years who smoke from 24% in 2001 to 12% in 2011
- Reduce the percentage of women who smoke during pregnancy from 32% in 2000/2001 to 12% in 2010/2011

Other outcomes relevant for cancer control can be found in the *Framework for a Healthy Alberta*,[669] which states that by 2012, Alberta should:

- Increase the proportion of women aged 50 to 69 who are screened for breast cancer, from 71% to 80%
- Reduce the mortality rate for breast cancer, from 24.2 to 22 per 100,000 women
- Increase the proportion of women aged 18 to 69 who are screened for cervical cancer, from 75.1% to 95%
- Reduce the mortality rate for cervical cancer, from 2.9 to 1.5 per 100,000 women
- Reduce the rate of people who get lung cancer, from 56 to 48 per 100,000 people
- Reduce the mortality rate from prostate cancer (currently 24.4 per 100,000 men)

While there are no targets or outcomes in the *Alberta Cancer Control Action Plan*, the ACB Multi-year Performance Agreement comprises 36 performance measures in relation to the four major goals of the *ACB Business Plan 2005-06*.[670] Included among these measures are the following quantifiable outcomes:

- For 90% of patients, achieve target wait times of four weeks from referral to consultation with an oncologist and two weeks from consultation to treatment for all tumor groups where medically appropriate
- 95% of patients to rate quality of services as satisfactory or better
- Alberta Cervical screening program implemented province-wide by 2007
- Alberta Breast cancer screening program implemented in majority of province by 2007

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[668] Tobacco use reduction targets were first delineated in the Report *Reducing tobacco use in Alberta: A comprehensive strategy* (2001); Official targets were then stipulated in the Provincial Strategy entitled *Alberta Tobacco Reduction Strategy (2002)*. Stated targets are drawn from: Alberta Tobacco Reduction Strategy - Highlights 2005-2006, pp. 5-6.

British Columbia

Measurable indicators relevant for cancer can be found in the Ministry of Health 2006/07-2008/09 Service Plan (targets set for 2010):

- To continue B.C.'s downward trend of tobacco use amongst those aged 15+ by a further 10 % by 2010 (from 2003 prevalence rate of 16% to 14.4%).
- To increase by 20% the proportion of the B.C. population currently classified as active or moderately active from the 2003 rate of 58.1% to 69.9% of the B.C. population by 2010.
- 20% increase in fruit and vegetable intake
- 20% reduction in overweight and obesity
- Waiting times for radiotherapy: 95.5% began treatment within four weeks of being ready to treatment in 2004/05. Target for 2006-2009: Maintain at or above 90% within four weeks.
- Waiting times for chemotherapy, 90% began treatment within two weeks of being ready to treat in 2004/2005. Target for 2006-2009: Maintain at 90% within two weeks

One outcome relevant for cancer control can be found in the 2005/06-2007/08 Performance Agreement (April 2005) between the BC Ministry of Health Services and the Health Authorities, namely the Provincial Health Services Authority (PHSA). The PHSA is held accountable for meeting the targets for the performance measures identified in the agreement, such as:

- For the next three years (2005/06 to 2007/08), increase the proportion of women aged 50 to 74 participating in screening mammography by 2% over the previous year with an increase by at least 3% within the Northern Health region, with a long term target of 70% participation rate.

Canada

A target for breast screening can be found in Health Canada's Evaluation Indicators Working Group Report:[671]

- Percentage of women aged 50-69 who have a screening mammogram (biennally) should be of 70% or greater.

Common wait time benchmarks were established for Canadian provinces in December 2005. The ones relevant for cancer control are following:

- Cancer surgery : no benchmarck
- Cancer Radiation therapy: to treat cancer within four weeks of patients being ready to treat

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[669] This document is a response to the Premier's Advisory Council on Health's (Mazankowsky Report) first recommendation: to stay healthy. The framework sets objectives and targets to guide the Government of Alberta's action in promoting health and preventing disease and injury. Date unknown, but was mentionned in Alberta 2004 budget. Available at: http://www.health.gov.ab.ca/key/reform_framework.html

[670] Alberta Cancer Board. Schedule B: Performance expectations, measures, and expected results, Multi-year Performance Agreement 2005/2006-2006/2007. Available at: http://www.cancerboard.ab.ca/pdf/about_acb/ar_2004-05.pdf

[671] Health Canada. Evaluation Indicators Working Group Report Guidelines for monitoring breast screening program performance, 2002, p.8.

- Breast cancer screening for women aged 50 to 69 every two years; and
- Cervical cancer screening for women aged 18 to 69 every three years after two normal tests.

The *CSCC Business plan 2006-2010* states that by 2033, CSCC implementation should result in:

- 45% reduction in the projected number of new cases
- 51% reduction in the projected number of cancer deaths
- Over $39 billion savings in direct health care costs,
- Preventing the loss of over $34 billion in total government tax revenues and
- Preventing the loss of over $101 billion in wage-based productivity.

The 2006-2010 Business Plan for the CSCC includes a set of agreed pan-Canadian indicators and measures to be used for evaluating the Performance of the CSCC's initiatives. These indicators are grouped into three categories: (1) population-based, which relate to prevention and treatment targets; (2) strategic-based, which relate to strategic investment areas and activities of the Council; and (3) operational-based, which relate to priority investment areas of the Council, planning controls, budget, and implementation of standards and indicators. Population-based targets are to be established by the Quality and Performance Assurance (QPA) Working Group, in partnership with the Council, to act as performance indicators of the CSCC. Moreover, the CSCC Council and its Priority Area Action Groups have established systemic objectives for each CSCC Priority Area Action Group.[672] Among these objectives are the following measurable outcomes:

- 100% of cancer patients will have access to supportive and palliative care services by 2010
- Over the next 10 years, implement the Human Resources Planning Information System
- Over the next three years, link and standardize surveillance and data collection systems across Canada

In 2003, the CSCC Standards Action Group commissioned a literature review and environmental scan for cancer control indicators.[673]

England

Some cancer targets/outcomes were set out before the NHS Cancer Plan, for which the Plan is subordinated. Since 1997, the government has pledged that it will:

- Reduce the death rate from cancer in people under 75 by at least 20% by 2010 (so that England's five-year survival rates for cancer will compare with the best in Europe).
- Reduce smoking in adults from 28% to 24% by 2010 (*Smoking Kills*, 1998 UK tobacco control strategy)

The *NHS Cancer Plan* (2000) has set out to:

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[672] CSCC. Establishing the strategic framework for the Canadian strategy cancer control. 2005 and CSCC. 2006-2010 business plan for the CSCC, 2006, p. 31.

[673] Canadian Council on Health Services Accreditation. Literature review and environmental scan for cancer control indicators. Submitted to the CSCC Standards Action Group, March 2004.

- Reduce smoking rates among manual groups from 32% in 1998 to 26% by 2010, and achieve
- Maximum one month wait from diagnosis to treatment for all cancers by 2005
- Maximum two month wait from urgent GP referral to treatment for all cancers by 2005
- By 2004 every patient diagnosed with cancer will benefit from pre-planned and pre-booked care

A target for breast screening can be found in NHS Breast Screening Program Annual Report (2005):[674]

- The standard is an acceptance rate after first invitation greater or equal to 70% among women aged 50-64.

Additional cancer control relevant targets were formulated in the *Priorities and planning framework 2003 – 2006*: [675]

- Reduce the rate of smoking, contributing to the national target of: 800,000 smokers from all groups successfully quitting at the 4 week stage by 2006.
- Extend breast screening to all women aged 65-70 by 2004

Moreover, a new cancer mortality inequality target was introduced in a Public Services Agreement [676] that seeks to:

- Achieve a reduction in the inequalities gap of at least 6% between the fifth of areas with the worst health and deprivation indicators and the population as a whole.

France

The *Cancer Plan 2003-2007* includes the following measurable outcomes:

- Reduce cancer mortality by 20% in the next five years (by 2007).
- Smoking should drop by 30% among the young; by 20% in the adult population, and there should be a 20% drop as well in the number of alcohol dependent adults
- 80% of all women aged 50 to 74 will be screened for breast cancer; 80% of all women aged 25 to 69 will be screened for cervical cancer.
- 100% of all patients must gain access to customized care programs
- 100% of all patients must have access to procedures for breaking the bad news consultations and quality information on support structures
- At least 10% of all patients are included in clinical trials in reference centers.

The *Loi sur la santé publique*[677] includes 100 public health objectives, including the following quantifiable one that are relevant to cancer control:

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[674] NHS Breast screening programmes 2005 review, p. 19. Available at: http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp-annualreview2005.pdf

[675] Department of Health (2002). Improvement, expansion and reform: The next three years. Priorities and planning framework 2003 – 2006, p. 14. Available at: http://www.dh.gov.uk/assetRoot/04/07/02/02/04070202.pdf

[676] Cited in The NHS Cancer Plan and the new NHS: Providing a patient-centered service, 2004, p. 10.

[677] Loi no 2004-806 du 9 août 2004 relative à la politique de santé publique, See annexe on Rapports d’objectifs de santé publique

- Reduce tobacco use prevalence from 33 to 25% amongst men and from 26 to 20% amongst women by 2008 (while targeting most specifically youth and social groups with high prevalence);
- Reduce obesity prevalence from 20% amongst adults (from 42% in 2003 to 33% in 2008);
- Reduce the proportion of people with a low rate of fruits/vegetables consumption by 20% (from a 60% prevalence in 2000 to 45%);
- Continu reducing cervical cancer incidence by 2.5% each year, namely by reaching a screening coverage rate of 80% for women between 25-69 years old of age and by using HPV testing;
- Reduce the proportion of advanced breast cancer, namely by increasing coverage rate of screening by 80% for women between 50-74 years old;
- Improve survival of cancer patients, namely by ensuring that 100% of those patients benefit from a multidisciplinary and coordinated care management.

New Zealand

In Clearing the Smoke. A five-year plan for tobacco control in New Zealand (2004-2009), tobacco control targets are the following:

- Reduce the adult (aged 15 and over) smoking prevalence from 25% to at least 20% or less by 2009.
- Reduce the tobacco products sold from 1187 cigarette equivalents per adult per year to less than 1000 by 2009.
- Reduce the smoking prevalence among people aged 15.19 from 26% to at least 20% by 2009.
- Reduce the smoking prevalence among adults with a household income under $20,000 from 33.7% for males and 32.6% for females to at least 30% (for both males and females) by 2009.
- Reduce the daily smoking prevalence among Year 10 students (14.15-year-olds) at low socioeconomic decile schools (ie, deciles 1 and 2) from 15% for males and 29.7% for females to at least 12% for males and at least 25% for females by 2009.
- Reduce the smoking prevalence of Māori adults from 49% to at least 40 percent by the 2009.
- Reduce the proportion of Māori females aged 14.15 smoking daily from 34.3% to at least 30% by 2009.
- Reduce the smoking prevalence of Māori women aged 15.24 from 57.5% to at least 50% by 2009.
- Reduce the proportion of indoor workers exposed to environmental tobacco smoke during working hours to zero by 2006. (Note: It was 17% in 2001.)

The National Cervical Screening Program of the National Screening Unit of the Ministry of Health has set the following targets:[678]

- Incidence: 8.0 for 2006 and 7.5 for 2011;
- Mortality: 2.5 for 2006 and 2.0 for 2011;
- Coverage (% eligible): 75 for 2006 and 80 for 2011

The Breastscreen Aotearoa Programme of the National Screening Unit of the Ministry of Health has set the following target:[679]

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[678] Summary Report. National Cervical Screening Programme: Targets for 2006 and 2011. Available at: http://www.nsu.govt.nz/Files/NCSP_targets_2006.pdf

- 70% or more of eliguible women receive a screen within the Programme in the most recent 24 months.

The *NZ Cancer Control Action Plan 2005-2010* provides a template which identifies desired outcomes/results, specific actions, key stakeholders, and milestones and/or measures and/or timeframes for each objective of the NZ Cancer Control Strategy. The Action Plan includes the following measurable outcomes:

- Reduce adult smoking prevalence to 20% or less by the end of phase 2 (by 2010)

The NZ Cancer Control Action Plan states that an increased coverage from 45 to 70 percent for Maori and Pacific Island women would produce a 10% reduction in breast cancer mortality.

- The target for the biennial breast screen participation rate has been set to 70% [680]

Radiotherapy wait times targets the following:[681]

- The interval between the patient's referral from a medical practitioner to the oncology department, and the beginning of radiation treatment should be within 24 hours for priority A patients (urgent): within 2 weeks for priority B patients (curative); within four weeks for priority C patients (palliative and other radical): and the start date for priority D patients (combined chemotherapy and radiation treatment) should be booked according to treatment schedule.

Nova Scotia

No cancer control relevant targets, indicators or outcomes could be found in the Department of Health Business Plans for the years 2003-04, 2004-05 2005-06 and 2006-07 (nor in their Annual Accountability Reports). No targets were found in the CCNS program documents and website.

Planned outcomes indicators for tobacco control are defined in the *Nova Scotia Tobacco Control Strategy Evaluation Framework* (2002) as reported in the *Nova Scotia Tobacco Control Strategy Evaluation* (2006):

- Percentage of Nova Scotians who think second-hand smoke is a significant cause of health problems will increase from 48% to 75% by 2005;
- All Nova Scotians will be covered by legislation providing 100% smoke-free places (workplaces and public places) by 2003;
- The number of smoke-free homes in Nova Scotia is increased from 55% to75% by 2005.
- 45% of smokers who use the 1-800 service will make at least 1 quit attempt at a 1 month follow-up;
- 65% of smokers who use the 1-800 service will have cut down the amount they smoke at a 1 month follow-up;
- 45% of nicotine addicted individuals that complete a nicotine addiction treatment program will not be smoking at a 12 month follow-up;
- The percentage of smokers who made at least one quit attempt in the previous 12 months will increase from 45% to 55% by 2004;

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[679] Ministry of Health. National Screening Unit. Breastscreen Aotearoa. National Policy and Quality Standards, 2004, p. 9.

[680] Andrew Page & Richard Taylor. Independent Monitoring Report Breastscreen Aotearoa January-June, 2005, p. 3 Available at: http://www.healthywomen.org.nz/MoHpro/Monitor.aspx

[681] See NZ Health Ministry, Cancer waiting times data, available at: http://www.moh.govt.nz/moh.nsf/UnidPrint/MH2099?OpenDocument

- The percentage of smokers (ever smokers) who are thinking about quitting (in the previous 12 months) will increase from 19% to 25% by 2004;
- The percentage of smokers (ever smokers) who are preparing to take action (in the previous 12 months) will move from 7% to 15% by 2004.
- New and strengthened communitybased initiatives for tobacco control;
- New and strengthened partnerships/coalitions for tobacco control;
- New and strengthened partnerships for tobacco control within ethno-cultural networks;
- New and strengthened community leadership for tobacco control;
- DHA tobacco strategies developed and implemented to support provincial strategy.
- Enhanced prevention services for youth (e.g. curriculum supplement implemented; information on the website);
- Enhanced nicotine treatment/cessation services for youth;
- 30% of youth that complete a cessation support program will not be smoking at a 1 month follow-up;
- The percentage of smokers (ever smokers) aged 15 to 19 who are thinking about quitting will increase from 33% to 40%;
- All schools in Nova Scotia implement and enforce 100% smoke-free schools and school ground policy by 2005;
- Sales to minors compliance rate is increased from 67% to 80% by 2004.

Some measurable targets are associated with the Nova Scotia Breast Screening Program, established in 1991:

- Reduce the mortality from breast cancer in Nova Scotia women aged 50-69 years of age by 30% within ten years following development of a province wide screening program. [682]
- 70% biennial participation rate for women aged between 50 and 69.[683]

The provincial target for triennial cervical screening is 85% participation rate.[684]

The Provincial Wait Time Project Steering Committee recommended that Cancer Care Nova Scotia lead a process to create a province-wide priority tool, priority bands, and target wait times for Referrals from General Practitioner to Specialist in medical oncology. The steering committee recommended that once this standard has been created that the information system used by Cancer Care Nova Scotia be modified to collect and report this information.[685]

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[682] See p. 3 of 2004 Annual report, available at: http://www.breastscreening.ns.ca/

[683] See p. 10 of 2004 Annual report, available at: http://www.breastscreening.ns.ca/

[684] See p. 35 of Understanding Cancer in Nova Scotia 2006.

[685] Implementation plan of the Nova Scotia wait time monitoring project steering committee, 2004, p. 8. Available at: http://www.gov.ns.ca/heal/waittimes/wait-time implement.pdf#search=%22wait%20time%20targets%20nova%20scotia%22

Ontario

The *Cancer 2020 Prevention and Screening Action Plan* includes 20 measurable targets, including five for tobacco use and five for screening. Among the latter are the following cancer control relevant meaurable ourcomes:

- Reduce the proportion of teens who are smoking from 19% (2001) to 2% (by 2020)
- Reduce the proportion of adults who are smoking from 26% (2001) to 5%
- Increase the proportion of women aged 50 to 69 who are screened for breast cancer from 62% (2001) to 90%
- Increase the proportion of women undergoing cervical screening from 82% (1998/99) to 95%
- Increase the proportion of Ontarians participating in an organized colorectal screening program from 10% (1999) to 90%

Ontario's Government set wait time targets in December 2005 for cancer surgery:[686]

- Cancer surgery (for priority categories 1, 2 , 3 and 4 respectively): immediate, 2 weeks, 4 weeks and 12 weeks wait from ready to treat to treatment
  Priority 1-- Threatens life of person, such as airway obstruction or bleeding
  Priority 2 -- Very aggressive tumours such as central nervous system cancer
  Priority 3 -- Person with known or suspected invasive cancer, that do not fall into Priority 1, 2 or 4
  Priority 4 -- Patients with slow-growing tumours

Target wait times for different cancer treatments were recently proposed by Cancer Care Ontario[687] and some of them include:

- Cancer surgery (for priority categories 1, 2 , 3 and 4 respectively): immediate, 14 days, 28 days and 84 days wait from ready to treat to treatment
- Radiation treatment (for priority categories 1, 2 and 3 respectively): immediate, 7 days, and 14 days wait from ready to treat to treatment
- Systemic therapy (for priority categories 1, 2 and 3 respectively): immediate, 7 days, and 14 days wait from ready to treat to treatment

In the *Ontario Cancer Plan 2005-2008*, the six priorities are each associated with a number of actions (termed action plans). Each action plan is in turn characterized by a description, deliverables and a list of outcomes. Those outcomes are not quantifiable but more like expected results.

The *Cancer System Quality Index* developed by the Cancer Quality Council of Ontario supports the assessment of the action plan's impact through the development of relevant quality and performance measures.

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[686] See Ontario MOHLTC backgrounder information at: http://www.health.gov.on.ca/english/media/news_releases/archives/nr_05/bg_121605.pdf

[687] Cancer Care Ontario. Improving access to cancer services: Wait time targets for cancer treatment. Report of the Wait times project 05/06, June 2006, p. 2.

Appendix 6A -- Key actors in cancer control governance by jurisdictions

Alberta

Alberta Health and Wellness (Department):
Alberta Health and Wellness is an arm of government that oversees the publicly funded health care system in Alberta. Key roles include providing leadership; protecting and promoting good health; preventing disease; setting direction, policy and provincial standards for the health care system; measuring and reporting on the performance of the system; setting priorities based on health needs; and determining the scope of financial, capital and human resources required.

Regional Health Authorities (RHAs, 2003-):
Health Authorities are separate from the department of health and include nine RHAs , two Provincial Health Boards: the Alberta Mental Health Board and the Alberta Cancer Board, as well as the Health Quality Council of Alberta. The Health Quality Council of Alberta (2002-) is mandated by the government to report on the quality, safety and performance of health services. RHAs are responsible for hospitals, continuing care facilities, community health services and public health programs. Key roles within each region include promoting and protecting the health of the population; determining priorities in providing health services, and allocating resources accordingly; ensuring that reasonable access to quality health services is provided throughout the region; and promoting health services in a way that responds to the needs of individuals and communities and supports the integration of services and facilities in the region. RHA's are accountable to the population they serve and to the Ministry of Health for the funding they receive.

Alberta Cancer Board (ACB, 1967-):
ACB is a provincial health board, initially established in 1967, that now operates under the authority of the Cancer Programs Act Chapter C-2, Revised Statutes of Alberta, 2000. It is mandated by the government to provide cancer services from prevention to care, and to coordinate the planning, development and delivery of programs and services in collaboration with the 9 Regional Health Authorities (RHAs). The legislated mandate of ACB includes to operate the Alberta Cancer registry. ACB is also mandated to manage fundamental and applied cancer research programs.

Alberta Coordinating Council for Cancer Control (ACCCC, 1999-):
This Council is advosory to the ACB and is comprised of representants from the Health Ministry, RHAs, ACB and the Canadian Cancer Society. It is chaired by ACB and the RHAs, and is involved in the development of the Provincial Cancer Control Strategy.

Some charitable/voluntary/advocacy organizations:

- *Alberta Breast Cancer Network*
- *Alberta Cancer Foundation:* A corporate entity and charitable organization governed by the Alberta Cancer Programs Act , which raises and receives fund on behalf of the Alberta Cancer Board (over $20M per year). About 70% of ACF funding supports research, while the remaining part supports patient programs, equipment purchase and cancer care across Alberta.
- *Alberta Healthy Living Network*
- *Canadian Cancer Society, Alberta and North West Territories Division (1938):* Provided funds to set up the Alberta Research Tumor Bank.
- *Kids Cancer Care Foundation*

British Columbia

Ministry of Health:
The Ministry is responsible for establishing and articulating clear expectations and target outcomes for health authority performance, monitoring and evaluating health authority performance against those expectations, and reporting to the public.

Provincial Health Services Authority (PHSA) and Regional Health Authorities (PHSA, 2001-):
B.C.'s health governance structure consists of six health authorities - a Provincial Health Services Authority and five Geographic Health Authorities. Health authorities are responsible for identifying population health needs, planning appropriate programs and services, ensuring programs and services are properly funded and managed, and meeting performance objectives. PHSA's mandate is to ensure the planning, coordination, accessibility, quality, efficiency and effectiveness of selected province-wide health care programs and services. PHSA funds and oversees BCCA activities since december 2001.

BC Cancer Agency (BCCA, 1974-):
The Agency is mandated by the BC government under the *Society Act* to develop and manage a provincial program for cancer control. BCCA is involved in cancer control program development and implementation, services provision, research and clinical practice guidelines development among other things. The BCCA is a public hospital (Hospitals Act), a teaching hospital, a separate legal entity (Society Act), and a Branch Society of the PHSA. Each regional centre of the BC Cancer Agency relates to "host" institutions, whose catchment falls within the jurisdiction of a regional health authority. BCCA is accountable to PHSA through performance agreement contracts.

Some charitable/voluntary/advocacy organizations:
- *BC Cancer Foundation (1935-):*

An independent charitable organization that raises and stewards resources to support research and compassionate care through the BC Cancer Agency.
- *Canadian Cancer Society, BC and Yukon Division (1938-):*

Major priorities are: Prevention, Advocacy for healthy public policy, Research funding, Information, Support.
- *Canadian Breast Cancer Foundation, BC and Yukon Chapter (1993-):*

Major priorities that emerged from a gap analysis of the trajectories of individuals suspected with breast cancer are:
Public education and Information in a timely manner, Navigation through the system, and Promotion of an integrated breast
health program (one-stop center).

Canada

Health Canada and Public Health Agency (2004-):
Health Canada is part of the public service and is responsible to communicate with the Canadian public about health promotion, disease prevention and safety messaging. The Public health Agency, created in 2004, is also part of the public service but is separate from Health Canada. Both structures report to the Minister of Health. The Agency's role is to coordinate federal efforts in identifying and reducing public health risks and threats and support national readiness to respond to health crises. It also works with other government departments and agencies on long-term strategies to confront both infectious and chronic disease and injury prevention. The Center for Disease Prevention and Control, formerly part of Health Canada, which hosted the Canadian Cancer Control Strategy Secretariat, was relocated to the Public Health Agency.

Canadian Council for Cancer Control (2002-):
The Council was created to implement the Canadian Strategy for Cancer Control (CSCC). The Council's leadership responsibilities include: policy development, advice to governments on cancer control initiatives, organization of stakeholders' forums, monitoring and reporting on progress toward implementation of CSCC and achievement of cancer control targets. Its corporate responsibilities are to maintain and revitalize the CSCC as a dynamic overall strategic plan, to conceive and publish a five-year revolving plan, an annual action plan and a budget, to review and evaluate the previous year's activities, and to report the abovementioned plans and evaluations to the Conference of Deputy Ministers, the forum of stakeholders, and to the Canadian Cancer Advocacy Network (CCAN). CCAN is a patient/survivor/stakeholder initiative formed to achieve a reduction in the burden of cancer through collaborative advocacy for changes in public policy governing the full spectrum of cancer control including primary prevention, screening, diagnosis, treatment, support services, palliative as well as paediatric cancers, based largely on the recommendations of CSCC.

Canadian Association of Provincial Cancer Agencies (CAPCA, 1980's-):
CAPCA is an interprovincial organization representing provincial/territorial cancer agencies and programs engaged in cancer control. It exists to support the reduction of the burden of cancer through effective leadership, collaboration, communication and advocacy for cancer control. It contributes to the development and implementation of the Canadian Strategy for Cancer Control. CAPCA has established a number of policy advisory committees in order to assist in addressing its priorities. These include: the Canadian Council of Cancer Registries and the Clinical Practice Guideline Initiative.

National Cancer Institute of Canada (NCIC, 1947-):
NCIC's mission is to undertake and support cancer research and related programs in Canada that will lead to the reduction of the incidence, morbidity and mortality from cancer. The latest ten-year plan include, among other things: positioning the NCIC in partnership with the Canadian Cancer Society as a credible voice on cancer control by targeting priority topics and subjecting them to rigorous, objective policy analysis that is linked to effective communications strategies

Some charitable/voluntary/advocacy organizations:
- *Cancer Advocacy Coalition of Canada (CACC):*

CACC is a non-profit cancer group dedicated to citizen advocacy. It provides annual evaluation of cancer system performance, published as Report Cards on Cancer.
- *Canadian Cancer Advocacy Network, renamed in 2006 as Canadian Cancer Action Network (CCAN):*

CCAN is a patient/survivor/stakeholder initiative formed to achieve a reduction in the burden of cancer through collaborative advocacy for changes in public policy governing the full spectrum of cancer control.Their prime focus is the promotion of the Canadian Strategy for Cancer Control.
- *Canadian Cancer Society (1938-):*

The Canadian Cancer Society is a national, community-based organization of volunteers whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer.

- National Cancer Leadership Forum (NCLF, 2003-2006):

The NCLF is a group of more than 90 people representing 30 major Canadian cancer organizations including provincial cancer control agencies, voluntary organizations, professional associations and drug companies dedicated to mobilizing the cancer community, the media, the Canadian public and the governments (provincial and federal) to ensure funding and implementation of the Canadian Strategy for Cancer Control (via a Campaign to control cancer). The Forum, supported by a leadership team, has held two stakeholders forum (2003, 2006). It ceased to exist as a forum following federal government funding announcement in November 2006. Activities of the forum now continue as the Campaign to Control Cancer.

England

Department of Health /National Health Service (NHS):
The Department of Health's work includes setting national standards, shaping the direction of health and social care services and promoting healthier living. It manages the health and social care system at a national level and provides strategic leadership to the NHS and social care organisations. It does not run the NHS or social services. It works with health and social care organisations, arm's length bodies and other public and private sector organisations to deliver health and social care. The NHS is structured and organized into commissioning (the process of planning and purchasing services) and service provision. The PCTs are the main decision-makers in the NHS because they have the responsibility for commissioning cancer services.

All-Party Parliamentary Group on Cancer (1998-):
The Group was established to keep cancer high on the political agenda; to campaign for excellence and equity in cancer care; to monitor implementation of the government initiatives on cancer; and to ensure that policy affecting cancer services is evidence-based and patient-centered. They published in 2004 the report titled: Meeting national targets, setting local priorities: the future of cancer services in England.

Cancer Policy Team:
This team has responsibility for developing, monitoring and reviewing policy, as well as advising Ministers (NAO Report, March 2005, p. 2)

Cancer Taskforce (2000-):
The Cancer Taskforce was set up to lead national implementation, bringing together cancer clinicians, GPs, patients and managers. Drawing on a wealth of wider expertise from across and beyond the NHS, it reflects the partnership needed at all levels to drive forward implementation. The Taskforce is chaired by the National Cancer Director. It monitors progress and identifies policy development needs. Advisory groups on individual cancer also were created. They include GPs, hospital specialists, nurse specialists, managers, voluntary groups and patient representatives.

National Cancer Director and Cancer Action Team (1999-):
The National Cancer Director is responsible for achieving national cancer targets set out in the NHS Cancer Plan. The National Cancer Action Team supports implementation of the Plan and development of Cancer Services Networks. It also leads on quality assurance of cancer services through the *Peer Review Program* that monitors standards in cancer care, and through development of standards for auditing, based on NICE Clinical Outcomes Guidance.

Cancer Care Group Workforce Team (Cancer CGWT):
The Cancer CGWT works alongside the Cancer Taskforce to deliver service improvement. It also links to other CGWTs to manage cross-cutting workforce development issues.

National Institute for Health and Clinical Excellence (NICE, 1999-):
NICE is an arm's length body of the Department of Health responsible for providing national evidence-based guidance on the promotion of good health and the prevention and treatment of ill health. This includes providing guidance for cancer, which form the basis for the development of measures against which individual services and cancer networks can be assessed such as the *Improving Outcome Guidance* and the *Manual for Cancer Services.*

NHS Institute for Innovation and Improvement (2005-):
This Institute is mandated to support the NHS in optimizing health service delivery among others. It superseeds the NHS Modernization Agency (2001-05) that hosted the Cancer Services Collaborative (1999-01) which provided strategic and operational support to Cancer Services Networks.

Healthcare Commission:
The Commission is an arm's length body of the Department of Health set up to promote and drive improvement in the quality of healthcare and public health. Main duties include among other things: to assess the management, provision and quality of NHS healthcare and public health services, and to review the performance of each NHS trust and award an annual performance (star) rating. The Healthcare Commission replaced the work of the Commission for Health Improvement in addition to taking over the private and voluntary healthcare functions of the National Care Standards Commission and some responsibilities from the Audit Commission, namely the elements which relate to efficiency, effectiveness and economy of healthcare.

NHS Strategic Health Authorities (SHAs, 2002-):
The Strategic Health Authorities are responsible for the strategic direction of services in their locality and for overall achievements of national parties. There are now 10 SHAs in England (down from 28 as of July 2006), serving as the local headquarters of the NHS. The mandate of the SHAs around cancer is to make sure that the Primary Care Trusts, and the Cancer Networks in their area meet the national priorities at the local level.

NHS Primary Care Trusts (PCTs, 2002-):
Created as a result of the NHS reform of April 2002, the Primary Care Trusts are a group of General Physicians and local administrators and practitioners that are responsible for planning services for populations of about 100,000 to 200,000. PCTs set priorities and allocate resources to implement national targets. 75% of the NHS funding to buy health care goes to the PCT, the remaining is held centrally and spent for national initiatives such as the screening programs, the Cancer Services Collaborative, the National Research Clinical Trials Network, etc.. The funding comes from the Department of Health and the Treasury. The performance of PCTs and the extent to which they succeed in balancing national and local priorities is monitored by Strategic Health Authorities (SHAs).

Cancer Services Networks (2001-):
The 34 existing Cancer Services Networks are large and complex non-statutory organizations that plan services for populations of one to 2 million people. They are virtual organizations that could be hosted anywhere but are usually hosted by a statutory organization, increasingly the PCTs. The Networks are the service delivery structure, bringing together all levels of care. They are responsible for the local implementation of the NHS Cancer Plan. The Network's executive team is composed of: a Network Director, a Medical Director (or Lead Clinician), a Nurse Director (or Lead), a Modernization Lead and administration staff. The Networks' role is to streamline services across the spectrum of cancer care offered by multiple organizations and health and social care professionals in the community, local hospitals, specialist cancer centers, cancer units, and hospices. They are accredited following a peer review, and funded by Primary Care Trusts based on the submission of action plans. The Network board is composed of the Chief Executives of those organizations both commissioning and providing services within that network. (Acute Care Trusts and Primary Care Trusts). This Board is accountable to its SHA.

National Cancer Research Institute (NCRI, 2001-):
NCRI is responsible for identifying gaps and opportunities in current cancer research and to facilitate collaboration across funding bodies across the UK. The NCRI oversees two research networks: The National Cancer Research Network (NCRN) and the National Translational Cancer Research Network. The NCRN's role is to

improving the infrastructure within NHS for clinical research in cancer and ensure that research is better integrated with cancer care. The cancer research networks are closely aligned with the cancer services networks.

Independant organization:
- *National Audit Office (NAO):*

NAO's role is to audit the financial statements of all government departments and agencies, and other public bodies. It reports to Parliament. It published three reports on the NHS Cancer Plan implementation and cancer services reform.

Professional organizations:
- *Association of Cancer Physicians*
- *Royal College of Radiologists (RCR)*
- *Royal College of Physicians (RCP):*

The above organizations have contributed to cancer policy namely by publishing reports such as: Review of the pattern of cancer services in England and Wales (ACP,1994); Cancer units. The provision of non-surgical specialist cancer services in district general hospitals (RCP and RCR, 2000); The cancer patient's physician: Recommendations for the development of medical oncology in England and Wales (RCP and ACP, 2000); Colorectal cancer screening in the UK;Joint position statement (2002).

Some charitable/voluntary/advocacy organizations:
- *Breast Cancer Care*

Breast Cancer Care is an Association providing information, practical assistance and emotional support for anyone affected by breast cancer.
- *Cancer BACUP*

Cancer BACUP is a charity, providing free cancer information service staffed by cancer nurses, publications on all aspects of cancer written specifically for patients and their families and a growing number of local centres in hospitals up and down the country, also staffed by specialist cancer nurses.
- *Macmillan Cancer Relief*

MacMillan is a charity that seeks to influence health and social care systems and Government policy to be more responsive to changing needs and expectations of people affected by cancer in the long term. They have produced the Gold Standards Framework for end of life care that is being implemented in the NHS. They fund cancer networks for multiple projects on supportive care.
- *National Cancer Alliance (NCA):*

NCA is a charity founded and led by cancer patients, to enable patients and carers to have a collective voice in the improvement of cancer services. The alliance represents cancer patients' views on key government policy group and published a number of influential studies on patient experiences of their care.

France

Direction Générale de la Santé (DGS):
This direction of the Health Ministry is at the heart of the health care system. It is responsible for: analysing health needs, developing health policies, overseeing health policy implementation, establishing public health initiatives, coordinating health protection and monitoring agencies, defining health professionals' educational curriculum and promoting user involvement.

Direction Générale de l'Hospitalisation et de l'Organisation des Soins (DHOS):
The DHOS is responsible for organizing health care services delivery in collaboration with the DGS, the Direction générale de l'action sociale (DAS) and the Direction de la sécurité sociale (DSS) and for ensuring the safety, quality, continuity and acessibility of the health care system among others.

Health Protection and Monitoring Agencies:
Those agencies are part of the public health system and are under the administrative supervision (*sous tutelle*) of the health Ministry. The InVS (Institut national de veille sanitaire) is responsible for cancer registries and the INPES (Institut national de prévention et d'éducation pour la santé) is responsible for cancer prevention initiatives.

Agences Régionales d'Hospitalisation (ARH, 1996-):
The 26 ARHs are responsible for the implementation of government policy regarding the functioning of hospitals within their regions. Their function include, most notably, the planning and implementation of regional priorities through the schémas régionaux d'organisation sanitaires (SROS). The SROS define for each region specific medical initiatives, which now include cancer care (since SROS III in 2006). ARHs are under the administrative supervision (*sous tutelle*) of the Health Ministry.

National Cancer Institute (INCa, 2004-):
INCa was created by law as a *Public Interest Group* to coordinate all actors involved in cancer control and to bring the cancer control policy at the international level. INCa is accountable to the Ministry for Health and to the Ministry for Research. It works in close collaboration with both Ministries, the Health Protection and Monitoring Agencies, national research organizations (INSERM, CNRS), patient organizations, national health insurance funds, and several federations of hospital/healthfacilities.

Fédération Nationale des Centres de Lutte Contre le Cancer (FNCLCC, 1964-):
FNCLCC is a not-for-profit association of 20 regional cancer centres established to defend the interests of those cancer centres and to collaborate with the Health Ministry on projects to improve cancer patients' care. The centres have a triple mission of care, research and education. The centers and its federation promote a multidisciplinary model of care, that integrates clinical research and education.

Independant organization:
- *Haute autorité de santé (HAS, 2005-):*

HAS is a consultative, public and independant organization of scientific expertise whose roles are to: 1) evaluate medical procedures, products and services reimbursed by the national health insurance, 2) implement health facilities accreditation process and 3) promote good healthcare practices among health professionals and the public. HAS has integrated the functions of the Agence National d'Accréditation et d'Évaluation en Santé (ANAES).

Some charitable/voluntary/advocacy organizations:
- *Association pour la recherche sur le cancer (ARC)*
- *Ligue nationale contre le cancer (LNCC, 1927-):*

LNCC is a not-for-profit association established to promote research, prevention and information and to advocate for cancer patients. The Ligue organized two public forums (États généraux des malades atteints de cancer) in 1998 and 2000 to communicate the needs of cancer patients and their families in the cancer policy development process.

New Zealand

Ministry of Health:
The Ministry of Health provides national policy advice, regulation, funding, and monitoring the performance. Some important components of cancer control are within the Ministry core businesses. The Ttobacco control strategy is under the Public Health Directorate. The National Screening Unit under the Public Health Directorate manages the national screening programs. Screening guidelines are elaborated by the NZ Guideline Group and the cancer registry is part of the NZ Health Information Service.

Principal Medical Advisor:
The Principal Medical Advisor is part of the executive team of the Health Ministry. Its role includes: provision of medical advice to the Director-General and the Minister; medical input into policy development; functioning as a liaison between the Ministry and the medical profession. The Principal Medical Advisor is seconded from the sector to ensure strong and ongoing sector linkages. He is involved in promoting the setting up of Regional Cancer Networks.

District Health Boards (DHBs, 2001-):
With the release of the New Zealand Health Strategy in 2000 came the establishment of 21 *District Health Boards* (DHBs). DHBs fund and provide health and disability support services throughout New Zealand.[688,689] The activities of the 21 DHBs are guided by two overarching strategies for the health and disability sector, the New Zealand Health Strategy and the New Zealand Disability Strategy. DHBs receive funding from the Ministry according to a population-based formula. This funding comes with service specifications or guidelines set forth by the Ministry of Health. DHBs are involved in the delivery of services across the full spectrum of cancer care and play a major role in implementing the cancer control strategy.[690] Health Ministry's expectations, namely for cancer control strategy implementation, are set out in specific DHB toolkits (Operation Policy frameworks). DHBs are playing an active role in the setting up of Regional Cancer Networks.

Cancer Control Council (2005-):
The Council was established by the Minister of Health under Section 11 of the *New Zealand Health and Disability Act*, to provide an independent and sustainable leadership in cancer control. The Council is accountable to the Minister of Health. Its role is to lead the cancer control sector to successfully implement New Zealand's Cancer Control Strategy, to provide independent oversight of actions to control cancer and implement the Strategy, and to foster collaboration, coordination, as well as to provide opportunities for non-government involvement.

Principal Advisor Cancer Control (2005-):
The Advisor was appointed by the Director-General of Health to provide leadership, advice, information and guidance to the Director-General of Health, the Ministry of Health and the Minister of Health on issues relating to cancer control. The Advisor's role is also to drive the implementation of the Strategy from within the Ministry of Health. The Advisor is also an ex officio member of the Cancer Control Council. This position is located within the Ministry's Clinical Services Directorate and has a close working relationship with the Deputy Director-General of Clinical Services. It is accountable to the Director-General of Health. It may also report to the Minister of Health on cancer control issues, having first notified the Director-General of Health.

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[688] Minister of Health (2003). Implementing the NZ Health Strategy 2003: The Minister of Health's third report on progress on the NZ Health Strategy. Wellingon: Ministry of Health.

[689] Minister of Health. Frequently Asked Questions About District Health Boards. Accessed September 24, 2003. Available at:http://www..moh.govt.nz/moh.nsf/30ad137c772c883e4c25665c002c4198/645b2d0c613f

[690] NZ action plan

New Zealand Cancer Treatment Working Party (NZCTWP):
The NZCTWP was established in 2001 as a union between three specialist working parties on Radiation Oncology, Medical Oncology, and Haematology. These parties published a report tilted: *Improving Non-Surgical Cancer Treatment Services in New Zealand* a review of and recommendations on cancer treatment services. This unified working Party has worked in partnership with the Ministry of Health and District Health Boards to develop strategies addressing the issues described in their report. The NZCTWP represents the professional cancer control community. The NZCTWP and its workgroups are contributing to the design and execution of many of the projects of Cancer Control Working Programme (2006-), established for the implementation of the Cancer Control Action Plan.

Cancer Control Trust (2001-2005):
Established with the funding support of the Cancer Society of NZ, the Child Cancer Foundation and the Health Ministry to promote and oversee the development of a national cancer control strategy for New Zealand. Produced a comprehensive review and a scoping plan for the Ministry of Health in 2001. The subsequent development of the National Strategy also involved a Cancer Control Steering Group (2001-2003). A Cancer Control Taskforce (2003-2005) was subsequently appointed to develop the Action Plan and to identify the form and function of the body that would lead, monitor and review implementation of the Strategy (the newly established Cancer Control Coucil).

Regional Cancer Networks (2006-):
Establising Regional Cancer Networks is a priority in the New Zealand Cancer Control Strategy Action Plan. Networks provide a formal structure to improve coordination of care for patients. Networks bring together organisations involved in the planning, funding and provision of cancer services, including consumers and their families, and are a mechanism to ensure that all the points in the cancer patient's journey are joined up. Most DHBs in New Zealand already have informal clinical cancer networks but creating a formal network will recognise, expand and enhance the current systems in place.

Some charitable/voluntary/advocacy organizations:

- *Cancer Society of New Zealand (1929-):*

The Cancer Society is a charity involved in prevention, advocacy for healthy public policy, research funding, information and support.

- *Child Cancer Foundation (1978-):*

National organisation with 4 divisions and 23 branches throughout New Zealand providing support for children and young people with cancer and their families, and the health professionals involved in their care. The Cancer Society and the Child Cancer Foundation gave 700,000 dollars between 2001 and 2004 for the development of the National Cancer Control Strategy.

Nova Scotia

Department of Health:
The department is responsible for managing the provincial Tobacco Control Strategy, the Nova Scotia Wait Times, Pharmacare and other programs that pertain to health problems in general, including cancer (Pharmacare includes a drug assistance program for cancer patients). Among its provincial programs are the Nova Scotia Breast Screening program and Cancer Care Nova Scotia (CCNS).

Cancer Systemic Therapy Policy Committee (2005-):
Committee created by the Department of health in collaboration with cancer care Nova Scotia to advise the government and recommend policies on new cancer drug therapies. The Commitee reports to the Deputy Health Minister.

District Health Authorities (DHAs, 2000-):
DHAs were created under the Health Authorities Act to govern, plan, manage, provide, control and strenghten health services in their cathchment area. These 9 DHAs also support the 37 Community Health Boards (CHBs) in their planning of community health projects related to health promotion and primary health care. DHAs are namely responsible for implementing CCNS Cancer district programs and patient navigation programs in collaboration with CCNS.

Cancer Care Nova Scotia (CCNS, 1998-):
Cancer Care Nova Scotia (CCNS) is a Provincial Program in the Acute and Tertiary Care Branch of the Department of Health created in 1998 by the Department of Health to coordinate, evaluate, and strengthen cancer services. It does so namely by developing service standards and monitoring their achievement. CCNS also provides advice to the Department of Health, the Regional Health Boards and care providers, based on best practices, stakeholders' input and research-based evidence. It does not deliver services, does not offer support to patients, does not have research centers and does not make fundraising. Working with others in the field of cancer and health, CCNS programs cover prevention, screening, education, treatment, follow-up care and palliation.

Some charitable/voluntary/advocacy organizations:
- *Canadian Cancer Society – Nova Scotia Chapter*
- *Nova Scotia Cancer Patient Education Committee*
- *Nova Scotia Alliance for Healthy Eating and Physical Activity (2001-)*
- *Breast Cancer Action Nova Scotia (1994-):*

An action group of survivors and other volunteers seeking to address the obstacles faced by women/families/friends living with breast cancer. In 2001, the group founded a province-wide network to bring together organizations, health care providers, support groups, and individuals who are working in the province to provide information and services to people affected by breast cancer. The network is currently funded by the Canadian Breast Cancer Initiative and Cancer Care Nova Scotia.

Ontario

Ministry of Health and Long Term Care (MOHLTC, 1999-):
The MOHLTC is responsible for setting strategic directions and provincial standards for high-quality, accessible health care.. The Ministry is responsible for administering the health care system and providing services to the Ontario public through such programs as health insurance, drug benefits, assistive devices, care for the

mentally ill, long-term care, home care, community and public health, and health promotion and disease prevention. It also regulates hospitals and nursing homes, operates psychiatric hospitals and medical laboratories, and co-ordinates emergency health services. The Smoke Free Ontario Strategy for Tobacco control is managed by the Public Health division of the Ministry. In April 2005, the MOHLTC replaced the 16 District Health Councils by 14 Local Health Integration Networks as the principal organizations responsible for planning, coordinating, integrating and funding the delivery of health care services within their geographic areas.

Cancer Care Ontario (CCO, 1997-):
Cancer Care Ontario is an operational service agency within the Management Board of Cabinet Establishment and Scheduling of Agencies Directives. CCO is accountable to the Minister of Health and Long-Term Care in exercising its mandate. CCO is governed by the *Cancer Act* (L.R.O. 1990). Its role is to steer and coordinate Ontario's cancer services and prevention efforts. CCO has an advisory, planning and a funding role. It also advises the Ontario government on all aspects of provincial cancer care, provides information to health care providers and decision-makers, and motivates better cancer system performance.

Cancer Quality Council of Ontario (CQCO, 2002-):
CQCO is a quasi-independant body of experts established by the Minister of Health and located within Cancer Care Ontario to improve the quality and performance of all cancer services so that patients receive care that is timely, accessible and appropriate. Working with its partners in the cancer system, CQCO monitors and reports on the quality and performance of the cancer system, and provides strategies for health care providers and decision makers to capitalize on opportunities to improve cancer services.

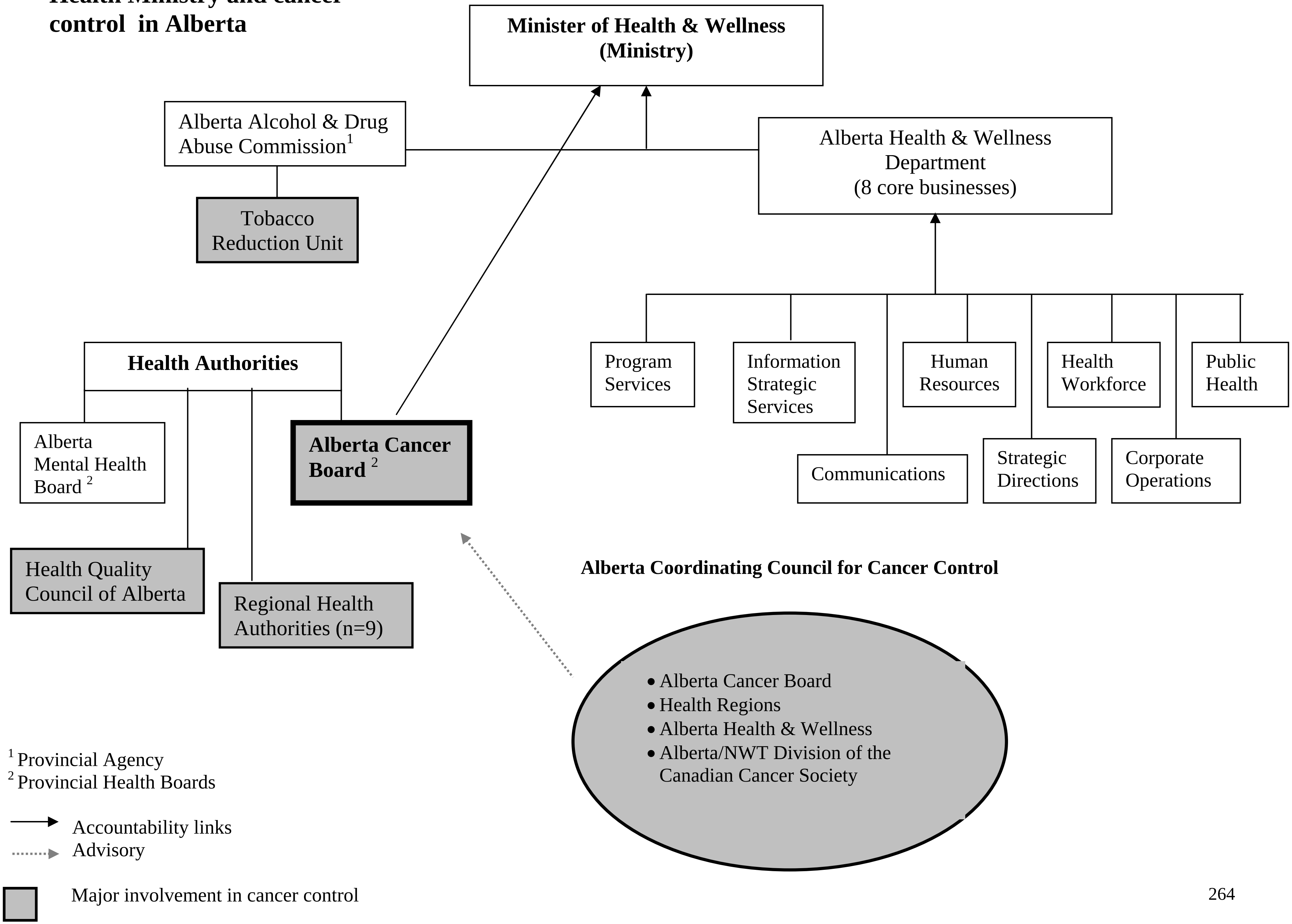
Local Health Integration Networks (LHINs, 2005-):
Through the Local Health System Integration Act (2006), the newly created 14 LHINs were given the mandate and power to plan, integrate and fund local health services – including hospitals, Community Care Access Centres, Community Health Centres, as well as home care, long-term care, mental health, addiction and community support services – for their specific geographic areas. LHINs differ from regional health authorities in that patient choice of physician and medical or acute services is not be limited by LHIN boundaries, LHINs are not providers of direct services and LHINs do not require consolidation of existing health organizations' governance structures, e.g. hospitals, long term care homes, etc. The networks allow local communities and health care providers to work together to identify local priorities, plan health services and deliver them in a more coordinated fashion. The LHIN are crown agencies, subject to Ministry of Government Service accountability policies and directives. The LHIN/Ministry relationship is subject to the new legislation, the Memorandum of Understanding, accountability as well as regular, ongoing dialogue between the Ministry, LHIN CEOs and Chairs of the LHIN Boards.

Integrated Cancer Programs -- Host Hospitals (2002-):
An Integrated Cancer Program (ICP) was created at every hospital that had a regional cancer centre (host hospitals). Through contractual arrangements between the so-called host hospitals and Cancer Care Ontario, the host hospitals are now responsible for the direct management and delivery of patient services and operation of the ICPs. Cancer Care Ontario, in partnership with the host hospitals, oversees those funds that are transferred to the ICPs. There are 14 ICPs.

Some charitable/voluntary/advocacy organizations:
- *Breast Cancer Support Services*
- *Canadian Cancer Society, Ontario chapter*
- *Ontario Breast Cancer Information and Exchange Project*

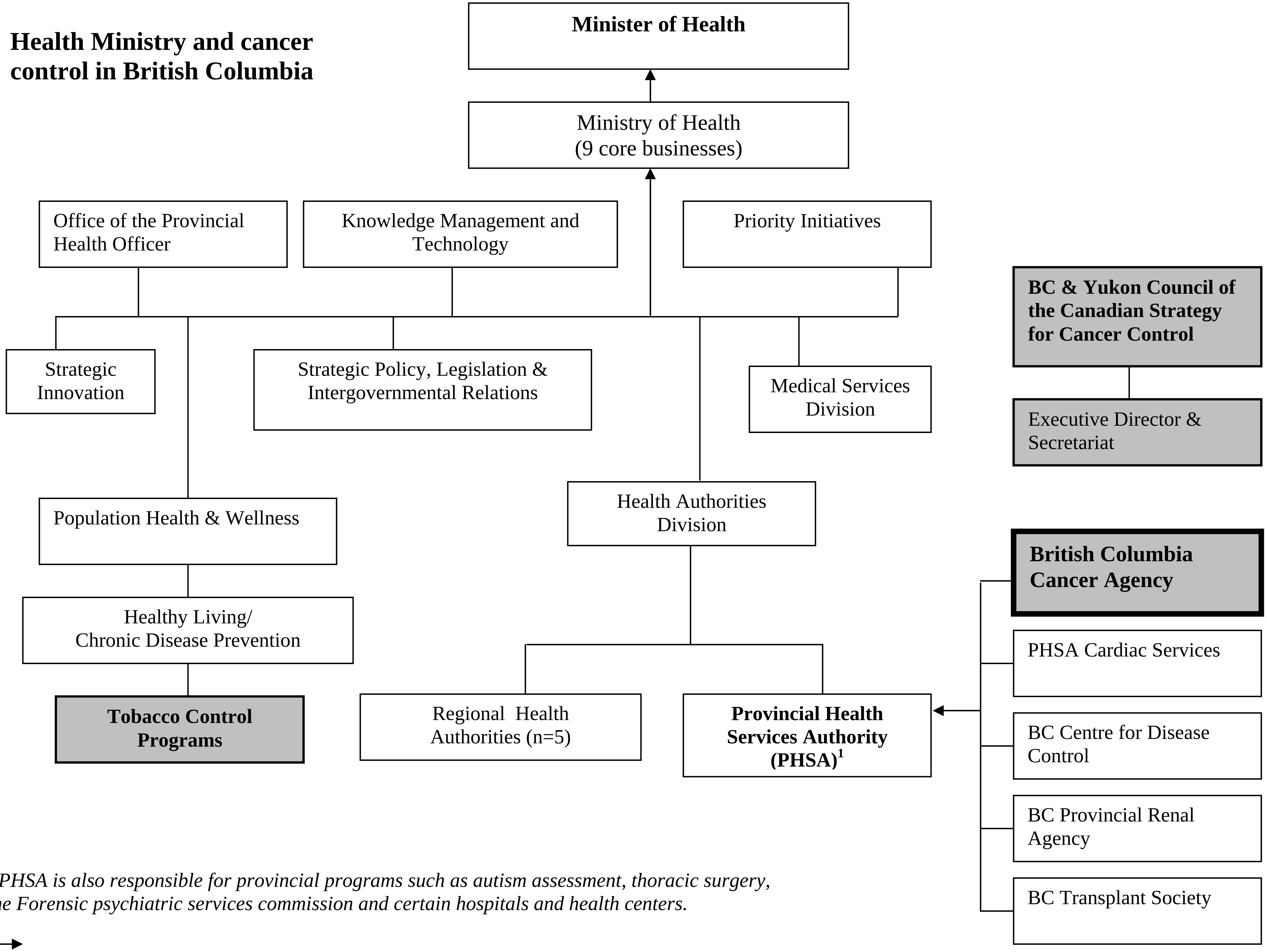
Appendix 6B -- Organizational charts of health ministries by jurisdictions

Health Ministry and cancer control in Alberta



[1] Provincial Agency
[2] Provincial Health Boards

Health Ministry and cancer control in British Columbia

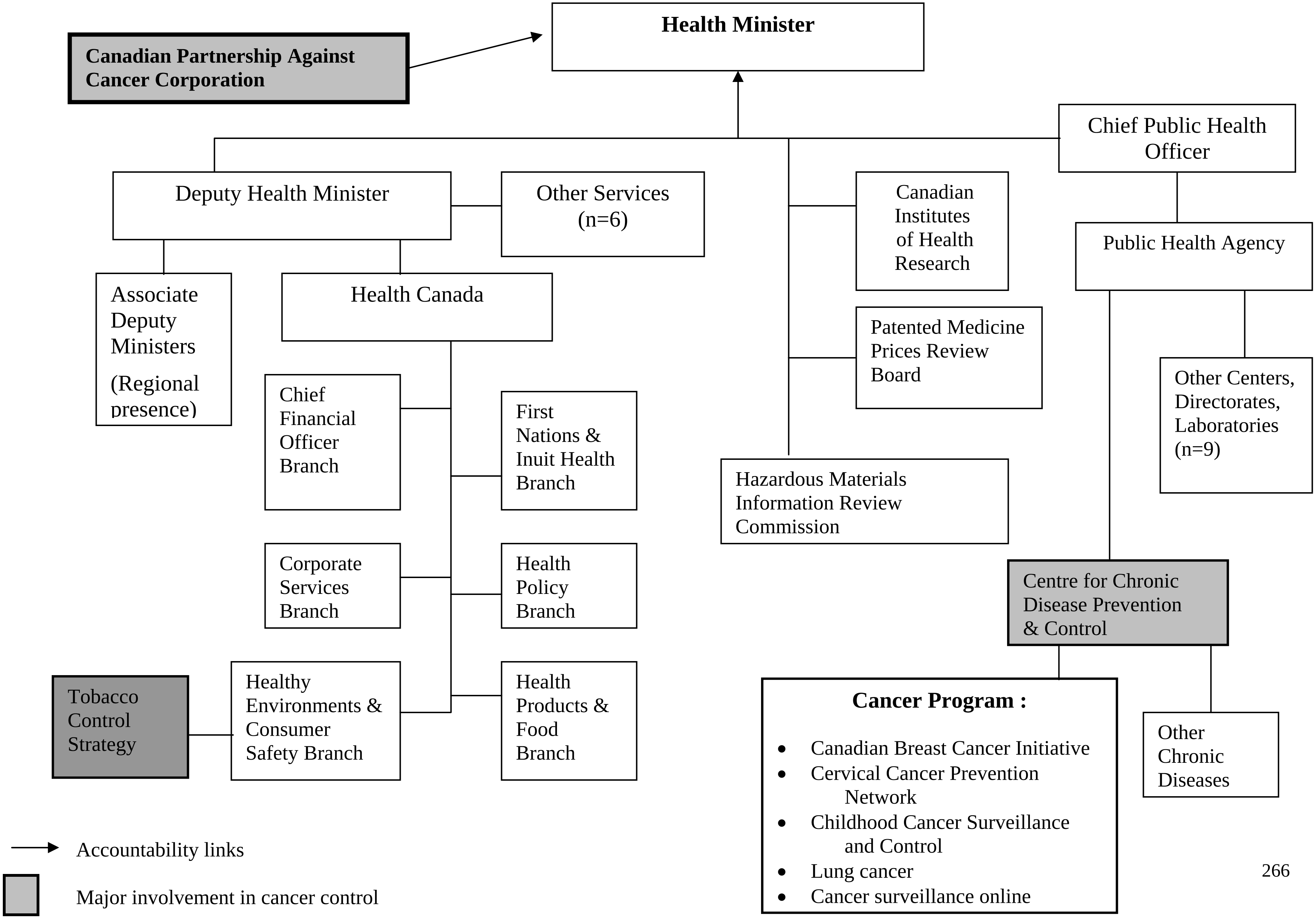


[1] *PHSA is also responsible for provincial programs such as autism assessment, thoracic surgery, the Forensic psychiatric services commission and certain hospitals and health centers.*

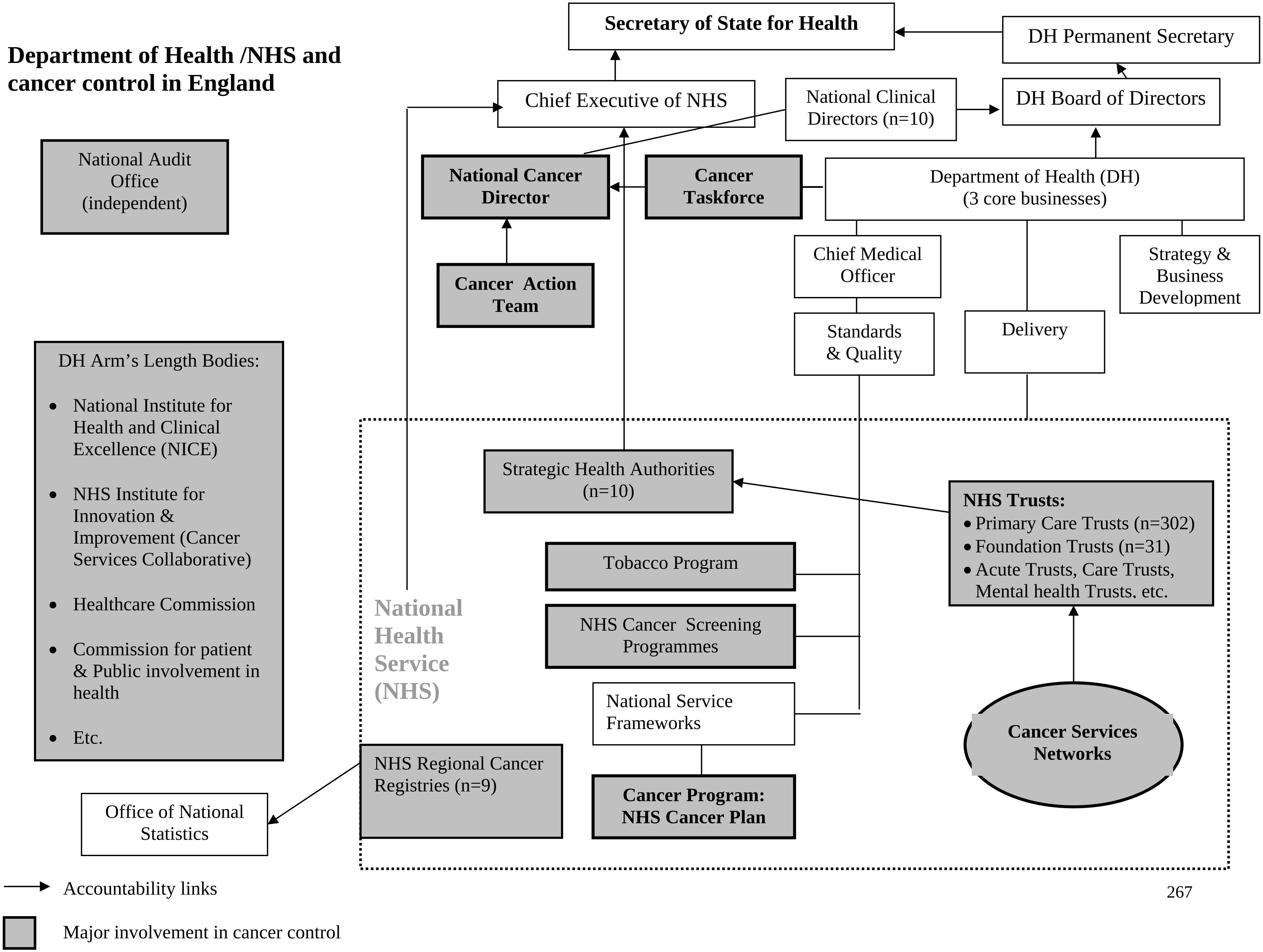
→ Accountability links

▨ Major involvement in cancer control

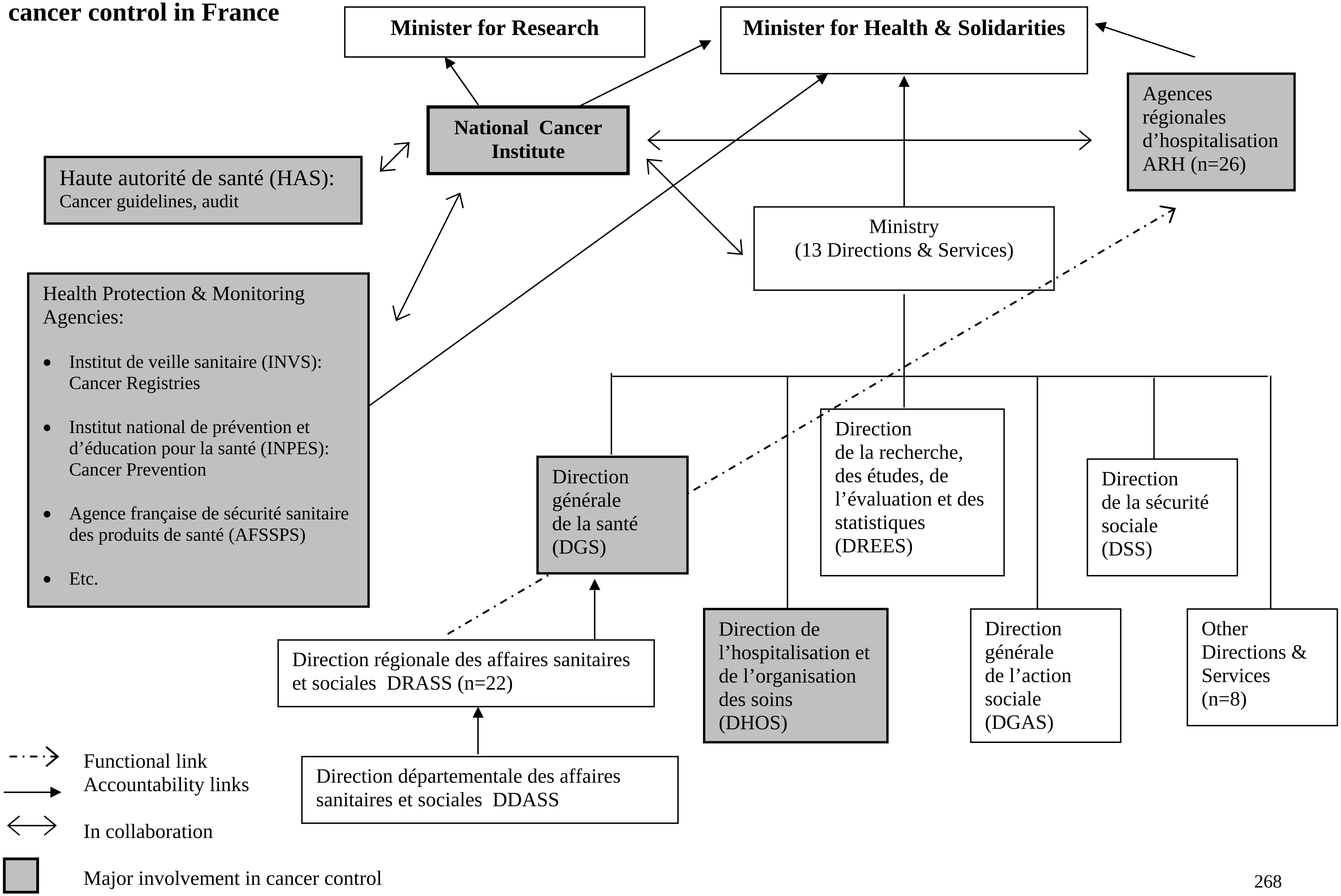
Health Ministry and cancer control in Canada



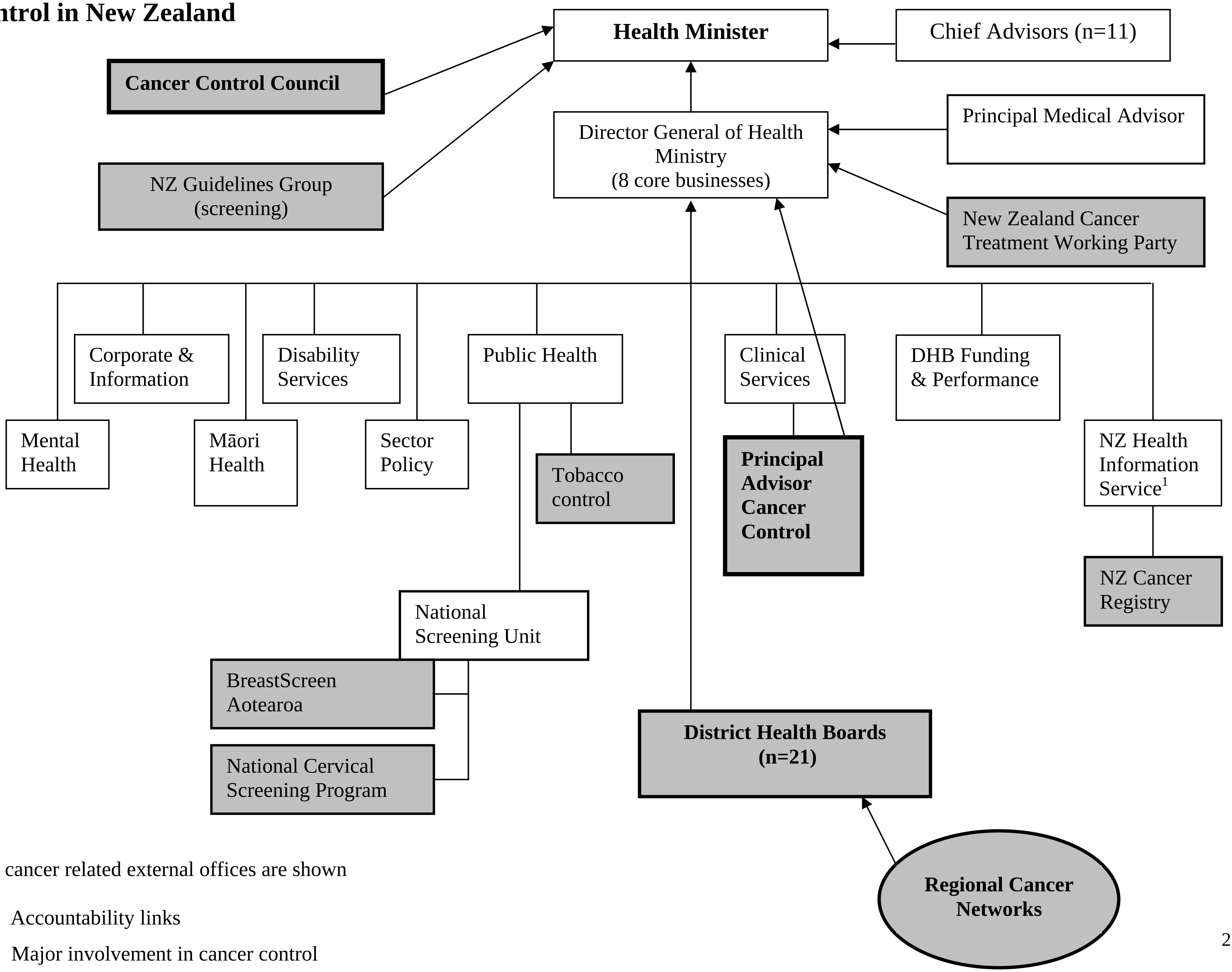
Department of Health /NHS and cancer control in England



Health Ministry and cancer control in France



Health Ministry and cancer control in New Zealand

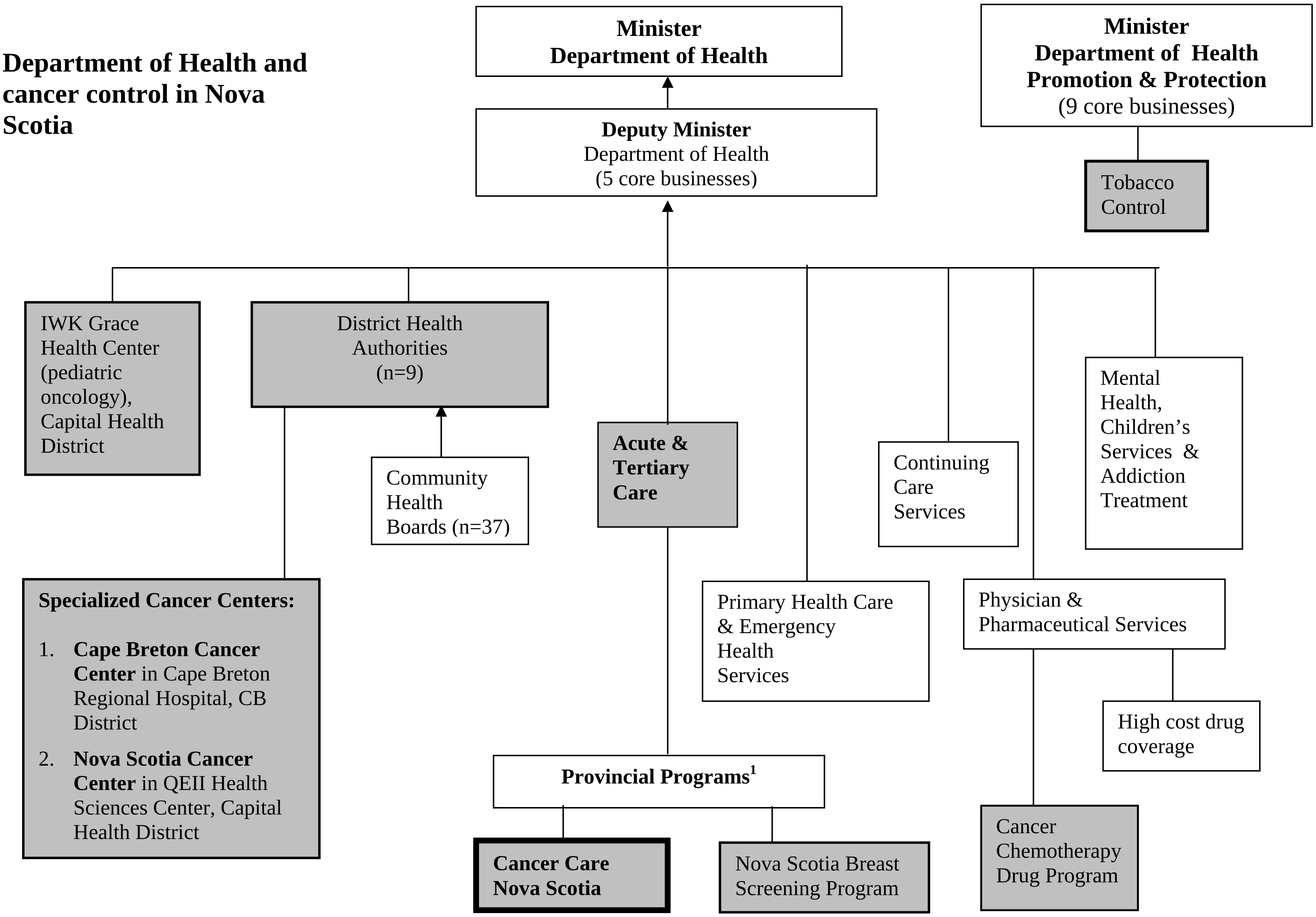


[1] Only cancer related external offices are shown

→ Accountability links

■ Major involvement in cancer control

Department of Health and cancer control in Nova Scotia

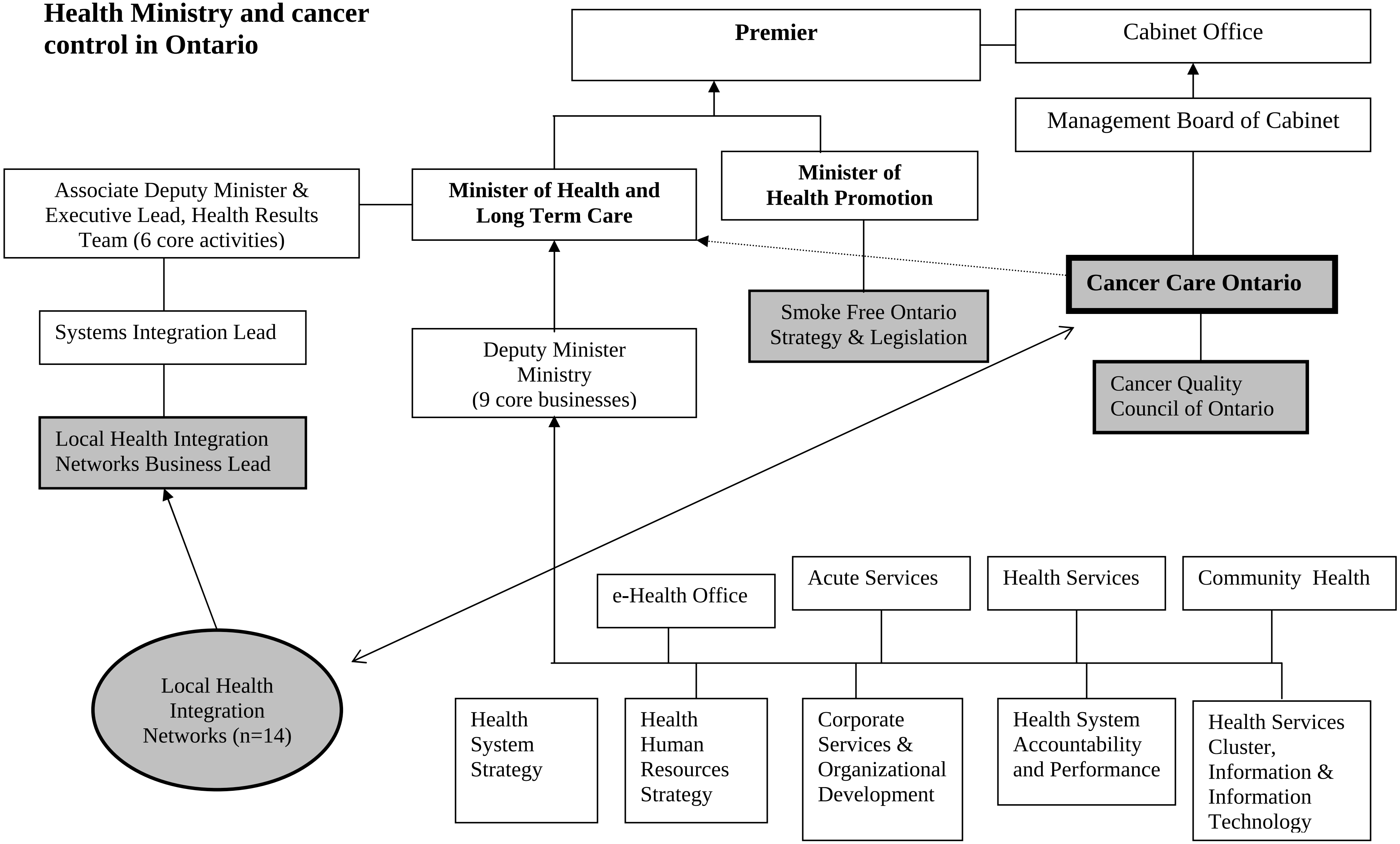


[1] Only cancer related programs are shown

→ Accountability links

▨ Major involvement in cancer control

Health Ministry and cancer control in Ontario



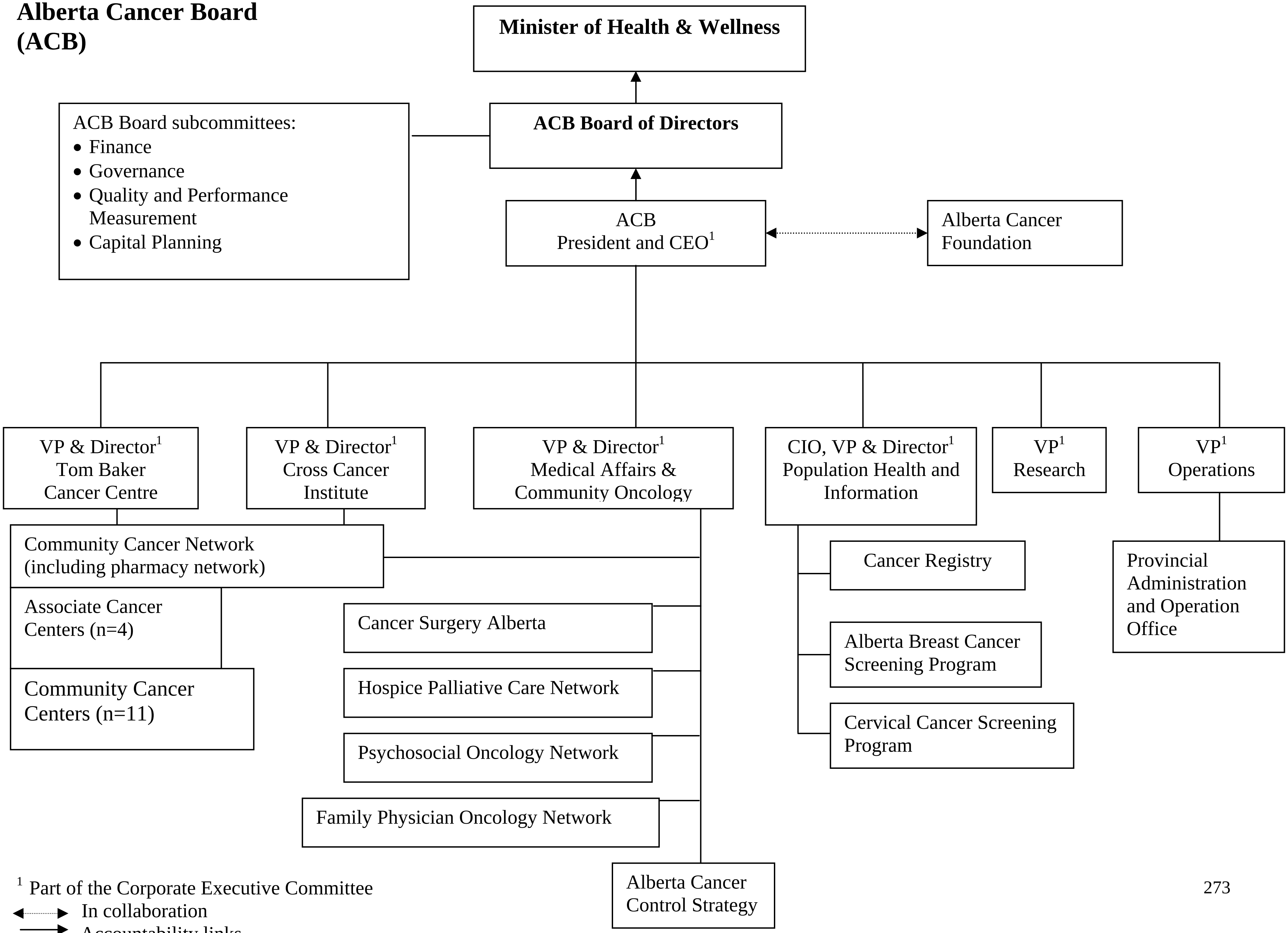
→ Accountability links
⇢ Advisory
↔ In collaboration

▨ Major involvement in cancer control

Sources: adapted from MOHLTC organizational chart, and additional information on the Ministry's website, available at: http://www.health.gov.on.ca/english/public/ministry/about.html

Appendix 6C -- Organizational charts of appointed governing bodies by jurisdictions

Alberta Cancer Board (ACB)

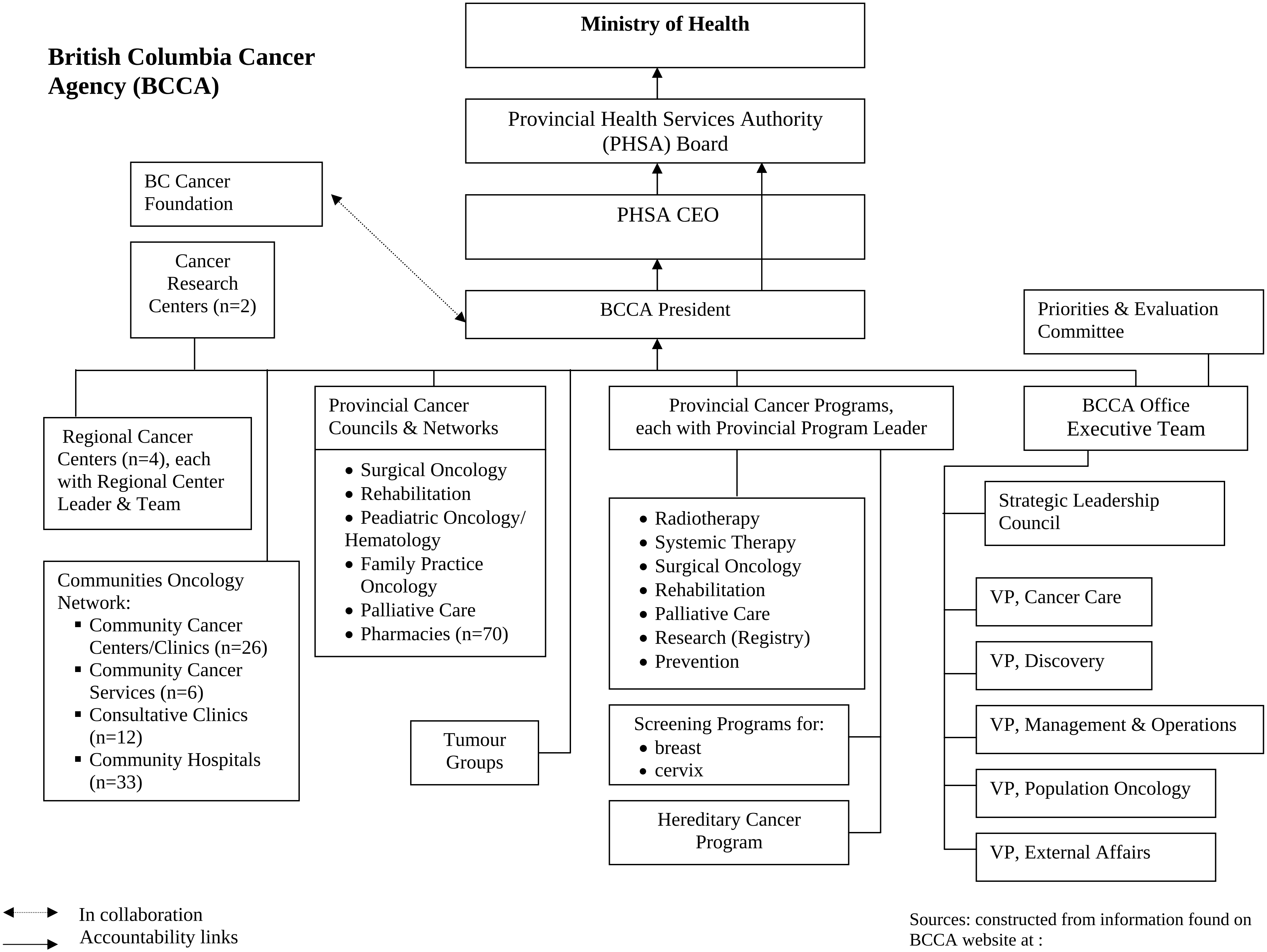


[1] Part of the Corporate Executive Committee

◄····► In collaboration

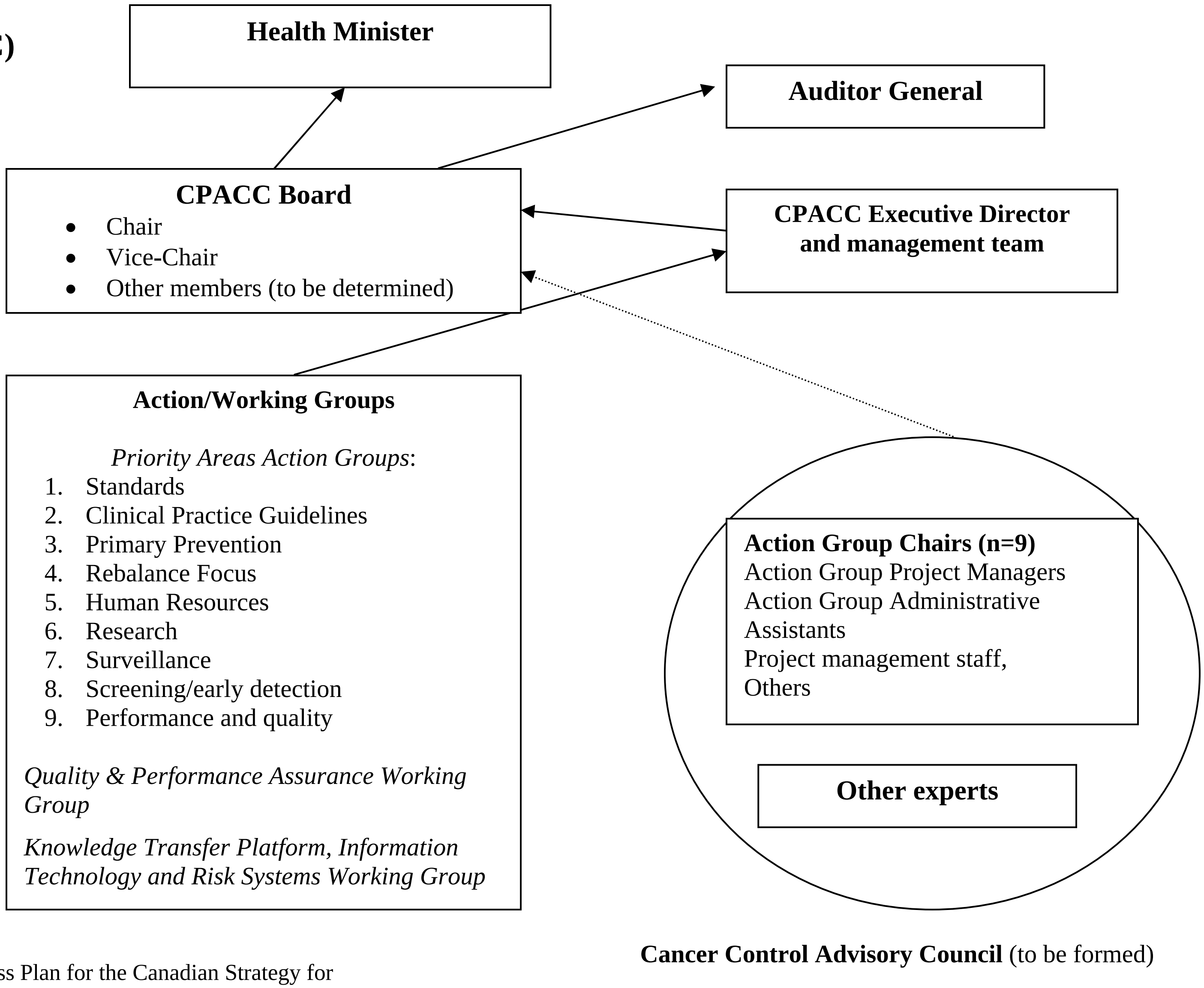
──► Accountability links

British Columbia Cancer Agency (BCCA)



Sources: constructed from information found on BCCA website at : http://www.bccancer.bc.ca/ABCCA/default.htm

Canadian Partnership Against Cancer Corporation (CPACC)



Health Minister

Auditor General

CPACC Board

- Chair
- Vice-Chair
- Other members (to be determined)

CPACC Executive Director and management team

Action/Working Groups

Priority Areas Action Groups:

1. Standards
2. Clinical Practice Guidelines
3. Primary Prevention
4. Rebalance Focus
5. Human Resources
6. Research
7. Surveillance
8. Screening/early detection
9. Performance and quality

Quality & Performance Assurance Working Group

Knowledge Transfer Platform, Information Technology and Risk Systems Working Group

Action Group Chairs (n=9)
Action Group Project Managers
Action Group Administrative Assistants
Project management staff,
Others

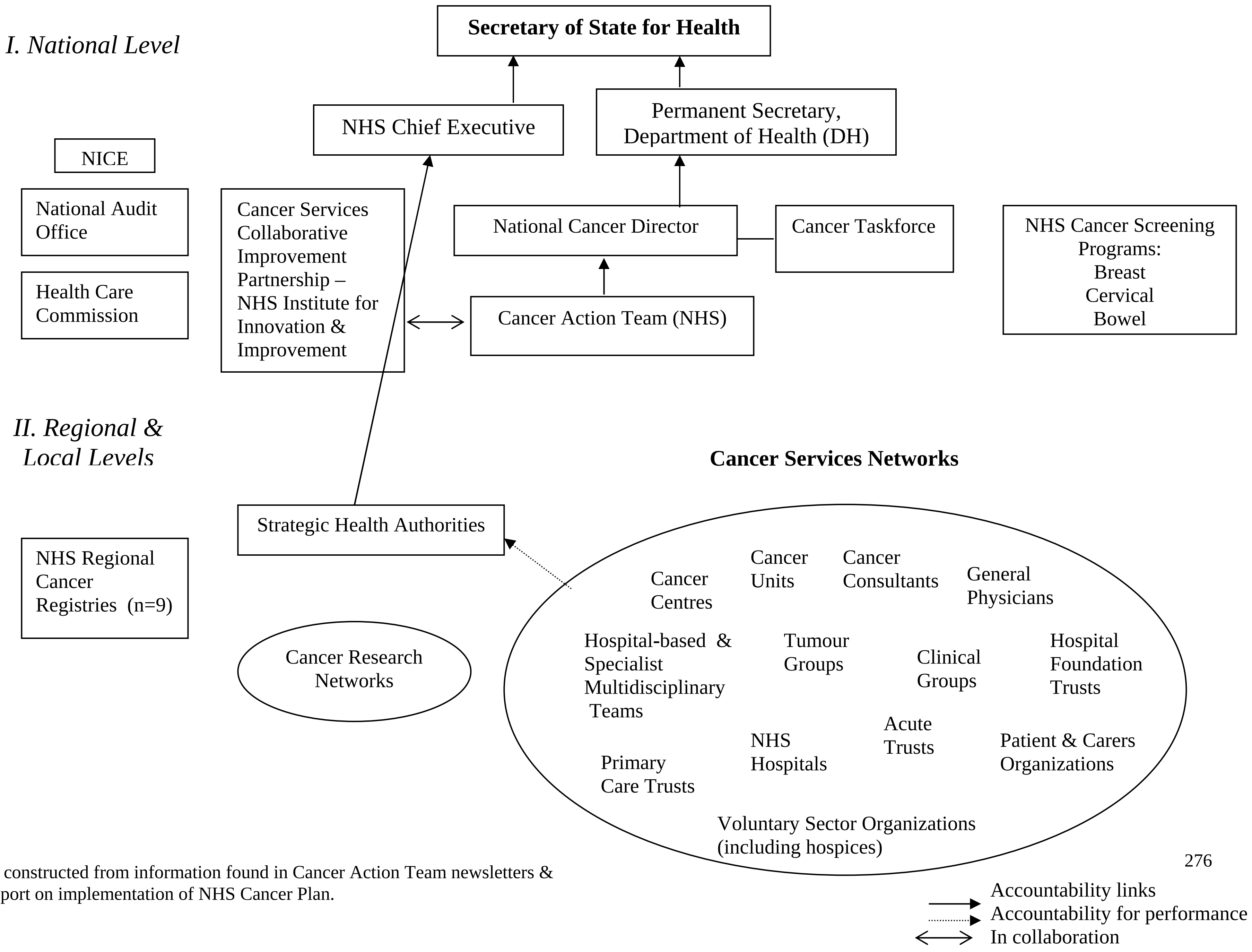
Other experts

Cancer Control Advisory Council (to be formed)

Sources: 2006-2010 Business Plan for the Canadian Strategy for Cancer Control; The CSCC: A Cancer Plan for Canada, Discussion Paper (July 2006)

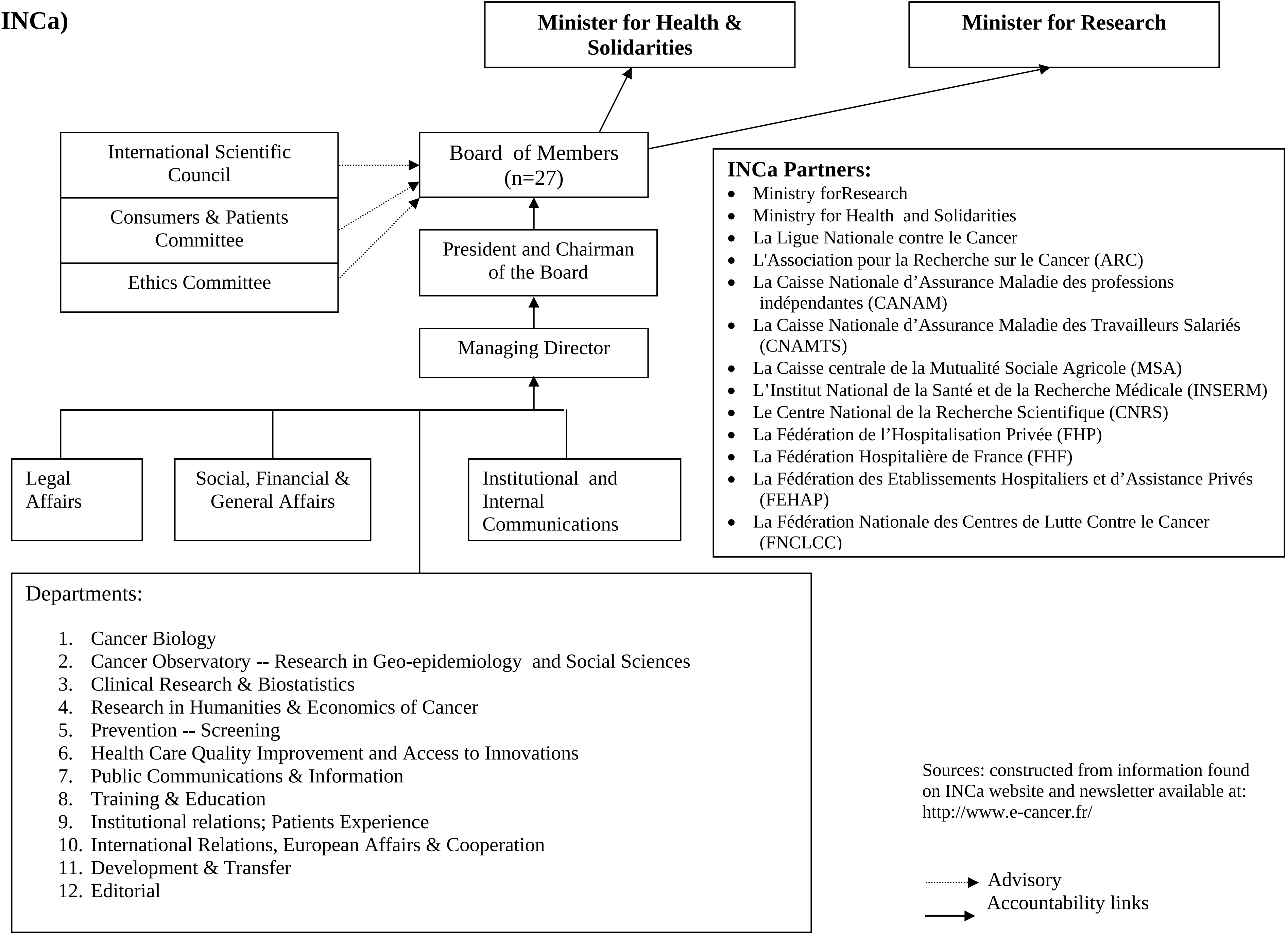
⟶ Accountability links
┈► Advosiry

Key governing players in England



Sources: constructed from information found in Cancer Action Team newsletters & NAO Report on implementation of NHS Cancer Plan.

France National Cancer Institute (INCa)



INCa Partners:

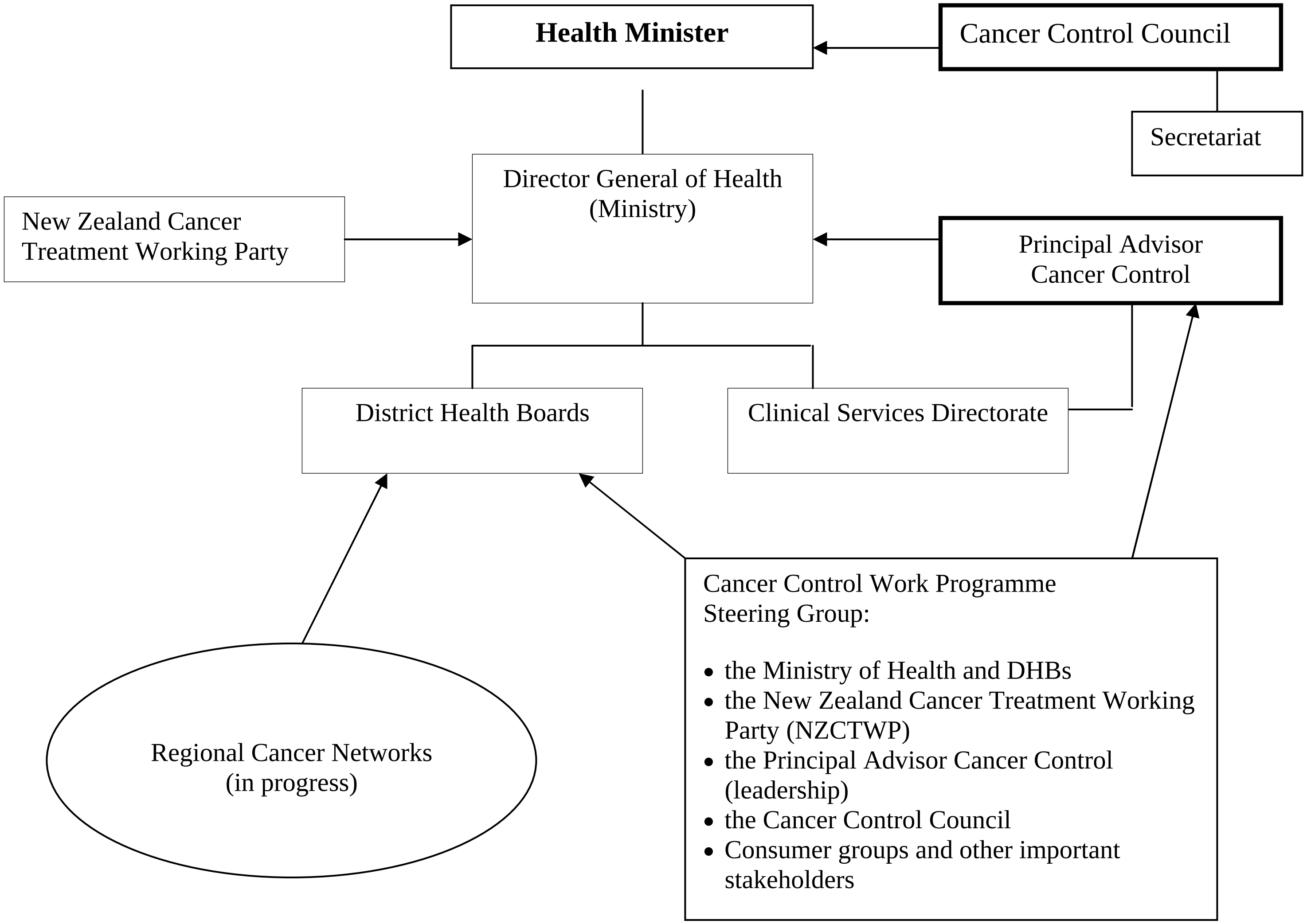
- Ministry forResearch
- Ministry for Health and Solidarities
- La Ligue Nationale contre le Cancer
- L'Association pour la Recherche sur le Cancer (ARC)
- La Caisse Nationale d’Assurance Maladie des professions indépendantes (CANAM)
- La Caisse Nationale d’Assurance Maladie des Travailleurs Salariés (CNAMTS)
- La Caisse centrale de la Mutualité Sociale Agricole (MSA)
- L’Institut National de la Santé et de la Recherche Médicale (INSERM)
- Le Centre National de la Recherche Scientifique (CNRS)
- La Fédération de l’Hospitalisation Privée (FHP)
- La Fédération Hospitalière de France (FHF)
- La Fédération des Etablissements Hospitaliers et d’Assistance Privés (FEHAP)
- La Fédération Nationale des Centres de Lutte Contre le Cancer (FNCLCC)

Departments:

1. Cancer Biology
2. Cancer Observatory -- Research in Geo-epidemiology and Social Sciences
3. Clinical Research & Biostatistics
4. Research in Humanities & Economics of Cancer
5. Prevention -- Screening
6. Health Care Quality Improvement and Access to Innovations
7. Public Communications & Information
8. Training & Education
9. Institutional relations; Patients Experience
10. International Relations, European Affairs & Cooperation
11. Development & Transfer
12. Editorial

Sources: constructed from information found on INCa website and newsletter available at: http://www.e-cancer.fr/

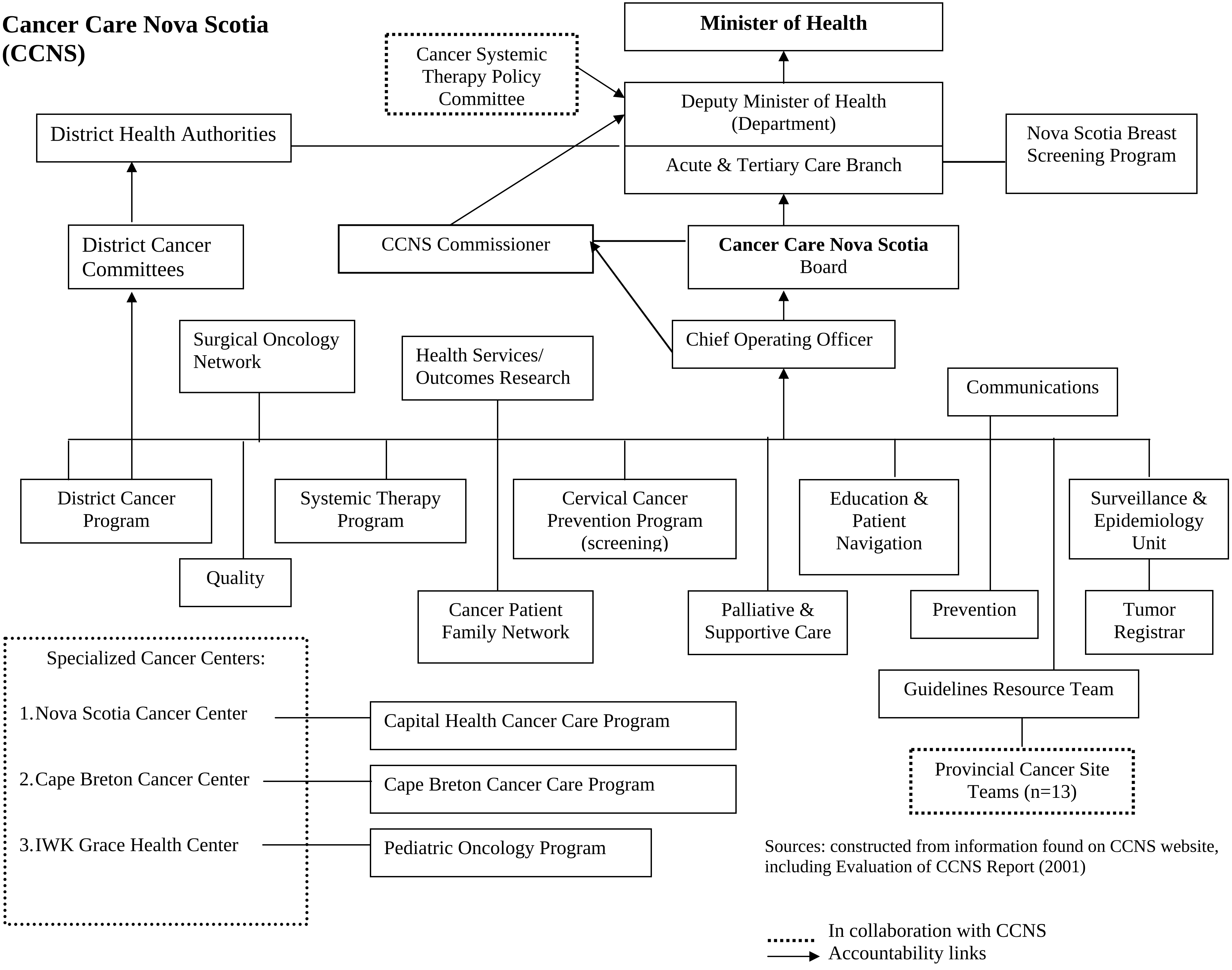
Key governing players in New Zealand



Sources: constructed from information found on NZ Ministry of Health website available at: http://www.moh.govt.nz/cancercontrol

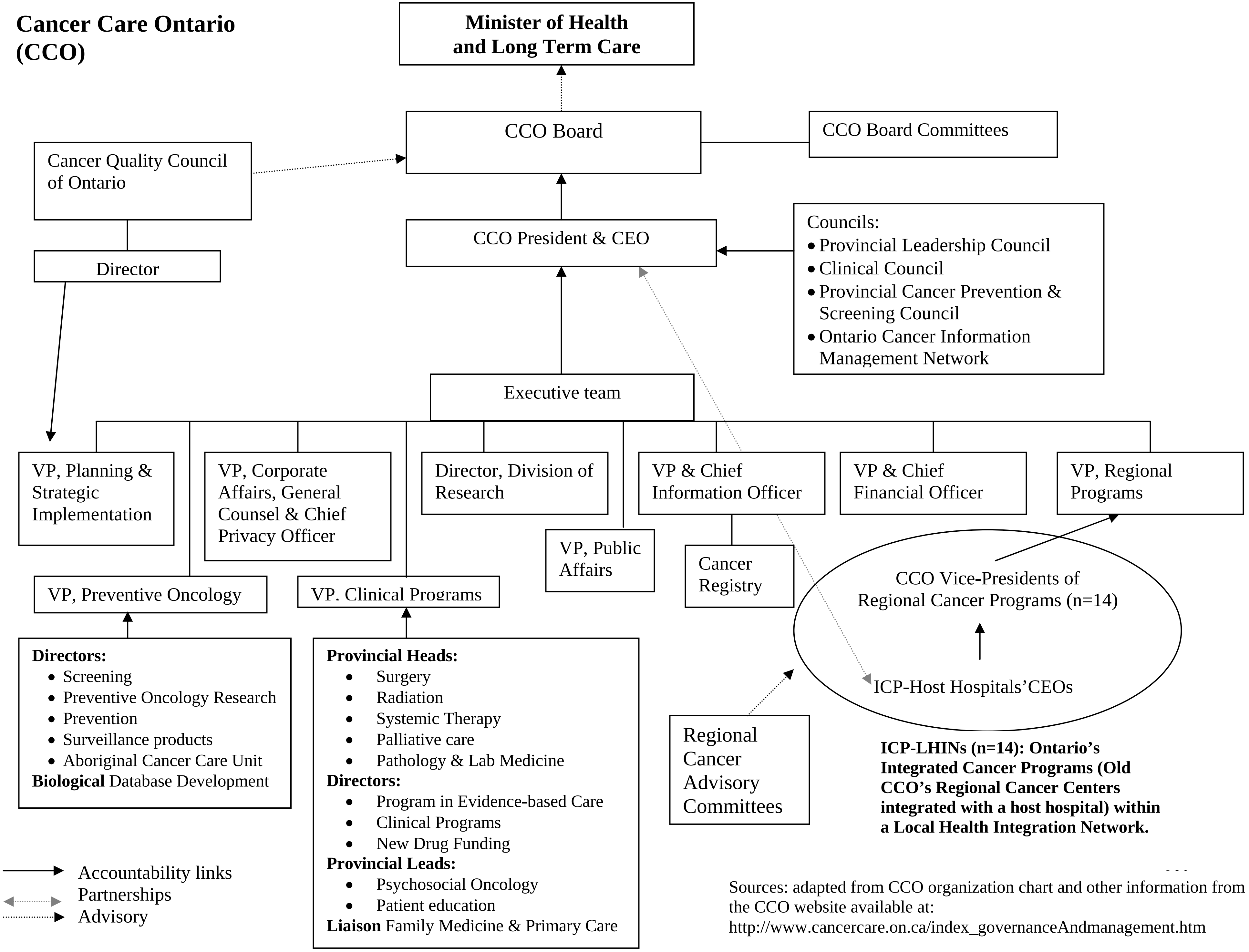
→ Accountability links

Cancer Care Nova Scotia (CCNS)



Sources: constructed from information found on CCNS website, including Evaluation of CCNS Report (2001)

Cancer Care Ontario (CCO)



Sources: adapted from CCO organization chart and other information from the CCO website available at: http://www.cancercare.on.ca/index_governanceAndmanagement.htm

Appendix 7A -- Main service quality facilitators by jurisdictions

An overview of the implementation of key SQFs in Alberta requires considering those that impact the work of Regional Health Authorities (RHAs) in cancer care. ACB works with RHAs to coordinate, plan, and deliver provincial cancer initiatives. RHAs play a key role in implementing the Alberta Cancer Control Action Plan.

Alberta

1. System capacity and sustainability:

Cancer drugs management systems:

- The ACB business plan stipulates as one of its priorities that ACB should strengthen the provincial process for approval, management and evaluation of cancer drugs as well as obtain lowest possible cancer drug purchase price. In this regard, an approval process for novel drug therapies is being piloted.[691]
- The Alberta Palliative Care Drug Program allows patients to be eligible for further prescription drugs at no cost after a fixed amount has been paid by the patient.[692]

Capital investments:

- Major expansion of the Cross Cancer Institute in Edmonton is in the planning stage to respond to projected increases in the need for cancer services over the next 10 years.[693] A capital enhancement and replacement strategy is in place.[694]
- ACB has proposed, and completed functional programming for, a new cancer institute in Calgary to serve the population of Calgary and southern Alberta.[695]
- The Southern Alberta Cancer Research Institute is also due to expand into new laboratory space under construction (in the Heritage Research Innovation Center).[696]

Human resources management initiatives:

- Human resources planning is one of the 5 priorities of the Alberta cancer control action plan. The ACB business plan also stipulates as one of its priorities that ACB and health authorities should collaborate on staff recruitment and retention.

Information management systems:

- The ACB's Division of Population Health and Information operates the Alberta Cancer Registry, a computerized database of all incidences of cancer in the province.
- A Provincial Electronic Health Record System (Alberta Netcare) was implemented in 2004. It is a province-wide clinical information system that links physicians, pharmacists, hospitals, home care, and other provides to patient's prescription history, allergies and laboratory test results on line.[697,698] This system is aligned with the Pharmacy Information Network.[699]

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[691] ACB. Business Plan 2002-03 to 2004-05

[692] MACO.Hospice Palliative Care in Alberta

[693] Alberta Government. (2004). Cross Cancer Institute begins planning expansion. http://www.gov.ab.ca.

[694] ACB Business Plan 2005-2006

[695] Personnal communication, Dr Anthony Fields, VP Medical Affairs and Community Oncology, ACB, February 1, 2007.

[696] Southern Alberta Cancer Research Institute. http://www.sacri.ucalgary.ca/about/intro.html

[697] Alberta Health and Wellness (2004). Alberta Health Reform Implementation Team: Final Report. www.health.gov.ab.ca

[698] Alberta Health and Wellness (2006). Alberta Netcare. www.albertanetcare.ca

[699] ACB. Business Plan 2002-03 to 2004-05

- The Integrated Cancer Care Network (ICCN) is ACB's internal electronic health record system. It is accessible at all ACB treatment facilities (tertiary, associate, community centres).[700,701] The ICCN facilitates on-line booking and scheduling, order entry, and results reporting; as well as provides decision support by making available information on treatments and patient preferences. An interface with the provincial Netcare system is in the implementation phase.[702]
- ACB's Cancer Surgery Alberta has developed a web-based surgical data collection system to document surgical procedures (Web Surgical Medical Records program-WebSMR).[703, 704] This system facilitates improvements in techniques, identifies areas in which continuing education or training is required; as well as provides clear guidelines and outcome indicators across health regions.
- The Alberta/NWT Chapter Alberta Research Tumour Bank (ARTB) is a provincial tumour bank initiative that provides a comprehensive collection of cancer specimens with related clinical information.[705]

2. Quality assurance and improvement:

Accountability agreements and performance contracts:

- Multiyear performance agreements (MYPA) between government and RHAs are currently in operation.[706] Such agreement is also in place between the government and the ACB.[707] These agreements are aimed at enhancing accountability and measure performance related to health reform criteria and other statutory responsibilities.[708] MYPA bind both partiers, with clear expectations specified by the government and obligations to the government.

Accreditation procedures:

- ACB is subject to external accreditation by the Canadian Council on Health Services Accreditation (CCHSA). This involves extensive self-assessment followed by site visit and review by CCHSA on a three year cycle. ACB's preparation in response to this process is coordinated by ACB's Provincial Quality Assurance Committee.[709]
- Various components of ACB's activities are also subject to external accreditation; for example, its diagnostic services are accredited by the College of Physicians and Surgeons of Alberta, and its Radiation Therapist Training School is accredited by the Canadian Medical Association.[710]
- The ACB business plan stipulates as one of its priorities that ACB should enhance provincial management of quality assurance and quality improvement activities.[711]

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[700] ACB. Business Plan 2002-03 to 2004-05

[701] ACB Business Plan 2005-2006

[702] Personnal communication, Dr Anthony Fields, VP Medical Affairs and Community Oncology, ACB February 1 2007 letter.

[703] Medical Affairs and Community Oncology. What is Cancer Surgery Alberta? http://www.cancerboard.ab.ca/maco/initiatives_surgery.htm

[704] Alberta develops world's first electronic surgical reporting. http://www.eurekalert.org/pub_release/2006-06/acb-adw061506.php

[705] Canadian Tumour Repository Network. Alberta Research Tumour Bank https://www.ctrnet.ca/index.php?pid=11100

[706] Alberta Government (2004) Alberta Health Reform Implementation Team: Final Report. www.health.gov.ab.ca

[707] Alberta Cancer Board. About the ACB. http://www.cancerboard.ab.ca/about/index.html

[708] Alberta Health and Wellness (2003). Multi-year performance agreement. Schedules A and B: information to the minister guidelines for regional health authorities and provincial boards.

[709] Personnal communication, Dr Anthony Fields, VP Medical Affairs and Community Oncology, ACB February 1 2007 letter.

[710] Personnal communication, Dr Anthony Fields, VP Medical Affairs and Community Oncology, ACB February 1 2007 letter.

[711] Information obtained on page 3 of the following: http://www.cancerboard.ab.ca/maco/pdf/hpcn_2003-05_workplan.pdf

Evidence-based clinical guidelines:

- One of he five priorities of the Alberta cancer control action plan is to establish a provincial coordinating infrastructure/body supported with human and financial resources that will coordinate all Clinical Practice Guideline (CPG) development efforts and liaise with the Canadian Strategy for Cancer Control.
- Six provincial tumour programs were established by ACB in 2002 to develop treatment guidelines and standards for waiting times and costing of clinical procedures: breast, gastro-intestinal, genito-urinary, lymphoma, lung and central nervous system.[712] Clinical practice guidelines are available for breast cervical and prostate cancer.[713] A methodology has been developed to monitor the use of guidelines.[714]
- A palliative care resource manual (Alberta Palliative Care Resource) was developed by the Hospice Palliative Care Network for primary care practitioners. This manual includes step-by-step suggestions regarding management strategies of common clinical problems. A choice of evidence-based assessment tools for palliative care is provided.[715]

Professional training and certification:

- Although not expressly mentioned in the ACCAP document or the ACB Business Plan, this is a core function of the ACB, with collaboration among Alberta's universities, colleges, regional health authorities, and the ACB to provide training and certification in a full range of disciplines and specialties related to cancer.[716]

Service delivery standards:

- Access standards are being established as the acceptable period of time a person can wait from when they receive the diagnosis to the time they receive the service. Access standards for breast and prostate cancer are being developed, and that these will form part of the RHAs agreement.[717]
- Clinical working groups of the Alberta Cervical Cancer Screening Program (colposcopy, laboratory, and primary care) have developed quality indicators and are beginning to review initial data and develop quality improvement strategies.[718] Moreover, the Program evaluation committee of the Alberta Cervical Cancer Screening Program oversees program quality and evaluation components. It provides feedback to healthcare professionals on the quality of their Pap smears.
- The Hospice Palliative Care Network promotes the use of the National norms put forth by the Canadian Hospice Palliative Care Association by organizing workshops to different groups of health care professionals throughout the province.[719]

Service performance tracking:

- The mandate of the Health Quality Council of Alberta (HQCA) is to promote and improve patient safety and report to the public on the quality, performance and accessibility of all health services, including cancer.[720, 721] To date, HQCA surveyed Albertans about their experience and satisfaction with the quality of health services and patient safety. Latest information suggest that the Council will

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[712] Alberta Cancer Board. Annual Report 2002-03.

[713] Alberta Health and Wellness (2006). Guidelines. www.health.gov.ab.ca

[714] ACB business Plan 2005-2006

[715] Hospice Palliative Care Network (2001). Alberta Palliative Care Resource Manual. Alberta Cancer Board. http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

[716] Personnal communication, Dr Anthony Fields, VP Medical Affairs and Community Oncology, ACB February 1 2007.

[717] Alberta Health and Wellness (2004). Alberta Health Reform Implementation Team: Final Report. www.health.gov.ab.ca

[718] The Alberta Cervical Cancer Screening Program Update. April (2003); vol. 3(1). http://www.cancerboard.ab.ca/accsp/aboutus3.html

[719] Hospice Palliative Care Network (2004). Annual Report 2003-2004. Edmonton, AB: Alberta Cancer Board http://www.cancerboard.ab.ca/maco/initiatives_palliative.htm

[720] Alberta Health and Wellness (2006). Health Quality Council established as a provincial health authority. http://www.gov.ab.ca

[721] Health Quality Council. http://www.hqca.ca

work in partnership with service providers to improve and promote patient safety and health service quality to all health services in Alberta through education, but will not monitor service standards or service providers' performance in a compliance or accountability context.[722]
- Alberta online Waitlist Registry provides up-to-date information about wait times in publicly funded surgical and diagnostic tests and services provided in public facilities. Information is available by service category, by facility, and by physician.[723] ACB provides Alberta Health and Wellness with quarterly information on wait times for breast and prostate cancer treatments (chemotherapy and radiation therapy).

In British Columbia, cancer SQFs were mainly drawn from the BCCA cancer control service program. In addition, given that the BCCA is a provincial program funded by the PHSA, the review also considered SQFs that are specific to the accountability relationship between the two entities and SQFs that are implemented as part of the PHSA's mandate to develop an integrated and accessible system of province-wide health services.

British Columbia

1. System capacity and sustainability:

Cancer drugs management systems:

- All of BCCA treatment policies go through a formal review process, firstly by the BCCA provincial systemic program committee, secondly by the BCCA priorities and evaluation committee, which is an arms-length committee reporting directly to the BC Cancer Agency executive. The Priorities and Evaluation Committee provides ranking and recommendations to the BCCA executive and budget committee, where the final decision is made.[724]
- Policies for safe handling of chemotherapy are made by the BCCA provincial systemic program committee. These policies are mandatory for all BCCA regional cancer centers, but advisory to all the community general hospitals that have cancer centers, as they are under the direct governance of regional health boards. Hence the BCCA advise on standards, but can't actually enforce them, except in the BCCA regional cancer centers.[725] However, BCCA requires specific standards to be met in order to provide funds to these community cancer centers and clinics.[726]

Capital investments:

- Construction of a new hospital and cancer center began in late 2004, with a target completion date of late 2008.[727]
- Planning and construction of additional radiation treatment bunkers at the Vancouver Center have begun, with planning for the installation of 5 linear accelerators by 2005-2006.[728]
- BCCA, in collaboration with UBC, Vancouver Hospital and Health Sciences Centre, BC Children's Hospital, and TRIUMF have established a Centre of Excellence for Functional Cancer Imaging.

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[722] Personal communication via letter from Alberta Connect 05/07/2006.

[723] Alberta Health and Wellness. Alberta Waitlist Registry. http://www.ahw.gov.ab.ca/waitlist/WaitListPublicHome.jsp

[724] Based on interview with BCCA key informant

[725] Based on interview with BCCA key informant

[726] Based on interview with BCCA key informant

[727] BCCA. Cancer services. Abbotsford Hospital and Cancer Center underway. http://www.bccancer.bc.ca/RS/AbbotsfordCentre/Abbotsford.htm

[728] PHSA. Three year service plan. 2005/2006 to 2007/2008

Capital funding for the PET/CT scanner came from the Emerging Technologies Fund (federal funding source) and flowed through PHSA.[729]

- Moreover, new radiotherapy facilities are underway at the Vancouver Cancer Centre and a digital mammography suite has been implemented.

Human resources management initiatives:

- The BCCA strategic plan includes the following priorities: to develop the physician/oncologist recruitment and retention plan with the health authorities in accordance with the need for regional and community oncology services and to ensure continuous attention to all of the "hard to recruit" oncology professional disciplines through recruitment, retention, and competitive remuneration considerations. The recruitment of a number of medical oncologists and hemo-oncologists is part of BCCA's latest main accomplishments. [730]

Information management systems:

- The BCCA operates the Cancer Registry, which contains personal and demographic information, diagnosis as well as death information on all cases of cancer diagnosed.[731] It uses the data to monitor trends and regional differences in cancer incidence and mortality, to project the number of new cases for planning of cancer treatment facilities and regional cancer care, to assess future workload demands, evaluate access to care, determine the success of treatment, and to measure the effectiveness of provincial screening program.[732]
- The BC Electronic Health Record (EHR)[733] provides a lifetime record of patients' health history and care received within the health care system. It is available electronically to authorized health care professionals as well as patients. The information is used for clinical analysis (chronic disease management-practice recommendations) as well as for performance analysis (e.g., program design waitlist management).
- The BCCA has also developed the Cancer Agency Information System. The CAIS enables physicians to view information about their patients on computers located throughout the cancer centers, community centers and clinics, including their own offices (see also BC's shaded box on distinctive feature for more details).
- The Image Distribution Network system (diagnostic imaging picture archive communication system-PACS) allows for the distribution, storage, and retrieval of cancer-related diagnostic images of all types such as tomography, MRIs, radiography, nuclear medicine, and ultrasounds at BCCA Cancer Centers and at some cancer clinics.[734,735]
- The BCCA has developed a Tumour Tissue Repository,[736] an infrastructure for tissue and blood storage, information, and analysis, The data will allow scientists to identify the link between genetic variables, tumour types and treatment outcomes.

2. Quality assurance and improvement:

Accountability agreements and performance contracts:

- Performance agreement contracts are in place between the Health Authorities (including PHSA) and the Ministry of Health Services. BCCA is part of the PHSA/MoH Performance and Accountability

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[729] PHSA. Steps forward to January 2004. http://www.phsa.ca/News/Steps-forward.htm

[730] See the section pertaining to BCCA in: PHSA accomplishments. Three years of progress. April 2002 to 2005

[731] BCCA. BC cancer statistics. http://www.bccancer.bc.ca/HPI/CancerStatistics/default.htm

[732] BCCA. BC cancer statistics. http://www.bccancer.bc.ca/HPI/CancerStatistics/default.htm

[733] Health Chief Information Officers Council (January 2003). BC Framework for an electronic HR for British Columbians. http://healthnet.hnet.bc.ca/pub_reports/ehr_framework.pdf

[734] PHSA Steps forward to January 2004. http://www.phsa.ca/News/Steps-forward.htm

[735] HP. (2005). British Columbia Cancer Agency improves patient care with distributed storage grid. http://h71028.www7.hp.com/ERC/downloads/5983-2892EN.pdf

[736] PHSA. Steps forward to January 2004. http://www.phsa.ca/News/Steps-forward.htm

Agreement, signed annually on the basis of a three-year plan, with specific performance and accountability targets.

Accreditation procedures:

- BCCA is accreditated by CCHSA as part of the rolling accreditation program of the PHSA. BCCA last accredited in 2005/06. Due again in spring 2009 following commissioning of Abbotsford Cancer Centre.[737]

Evidence-based clinical guidelines:

- Eighteen *Provincial Tumor Groups* (PTGs) responsible for providing latest evidence-based standards of care and management for specific cancer sites: breast; gastrointestinal; genitourinary; gynecology; head/neck; hereditary; leukemia; lung; lymphoma; musculoskeletal/sarcoma; neuro-oncology; ocular/orbital; pediatric; primary unknown; skin; supportive care; tumour marker-assays; and screening for cancer. PTGs comprise oncologists, radiologists, pathologists, oncology nurses, pharmacists and practitioners from health disciplines contributing to specialized oncology care.[738] Tumor groups have extended their activities beyond treatment policies and clinical management guidelines to the translational research and education domains. There are currently 180 clinical practice guidelines available, including referral information reports required by the admitting department.[739]

Professional training and certification:

- Health professionals are trained and certified through accredited training programs. All medical professionals require certification and licensure (through university qualifications and Royal College certification and licensure). All physicians are appointed by the PHSA Board and re-appointed annually subject to appropriate submission of information.[740]

Service delivery standards:

- Provincial practice standards and management guidelines are in place.[741]
- BCCA has Web-based pre-printed chemotherapy orders, which provide 180 treatment protocols with parameters for prescribing, preparing, and administering treatment.[742] These are routinely used by physicians, pharmacists, and chemotherapy nurses to check doses and schedules of treatment.[743]
- The *Provincial Surgical Oncology Council and Network*, established in 2001 aims to provide a structure and a system to enable the integration of quality surgical oncology services.[744] The Network comprises all providers of surgical oncology services from surgeons in remote areas to sub-specialists.

Service performance tracking:

- A quality framework, created by PHSA is implemented to track how well the province-wide system of integrated health services is performing.[745] The framework includes five dimensions: availability and access (wait times, remote access through outreach clinics or telehealth, patient diversions), service quality and appropriateness (readmission rates, mortality rates), resources (people, equipment, and space), satisfaction (patients, providers, community), and value (financial information such as cost per case)

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[737] Personnal communication, Dr Simon Sutcliffe, President, BCCA, January 29, 2007 letter.

[738] BCCA (2006). Cancer management guidelines. http://www.bccancer.bc.ca/HPI/Cancer ManagementGuidelines/default.htm

[739] BCCA. Cancer management guidelines. http://www.bccancer.bc.ca/HPI/CancerManagement Guidelines/default.htm

[740] Personnal communication, Dr Simon Sutcliffe, President BCCA, January 29, 2007 letter.

[741] BCCA. Strategic Plan 2005.

[742] PHSA. Three year progress. April 2002-2005

[743] PHSA. (April 2003). Health service design plan. From vision to reality

[744] BCCA Surgical Oncology Network. http://www.bccancer.bc.ca/HPI/SON/default.htm

[745] PHSA. Steps forward to January 2004. Available at: http://www.phsa.ca/NR/rdonlyres/9562DD6C-C3A4-465D-AA47-75ECDECED6A0/6222/StepsForwardtoJan2004.pdf

- The BC Ministry of Health provides information on provincial median wait times for cancer radiation treatment. It also has a Surgical Wait Times that provides detailed information by surgical specialty.

In Canada cancer SQFs do not apply to direct service delivery as it is a provincial responsibility. Review of federal level SQF mainly focused on the activities related to the Canadian Strategy for Cancer Control, but other federal health organizations were also considered such as the Canadian Association of Providial Cancer Agencies (CAPCA) and Health Canada.

Canada

1. System capacity and sustainability:

Cancer drugs management systems:

- In Canada, approximately half of prescription drug purchases are funded through 16 federal, provincial, and territorial drug plans. At the federal level, a Common Drug Review process was established in 2004 by the Canadian Agency for Drugs and Technologies in Health (formerly CCOHTA).

Human resources management initiatives:

- The CSCC stipulates as one of its priority the development of a national human resources database. Planned actions include: to create a platform that can monitor, analyze and track human resources in the Canadian cancer system and to develop a human resources planning information system. The Canadian Association of Provincial Cancer Agencies' Human Resource Planning Information System (CAPCA-HR-PIS) has been created to serve as a standards-based tool to support provincial and national planning strategies for cancer control related to human resources and capital investment.[746] It is currently being pilot tested in Nova Scotia and New Brunswick.[747]

Information management systems:

- The Canadian Cancer Registry (CCR) is an administrative survey that collects information on cancer incidence in Canada. The CCR is a collaborative effort between the thirteen Canadian provincial and territorial cancer registries and the Health Statistics Division of Statistics Canada, where the data are housed. Ultimate authority and responsibility for the degree of coverage and the quality of the data reside with the provinces and territories.[748]
- CSCC is championing the creation of an online Cancer Knowledge Resource for the sharing of knowledge created by the Priority Areas Action Groups.[749] This online resource will provide: information on evidence-based knowledge; tools to facilitate the development and dissemination of evidence-based knowledge; a central holding of guidelines, systematic reviews, health technology assessments, benchmarks, environmental scans, gap analysis; and a locale to facilitate opportunities for collaboration among health care providers, policy-makers, researchers, people affected by cancer, and CSCC. The overall objective of this CKR site is to facilitate quality improvement.
- CSCC Council's knowledge platform, information technology and Cancer Risk Management System will support the work of the Council and the implementation of the CSCC. This system will have both internal and external uses (see Canada's distinctive feature for more details).[750]
- More generally, the *Canada Health Infostructure Partnerships Program* funded provincial/territorial telehealth and electronic health records projects.[751]

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[746] http://www.capca.ca/english.asp?Pageid=226&ParentID=2

[747] CSCC Special Issue Bulletins. (2004-2005) available for each action group. www.cancercontrol.org

[748] http://www.statcan.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3207&lang=en&db=IMDB&dbg=f&adm=8&dis=2

[749] CSCC 2006-2010 Business Plan. April 2006.

[750] CSCC 2006-2010 Business Plan. April 2006.

[751] http://www.hc-sc.gc.ca/hcs-sss/ehealth-esante/infostructure/finance/chipp-ppics/index_e.html

2. Quality assurance and improvement:

Accreditation procedures:

- The CSCC Rebalance Focus Action Group stipulates as one of its priorities to build accreditation capacity in Canada for supportive and palliative care.[752] Progress to date include the review from the Canadian Council on Health Services Accreditation of cancer services quality indicators for the CSCC working group on standards.[753]

Evidence-based clinical guidelines:

- The mandate of the CSCC Clinical Practice Guidelines (CPG) Action group is to champion the optimal use of evidence through CPG for cancer control. The CPG products will enhance the ability of the different provinces/territories, municipalities, NGOs and individual Canadians to access, evaluate, use and share knowledge about the best cancer control practices.[754] Progress to date include a CPG Adaptation Project to evaluate the feasibility and utility of using national interdisciplinary panels to evaluate the quality, content, and currency of existing CPG's and to make recommendations about how to adapt and endorse CPG recommendations. The deliverables of the CPG Adaptation Project will serve as the foundation for the CPG Cancer Knowledge Resource and a CPG Adaptation Tool Kit.[755]

Service delivery standards:

- The CSCC Standards Action Group's business goal for 2006-2010 is to provide information and knowledge for provinces/territories, municipalities, NGOs and individual Canadians on establishing standards and indicators on cancer care for the purpose of fostering improved access and quality of care.[756] To date, the Canadian Council on Health Services Accreditation produced a review of cancer services quality indicators for the CSCC Standards Action Group in 2004.
- Moreover, specific cancer control indicators can be found in the following documents: Health Canada. Report from the Evaluation Indicators Working Group: Guidelines for Monitoring Breast Screening Program Performance (2002).

Patient participation:

- Through representation at the CSCC Council.

Service performance tracking:

- The quality of health care received is monitored through reports from the Health Council of Canada, including waiting time for radiotherapy. See also Healthy Canadians a federal report on comparable health indicators 2002.[757]

In England, SQFs that apply to cancer control intervention are broad, and are implemented as part of the National Health Service (NHS), the Department of Health, and the Cancer Services Collaborative (CSC), which is a major NHS program that aims to improve the experience and outcomes for patients with suspected or diagnosed cancer. More generally, the Health Act 1999 sets out a statutory duty of quality to be implemented through a framework of clinical governance, the systems and practices that ensure the highest possible standards of care for patients.

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[752] CSCC Business plan 2006-2010, p. 42.

[753] Canadian Council on Health Services Accreditation. Literature review and environmental scan for cancer control indicators. Submitted to the CSCC Standards Action Group, March 2004.

[754] CSCC Business plan 2006-2010, p. 38.

[755] http://209.217.127.72/cscc/pdf/CPG_AG_SpecialIssue_BulletinsJan2005.pdf

[756] CSCC Business plan 2006-2010, p. 37.

[757] http://www.hc-sc.gc.ca/iacb-dgiac/arad-draa/english/accountability/indicators.html

England

1. System capacity and sustainability:

Cancer drugs management systems:

- The NHS maintains a list of drugs to be excluded from the NHS subsidy.

Capital investments:

- In addition to developing a cancer facilities strategy, the cancer plan stipulates substantial investments from the New Opportunities Fund and additional funding in NHS Plan for 50 MRI scanners, 200 CT scanners, and 45 linear accelerators, as well as the modernisation of pathology services. Progress to date include substantial investment from the New Opportunities Fund for MRI scanners, CT scanners, and linear accelerators.[758]

Human resources management initiatives:

- The cancer plans includes major targets in workforce recruitment such as nearly 1,000 extra cancer consultants,[759] increases in the number of specialist trainees, as well as more cancer nurses, radiographers, and other professionals. The National Cancer Director works closely with the NHS Workforce Review Team[760] to forecast future workforce requirements for cancer. A cancer care group workforce team was established to oversee specific programs addressing workforce shortages. Progress as of 2003 included a 22% increase in new cancer consultants hired, training places that more than doubled, and substantial increases in oncology nurses.

Information management systems:

- The Cancer registration system is conducted by nine independent regional registries in England.[761]
- A national cancer dataset has been developed by NHS Information Authority, which acts as a catalogue of data items and definitions for local use.
- Electronic health records have a HealthSpace, which allows patients to make their preferences known to the clinical team treating them.
- The cancer plan includes the development of a new primary care clinical dataset for cancer patients and the target that by 2004, every patient diagnosed with cancer will benefit from pre-planned and pre-booked care.

2. Quality assurance and improvement:

Accountability agreements and performance contracts :

- Cancer networks' boards are accountable to their constituents (which include commissioning PCTs and other Trusts) and have accountability agreements with their Strategic Health Authorities regarding performance (re. meeting targets set by cancer plan).[762]
- The Healthcare Commission is responsible for developing assessment criteria that it will use to determine whether core standards have been met by the PCTs, Trusts and NHS Foundation Trusts, and to judge their progress against these standards.[763]

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[758] National Audit Office (2005). The NHS Cancer Plan: A progress report. Department of Health p.33

[759] Cancer consultants comprise six medical specialties where the work is wholly or largely cancer-related: clinical radiology, histopathology, haematology, clinical oncology, medical oncology and palliative medicine. In: The NHS Cancer Plan (2003). Three year progress report. Maintaining the momentum, p. 51.

[760] http://www.healthcareworkforce.org.uk/wrt/default.aspx

[761] Cancer statistics- registration 2003. Introduction. http://www.statistics.gov.uk/downloads/theme_health/MB1_34.pdf

[762] See for example: http://www.essex.nhs.uk/documents/improvement/macn_accountability_agreement.pdf

[763] NHS. National Standards, Local Action: Health & Social Care Standards and Planning Framework, 2005/06-2007/08, p. 14.

Accreditation procedures:

- All hospitals providing cancer services are assessed rigorously against the standards via peer review visits (reports are then sent to the Trusts which are then expected to remedy deficiencies).[764]

Evidence-based clinical guidelines:

- The Improving Outcomes Guidance program of the National Institute for Health and Clinical Excellence (NICE) covers a range of services which are most likely to improve outcomes for different types of cancers.[765] NICE has developed evidence-based recommendations on all aspects of cancer care and services.[766]
- The National Cancer research Institute also produces clinical guidelines on cancer prescription drugs (e.g.: herceptin for breast cancer).

Patient participation:

- Mostly "one off" activities, through collaboration with the voluntary sector, and often integrated to clinical governance and/or complaints procedures.[767]

Professional training and certification:

- National training initiatives for endoscopy, training programs for palliative care.[768]
- The government introduced new roles and skill mix for diagnostic, radiotherapy, breast screening and cervical screening. [769,770]
- Cancer plan includes new training in communication skills

Service delivery standards:

- The NICE Improvement Outcomes Guidance reports inform the development of standards for inclusion in the Manual of Cancer Service Standards. Cancer networks are expected to demonstrate to SHAs that they have suitable plans for implementing the guidance program.[771]
- The *National Service Framework* for cancer is the 2000 NHS Cancer Plan.
- More generally, all organizations providing care across NHS are expected to meet or aspire to a level of quality specified in the *Standards for Better Health* document.[772]

Service redesign initiatives:

- *Cancer Services Collaborative* 'Improvement Partnership', a NHS program, supports Cancer Networks (local cancer service teams) to improve their cancer and diagnostic services, as well as reduce wait times.[773] It does so by helping networks look at their own services and provides the support (tools and methodology) that they need to make significant improvements by redesigning the way that care is delivered. Local health communities (including commissioners and providers) are guided in developing integrated service improvement plans (ISIPs) through the Delivering Quality and Value Strategy of the NHS Institute for Innovation and Improvement.[774] The ISIPs are intended to help improve the quality and value of services everywhere by focusing on areas that will bring the greatest potential as well as productivity and efficiency gains.

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[764] The NHS Cancer Plan (2003). Three year progress report. Maintaining the momentum. p. 11, 42

[765] The NHS Cancer Plan and the new NHS. Providing a patient-centered service.

[766] The NHS Cancer Plan and the new NHS. Providing a patient-centered service. p. 25

[767] See key findings from the following study of user involvement in the Avon, Somerset & Wiltshire Cancer Services Network. Available at: http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/HealthInPartnership/TheStudies/StudiesArticle/fs/en?CONTENT_ID=4127449&chk=SA6zVn

[768] National Audit Office (2005). The NHS Cancer Plan: A progress report. Department of Health p.30

[769] National Audit Office (2005). The NHS Cancer Plan: A progress report. Department of Health p.33

[770] National Audit Office (2005). The NHS Cancer Plan: A progress report. Department of Health p.54

[771] The NHS Cancer Plan (2003). Three year progress report. Maintaining the momentum. pp. 11 & 39.

[772] NHS. National Standards, Local Action: Health & Social Care Standards and Planning Framework, 2005/06-2007/08, p. 21.

[773] Cancer Services Collaborative. http://www.cancerimprovement.nhs.uk/App_Includes/PrintPreview/PrintFriendly.htm

[774] Institute for Innovation and Improvement (2006). Deliverying quality and value- Focus on: productivity and efficiency. www.institute.nhs.uk

- Service Improvement Guides have been developed by the Cancer Services Collaborative for 11 areas of cancer care.[775] These guides illustrate some of the improvements in services that have been tested (see distinctive feature section for England).

Service performance tracking:

- Monitoring of waiting times have been routinely conducted since 1999.[776]
- The National Clinical Audit Support Program collects clinical audit data for analysis, performance monitoring, and service analysis.[777]
- Clinical governance support teams have been set up to help organizations focus on high-quality clinical services, and the Healthcare Commission regularly assesses NHS organizations' progress toward implementation.[778]
- National Surveys of NHS Patients program, launched in 1997, comprises a series of surveys designed specifically for monitoring the performance of the NHS, as seen from the perspective of patients.[779] Part of the National Surveys is to monitor improvement in cancer, following the implementation of the National Cancer Plan in 2000. The first survey of patients' perspective of cancer services (in terms of location of care, access to care, diagnosis, treatment, hospital environment, and out-patient appointments) therefore is used as a benchmark from which the implementation of the cancer plan can be monitored.

In France, SQFs for cancer are drawn from focusing on the national cancer plan's steps that have been implemented, among which several are directed at improving system sustainability, quality assurance, and quality improvement. See Institut national du cancer. Plan cancer 2003-2006. Ce qui a changé, April 2006, including the Appendix: Suivi des 70 mesures du plan cancer.

France

1. System capacity and sustainability:

Cancer drugs management systems:

- The Haute Autorité de Santé (HAS)[780] has several Commissions, among which is the *Commission de Transparence* that assesses new drugs reaching the market to determine whether these drugs should be part of the national list of reimbursed medications.
- An activity-based pricing system ensures that all patients, regardless of whether treated in hospital or in the private sector have access to expensive and innovative medication. The system also specifies rules for access to funding as well as prescription monitoring and regulation modes.
- As of 2004, a modification to the reimbursement drug plan has made it possible for all patients to have access to innovative drugs.

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[775] Cancer Services Collaborative. Service Improvement Guides. http://www.cancerimprovement.nhs.uk

[776] The NHS Cancer Plan (2003). Three year progress report. Maintaining the momentum. p. 38

[777] The NHS Cancer Plan (2003). Three year progress report. Maintaining the momentum. p. 44

[778] The NHS improvement plan. Putting people at the heart of public services. p. 22

[779] National Surveys of NHS Patients. (2002). Cancer: National Overview 1999/2000. NHS Cancer Plan: A baseline survey. Department of Health.

[780] HAS is a consultative, public and independant organization of scientific expertise whose overall mandate is to introduce a system to regulate the quality of healthcare that is based on sound foundations and that uses an approach based on quality. HAS main functions are to: 1) evaluate medical procedures, products and services reimbursed by the national health insurance, 2) implement health facilities accreditation process and 3) promote good healthcare practices among health professionals and the public. See HAS Annual report to parliament and to the government, 1 July 2005. Available at :http://www.anaes.fr/anaes/anaesparametrage.nsf/Page?ReadForm&Section=/anaes/Rechercher.nsf/Rechercher?OpenAgent&Fuzzy=c&query=cancer&sectrec=all

Capital investments:

- New equipment (PET scans, CT scans, MRI machines) and replacement of old machines are being put in place with significant investments from the *Plan Hôpital 2007*, a hospital modernization plan that has committed 10 billion euros from 2002-2007.[781]

Human resources management initiatives:

- Although no specific cancer human resources management strategy is in place, France has increased the number of professionals in oncology including: oncology interns, psycho-oncologists, radiologists, radiophysicists, nurses, hematologist, oncologists, allied health professionals, technicians and other specialists in nuclear medicine.

Information management systems:

- General registers are currently in place, with current studies aimed at determining the feasibility of creating three new urban registers.
- An official partnership was recognized between the InVS (Institut national de veille sanitaire) and the FNCLCC (Fédération nationale des centres de lutte contre le cancer) to conduct regional epidemiological analyses, which will assist regional health care policies.
- A communicative file transfer system (dossier communiquant en cancérologie) within each and every oncology network is currently being piloted in four regions. The system will facilitate the transmission of data relative to patient care, regardless of where individual patients receive treatment.
- INCa is setting up a national information and reporting system in close collaboration with the Ministry of Health, the ARH, and the national bodies such as INVS and assurance maladie. Another important project is the setting up of an *Enquête cancer* (cancer survey) in order to provide regular progress report on the state of cancer control.

2. Quality assurance and improvement:

Accountability agreements and performance contracts:

- A document outlining care quality and safety criteria as well as the organization of delivering at-home chemotherapy has been developed to assist networks. The document is set within a legal and financial framework

Accreditation procedures:

- The National Cancer Institute is in the process of finalizing criteria for quality, which all establishments offering cancer care will need to satisfy in order to meet approval as of 2007.
- The Haute Autorité de Santé conducts an accreditation process that entails self-assessment, peer review visits and follow-up.

Evidence-based clinical guidelines:

- The FNCLCC (Fédération nationale des Centres de lutte contre le cancer) has a Standards, Options and Recommendations (SOR) program devoted to developing CPG's tailored to specialist, general health care professionals and even for patients.[782]
- HAS (which has integrated the former ANAES) is producing a number of assessment reports related to cancer prescription drugs, innovative technologies, and professional practices.
- Follow-up of the national cancer plan indicates that four multidisciplinary scientific groups have been formed and are currently outlining clinical practice recommendations in 4 areas of cancer care: breast, lungs, urological, and digestive.
- Regional Cancer Networks will be responsible for drawing up the regional guidelines based on national guidance.[783]

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[781] Taken from Circulaire No DHOS/SDO/2005/101 du 22 février 2005 relative à l'organisation des soins en cancérologie, p. 4. Available at: http://www.sante.gouv.fr/htm/dossiers/cancer/circ101.pdf and information on Plan hôpital 2007 on the Health Ministry website at: http://www.sante.gouv.fr/

[782] http://www.fnclcc.fr/sor/structure/index-sorspecialistes.html

[783] Circulaire No DHOS/SDO/2005/101 du 22 février 2005 relative à l'organisation des soins en cancérologie. Available at: http://www.sante.gouv.fr/htm/dossiers/cancer/circ101.pdf

Patient participation:

- The Cancer National Institute's Board has a Consumer and Patient Committee

Professional training and certification:

- Cancer plan stipulates in one of its priorities to Strengthen basic training in oncology so as to increase the potential number of physicians with expertise in cancer care. Progress to date include: an agreement among the Deans of the Faculty of Medicine to make compulsory an internship in oncology, as of the 2nd year of medical training. There are also efforts to increase staffing in departments so as to increase the number of interns trained in oncology. Moreover, a new medical qualification system is in place, stipulating the conditions and procedures of having specialized training in oncology recognized.
- Cancer plan stipulates in one of its priorities to strengthen paramedical training schemes for cancer care staff through more focused training

Service delivery standards:

- Specific measures for organizing cancer services have been stipulated in a legal document (Circulaire), which aims to guarantee service quality. The document stipulates that all health facilities providing cancer services must offer organized services based on: multidisciplinarity, use of validated guidelines and coordinated work (network).[784]

Service redesign initiatives:

- Cancer plans includes as one of its priorities to develop conditions for systematic coordination of all health care players through the generalization of oncology networks, and through regulated grading of health care institutions.
- The Mission national d'Expertise et d'Audit Hospitalier (MEAH) produced a report examining the internal organisation of radiology services and provided recommendations to reduce waiting times.[785]

Service performance tracking:

- The InVS has secured in place a system to track performance of the breast cancer screening program, which includes conducting regular analysis.
- The nation-wide cancer mobilization plan (2003) identifies a number of quantitative indicators, corresponding to outcome goals in five years time, ie in 2007. These indicators will be monitored on a yearly basis. INCa to carry out its first assessment (*Enquête cancer*) in 2006.

In New Zealand, national requirements for quality assurance and improvement programs are laid down in the NZ Public Health and Disability Act 2000. This Act calls for a strategy for nationally consistent standards with regard to quality assurance and improvement programs applying to all health and disability service providers.

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[784] Circulaire No DHOS/SDO/2005/101 du 22 février 2005 relative à l'organisation des soins en cancérologie.

[785] MEAH. Organisation des services de radiothérapie : chantier approfondissement » Rapport intermédiaire - fin de phase 1 - Avril 2006, 64p. Available at: http://www.meah.sante.gouv.fr/meah/index.php?id=309

New Zealand

1. System capacity and sustainability:

Cancer drugs management systems:

- The existing centralized drug review process includes cancer medications.

Capital investments:

- Among the list of priorities for implementation of the NZ Cancer action plan is to plan for capital expenditure on cancer control, including equipment, drugs and new initiatives.

Human resources management initiatives:

- One of the priorities of the NZ Cancer action plan is to complete a cancer control workforce development plan, ensuring consideration of cancer workforce shortages for Mäori and Pacific peoples. Surveys of the health care force are currently underway by a variety of ministerial and professional organizations to estimate the future health workforce needs.

Information management systems:

- Among the priorities of the NZ Cancer action plan is to develop a nationalised, standardised clinical cancer data set and that a national minimum palliative care data set be used to monitor outcomes in DHB's and cancer networks.
- There are plans to expand and enhance the cancer registry by establishing linkages between the registry and clinical, pathology, and palliative care data sets, as well as have a consistent collection of ethnicity data.

2. Quality assurance and improvement:

Accountability agreements and performance contracts:

- DHbs are funded on a population basis and musr develop service plansd that meet national policies, including the NZ cancer control action plan.

Accreditation procedures:

- One of the priorities of the NZ Cancer action plan is to set up an accreditation programme for defining and monitoring service quality. More generally, audits, monitoring, and certification arrangements are carried out as outlined in the Health and Disability Services (Safety) Act 2001.[786]

Evidence-based clinical guidelines:

- One of the priorities of the NZ Cancer action plan is that DHBs ensure that local/regional guidelines/protocols are in place for all major cancers and that groups to develop guidance for children, adolescents and adults be established.
- The New Zealand Guidelines Group (NZGG) is an independant organization funded by the Ministry of Health and through contract with other health agencies such as the National Health Committee (NHC) to provide expertise and information on guidelines development and implementation. NZGG and the NHC are bot involved in producing guidance on cancer services.[787]

Patient participation:

- One of the priorities of the NZ Cancer action plan is that all cancer control groups and related activities will have informed consumer representatives and will be linked to a consumer organization or network

Service delivery standards:

- One of the priorities of the NZ Cancer action plan is to ensure timely and acceptable access to cancer services by establishing standards.

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[786] Ministry of Health. Cancer Control Taskforce (2005). The New Zealand Cancer Control Strategy : Action Plan 2005-2010. Accessed : *** Available at : http:www.moh.govt.nz/cancercontrol.

[787] New Zealand Guidelines Group's website. Available at: http://www.nzgg.org.nz/index.cfm?fuseaction=about&fusesubaction=docs&documentid=78

- The NZ Minister of Health has published a document entitled, "Improving quality: a systems approach for the NZ Health and disability sector" that offers a common approach and language to guide and plan quality improvement (as well as quality assurance) in sectors overseen by District Health Boards (DHBs) throughout the NZ health and disability system.[788]
- The *National Screening Advisory Committee*, within the Ministry of Health National Screening Unit, advises the Director-General of Health on screening policy and practice, including cancer screening.[789]

Service redesign initiatives:

- One of the priorities of the NZ Cancer action plan is to conduct pilot studies to map and analyse the cancer patients' journey and clinical pathway

Service performance tracking:

- Monitoring of performance of the National Cervical Screening and the Breast Screening Programs as outlined in the Operational Policy and Quality Standards Manual and the National Operational Manual, respectively is carried out by an Independent Monitoring Group.[790]
- Cancer waiting times are reported monthly to the Ministry of Health from each of the six Cancer Centers.[791]

In Nova Scotia, CCNS, along with the Nova Scotia Department of Health have secured in place a number of SQFs that sustain the cancer control intervention, as well as assure and improve on the quality of efforts to fight cancer.

Nova Scotia

1. System capacity and sustainability:

Cancer drugs management systems:

- The 1996 Plan for action included in one of its recommendations that CCNS assume responsibility for a provincial cancer formulary service in order to: (1) ensure consistent drug availability across the province; (2) develop, communicate, and maintain appropriate guidelines for the preparation of cancer pharmaceuticals; (3) monitor the use of cancer pharmaceuticals, including adherence to treatment guidelines; (4) integrate the use of cancer pharmaceuticals into a provincial cancer information system; and (5) advise the Department of Health on new cancer agents in a timely fashion.
- The 1996 Plan for action also included in one of its recommendations that the cost of cancer pharmaceuticals, established by clinical guidelines and provided on an ambulatory basis, be borne by the Department of Health, consistent with prevailing terms, conditions and the policy of insurer of last resort.
- Progress to date include the following: A Cancer Systemic Therapy Policy Committee has been established to make funding recommendations with regard to new drugs.[792] The Committee members includes representatives from the Dept of Health, CCNS, District Health Authorities CEO's, clinicians, a pharmaco-economist and an ethicist. The Committee provides recommendation to the Deputy Minister of health.It also works on operational issues to make costly drugs available closer to the patient's home.[793]

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[788] Minister of Health (2003). Improving quality (IQ) : A systems approach for the NZ Health and Disability Sector.

[789] http://www.moh.govt.nz/moh.nsf/wpg_index/About-National+Screening+Unit+-+NSAC

[790] Ministry of Health. Cancer Control Taskforce (2005). The New Zealand Cancer Control Strategy : Action Plan 2005-2010. Available at : http:www.moh.govt.nz/cancercontrol.

[791] Ministry of Health (2005). Cancer waiting times data page. http://www.moh.govt.nz/cancerwaitingtimes

[792] CCNS Many Hearts, many minds, one goal: Newsletters (November 2005 and September 2006)

[793] Nova Scotia Department of health. 2005-06 Accountability Report, p. 22.

- Health care professionals and patients have access to drug therapy information via the CCNS website.[794] Options include drug monographs, mediation information sheets to patients, and description of treatment regimens.
- More generally, The Nova Scotia Formulary details which drugs and supplies are benefits under the following Pharmacare programs: the Nova Scotia Seniors' Pharmacare Program, Community Services Programs, and Drug Assistance for Cancer Patients.[795]
- The Department of health established the New cancer drug Fund to finance new high cost drugs.

Human resources management initiatives:

- Among the first accomplishements of the Commissionner was the hiring of three radiation oncologists.[796]
- Nova Scotia is one of the pilot provinces for the CSCC's Human Resource Planning Information System (See Canada's SQF).

Information management systems:

- The 1996 Plan for action included in one of its recommendations that CCNS should have appropriate information technology to support cancer research and planning, and the surveillance and analysis of cancer information for all stakeholders.
- Nova Scotia has a cancer registry in operation since 1964, which is now being operated by the Cancer Surveillance and Epidemiology Unit of CCNS,[797] with information technology support from the Capital Health region (as part of the Oncology Patient Information System OPIS).[798] The Cancer Surveillance and Epidemiology Unit of CCNS also published in 2006 a staistical report on the state of cancer in Nova Scotia, focusing on 2000-2004.

2. Quality assurance and improvement:

Accreditation procedures:

- The 1996 Plan for action included in one of its recommendations that Regional Health Boards and facilities wishing to expand or establish new programs in cancer care, must be endorsed by CCNS. Only approved programs would be funded.

Evidence-based clinical guidelines:

- Thirteen *Cancer Site Teams* (CSTs) are in place to ensure high quality care of services system-wide by developing standards and clinical practice guidelines for each type cancer: breast; gastrointestinal; genitourinary/prostate; gynecological; head/neck; leukemia; lymphoma; musculoskeletal; neurological; pediatric; skin/melanoma; supportive care; thoracic.[799] CSTs comprise oncologists, nurses, pharmacist, surgeons, dietitians, social workers, among others. CCNS and the CSTs have produced 23 medication and 5 disease and symptom management guidelines to date. The guideline for cancer pain management is scheduled for publication in 2006. While the disease and symptom management guidelines are intended for front-line health professionals, the medication guidelines are developed to help decision-makers review new medications available for cancer treatment.[800]

Patient participation:

- Patients and their family participate in various initiatives to improve cancer services through their membership on the *Cancer Patient Family Network*, a support and information network created by CCNS.

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[794] CCNS. http://www.cancercare.ns.ca/inside.asp?cmPageID=202

[795] http://www.gov.ns.ca/health/pharmacare/benefits_faq.htm#formulary

[796] CCNS Many Hearts, many minds, one goal: Newsletter (January 2000)

[797] CCNS. http://www.cancercare.ns.ca/inside.asp?cmPageID=134

[798] CCNS Newsletter , November 2002

[799] CCNS. Cancer Site Teams. www.cancercare.ns.ca/media//documents/cancer_site_teams_fact_sheet pdf

[800] CCNS Many Hearts, many minds, one goal: Newsletter (January 2006)

Professional training and certification:

- CCNS developed Excellence in Cancer Care,[801] a series of continuing education programs for health professionals such as: Interprofessional Core Curriculum[802], which provides community-based primary care health professionals with knowledge regarding the role of other health professionals in the care continuum; Communication Skills that aims to build communication skills using evidence-based best practices;[803] and the Palliative Care Front-Line Education Program,[804] an interdisciplinary course designed to provide front-line health care workers with the knowledge/information they need to ensure the delivery of high quality palliative and supportive care. CCNS also co-led the development of the Hospice and Palliative care Certification Program.[805]

Service delivery standards:

- Provincial programs such as CCNS and the Nova Scotia Breast Screening Program are responsible for developing service standards, monitoring their achievement, and providing advice to the Department of Health based on best practices, stakeholder input and research-based evidence.
- The CCNS Systemic Therapy Program published a *Systemic Therapy Manual for Cancer Treatment* in 2004.
- A *Levels of Care Steering Committee* was established in 2005 to provide guidance on the development of the Levels of Care Framework, which stipulates the type of cancer services that can safely and appropriately be administered in a particular location, such as a hospital, a doctor's office or a patient's home. The Framework applies the Department of Health's process for developing health system standards. In principle there is acceptance among districts of the four defined Levels of Care: basic, intermediate, advanced, and sub-specialized.[806]

Service performance tracking:

- The Nova Scotia Department of Health launched its Wait Time Website, which provides average wait times for a number of tests, treatments, and services, including certain cancer treatments.[807]
- The CCNS's Cervical Cancer Prevention Program provides family physicians with personalized feedback (via Specimen Adequacy Reports) on the quality of the Pap tests they performed during the year.[808,809]
- Cancer patient satisfaction surveys have been used to obtain information on overall ratings of the care experience in Nova Scotia's two specialized cancer centers (in terms of access to care, information, education and communication, emotional and physical support; coordination and continuity of care; respect for patient preferences),[810] as well as the patient navigation system.[811]

In Ontario, SQFs that underpin the integrated cancer system are identified by reviewing CCO's cancer plan and 2005 Progress Report as well as several policy documents that outline specific strategies for cancer prevention and screening, reducing waiting times, improving services in the greater Toronto area as well as improving services to its Aboriginal communities. In addition, we also consider initiatives of the Minister of Health and Long-Term Care that aim to improve the cancer system throughout Ontario.

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[801] CCNS. http://www.cancercare.ns.ca/inside.asp?cmPageID=85
[802] CCNS Many Hearts, many minds, one goal: Newsletter (March 2005)
[803] CCNS Many Hearts, many minds, one goal: Newsletter (January 2005)
[804] CCNS (March 2005). Palliative care front-line education. Evaluation Report.
[805] CCNS Many Hearts, many minds, one goal: Newsletter (September 2004)
[806] CCNS Many Hearts, many minds, one goal: Newsletter (September 2005)
[807] CCNS Many Hearts, many minds, one goal: Newsletter (November 2005)
[808] CCNS Many Hearts, many minds, one goal: Newsletter (March 2005)
[809] CCNS Many Hearts, many minds, one goal: Newsletter (March 2006)
[810] CCNS Many Hearts, many minds, one goal: Newsletter (July 2005)
[811] CCNS. Cancer Patient Navigation (March 2004). Evaluation findings

Ontario

1. System capacity and sustainability:

Cancer drugs management systems:

- Ontario cancer plan stipulates as one of its priority to implement a new approach to funding new and expensive anti-cancer drug. In 2005, a CCO–Drug Quality and Therapeutics (DQTC) subcommittee was created to review and make recommendations on all cancer therapies, regardless of whether the drugs are eligible for the Ministry's Ontario Drug Benefit Program or CCO's New Drug Funding Program (NDFP).
- The New Drug Funding Program (NDFP) ensures that Ontario patients have equal access to high-quality intravenous (IV) drugs. The NDFP, administered by Cancer Care Ontario on behalf of the Ministry of Health and Long-Term Care, provides about 75% of the overall funding for IV cancer drugs in Ontario. The Program infrastructure validates and tracks more than 90,000 reimbursement requests annually.[812]
- CCO Drug Formulary is an online Cancer Drug and Regimen information website, reflecting the choices of chemotherapy used across Ontario. Supportive Care and Symptom Control Regimens, and Patient Information sheets are also available.
- CCO has a Provincial Working Group on the Delivery of Oncology Medications for Private Payment in Ontario Hospitals that submitted recommendations to the Ministry of Health and Long-Term Care for the provision of unfunded IV cancer drugs (July 2006). If the recommendations are accepted by the ministry, the government will issue policy direction to the hospitals. In the meantime, the recommendations are available as guidance to hospitals, but are not provincial policy.[813]

Capital investments:

- Ontario cancer plan stipulates in its priorities to: (1) fund new capital construction requirements in priority areas of the province; (2) fund outstanding post-construction operating plans; (3) fund additional capital equipment and (4) shift from a strategy of capital equipment replacement to one of planned capital acquisition. In 2005, the Ministry of Health and Long-Term Care (MOHLTC) announced the building of 4 new Cancer Centres and made other significant investments to increase the capacity of cancer services, including capital improvements, facility expansion, and equipment acquisition.[814] This is in addition to new facilities and expansions that were completed or near completion in 2004.[815]

Human resources management initiatives:

- The Ontario cancer plan stipulates as one of its priorities to implement innovative health human resources, such as nurse endoscopists and oncology nurse practitioner projects.
- HealthForceOntario, a strategy stemming from the MOHLTC, takes a 3-pronged approach to maximizing health care resources by creating advance practice roles, helping foreign-trained health professionals' to work in Ontario; and establishing a marketing and recruitment center to recruit needed health professionals.[816]

Information management systems:

- The Ontario Cancer Registry (OCR) is a computerized database of information responsible for gathering, processing and storing all newly diagnosed cases of cancer, except non-melanoma skin

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[812] Ontario Cancer Plan 2005-2008 p.92

[813] http://www.cancercare.on.ca/index_cancerDrugs.htm#freedrugs

[814] Ontario Cancer Plan 2005 Progress Report, p. 9.

[815] Ontario Cancer Plan 2005-2008 p.77-78

[816] Cancer Care Ontario. Ontario Cancer News. Advance practice roles maximize health care resources and enhance access to cancer services. May 2006; vol. 4. http://www.cancercare.on.ca/OntarioCancerNewsArchives/index_552.html

cancer. Included in the OCR database are all Ontario residents who who have been diagnosed with cancer or have died from cancer. More than 1.3 million cases have been registered for the interval 1964-2002. Statistical information on cancer in Ontario can be displayed via CanQuery, an interactive, web-based tool.

- The Pathology Information Management System (PIMS) allows to electronically collect and monitor how thoroughly pathologists report information. It has been implemented in 45 labs representing nearly 90% capture of pathology reports across the province. It will be used in the future as a tool to support synoptic reporting by pathologists.[817, 818]
- The iPort, launched in 2005, is a web-based analytic tool that provides cancer planners, managers, and policy-makers with instant access to clear, accurate and consistent provincial and regional level cancer surveillance statistics.[819] In 2006, iPort 2.0 was launched; it includes information on radiation and system therapies that occurred in the Integrated Cancer Programs and their affiliates, as well as index cancer surgeries at hospitals throughout Ontario.[820]
- The Cancer System Quality Index,[821, 822] is a system-wide monitor that allows CCO to track the quality and consistency of all key services delivered across the spectrum of Ontario's cancer system from prevention through to palliation, with focus on accessibility, outcomes, evidence in best standards of practice, efficiency; and measurement (see details in other categories below).
- Initiated by the MOHLTC, the Data Tracking, Referral, and Analysis of Capacity for Cancer (D-TRACC) provides management and information on cancer treatment, activity, quality, and accessibility.[823] This includes tracking and reporting on access to cancer treatment and wait times in Ontario; tracking and analyzing the quality of care; improving human resource planning and funding by identifying demand, capacity, and constraints in the cancer treatment system; providing outcome analysis by site, stage, and treatment type; identifying constraints within the cancer system.
- With recent funding from the Access to Cancer Services Innovation Fund, the integrated cancer program at Kingston General Hospital, together with CCO has developed a computerized system to track patient's journey through the cancer care system, recording wait times specific to seeking and receiving care in lung and breast cancer.[824] These data will serve to establish provincial wait time benchmarks.

2. Quality assurance and improvement:

Accountability agreements and performance contracts:

- In 2005–06, CCO negotiated accountability agreements with 37 hospitals to begin reducing waiting times. In addition to increasing service volumes, the accountability agreements ensure performance in service delivery and clinical quality. The agreements also require quarterly performance and data reporting, clinical quality assurance and participation in the Regional Cancer Program development. The funding of additional volumes of cancer surgeries to reduce wait times has forged a new relationship between surgery providing hospitals and CCO. As of October 2006, 42 hospitals have

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[817] Cancer Care Ontario. Information Management http://www.cancercare.on.ca/index_about CCOInfoManagement.htm

[818] CCO. Ontario Cancer News. Cancer pathology reporting now automated. May 2005 (vol. 3; n. 4).

[819] Cancer Care Ontario. Ontario Cancer News. Cancer Innovations highlighted at Health Care Expo. April 2006; vol. 4. http://www.cancercare.on.ca/OntarioCancerNewsArchives/200604/index_535.html

[820] Cancer Care Ontario. Ontario Cancer News. Cancer Innovations highlighted at Health Care Expo. April 2006; vol. 4. http://www.cancercare.on.ca/OntarioCancerNewsArchives/200604/index_535.html

[821] Cancer Care Ontario. Cancer System Quality Index. http://www.cancercare.on.ca/qualityindex.

[822] Cancer Care Ontario. Ontario Cancer News. Web report evaluates Ontario's cancer system. April 2006; vol. 4. http://www.cancercare.on.ca/OntarioCancerNewsArchives/200604/index_534.html

[823] Partners in Cancer Care- Building a quality improvement coalition. 2002-2007 Information Management Strategy Plan. (Final Report). November 2002.

[824] Cancer Care Ontario. Ontario Cancer News. Innovation fund projects released from across the province. January 2005; vol. 3. http://www.cancercare.on.ca/ontariocancernewsarchives/200501/392_0105story2.html

signed an agreement with CCO to perform additional surgeries and to participate in quality improvement activities (increased stage capture and multi-disciplinary case conferences).[825]

- CCO promotes accountability of all participants in the cancer system, and especially of the clinicians who care for the patients, through its new Clinical Accountability Framework (CAF). The CAF requires clearly defined local, regional, and provincial roles and responsibilities. In 2005, the CAF was incorporated into the Program in Evidence-Based Care's matrix of guideline development groups comprising over 1,000 Ontario clinicians.
- CCO has submitted recommendations for alternate physician payment plans to the Ministry. These recommendations seek to integrate clinical quality goals into physician and surgeon performance agreements.[826]

Accreditation procedures:

- CCO has created a strategy to partner with accreditation bodies and other stakeholders to create a long-term system of support for the ongoing development, dissemination, and performance monitoring of organizational standards throughout the cancer system.[827]
- CCO has recommended that the MOHLTC require all Ontario mammography facilities (hospitals and independent health facilities) be accredited by the Canadian Association of Radiologists Mammography Accreditation Program (CAR-MAP).[828]

Evidence-based clinical guidelines:

- The Ontario cancer plans stipulates that CCO will promote an evidence based culture in the cancer care community and facilitate continuing professional development and rapid incorporation of new knowledge into practice.
- The Program in Evidence-Based Care (PEBC), established by CCO,[829] develops evidence-based care information for providers and the public, maintains quality and currency of resources, ensures availability and accessibility of resources, and disseminates and evaluates resources.[830] There are three *Guideline Development Groups* for cancer screening, supportive care, and therapeutic radiopharmaceutical as well as 11 *Disease Site Cancer Groups*: breast, gastrointestinal, genitourinary, gynecology, head/neck, hematology, lung, melanoma, neuron-oncology, sarcoma, and systemic treatment. All 14 groups are responsible for ensuring the production, dissemination, implementation, evaluation, and updating of guidelines, standards, and planning tools.[831] CPG development includes surveys of oncologists' opinions, using a structured questionnaire, about draft recommendations that were developed by the expert panels. By the end of summer 2006, there will be standards for hepatic, pancreatic and biliary tract cancer surgery and multidisciplinary cancer conferences standards.[832] The work on clinical practice guidelines has now been expanded to include standards. Implementation of guidelines and standards is pushed by the clinicians and staff of the clinical programs division of CCO working with the 14 regional cancer programs.[833]
- The Systemic Therapy Computerized Physician Order Entry (OPIS/CPOE) is a software that helps physicians access up-to-date practice guidelines to make better decisions regarding the ordering of systemic therapy. It also serves to coordinates chemotherapy treatment faster.[834, 835]

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[825] Personnal communication, Dr Terry Sullivan, CEO, CCO, October 23, 2006 letter.

[826] Ontario Cancer Plan 2005 Progress Report, p. 36.

[827] Ontario Cancer Plan 2005 Progress Report, p. 18.

[828] Ontario Cancer Plan 2005 Progress Report, p. 28.

[829] Ontario Cancer Plan p.50

[830] Cancer Care Ontario. About the Program in Evidence-Based Care. http://www.cancercare.on.ca/index_AboutthePEBC.htm

[831] CCO. About the Program in Evidence-Based Care. http://www.cancercare.on.ca/index_AboutthePEBC.html.

[832] Cancer Care Ontario. Ontario Cancer News. Innovation fund projects released from across the province. January 2005; vol. 3. http://www.cancercare.on.ca/ontariocancernewsarchives/200501/392_0105story2.html

[833] Personnal communication, Dr Terry Sullivan, CEO, CCO, October 23, 2006 letter.

[834] Cancer Care Ontario. Ontario Cancer News. Cancer Innovations highlighted at Health Care Expo. April 2006; vol. 4. http://www.cancercare.on.ca/OntarioCancerNewsArchives/200604/index_535.html

Patient participation:

- Patient and consumer involvement in planning and evaluating activities is considered as one among many facilitators for achieving Regional Cancer Programs' responsibilities. Each Regional Cancer Program (RCP) created a steering committee to oversee RCP implementation that is representative of participants (including clinicians and patient/consumer representatives) from across the continuum of care. [836]

Professional training and certification:

- A new radiation therapy training program was launched in 2005 in Hamilton.

Service delivery standards:

- The Ontario cancer plan stipulates that CCO will broaden the scope of program standards and guidelines across the continuum of care, addressing known needs and opportunities in cancer-related imaging, pathology, and palliative care. CCO now has active clinical leadership who are developing provincial approaches to quality improvement in pathology, imaging, family practice, patient education, and psychosocial oncology.[837]
- The Ontario Cancer plan seeks to expand the use of organizational standards to ensure that a consistent level of quality of cancer services is available throughout Ontario
- In 2002, the *Cancer Quality Council of Ontario* (CQCO) was established with the mandate to monitor and publicly report independently on the Ontario cancer system.[838] The Cancer Quality Council of Ontario monitors, assesses, and provides tools to improve the quality of services across the cancer system, namely cancer services standards through the Cancer System Quality Index (CSQI).
- The Palliative Care Integration Project (managed by CCO) is pushing out tools and standards to ensure efficient, high quality palliative care delivery to cancer patients across the continuum of care and across the province. Initiated in the Kingston region, the project demonstrated improvement in the continuity and variability of palliative care services through: (1) the development of evidence-based collaborative care plans (CCPs) and symptom management guidelines, (2) use of common, validated assessment tools, and (3) application of the CCPs, symptom management guidelines and assessment tools in the different care settings in the region. The tools and collaborative care plans are now being implemented province-wide (2006). By the end of 2006, CCO will have regional improvement coordinators working to implement these tools and standards across the province. The initial work will focus on lung cancer patients.
- CCO intends to publish its first set of evidence- and consensus-based program standards for Ontario palliative care services, as well as to initiate performance reporting by refining quality measures reported in the Cancer System Quality Index (CSQI).[839]

Service redesign initiatives:

- The Ontario cancer plan stipulates as one of its priorities to fund high-impact process improvement projects that increase throughput across the cancer system.The Access to Cancer Service Innovation Fund (ACIF) was announced in 2005. This Fund supports initiatives that aim to improve access and reduce wait times.[840] With recent funding from the ACIF, for example, stakeholders and decision-makers in the Kingston region initiated the Palliative Care Integration Project (see above in service delivery standards). CCO has adopted the approaches used in Rapid Cycle Quality Improvement to

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[835] Cancer Care Ontario. Information Management http://www.cancercare.on.ca/index_about CCOInfoManagement.htm

[836] Ontario Cancer Plan 2005 Progress Report, p. 20-21.

[837] Personnal communication, Dr Terry Sullivan, CEO, CCO, October 23, 2006 letter.

[838] Sullivan et al. 2004

[839] Ontario Cancer Plan 2005 Progress Report, p. 21.

[840] Cancer Care Ontario. Ontario Cancer News. Innovation fund projects released from across the province. January 2005; vol. 3. http://www.cancercare.on.ca/ontariocancernewsarchives/200501/392_0105story2.html

accelerate province-wide uptake of assessment tools, collaborative care plans and symptom management guidelines developed in the Palliative Care Integration Project.[841]

Service performance tracking:

- The Ontario cancer plan has many priority actions in this area including to: (1) implement a framework for indicator reporting at the program, organizational and systems levels to improve quality; (2) expand the scope and quality of data collected for performance monitoring and system planning; (3) accelerate data extraction, analysis and reporting cycles for ongoing performance improvement that includes data management, warehouse, intelligence tools, and analytic capacity; and (4) implement new performance reporting systems associated with accountability agreements and implementation of the Ontario Cancer Plan.
- The Cancer System Quality Index (CSQI) is a publicly accessible Web site consisting of 25 evidence-based measures of cancer system quality across the full spectrum of cancer services, from prevention to end-of-life care. The CSQI's purpose is twofold: to provide the public with a tool to assess the performance of the cancer system, and to provide managers with a tool to understand and improve the performance of the cancer system.
- Wait times for cancer surgery are being tracked and reported to the province on the government's wait times web site.[842] In addition, CCO reports on wait times (median time from referral to treatment) for radiation therapy, systemic therapy by cancer site (central nervous system, genitourinary, gynaecologic, breast, lung, head/neck, haematology, gastrointestinal, and sarcoma) and by treatment facilities.[843]
- The D-TRACC system also provide management and information on cancer treatment, activity, quality, and accessibility (see above in the information management system category).
- The integrated program at Kingston General Hospital, together with CCO, created an electronic wait list software that tracks data from various clinical databases to provide a snapshot of a patient's journey through the cancer care system from the detection of an abnormality to treatment, and all points in between. Currently, this program focuses on patients with lung and breast cancer. The plan is to use the information being monitored to identify system barriers and to establish provincial wait time benchmarks

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[841] Personnal communication, Dr Terry Sullivan, CEO, CCO, October 23, 2006 letter.

[842] Ministry of Health and Long-Term Care. Wait Times in Ontario. http://www.health.gov.on.ca/transformation/wait_times/wait_mn.html

[843] http://www.cancercare.on.ca/radiation_cnsprint.htm

Appendix 8A -- Progress in achieving measurable indicators of outcome by jurisdictions

Canada	
Measurable outcomes for CSCC in Business Plan 2006-2010: • 45% reduction in the projected number of new cases by 2033 • 51% reduction in the projected number of cancer deaths by 2033 b. Save over $39 billion in direct health care costs c. Prevent the loss of over $34 billion in total government tax revenues d. Prevent the loss of over $101 billion in wage-based productivity	**Review of Progress:** • The CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that Canada had an 18 % increase in new cancer cases between 1996 and 2006.
Measurable outcomes among the systemic objectives for each CSCC Priority Area Action Group: • 100% of cancer patients will have access to supportive and palliative care services by 2010 • Over the next 10 years, implement the Human Resources Planning Information System • Over the next three years, link and standardize surveillance and data collection systems across Canada	
Target for breast screening in Health Canada's Evaluation Indicators Working Group Report: • Percentage of women aged 50-69 who have a screening mammogram (biennally) should be of 70% or greater.	• The 2006 Canadian Cancer Statistics Report indicated that by 2003, every province had an organized program offering biennial mammography screening to asymptomatic women between the ages of 50-69 with no previous history of breast cancer. Although none of the organized programs have achieved the nationally established target of 70% participation, the proportion of women in organized screening has increased over time, reaching 34% nationally by 2002. In 2003, about 61% of women aged 50-69 reported having screening mammography in the last two years, a considerable increase from the 53% reported in 2000/01.
Benchmarks established for Canadian provinces in December 2005. The ones relevant for cancer control are following: • Cancer radiation therapy: to treat cancer within four weeks of patients being ready to treat • Breast cancer screening for women aged 50 to 69 every two years; and • Cervical cancer screening for women aged 18 to 69 every three years after two normal tests.	
Targets for smoking reduction: None found	• Canadian Tobacco Use Monitoring Survey indicates that rates of current smokers fell from 26% in 2000/01 to 23% in 2003 to 22% in 2005.

New Zealand

Measurable outcomes for the NZ Cancer Control Strategy Action Plan:	**Review of Progress:**
• Reduce adult smoking prevalence to 20% or less by the end of 2010 **Target for the biennial breast screen participation rate**: • 70% particiaption aret for eligible women aged 50-64. (increased coverage from 45 to 70 percent for Maori and Pacific Island women would produce a 10% reduction in breast cancer mortality) **Radiotherapy wait times targets**: The interval between the patient’s referral from a medical practitioner to the oncology department, and the beginning of radiation treatment should be: • within 24 hours for priority A patients (urgent): • within 2 weeks for priority B patients (curative); • within four weeks for priority C patients (palliative and other radical): • start date for priority D patients (combined chemotherapy and radiation treatment) should be booked according to treatment schedule	• Ministry of Health report revealed that the percentage of smokers in the general population has dropped from 25% in 2001 to 23.4% in 2004. For the Māori population, the prevalence has dropped from 52% in 2001 to 47% in 2004; and for the Pacific population, the prevalence has dropped from 32% in 2001 to 29%. • Independent Monitoring Group report revealed that the biennial participation rate for women aged 50-64 years to the BreastScreen Aotearoa (BSA) program was 64%. • The Ministry of Health collects wait times data for radiotherapy since 1998 and publicly reports data monthly. Since March 2005, more than 80% of all patients (and more than 90% of Priority C patients) waited less than 8 weeks between the first specialist assessment and the start of radiation treatment in all 6 cancer centres.

France

Measurable outcomes for the 2003-2007 Cancer Plan:	Review of Progress:
• To bring cancer-caused mortality down by 20% in the next five years • Smoking should drop by 30% among the young; by 20% in the adult population, and there should be a 20% drop as well in the number of alcohol dependent adults. • 80% of all women aged 50 to 74 will be screened for breast cancer; 80% of all women aged 25 to 69 will be screened for cervical cancer. • 100% of all patients must gain access to customized care programs. • 100% of all patients must have access to procedures for breaking the bad news consultations and quality information on support structures • At least 10% of all patients are included in clinical trials in reference centers.	INCa Three-year Progress Report indicates that: • Between 1990 and 2002, cancer mortality rate increased by 7.2% with significant differences (1 to 1.3 fold) between regions. • The prevalence of smoking (12-75 years of age) has dropped to 29.9% in 2005 (compared to 33.1% in 2000); The prevalence of smoking among teens (15-19 years of age) has dropped to 31.3% in 2005 (from 40.9% in 2000). INVS Report indicated that: • Participation rates of women between 50-74 years of age to organized breast cancer screening program (which was generalized to all regions in 2005) increased gradually from 2003 to 2005: from 33 % in 2003, to 40 % in 2004 and 45 % in 2005. INCa Three-year Progress Report indicates that: • Between June 2004 and May 2005 18,500 patients (from 58 facilities) benefited from the "breacking the bad news" consultation, and 90% of the patients' case were reviewed in a multidisciplinary consultation meeting, among which 35% of those patients benefited from supportive care.

Ontario

Cancer 2020 Prevention/Screening Action Plan Targets (by 2020):	**Review of Progress:**
• Reduce the proportion of teens who are smoking from 19% (2001) to 2% • Reduce the proportion of adults who are smoking from 26% (2001) to 5% • Increase the proportion of women aged 50 to 69 who are screened for breast cancer from 62% (2001) to 90% • Increase the proportion of women undergoing cervical screening from 82% (1998/99) to 95% • Increase the proportion of Ontarians participating in an organized colorectal screening program from 10% (1999) to 90%	The 2005 Canadian Tobacco Use Monitoring Survey indicates that: • Rate of cigarette smoking among Ontarians aged 12 and over fell from 24.5% in 2000/01 to 22.3% in 2003 to 21.9% in 2005 The Ontario Cancer Plan Progress Report indicates that: • 27% of women aged 50-69 is being screened through the Ontario Breast Screening Program. Other women in this age group are being screened through stand-alone programs with inconsistent quality standards. The Cancer System Quality Index 2006 indicates that: • Breast cancer screening (including organized) increased to 56.4% in 2005, up from 52.5% in 2004. • Still in 2005, only 10% of the Ontario population aged 50-74 undergoes colorectal cancer screening.
Cancer surgery wait time targets set by Ontario Government in December 2005: • Cancer surgery (for priority categories 1, 2 , 3 and 4 respectively): immediate, 2 weeks, 4 weeks and 12 weeks wait from ready to treat to treatment Priority 1-- Threatens life of person, such as airway obstruction or bleeding Priority 2 -- Very aggressive tumours such as central nervous system cancer Priority 3 -- Person with known or suspected invasive cancer, that do not fall into Priority 1, 2 or 4 Priority 4 -- Patients with slow-growing tumours	
Target wait times for different cancer treatments were recently proposed by Cancer Care Ontario and some of them include: • Cancer surgery (for priority categories 1, 2 , 3 and 4 respectively): immediate, 14 days, 28 days and 84 days wait from ready to treat to treatment • Radiation treatment (for priority categories 1, 2 and 3 respectively): immediate, 7 days, and 14 days wait from ready to treat to treatment • Systemic therapy (for priority categories 1, 2 and 3 respectively): immediate, 7 days, and 14 days wait from ready to treat to treatment	A Press release by the Ontario Government indicated that: • Median radiation wait times have dropped from 6.6 weeks in 2003 to 4.1 weeks in 2006 – a 38% reduction. Results from the 2005 Cancer System Quality Index revealed that: • Average wait for radiation treatment was 4.7 weeks, down from 7.0 in 2002.

England

Measurable targets set by Department of Health:

- Reduce the death rate from cancer in people under 75 by at least 20% by 2010

1998 UK tobacco control strategy:

- Reduce smoking in adults from 28% to 24% by 2010

Measurable targets from the NHS Cancer Plan (2000):

- Reduce smoking rates among manual groups from 32% in 1998 to 26% by 2010, and achieve
- Maximum one month wait from diagnosis to treatment for all cancers by 2005
- Maximum two month wait from urgent GP referral to treatment for all cancers by 2005
- By 2004 every patient diagnosed with cancer will benefit from pre-planned and pre-booked care

Standard of NHS Breast Screening Program:

- An acceptance rate after first invitation greater or equal to 70% among women aged 50-64.

Measurable targets in the Priorities and planning framework 2003/06:

- 800,000 smokers from all groups successfully quitting at the 4 week stage by 2006.
- Extend breast screening to all women aged 65-70 by 2004

Target in 2004 Public Services Agreement:

- Reduction in the inequalities gap of at least 6% between the fifth of areas with the worst health and the population as a whole.

Review of Progress:

March 2004 NAO report revealed that:

- Cancer services are leading to lower incidence and mortality rates, as well as better survival rates.
- Improvement in survival and mortality rates were higher for the better off compared to those less well off or in areas with high levels of deprivation.

The 2004/05 General Household Survey on Smoking and drinking among adults indicated that:

- In 2004, 25% of adults aged 16 or over in England were current cigarette smokers.
- In 2003, it was 26% (28% of men and 24% of women).
- Between 1998/99 and 2004/05, the proportion of smokers fell from 28 to 25%.

March 2005 NAO report revealed that:

- Targets set for waits for diagnosis and treatment are within expectations, for example, 99.2% of patients with suspected cancer are seen by a specialist within 2 weeks; between 95% and 100% of patients are urgently referred to treatment by their GPs; 89.9% of patients diagnosed with cancer are treated within 31 days.
- Smoking among manual groups has been reduced to 31% from 33,5 in 1998.

The 2005 review of the NHS Breast Screening Programme indicates that:

- Attendance rate at first invitation for breast screening was 72.8% among eligible women of 50-64 years of age and 72.4% when considering eligible women of 50-70 years of age.
- This high participation rate has been consistently observed since 1999
- Extending the program to include all women from 50 to 70, and combined with the introduction of two-view mammography, resulted in substantial rise in the number of cancer detected.

Nova Scotia

Measurable target for the Cervical Cancer Prevention Program:

- 85% triennial participation rate to organized cervical cancer screening

Measurable targets from the Nova Scotia Breast Screening Program:

- Reduce the mortality from breast cancer in women aged 50-69 years by 30% within ten years following development of a province wide screening program.
- 70% biennial participation rate for women aged between 50 and 69.

Canadian benchmarck for radiation therapy wait time:

- To treat cancer within four weeks of the patients being ready to treat (2005).

Targets for smoking reduction:

- Planned outcomes indicators for the Tobacco Control Strategy (2001) were defined in the Nova Scotia Tobacco Control Strategy Evaluation Framework (2002). See Appendix 5 C for details.

CCNS Goals:

- To have high quality cancer care across the province
- To reduce the number of people diagnosed with cancer, and dying from cancer
- To enhance cancer research in Nova Scotia
- To bring reliable and helpful information to Nova Scotians

Review of Progress:

Understanding Cancer in Nova Scotia (2006) reports that :

- Participation rate for triennial cervical screening was 66% in 2004.
- Participation rate for biennial breast cancer screening was 43% in 2004

The 2006 Canadian Cancer Statistics Report indicated that:

- Participation rate of asymptomatic women between the ages of 50-69 with no previous history of breast cancer to organized biennial mammography screening was over 30% by 2002. In 2003, about 50% of women aged 50-69 reported having screening mammography in the last two years, from 45% in 2000/01.

The Health Council of Canada 2006 report indicated that:

- In Nova Scotia, radiation therapy average wait times are within 1 day for emergency cases; in 5 to 7 days for urgent cases; in 20 to 21 days for semi-urgent cases; and in 32 to 36 days for less urgent cases.

Nova Scotia Tobacco Control Strategy Evaluation (2006) reports that:

- A majority of the planned outcomes documented in the evaluation framework were achieved.

The 2006 Canadian Tobacco Use Monitoring Survey indicates that:

- Rates of cigarette smoking among Nova Scotians aged 12 and over, fell from 28.2% in 2000/01 to 23.6% in 2003 to 22.7% in 2005.

NRC Picker National Satisfaction Survey among cancer patients in 2004 and 2005 revealed that:

- In 2005, 78% of respondents from the Cape Breton Cancer Centre and 71% of patients from the Nova Scotia Cancer Centre reported their experience as excellent, very good or good. The Canadian average was 68.5%.
- In 2004, 79% of respondents from the Cape Breton Cancer Centre and 61% of patients from the Nova Scotia Cancer Centre reported their overall care as excellent. The Canadian average was 50%.

	CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that: • Nova Scotia had an 8% increase in new cancer cases between 1996 and 2006. Understanding Cancer in Nova Scotia (2006) reports that : • Cancer mortality rate among males increased 14.3% between 1971 and 2004. The rate reached its peak in 1992, and has since declined at a rate of 1.2% per year to 243 deaths per 100,000. This trend was largely due to lung cancer, which decreased at a rate of 1.8% per year during the same period. In females, cancer mortality rate has remained stable, with an average of 166 deaths per 100,000.

British Columbia

Cancer Indicators in PHSA's Performance Agreement with Health Ministry: • Increase the proportion of women aged 50 to 74 participating in screening mammography by 2% over the previous year with an increase by at least 3% within the Northern Health Region, with a long term target of 70% participation rate **Cancer Indicators in Ministry of Health 2006/07-2008/09 Service Plan (targets set for 2010):** • Smoking rates for those aged 15 and older, reduction from 15% in 2004 to 14.4% by 2010 • Waiting times for radiotherapy, 95.5% begin treatment within four weeks of being ready to treatment in 2004/2005. Maintain at or above 90% within four weeks. • Waiting times for chemotherapy, 90% begin treatment within two weeks of being ready to treat in 2004/2005. Maintain at 90% within two weeks **Canadian benchmark for radiation therapy wait times:** • Treat cancer within four weeks of patients being ready to treat (2005)	**Review of Progress:** The 2006 Canadian Cancer Statistics Report indicated that: • Participation rate of asymptomatic women between the ages of 50-69 with no previous history of breast cancer to organized biennial mammography screening reached 50% by 2002. In 2003, about 60% of women aged 50-69 reported having screening mammography in the last two years, from 50% in 2000/01. CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that : • British Columbia had a 16% increase in new cancer cases between 1996 and 2006. The Canadian Tobacco Use Monitoring Survey 2006 indicates that: • Rate of cigarette smoking among British Columbians aged 12 and over, from 20.6% in 2000/01 to 18.8% in 2003 to 17.8% in 2005. Health Council of Canada 2006 reported: • A median wait time of 0.9 weeks for radiation therapy. The BC Ministry of Health indicated in 2006 that: • In 2004/05, over 95% of British Columbians requiring radiotherapy started treatment within four weeks of being medically able to receive it. • Regarding chemotherapy, there is no significant wait for British Columbians. • The 5 year age-standardized mortality rates for all cancers fell from 16.9 per 10,000 in 1999 to 15.9 per 10,000 in 2004.

Alberta

ACB targets for the year 2025:
- Reduce the projected incidence of cancer by 35%
- Reduce the projected mortality from cancer by 50%
- Eliminate or reduce suffering of all persons living with cancer

Framework for Healthy Alberta 2012 Targets:
- Increase proportion of women aged 50 to 69 screened for breast cancer from 71% to 80%
- Increase proportion of women aged 18 to 69 screened for cervical cancer from 75.1% to 95%
- Reduce mortality rate for cervical cancer from 2.9 to 1.5 per 100,000
- Reduce mortality rate for breast cancer from 24.2 to 22 per 100,000
- Reduce mortality rate from prostate cancer
- Reduce rate of people who get lung cancer from 56 to 48 per 100,000 people

Alberta Tobacco Reduction Strategy (ATRS) 2011 Targets:
- Reduce the consumption of tobacco products in Alberta by 50% from 2001 to 2011
- Reduce the percentage of Albertans age 15+ who smoke from 25% in 2001 to 17.5% in 2011
- Reduce the percentage of youth age 15 -19 years who smoke from 24% in 2001 to 12% in 2011
- Reduce the percentage of women who smoke during pregnancy from 32% in 2000/2001 to 12% in 2010/2011

Measurable outcomes in ACB 2005/2006-2006/2007 Multi-year Performance Agreement:
- For 90% of patients, achieve target wait times of four weeks from referral to consultation with an oncologist and two

Review of Progress:
CSCC Business Plan estimated, based on the 2006 Canadian Cancer Statistics Report, that:
- Alberta had a 48% increase in new cancer cases between 1996 and 2006

The Health Quality Council of Alberta reported in 2005 that:
- Cancer incidence rates are expected to double between 2000 and 2020.

Cancer in Alberta: A regional picture 2006, based on 2003 data, reported a rise in cancer incidence, no significant change in cancer mortality, and better survival rates for those diagnosed in the past several years.
- The age-standardized incidence rate for lung cancer was around 61 per 100,000 and 42 per 100,000 for men and women, respectively.
- The age-standardized mortality rates for breast and prostate cancer were around 25 per 100,00 and 27 per 100,000 respectively.

The 2006 Canadian Cancer Statistics Report indicated that:
- Participation rate of women aged 50-69 to organized biennial mammography screening was just over 10% by 2002.
- In 2003, about 62% of women aged 50-69 reported having screening mammography in the last two years, from 50% in 2000/01.

Canadian Tobacco Use Monitoring Survey 2005 indicates that:
- Rate of cigarette smoking among Albertans aged 12 and over fell from 27.7% in 2000/01 to 23% in 2003 to 22.8% in 2005.

ATRS Highlights 2005-2006 reports that:
- Rate of cigarette smoking among Albertans aged 15 and over was 20% in 2003 and 2004, but increased to 21% in 2005. Rate among 15-19 years was 18% in 2003, 16% in 2004, but increased to 19% in 2005.

Health Council of Canada 2006 reported:
- Wait times for breast and prostate cancer of 2-5 weeks from referral to

weeks from consultation to treatment for all tumor groups where medically appropriate • 95% of patients to rate quality of services as satisfactory or better • Alberta Cervical screening program implemented province-wide by 2007 • Alberta Breast cancer screening program implemented in majority of province by 2007	appointment with oncologist, and <2-3.5 weeks from appointment to therapy. ACB’s annual report for 2004-2005 stated that: • Over 90% of patients rate quality of services as high • Alberta Cervical screening program was implemented in two health regions. • Alberta Breast screening program was launched

Appendix 9A: List of main policy documents: Québec

Québec	
Stages of Policy Process	**Documents/events**
I. Strategic Development	1992: Ministère de la Santé et des Services sociaux (MSSS), Direction de la Santé publique. La politique de la Santé et du bien-être (Objective no 9 on cancer) 1992 (May): Comité ministériel sur l'organisation des services en cancérologie au Québec. Rapport. 1993: Conseil du statut de la femme. Au-delà de la mammographie de dépistage, le cancer du sein. 1993: Conseil du statut de la femme. Position du Conseil du statut de la femme sur la mammographie de dépistage. 1995: MSSS. Comité consultatif sur le cancer (CCC) – Groupe de travail interdirectionnel. Pour une meilleure compréhension des besoins des personnes atteintes de cancer. 1996 : MSSS. CCC – Sous-comité sur le soutien et les soins palliatifs. Les services de soutien et de soins aux personnes atteintes de cancer. 1997: MSSS. CCC -- Sous-comité sur les données statistiques. Le cancer au Québec: statistiques de base. 1997: MSSS. CCC-- Sous-comité sur le dépistage du cancer. Le dépistage systématique du cancer: orientations. 1997 : MSSS. CCC -- Sous-comité sur la promotion de la santé et la prévention du cancer. La promotion de la santé et la prévention du cancer. 1997: MSSS. CCC -- Sous-comité sur l'investigation, le traitement et l'adaptation. L'investigation, le traitement et l'adaptation. 1999 (May): Conseil québécois de lutte contre le cancer (CQLC). Comité radio-oncologie – Rapport du Comité radio-oncologie. 2000: CQLC -- L'intervenant pivot en oncologie: un rôle d'évaluation, d'information et de soutien pour le mieux-être des personnes atteintes de cancer. 2001: CQLC -- Avis sur les délais dans le traitement chirurgical du cancer. 2001 (July): CQLC -- Cancer de l'appareil digestif. Critères d'organisation par niveau de services. 2004 (February): MSSS. Groupe de travail ministériel en cancer. Unifier notre action contre le cancer. Rapport de la démarche ministérielle visant l'amélioration de la gestion et de l'impact du programme québécois de lutte contre le cancer. 2004 (April): MSSS. Direction générale des services de santé et médecine universitaire – Comité aviseur. Le continuum de services pour les personnes atteintes de cancer et leurs proches : paramètres d'organisation. 2005 (March): CQLC. Comité de l'évolution de la pratique infirmière en oncologie -- Pour optimiser la contribution des infirmières à la lutte contre le cancer, Recommandations et avis.

	2005 (March): CQLC. Comité des représentants de la population atteinte de cancer et des proches au Québec -- Besoins des personnes atteintes de cancer et de leurs proches au Québec, Recommandations et avis. 2005 (March): CQLC. Comité de la première ligne médicale de lutte contre le cancer -- Le médecin de famille et la lutte contre le cancer, Recommandations et avis. 2005 (March): CQLC. Comité de soutien, d'adaptation et de réadaptation -- Le soutien, l'adaptation et la réadaptation en oncologie au Québec, Recommandations et avis. 2005 (August): MSSS. Direction de la lutte contre le cancer (DLCC) -- Comité des équipes interdisciplinaires de lutte contre le cancer. Les équipes interdisciplinaires en oncologie, Recommandations et avis. 2005: MSSS. DLCC -- Forum sur le cancer du colon et du rectum, 30 septembre. 2005: MSSS. DLCC -- Colloque annuel du PQLC sur le cancer de la prostate, 18 novembre 2005. 2006: Institut national de santé publique (INSPQ) -- Soins palliatifs de fin de vie au Québec : définition et mesure d'indicateurs. Partie 1 : Population adulte (20 ans et plus). 2006: MSSS. DLCC. Groupe de travail sur les normes en matière de soins palliatifs pédiatriques (L. Côté-Brisson, Chair) -- Normes en matière de soins palliatifs pédiatriques.
II. Formal strategy, action plan and/or program	1993 (November): MSSS -- Plan d'action ministériel en radiothérapie et en cancérologie 1993 (November): MSSS -- Plan d'action pour le dépistage du cancer du sein 1996: MSSS -- Programme québécois de dépistage du cancer du sein. Cadre de référence. 1998: MSSS -- Programme québécois de lutte contre le cancer. Pour lutter efficacement contre le cancer, formons équipe. 2001: CQLC – Plan stratégique 2001-2003. 2001: MSSS – Plan stratégique 2001-2004 du Ministère de la Santé et des Services sociaux 2001: MSSS -- Plan québécois de lutte contre le tabagisme 2001-2005 2001: MSSS. Centre de Coordination de la lutte contre le cancer au Québec (CCLCQ) -- Plan d'action 2001-2002. 2003: CQLC -- Stratégie et plan d'action 2003-2005. 2003: MSSS -- Programme national de santé publique 2003-2012 2004: MSSS -- Politique en soins palliatifs de fin de vie. 2004: Notes pour une allocution du Ministre de la Santé et des Services sociaux, monsieur Philippe Couillard, à l'occasion du Forum sur le cancer, 23 avril 2004. 2005: MSSS -- Plan stratégique 2005-2010 du Ministère de la Santé et des Services sociaux. 2006: MSSS -- Plan québécois de lutte contre le tabagisme 2006-2010 2006: MSSS -- Investir pour l'avenir 2006-2012. 2007: DLCC – Orientations prioritaires 2007-2012 du programme québécois de lutte contre le cancer.

III. Program operations and/or progress of reform implementation	2000: INSPQ -- Étude du processus d'implantation du Programme québécois de dépistage du cancer du sein (PQDCS) 2001: MSSS -- Un centre de coordination nationale de lutte contre le cancer. 2002: MSSS – Rapport annuel de gestion 2001-2002 2003: INSPQ -- Déterminants du taux de référence lors d'une première mammographie de dépistage – PQDCS 1999 2003: INSPQ -- Facteurs associés aux variations du taux de détection - PQDCS 1998-1999 2003: MSSS – Rapport annuel de gestion 2002-2003 2003: MSSS. CCLCQ -- La lutte contre le cancer dans les régions du Québec : Un premier bilan. 2004: MSSS -- Bilan 1998-2003 - Programme québécois de dépistage du cancer du sein 2004: MSSS – Rapport annuel de gestion 2003-2004 2005: Notes pour une allocution du ministre de la Santé et des Services sociaux, monsieur Philippe Couillard, à l’occasion du deuxième Forum sur le cancer au Québec, le 22 avril 2005. 2005: INSPQ -- Programmation 2005-2008. 2005: INSPQ -- Stratégie d'invitation et taux de participation à la mammographie de dépistage - PQDCS 1998-2000 2005: MSSS -- Report on the progress made regarding the bilateral agreement entered into during the federal-provincial-territorial meeting of the First Ministers on health, September 2004. 2005: MSSS – Rapport annuel de gestion 2004-2005 2006: MSSS – Rapport annuel de gestion 2005-2006 2006: DLCC -- Rapport d’activité 2005-2006.
IV. Evaluation of program/action plan implementation	2003: INSPQ -- Évaluation de l’exhaustivité du Fichier des tumeurs du Québec 2004: D Roberge, J.-L. Denis et al -- Évaluation du réseau intégré de soins et de services en oncologie : l’expérience de la Montérégie. Canadian Health Services Research Foundation Report. 2004: Réseau québécois d’action pour la santé des femmes -- Dépistage du cancer du sein : ce que vivent les femmes en attente de diagnostic, Rapport. 2006: INSPQ -- Surveillance de la lutte contre le cancer du sein – Évolution entre 1993 et 1998 de l'étendue de la maladie au moment du diagnostic, des procédures d'investigation, du traitement et de la survie relative.
V. Outcome assessment	2003: INSPQ -- La survie reliée au cancer pour les nouveaux cas déclarés au Québec, de 1984 à 1998 - Survie observée et survie relative. 2004: INSPQ -- Inégalités sociales et mortalité des femmes et des hommes atteints de cancer au Québec, 1994-1998. 2004: Highlights. Québec report on comparable health indicators. 2005: INSPQ -- La prévalence du cancer au Québec en 1999. 2005: INSPQ -- Données d'incidence et de mortalité pour les principaux sièges de cancer au Québec - Projections 2004 - Édition révisée. 2006: INSPQ -- Portrait de santé du Québec et de ses régions. 2006: INSPQ -- Évaluation d’impact du programme de prévention du tabagisme.

Appendix 9B: Stated goals to intended actions: Québec

Québec	
Programme québécois de lutte contre le cancer. Pour lutter efficacement contre le cancer, formons équipe (1998).	**Orientations prioritaires 2007-2012 du programme québécois de lutte contre le cancer (2007).**
Goals: To improve access, continuity and the quality of care. **Vision:** To create a cancer control provincial network, that would integrate regional cancer networks. **Directions :** **1.** ***A global approach to cancer control.*** A perspective that: (1) combines population-based and individual-based approaches to health policy planning; (2) acknowledges the importance of considering cancer control as a continuum of services in the organization of health care services; and (3) advocates a concerted effort to meeting the multiple needs of cancer patients and their family. **2.** ***Patient-centeredness*** as a guide to the organization, management and provision of health care services. An approach defined from the values and principles expressed in Québec law, and coherent with major principles for biomedical ethics (autonomy, beneficience, justice).[844]	**Goals :** • Reduce cancer incidence through health promotion and cancer prevention; • Reduce cancer mortality through screening and early detection; • Improve access to investigation, diagnosis, treatment, support and rehabilitation services; • Make palliative care services available for all cancer patients and for all patients with deadly diseases; • Exert cancer surveillance; • Intensify cancer research and knowledge utilization; and • Monitor progress and assess outcomes. **Five Priority Areas for action (axes d'intervention) and associated objectives and measures** **Priority Area 1: Consolidate the foundations for an integrated and hierarchical organization of cancer services**

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[844] The *Loi sur les services de santé et sur les services sociaux* stipulates that: (1) The raison d'être of health care services are the persons that need them ; (2) Respect for user and acknowledgement of his/her rights must guide service provision; (3) In all interventions, users must be treated with politeness, fairness and understanding, with respect for his/her dignity, autonomy and needs; (4) Users must, as aften as possible, be involved in their own care; (5) With adequate information, users must be encouraged to use services in a judicious way.

[845] PQLC, 1998, p. 99.

[846] PQLC, 1998, p. 100.

3. ***Quality*** as the priority criteria for decision-making. A perspective that rests on the use of scientific evidence about relevance, effectiveness, efficiency, quality of life and satisfaction of cancer patients and the population as main criteria for defining the required services at each phase of the cancer control continuum and for each type of cancer. Balanced against the available resources in a particular region, these criteria are intended to serve as guides for defining access to services at the local, regional and supraregional levels. **Strategy of Integration:** the concerted and coordinated efforts of all service providers in the fight against cancer. **Three types of recommendations:** 1. **Organizational means** to be put in place in order to structure the fight against cancer and to promote an integrated approach to organized service delivery. 2. **Proposed objectives** in terms of health, quality of life or organization of services to be used as targets for monitoring and assessing the implementation of the program. 3. **Evidence-based quality criteria** of relevance, effectiveness, and efficiency to guide the regional organization of service delivery so that quality of services is maintained and levels of access (local, regional, provincial) are clearly defined.	**Objective 1.1:** Ensure cancer control is a priority within the health services and social care system (measures 1-3) **Objective 1.2:** Continue the implementation of a functional cancer control network (measures 4-6) **Objective 1.3:** Consolidate a hierarchical organisation of cancer care and control services (measures 7-12). **Priority Area 2: Promote health as well as prevention and early detection of cancer** **Objective 2.1:** Promote a healthy lifestyle (healthy diet, active living, avoid tobacco use) and create environments that sustain this healthy lifestyle (measures 13-17) **Objective 2.2:** Reduce exposure to environmental and work-related carcinogenic agents (measures 18-21) **Objective 2.3:** Facilitate acces to organized screening programs for certain cancers when proven effective and feasible, and ensure quality standards are met (measures 22-24) **Objective 2.4:** Optimize existing capacity for cancer-related health surveillance (measure 25). **Priority Area 3**: **Facilitate the cancer patient journey through the continuum of care and services** **Objective 3.1:** Improve accessibility and quality of cancer care and services through optimal use of resources (measures 26-30) **Objective 3.2:** Facilitate home care and follow-up for all cancer

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[847] PQLC, 1998, p. 101.
[848] PQLC, 1998, p. 102.
[849] PQLC, 1998, pp. 103-104.
[850] PQLC, 1998, pp. 162-163.
[851] PQLC, 1998, p. 174.

Recommendations on the organizational means: 1. Accountability framework between the Health Ministry and the Regional health Boards 2. Mandate and composition of the Regional Cancer Committees 3. Mandates of Health Ministry, INSPQ and the Regions regarding prevention and screening initiatives 4. Mandate and composition of regional population health interventions teams 5. Mandate and composition of local interdisciplinary cancer teams 6. Mandate and composition of regional interdisciplinary cancer teams 7. Mandate and composition of supraregional interdisciplinary cancer teams 8. Definition of the *intervenant pivot* ("enhanced" patient navigator) 9. Establishment of *corridors de services* (referral pathways) 10. Definition of the standardized cancer file (dossier oncologique) 11. Modifications to working arrangements and funding 12. Modifications to payment arrangements 13. Knowledge acquisition (training of health professionals) 14. Knowledge and competence maintenance 15. Research 16. Mandate of the Conseil Québécois de lutte contre le cancer (CQLC) 17. Education toward early cancer detection 18. Opportunistic screening 19. Criteria for the implementation of organized cancer screening programs 20. On organized breast cancer screening 21. On organized cervical cancer screening 22. On organized colorectal cancer screening 23. On organized prostate cancer screening 24. On the organization of breast cancer screening 25. On the organization of cervical cancer screening 26. **On pathology**: The PQLC recommended that the College of physicians in collaboration with the the association of pathologists and the CQLC	patients, by ensuring access to a general physician (measure 31) **Objective 3.3:** Provide quality end-of-life palliative care for all patients in need and their close relatives, irrespective of age or type of illness (measures 32-39) **Objective 3.4:** Consider the perspectives of the patients and that of their close relatives providing care (measures 40-41) **Objective 3.5:** Further continuity and complementarity of health services provided by Québec health system facilities and local aboriginal facilities (measure 42). **Priority Area 4: Support evidence-based practice in cancer control** **Objective 4.1:** Promote general physician's role in cancer control (prevention, screening and care) (measures 43-44) **Objective 4.2:** Promote best practices at the regional level (measures 45-46) **Objective 4.3:** Encourage RUIS involvement in cancer control (measures 47-49) **Objective 4.4:** Further the use of evidenced-based practice (measures 50-53) **Objective 4.5:** Ensure cancer control issues are prioritized by cancer research organisations (measure 54) **Objective 4.6:** Further knowledge exchange with cancer control partners in Canada and abroad (measure 55). **Priority Area 5: Assess achievements against outcomes** **Objective 5.1:** Establish ministerial outcome targets to be focused especially on access as a dimension of quality and efficacy (measures 56-58) **Objective 5.2:** Get the necessary information for proper management of cancer control interventions (measures 59-60).

undertake the standardization of the nomenclature used to describe pathological specimens in order to facilitate comparability.[845] 27. **On chemotherapy**: The PQLC recommended that drug costs be minimized, namely by establishing strict criteria for their use and by examining the opportunity for wholesale buy, and it recommended that standards be established for the preparation and administration of chemotherapeutic regimens.[846] 28. **On surgical oncology**: The PQLC recommended that regional cancer programs define mechanisms to coordinate the services needed before and after hospitalisation, and the need for additional resources for these services.[847] 29. **On radiation therapy**: The PQLC defined norms regarding the mandate, equipment, and human resources according to levels of care (regional, supraregional).[848] 30. **On investigation, treatment, and rehabilitation:** The PQLC defined norms regarding levels of health services according to local, regional and supraregional mandates.[849] 31. More specific recommendations according to cancer site, namely the mandates for local, regional and supraregional interdisciplinary cancer teams in the following areas: hemato-oncology, gyneco-oncology, head and neck cancers, skin cancers, breast cancers, lung cancer, colorectal cancers, genito-urinary cancers and paediatric cancers. 32. **On palliative care**: The PQLC defined a series of criteria for local, regional and supraregional cancer teams to ensure the quality of palliative care, and recommends that ressources other than hospital-based services be available to provide more alternative to patients.[850] 33. **On supportive care**: The PQLC recommended that: 1) supportive care	**Unifier notre action contre le cancer. Rapport de la démarche ministérielle visant l'amélioration de la gestion et de l'impact du Programme Québécois de lutte contre le cancer (2004).** **Priority measures:** **1. Organization of integrated services:** To establish an integrated service delivery organization at the local, regional and supra regional levels, including an "enhanced" patient navigator, a procedure for access, and relevant referral pathways, to ensure an optimal (and needs-based) trajectory for cancer patients. **2. Clinical governance:** That clinical governance mechanisms be adapted and implemented to increase the proportion of clinical practice that meets the highest standards **3. Continuous quality improvement:** That evidence-based methods for results-based management be implemented for program management with the perspective of continuous quality improvement, and giving the priority to breast cancer **4. United governance:** That all functions and responsibilities of implementing the PQLC and of achieveing targetted goals be placed under the authority of a National Cancer Director within the Health Ministry. **5. Implementation of recommendations:** That the implementation of the recommendations be prioritized so that it may begin as soon as the next fiscal year (April 2004). **6. Funding of the recommentations:** That an adequate investment

services be offered as soon as the diagnosis is established; 2) expertise in supportive care be integrated to local, regional and supraregional cancer teams; 3) a continuum of home and facilities-based services be provided to allow patients to exercice choice; 4) health professionals and volunteers be adequately trained based on a humanistic and global approach to cancer care; and 5) a quality of life and rehabilitation measure be validated and standardized.[851]

34. Conditions for the implementation of the monitoring and assessment framework

Proposed objectives:

1. Health targets regarding tobacco use
2. Proposed measures (provincial level) in tobacco control
3. Proposed measures (regional and local levels) in tobacco control
4. Health targets regarding healthy eating
5. Proposed measures (provincial level) in healthy eating
6. Proposed measures (regional and local levels) in healthy eating
7. Health targets regarding environmental exposure
8. Proposed measures regarding asbestos
9. Proposed measures regarding UV radiation
10. Proposed measures regarding other environmental carcinogenic agents
11. Proposed research topics regarding environmental exposure to potential carcinogens

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La radio-oncologie au Québec. Plan d'action 2000-2008 (2000)

Goals :

1. to achieve a balance between service capacity and demand
2. to facilitate access of cancer patients to the quality services they are entilted to.

be available to ensure the optimal implementation of the recommendations.

Details of the recommendations:

#1: Integrated service organization

1.1: That the regional Agency be responsible for gradually establishing a basket of cancer services at the local level, so that by March 2007 each Local Service Network will have its local interdisciplinary cancer team.

1.2: That the regional Agency be responsible for establishing a basket of specialized cancer services at the regional level, for all the regions by March 2005.

1.3: That the regional Agency be responsible for establishing a basket of highly specialized cancer services by March 2006, to concentrate expertise and to develop a critical mass in certain highly specialized centers, as well as to ensure adequate service provision for the population in each Québec region.

1.4: That four large cancer territories be established based on RUIS territories, and that those territorial cancer activities be coordinated by a Territorial Table composed of Cancer program key-actors from the local, regional and supra regional levels.

1.5: That each RUIS creates an interdisciplinary cancer program by March 2005, and that the program director sits at the territorial Table that will coordinate the PQLC.

1.6: That supportive care needs be prioritized at all levels of the cancer program implementation and, as a result, that**:**
- supportive care services (informationnal, psychological, emotional,

Recommendation #1:
To increase the effectiveness of existing radio-oncology centers in Québec:

- replace outdated equipment, add 16 new machines by 2008;
- use new technologies;
- hire medical and professional staff;
- allocate the necessary resources for operating the equipment

Recommendation #2:
To build 4 new radio-oncology centers

Recommendation #3:
To implement the recommendations on human resources planning made by the three radio-oncology human resources planning committees: technologists, medical physicians, radio-oncologists

Recommendation #4:
To mandate the Radio-oncology Coordination Center with the responsibility to implement and monitor the action plan and to involve the Radio-oncology Committee in the follow up of the action plan, and in a updating of the planning.

Rapport du Comité ministériel sur l'organisation des services en cancérologie au Québec (Mai 1992)

Recommendations on prevention: to develop a primary prevention program focused on tobacco use reduction, on healthy eating and on protection from sun exposure

Recommendations on screening: to develop organized screening programs for breast and for colon cancers.

practical, social and spiritual) be offered as soon as the cancer diagosis is established, and that access to those services be under the prime responsibility of the "enhanced" patient navigator
- supportive care services be offered in partnership with the voluntary and community sectors
- all cancer patients and their close relatives and friends receive in a routine and structured manner the needed information on the disease, required care, resources and available programs in their community
- systematic evaluation of user satisfaction regarding quality of services provided be conducted using instruments that have been validated and normalized at the provincial level.
- the patients and their close relatives and friends may be able to voice their opinion to the directors at all levels of management (local, regional, central).

1.7: That all the knowledge and experience acquired in pediatric oncology be consolidated and, to do so, that:
- the pediatric oncology network be consolidated as part of the initial phase of the implementation of the present measures
- all children below 18 years of age be directed to one of the 4 pediatric centers in Québec to ensure access to required care according to the most current research and treatment protocols
- work be undertaken to clarify the management of young adults 18-25 years of age with a pediatric cancer, to ensure access to the required care according to the most current research and treatment protocols

1.8: That the Comité aviseur in oncology may continue its work so that:
- A mechanism be set up for the recognition of local, regional and supra regional teams according to explicit quality criteria
- The formal designation of teams/facilities be initiated as soon as the spring of 2004
- The four territories may rely on a service provision that responds to

Recommendation on treatment modalities: that treatment options of various cancer cases be discussed within multidisciplinary committees including surgical oncologists, and that the latter be involved in producing standardized treatment guidelines. **Recommendations on radio-oncology:** that tertiary cancer services , namely radio-oncology, align with north-american standards of care ; that appropriate access be ensured to populations living in the periphery of urban centers; that measures be immediately taken to increase human resources in radio-oncology; that priority be given to the implementation of recommendations made in the 1985 report: « Situation de la radiothérapie au Québec ». **Recommendations on anti-cancer drugs:** that the MSSS reexamines the underfinancing of anti-cancer drugs, including the impact of the ambulatory drug program on the budget of health facilities and that it also examines the possibility of having certain anti-cancer drugs manufactured in Québec. **Recommendations on clinical practice guidelines:** that the professional corporation of Québec physicians clarifies and disseminates clinical practice guidelines and ensures their implementation to improve cancer care; that faculties of Medicine work together to develop and disseminate standardized protocols for multidisciplinary care in oncology within university-teaching hospitals and that they assess and update these protocols. **Recommendation on supportive and palliative care:** to implement a quality of life program for patients with cancer and their families throughout Québec in order to ensure integrated and non-fragmented services from diagnosis to end-of-life, whether at home or within care facilities. **Recommendation on education:** to improve continuing medical and	their respective needs **#2: Clinical governance** **2.1:** That standards for organization, functioning and care experts be adapted or produced for each cancer site, in order to facilitate adequate interdisciplinary disease management, and to equip health care assessment and peer-review, so as to: - prioritize most prevalent cancer sites or cancer sites that are most vulnerable to practice variations - ensure a partnership between AETMIS and the professional associations - study the feasibility of adapting NICE Guidances on cancer services - give priority attention to care protocols including interventions in radio-oncology **2.2:** That Québec experts adopt, in collaboration with experts from Canada and France, clinical practice guidelines to clarify rules for the optimal use of costly new technologies relevant for oncology and that those guidelines be largely disseminated in partnership with the Groupe d’étude en oncologie du Québec (GÉOQ). **2.3:** That cancer tumour boards be established at the regional level first, in collaboration with the GÉOQ and the association of the CMDP (collège des médecins, dentistes et pharmaciens), and according to the criteria that were defined for the recognition of cancer teams in order to: allow exchanges between peers and between the local and regional levels, discuss patient care plans and to allow for feedback on clinical results obtained. **2.4:** That a feasibility study be conducted by March 2005 on the optimal utilization of cancer drugs in collaboration with the Conseil du medicament.

paramedical education using tertiary care centers resources. **Recommendations on research:** that the Fond de la recherche en santé du Québec examines the feasibility of forming a network for basic, epidemiological, and clinical oncology research, including universities and hospitals throughout Québec in collaboration with existing health facilities; to strengthen support to fundamental research in oncology, namely the infrastructures within university teaching hospitals specializing in oncology. **Recommendations on information systems:** that MSSS mandates the *Fichier des tumeurs* to publish annual cancer statistics for Québec including survival rates in ways similar to the Canadian cancer statistics ; that MSSS undertakes a study on the direct and indirect costs related to cancer; that MSSS examines the possibility of applying a cost-benefit method for assessing treatment protocols. **Recommendations on service organization:** that Québec develops an integrated cancer control policy ; that a permanent expert consultative committee on cancer control be set up, as well as a permanent coordinating structure within the Ministry of Health and Social Service; to ask regional boards to develop in collaboration with the relevant partners regional plans for cancer services organization, based on a levels of care system linking primary with secondary and tertiary care centres into an integrated and coordinated network, ensuring that faculties of Medicine are part of this network planning, that should combine care, education, and research as well as taking into account the pairing of each faculty of Medicine with the various regions within the province.	**2.5:** That the clinical expertise build under the leadership of the Conseil québécois de lutte contre le cancer (CQLC) and its associated clinical governance functions be integrated within the new governing structure by April 1st 2004, based on a defined transition plan. **#3: Continuous quality improvement** **3.1:** That the document entitled « *La lutte contre le cancer dans les régions du Québec : un premier bilan* » be largely disseminated to promote transparency of cancer control achievements in Québec and to strenghten the mobilisation of all the relevant actors. **3.2:** Regarding informational resources, it is recommended that: - the Fichier des Tumeurs be updated and modernized to increase its potential for planning and decision-making (by March 2005). - the deployment of the SGAS be completed for radio-oncology and that its development for surgical oncology be initiated (by December 2004). - an assessment be done on the informational resources available for cancer control and that basic indicators be defined to ensure continuous monitoring of the quality of the cancer control system (by December 2004) - an assessment be done on the utility of establishing a central cancer registry based on the traumatology model to support feedback to clinicians on their patients and their practices, peer discussions, research, and outcome assessment (by March 2005). **3.3:** That formal collaborative links be established with the FRSQ cancer research network and that a joint working plan be produced and implemented. **3.4:** That steps toward the designation of cancer teams, as well as the

implementation of quality assurance mechanisms and clinical governance be first conducted for the breast cancer trajectory before they are applied to other cancer sites.

3.5: That the PQDCS be subject to an overall assessment in order to determine priority adjustments to improve management and impact of this program and to ensure its continuous evaluation.

#4: United Governance

4.1: That the position of National Cancer Director be created within the Health Ministry. In the name of the Minister of Health and Social Services, this position would have the mandate of: a) seeing to it that a global basket of services aimed at preventing, curing disease and supporting patients and their family is available, and b) reporting annually and publicly on the progress observed in the fight against cancer in Québec.

4.2: That the National Cancer Director be a physician holding the required competence given the scope of the cancer control continuum, as well as the necessary professional and administrative authority to perform its mandate.

4.3: That the National Cancer Director determine the priority targets to be included in the management and performance agreements between the Health Ministry and the Regions to advance cancer control in Québec.

4.4: That all the human resources needs in oncology (medical, professional, technical) be considered a priority by the relevant Ministry branches in close collaboration with the educational and training sectors.

4.5: That the National Cancer Director may rely on a team equiped

	with the required competence, strenght, budgets, and links for the optimal exercice of its mandate. In that respect, it is recommended that all of the Ministry's human and budgetary resources with a principal or exclusive link to cancer control be placed under the authority of the National Cancer Director. These include the following activities in cancer control: - Priority outcomes determination for and the associated monitoring activities; - Clinical governance, including practice guidelines, guides, organizational norms. - Monitoring and quality assurance, including the updating of the fichier des tumeurs and the exploitation of various information systems; - Coordination of radio-oncology, of hotel accomodation services, supportive and palliative care and collaboration with voluntary and not-for-profit organizations involved in cancer control; and - Network coordination, including the designation, agreement and good functionning of cancer control teams. **Recommendations for the implementation of the Ministerial working group report and recommendations:** 1. That cancer control be formally recognized as a priority and, consequently, that a communication plan be prepared to disseminate the Ministry's commitment, the vision put forth in this report, and to facilitate a large mobilisation of cancer control partners and the public. 2. That the National Cancer Cobntrol Director be nominated as soon as possible in order to act on short temr recommendations as soon as possible and that the united governance be operational by April 2004. 3. That the National Cancer Director tables by June 30, 2004 a three-

year action plan defining the priorities for the entire continuum of cancer control, from prevention to palliative care.

4. That the National Cancer Director establishes collaborative links with cancer leaders in other canadian provinces, in CAPCA, with the CSCC, and with the National Health Service in the UK, to take advantage of their experience.

Recommendations for the funding of the Ministerial working group recommendations:

1. That the regional Agencies make the required investments to achieve the priority targets established under recommendation #1 on the organization of intergated services, within their current budget, and as soon as their next financial exercice.

2. That the Health Ministry undertakes by December 2005, the necessary work to be abale to determine the level of resources actually committed to cancer control at the local, regional and national levels.

3. That special attention be given to the investments required for the consolidation and development of radio-oncology service infrastructure, in order to fully implement the 2000-2008 action plan within the set deadline.

4. That representations be made to the Federal government in collaboration with the Health Ministers of the other canadian provinces and the CSCC to assess the potential for additional financing or fiscal programs for achieving priorities common to the two levels of government.

Appendix 9C: Values and guiding principles: Québec

Québec

Expressed in the PQLC:
Accessibility of care (closer to patients' residence)
Beneficience and non-maleficience
Caregivers' support/education
Collaborations/cooperation/partnerships/consultation
Comprehensiveness of cancer control (global approach)
Continuity of care
Efficiency
Effectiveness
Equity (to ensure fairness across regions in the development of a strong provincial cancer system)
Evidence-based approach
Humanization of care
Interdisciplinary care
Integrated care
Patient-centered care
Performance oriented/outcome-focused
Population-based approach
Quality care
Research/knowledge translation driven (CQLC)
Respectful of jurisdiction/framework flexibility (decentralization to regions)
Sustainability/human resources

Expressed in the Ministerial Cancer Working Group Report (2004)
*Accountability**
Accessibility of care (closer to patients' residence)
Collaborations/cooperation/partnerships/consultation
Comprehensiveness of cancer control
Continuity of care
Display leadership/action oriented

Efficiency (optimal use)
Effectiveness
Equity (to ensure fairness across regions in the development of a strong provincial cancer system)
Evidence-based approach
Integrated care
Interdisciplinary care
Performance oriented/outcome-focused
Population-based approach
Research/knowledge translation driven
Respectful of jurisdiction/framework flexibility (decentralization to regions)
Tranparency

Expressed in the DLCC five-year action plan (Orientations prioritaires 2007-2012)
Accessibility of care (closer to patients' residence)
Caregivers' support/education
Collaborations/cooperation/partnerships/consultation
Comprehensiveness of cancer control
Continuity of care
Efficiency (optimal use)
Effectiveness
Equity (fair access to services)
Evidence-based approach
Integrated care
Interdisciplinary care
Patient-centered care (explicit principle)
Performance oriented/outcome-focused
Population-based approach
Quality care (explicit principle)
Research/knowledge utilisation
Shared responsibilities* (explicit principle)

*Italics are to indicate the novelty compared to previous policy document

Appendix 9D: Targets and indicators of outcome: Québec

Québec

The shaded box below brings together all the targets and indicators of outcome that are relevant for cancer control. They are classified according to the official documents in which they were found and beginning with the most recent. Some are no longer current, but were included for the sake of comprehensiveness.

In MSSS *Investir pour l'avenir 2006-2012*:[852]
- A 2% decrease of obesity prevalence among youth and young adults by 2012
- A 5% decrease in the prevalence of overweight youth and adults by 2012

On MSSS website, section on Access to specialized services/cancer/oncological surgeries, a target is defined for surgical oncology, which was formulated in 2006:[853] The goal is to achieve a waiting time of less than four weeks for all types of cancer. [854]

On MSSS website, section on Access to specialized services/comparative table of guidelines and access targets, a target is defined for radiotherapy, which was formulated in 2006: 90% of patients treated within a period of four weeks. [855]

In MSSS *Plan stratégique 2005-2010*, [856] relevant cancer control indicators were included, with the following measurable targets: [857]
- Proportion of local territories with healthy living and chronic disease prevention services
- Summary of actions regarding the update of tobacco control law
- Number of smokers having received smoking cessation services (2005-06 target is 4937)
- Breast cancer screening participation rate (2004-05 target is a 5% increase from 43,6 to 48,6%)
- Proportion of designated breast cancer screening centers having implemented quality assurance measures (2004-05 target is a decrease in the

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[852] http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2006/06-289-01.pdf

[853] See MSSS webpage on Access to specialized medical services / cancer/ oncology surgeries. Available at: http://wpp01.msss.gouv.qc.ca/appl/g74web/Oncologie.asp. Accessed on January 30, 2007.

[854] The waiting time is defined as the period between the date the patient is deemed medically ready to undergo treatment and the actual date of treatment.

[855] See MSSS webpage on Access to specialized medical services / Comparative table of guidelines and access targets. Available at: http://wpp01.msss.gouv.qc.ca/appl/g74web/tableaucomparatif.asp

[856] MSSS. Plan stratégique 2005-2010 du Ministère de la santé et des services sociaux, pp. 23-24.

[857] MSSS. Rapport annuel de gestion 2004-2005 and Rapport annuel de gestion 2005-2006.

investigation reference rate of 1% at initial screening and of 0,5% at subsequent screenings)

- Number of interdisciplinary teams at local, regional and supraregional levels (2005-06 targets are 28 for local and 5 for regional teams)
- Number of ready to treat patients having waited for more than 8 weeks before beginning radiation therapy (2004-05 and 2005-06 targets : 0)
- Number of people receiving palliative care at home (2004-05 target is 19 000; 2005-06 target is 20 484)[858]
- Mean number of palliative care interventions at home (2004-05 target is 13,4; 2005-06 target is 14)[859]

In MSSS *Programme national de santé publique 2003-2012*:

- Reduce rate of tobacco use among 15 + from 24% to 18%
- Reduce breast cancer mortality rate by 25% among women aged 50-69
- 80% of adults eating 5 servings of fruits and vegetables a day
- Increase by 5% the proportion of 15+ doing adequate exercice (reduce sedentarity from 53% to 48%)
- Contibute to reducing lung cancers attributed to the major carcinogenic products in the environment
- Decrease incidence of skin cancers
- Decrease the incidence of respiratory track, bladder, and other cancers by reducing workers' exposure to carcinogenic substances

In MSSS *Plan stratégique 2001-2004*, two indicators were initially defined, [860] with more specific measurable targets being included over the years:

- Dissemination of a public health action plan:
    - See Programme national de santé publique 2003-2012
- Implementation of the PQLC:
    - Proportion of regional cancer plans submitted to Health Ministry: 2003-04 target is 100% by March 31 2004;[861] 2004-05 target is 100% by March 31 2005[862]
    - Number of patients on a radio-oncology waiting list for more than 8 weeks (2003-04 target is 0)[863]

In MSSS *Programme de lutte contre le cancer (1998)* (targets for 2002):

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[858] It was 19 420 in the Rapport annuel de gestion 2005-2006, p. 55. Revised target provided by DLCC.

[859] It was 15,29 in the Rapport annuel de gestion 2005-2006, p. 55. Revised target provided by DLCC.

[860] MSSS. Plan stratégique 2001-2004 du ministère de la santé et des services sociaux, 2001, pp. 31 and 35.

[861] MSSS. Rapport annuel de gestion 2003-2004, p. 73.

[862] MSSS. Rapport annuel de gestion 2004-2005, p. 52. Exceptionnally, this report presents achievements againsts goals in both MSSS 2001-2004 Strategic Plan and 2005-2010 Strategic Plan.

[863] MSSS. Rapport annuel de gestion 2003-2004, p. 73.

- Reduce smoking rate among Québecers aged 15 and over to 28% from 35,4% in 1994
- Prevent smoking in 75% of working areas, 75% of public places in general and in 100% of public places that children attend
- 90% of population to eat 5 or more servings of fruits and 6 servings of cereal products/day.
- Reduce intake of fat to 30% or less of total caloric intake.

In MSSS *Programme national de dépistage du cancer du sein – Cadre de référence (1996)*:

- 70% participation rate of eligible women aged between 50-69 to biennial mammography

In MSSS *Politique de la santé et du bien-être (1992)* relevant targets were:

- Reduce breast cancer mortality rate by 15% by 2002
- Stabilize lung cancer mortality rate by 2002

Appendix 9E: Key actors in cancer control governance: Québec

Key actors – Québec

Ministry of Health and Social Services (MSSS): The Ministry's mission is to maintain, improve and restore health and well being of québecers by offering health and social services. According to this mission the ministry's main goal is to ensure the good functioning of the health system. Toi improve health and well being, the Ministry determines priorities, goals and directions in the field of health and socail services and ensure their application. The Ministry also establishes health policies and ensures that they are being implemented by the Agencies for health and social services. The MSSS - Public Health Branch, is responsible for health promotion, prevention, and in the case of cancer is responsible for the organized breast cancer screening program and for the Fichier des tumeurs du Québec. The MSSS - Health Services and Academic Medicine Branch hosts the DLCC (2004-), which is responsible for the organization of cancer control services and for the implementation of the policy on palliative care.

Agencies for health and social services (and local network development) (Agencies, 2003-):
The regional authorities are responsible for the coordination of health and social services for their respective catchment area. Since 2003, the 18 regional health boards were transformed into 15 Agencies and 3 organizations situated in the Northern territories. Agencies are responsible for the coordination and implementation of health and social services in their region, namely the financing, human resource allocation, and access to specialized care. Agencies also facilitate the development of local health and social services networks. They still have a public health mandate, i.e., they offer general public health services at the regional level, and the public health units remain under Agencies' authority.

University Integrated Health and Social Services Networks (RUIS, 2005-): These networks were set up in 2003, but were officially xcreated in December 2005, with the adoption of major changes to the Loi sur la santé et les services sociaux. The 4 RUIS are territorial networks linking one university and university-teaching hospital with affiliated hospitals. These networks usually include a University hospital center (CHU), affiliated hospitals (CHA) University Institutes (IU) and the university to which all theses hospitals are affiliated. The RUIS have a four-part mission related to health services, education, research and health technology assessment. The RUIS are mandated to provide advice on various subjects to the regional Agencies within their catchment area. Moreover, each RUIS must assist the Regional Agencies within their RUIS territory in achieving better coordination of care in order to avoid fragmentation of services.[864] To facilitate the realization of the RUIS mission and to coordinate RUIS actions, the Ministry established a statutary Committee called *Table de coordination nationale des RUIS*, which must provide an annual progress report to the Minister of Health and Social Services.[865] This Table also created a number of sectorial tables, among which is the RUIS sectorial table in oncology.

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[864] D'Anjou H (Ordre des infirmières et infirmiers du Québec). Document explicatif sur la loi modifiant la loi sur les services de santé et les services sociaux et d'autres dispositions législatives (projet de loi 83) sanctionnée le 30 novembre 2005. octobre 2006, p. 15. Available at : http://www.oiiq.org/uploads/publications/autres_publications/DocExplicatif83.pdf

[865] D'Anjou H. op. cit. p. 15.

Health and social services centers (CSSS, 2003-):
The CSSS are statutory entities that result from the merging of the Province's existing health and social services facilities. There are 95 CSSS that serve as the hubs of the 95 Local Health and Social Services Networks (*Réseaux locaux de santé et de services sociaux, RLS*). The role of the CSSS is to provide leadership regarding the health services to be offered to its population. Before the modifications to the law (LSSSS), this was a responsibility of the regional health boards. With the recent changes to the law, the CSSS is now responsible for: a) Offering a comprehensive basket of services (from prevention to palliative care) to the entire population defined by its catchment area; b) Coordinating the services provided by the various service providers (institutions and health professionals) within its local network (RLS) and establishing links with those services providers through agreements or other modalities; and c) Agreeing upon management and performance agreements with the regional Agency and being accountable to the Agency for the results obtained. The RLS are composed of a CSSS and CSSS partners, such as hospitals (general, specialized and university), community pharmacies, private medical clinics and offices, including the *Groupe de médecine familiale* (GMF), rehabilitation centers, youth protection centers, other community resources, etc. The CSSS are accountable to their regional Agency.

Independent and arm's length organizations:

- *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS, 1988-): AETMIS' mission is to advise the Minister of Health and Social Services and other decision makers within the Health Ministry, as well as to support, by means of assessment, decision-makers in the Québec healthcare sector. Its assessments focus on the introduction, acquisition and use of health technologies, and on the methods of dispensing and organizing services. It reports to Québec's Minister of Health and Social services.
- *Commissaire à la santé* (2006-): This independant organization will assess the performance of the health and social services system, advise the government on the choice to make to ensure the continuous improvement of the health and social services system and to advise on ethical issues ragarding the health.
- *Conseil du médicament* (2002-): The Conseil is responsible for assisting the Minister of Health and Social Services in updating the list of drugs covered by the RAMQ.[866] It makes recommendations regarding the registration of anti-cancer drugs on the lists of insured drugs.
- *Institut national de santé publique du Québec* (INSPQ, 1997-): INSPQ was created to improve the coordination, development and use of expertise in public health. Its mission is to support the Health Ministry and the regional health authorities in executing their public health mission. INSPQ is also responsible for the management of the laboratories and centres in Québec which offer expertise in public health. Activities in cancer control include 1) the implementation, quality assurance monitoring and assessment of the organized breast cancer screening program, and several studies namely to develop and measure indicators for cancer control spanning all aspects of the continuum : prevention, early detection, treatment, rehabilitation and palliative care. A proposal was submitted to the MSSS in December 2004 by the Direction de la lutte contre le cancer to mandate INSPQ for the performance assessment of the implementation of the PQLC.[867]
- *Régie de l'assurance-maladie du Québec*: This organization is responsible for managing the Régime d'assurance maladie and the Régine public d'assurance médicaments.

Charitable/voluntary/advocacy organizations:

- *Coalition priorité cancer au Québec* (2001-): The Coalition is a group of voluntary, community, and professional organizations involved in cancer control in Québec created in 2001. The Coalition's goal is to mobilize all stakeholders including government in advancing cancer control. Members of the Coalition include : Action Cancer Montérégie, Association des radio-oncologues du Québec, Association du cancer de l'Est du Québec, Association québécoise des infirmières en

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[866] http://www.cdm.gouv.qc.ca/site/index.php?fr_le_conseil
[867] See INSPQ webpage titled: Nos activités en…/ habitudes de vie et maladies chroniques/ lutte au cancer. Available at: http://www.inspq.qc.ca/domaines/index.asp?Dom=40&Axe=45

oncologie, Association québécoise des soins palliatifs, Fondation québécoise du cancer, Institut de l'anémie, Leucan, Ordre des technologues en radiologie du Québec, Organisation montréalaise des personnes atteintes de cancer, Organisation québécoise des personnes atteintes de cancer, Organisme gaspésien des personnes atteintes de cancer, Réseau d'échange d'information sur le cancer du sein, Société canadienne du cancer.

- *Fondation québécoise du cancer*: The Fondation offers many services to cancer patients and their families, including accomodation at their Hôtellerie in Sherbrooke, Montréal and Gatineau, a free and confidential helpline (Info-cancer), a pairing with a cancer survivor service, a documentation center and a website, which is one of the most important french portal in Québec for cancer information : www.fqc.qc.ca
- *Organisation québécoise des personnes atteintes de cancer*
- *Réseau québécois pour la santé du sein* : involved in a class action suit against 12 Québec hospitals for women waited more than 8 weeks to get radiotherapy
- *Société canadienne du cancer - division du Québec :* The Canadian Cancer Society is a national, community-based organization of volunteers whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. Major priorities are: Research funding, information and support (service info-cancer, helpline), prevention (tobacco control, sun protection, etc), and advocacy.

Appendix 9F: Evolution of the Québec central governing structure for cancer control

The initial proposition (Cancer Advisory Committee report, 1997)

In its 1997 report, the *Comité consultatif sur le cancer* (Cancer Advisory Commitee, CAC) proposed the creation of the *Conseil Québécois de Lutte contre le Cancer* (CQLC) to provide a permanent space, open to all cancer stakeholders, to express their needs and concerns, to exchange information and to transfer knowledge in order to contribute to maximizing cancer control expertise for the entire health network.[868]

The CAC recommended that the CQLC should: [869] (1) help with the implementation of the Québec cancer control program; (2) facilitate knowledge transfer; and (3) provide advice to the Health Minister, namely regarding:

- Issues linked to service accessibility and modes of organization and to the needs of the various populations affected by cancer
- Service quality criteria (effectiveness, efficiency, relevance)
- Best practices based on scientific evidence
- Information management systems and assessment mechanisms required to assess cancer control intervention and network organization
- Updates on the goals and objectives to guide the relevant programs.

Moreover, the CAC stipulated that the most immediate priority for the CQLC would be to support the implementation of the integrated cancer control network, a function the CAC deemed essential in order to assist the regions in rapidly developing their regional network.[870] The second function to be associated wth the CQLC related to knowledge transfer, while the third related to an advisory role to the Minister of Health and Social Services. The CAC also listed the conditions/powers that the CQLC would require in order to perform its advisory role, but did not do so concerning CQLC other functions. The accountability framework between the Health Ministry and the Regions that was also proposed in the CAC report did not include the CQLC.[871]

The first wave of governing structure: CQLC and Health Ministry (1998 to 2001)

When the CAC report was made into official cancer policy in 1998, the government created the CQLC as an advisory organization, at arm's length to the Minister of Health and Social Services, to advise the Minister and Ministry on cancer control matters. Its mandate was to "*provide the Minister of Health and Social Services with advice on cancer control* [...] *The CQLC also promotes cancer control by facilitating knowledge transfer and the dissemination of information.*"[872]

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[868] PQLC p. 62.
[869] PQLC p. 63.
[870] PQLC p. 62.
[871] PQLC pp. 47-48.
[872] MSSS. Rapport annuel de gestion 2001-2002, p. 89.

The CQLC was composed of more than 150 members and included 24 Committees: Comité de l'évolution de la pratique en oncologie (CEPO); 14 tumour site boards (comités des sièges tumoraux); Comité de l'évolution de la pratique infirmière en oncologie; Comité des pharmaciens; Comité des pathologistes; Comité des cancers pédiatriques; Comité des cancers héréditaires; Comité de la première ligne en oncologie; Comité de soutien et de réadaptation; Comité des standards organisationnels; and Comité des représentants de la population. CQLC productions comprised: (1) multiple *avis* (guidance reports) on service organization, clinical practice and cancer drugs use; (2) annual forum of the PQLC; and (3) a monthly electronic bulletin.[873]

The CQLC mandate did not include a direct role in the implementation of the cancer program, nor in the monitoring of such implementation, as was recommended by the CAC. Such responsibility was kept within the Health Ministry. In June 1999, Québec's 18 Regional Health Boards were instructed by the Health Ministry to begin the implementation of the PQLC, and to establish an integrated regional cancer control network based on Ministry's guidance.[874] In the fall of 1999, a group was created within the Health Ministry to support the Regional Health Boards in their implementation of the PQLC.[875] One year after, the Health Minister announced that a more formal body would be created within the Ministry to coordinate the implementation of the PQLC.[876] This body was needed namely to improve the coordination of existing resources toward cancer control and to strenghten cancer control leadership. Two propositions were submitted to the Minister of Health and Social Services, one by the CQLC and another one by the Medical and Academic Affairs Branch of the Health Ministry. The Health Minister reiterated the leadership role of the Health Ministry, and asked the Medical and Academic Affairs Branch to formulate a final proposition for a coordinating body.[877]

The second wave of governing structure: CQLC, CCLCQ and Health Ministry (2001-2004)

In March 2001, the Health Ministry approved the creation of the *Centre de coordination de la lutte contre le cancer au québec* (CCLCQ) to facilitate Ministry's leadership, and to improve the coordination of cancer control efforts. The CCLCQ was positioned within the Medical and Academic Affairs Branch and governed by a *Comité ministériel cancer* made up of the CCLCQ director, senior officials from three Ministry branches concerned with cancer control, and presided by the director of the Medical and Academic Affairs Branch. The CQLC President was an invited member (see Figure 6 below).

The CCLCQ was mandated to work in a complementarity fashion with the CQLC and the Regional Health Boards in organizing and managing cancer control efforts. As a result, some of the originally proposed roles for the CQLC were attributed to the CCLCQ or became a joint

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[873] MSSS. Rapport annuel de gestion 2001-2002, p. 89.

[874] Le relais. Bulletin d'information de la Régie régionale de la santé et des services sociaux - Montérégie, vol. 4, no. 1 janvier 2002. Available at : http://www.bibliotheque.assnat.qc.ca/01/PER/824582/2002/Vol_4_no_1_(janv_2002).pdf

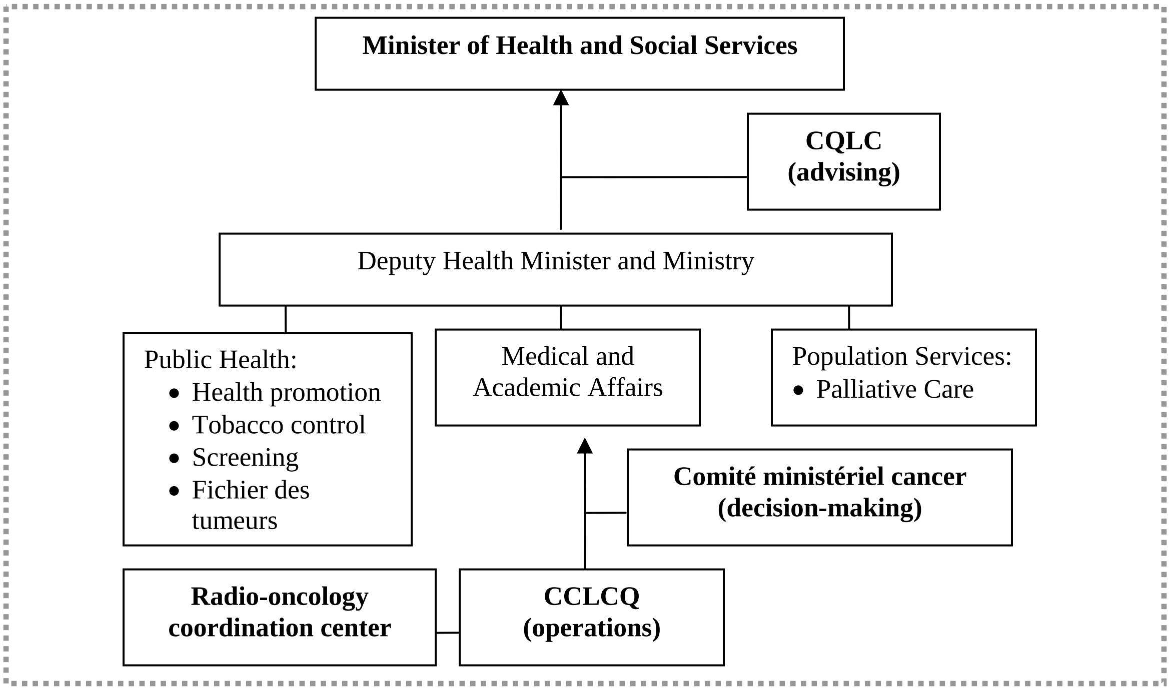
[875] MSSS. Direction générale des affaires médicales et universitaires (Lacroix L, Côté-Brisson L, Turgeon L.). Un centre de coordination nationale de lutte contre le cancer, 2001, p. 3. Available at: http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2001/01-902-01.pdf

[876] Ibid

[877] Ibid p. 4.

responsibility between CQLC and CCLCQ.[878] The CCLCQ came into operation in May 2001. It was assisted by 12 working groups: prevention, screening and surveillance; pediatrics; treatments and rehabilitation; supportive and palliative care; training; human resources; research; information management systems; service organization (cancer teams and cancer programs); assessment; intergovernmental affairs; and budget.

Figure 5. Cancer control governance in Québec 2001-2004[879]



The CCLCQ published its first annual action plan in October 2001, followed by a three-year (2002-2005) action plan. The initial plan included steps to improve cancer control through: (1) the creation of a network of cancer control partners; (2) actions on the cancer control continuum; (3) actions to intensify cancer control efforts within the regions; and (4) establish an outcome-based management process. These four axes of work included the following goals among others:[880]

- Collect evidence on health status, health services, available resources, inequalities, etc, in order to monitor ongoing cancer control efforts and communicate the situation to decision-makers and the public
- Design a rationale for differentiating cancer services according to access levels (local, regional, supraregional); to define criteria for designating local, regional and supraregional (highly specialized) teams; to define accreditation criteria for highly specialized cancer teams
- Ensure access to radiation therapy within set waiting times targets

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[878] CQLC. Stratégie et plan d’action 2003-2005, p. 9.

[879] MSSS. Direction générale des affaires médicales et universitaires (Lacroix L, Côté-Brisson L, Turgeon L.). Un centre de coordination nationale de lutte contre le cancer, 2001, p. 10.

[880] CCLCQ. Plan d’action 2001-2002, October 2001, p.6.

- Establish a partnership with, and ensure the buy-in of, the regions regarding the prioritization of cancer control reforms

In a CCLCQ assessment that took stock of the regions' efforts in the fight against cancer,[881] it was noted that: (1) cancer care was not formally recognized as a priority in many facilities; (2) collaborations between specialists and primary care physicians were for the most part on a case by case basis; and (3) collaborations between facilities and the voluntary sector were underdevelopped. This assessment demonstrated that despite existing efforts, important changes needed to occur to successfully drive the implementation of the PQLC. Three challenges had been identified by the CQLC that would frame its future priorities: (1) make cancer control a national priority; (2) improve the quality of cancer care and services within the cancer control continuum; and (3) contribute to improve access to, and integration of, cancer care and services in a cancer control approach.[882]

A second proposition (Ministerial Cancer Working Group Report, 2004)

In April 2003, the newly elected Minister of Health and Social Services made cancer one of his top priorities and established a Ministerial Cancer Working Group to make recommendations on how to improve the management and impact of the PQLC. The Working Group mandate included a reassessment of existing cancer control governance. It was asked to propose a unified organization and appropriate transition mechanisms to ensure an effective provincial leadership in cancer control. To fulfil this mandate, the Ministerial Cancer Working Group held a consultation[883] with some representatives of cancer patients and a number of representatives of cancer control stakeholders within the Health Ministry and the network of health and social services. The Working Group also requested AETMIS to provide an overview of cancer control strategies in selected jurisdictions that included existing approaches to governance.

The Ministerial Working Group report indicated that during the consultation process, many stakeholders felt the existing governing organization was ambiguous, and that there was no clear definition of accountability at the various local, regional and provincial levels. The Working Group report also noted that the CCLCQ was struggling to ensure the coordination of all efforts in a context where it did not have appropriate level of authority to call for the necessary actions and accountability.[884]

The Ministerial Cancer Working Group recommended that all functions and responsibilities associated with the implementation of the PQLC and with achieving the planned outcomes be

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[881] MSSS. CCLCQ. La lutte contre le cancer dans les régions du Québec : Un premier bilan. Bibliothèque nationale du Québec, 2003. Released to the public April 30, 2004 by the newly created Direction de lutte contre le cancer.

[882] CQLC. Stratégie et plan d'action 2003-2005. Septembre 2003, 57 p.

[883] This consultation was focused on a document prepared by the CCLCQ that proposed a number of priorities for action and that presented two models of governance: one within the Health Ministry vs. one outside the Ministry, such as an Agency. The invited representatives were asked to rank the priorities and indicate which governing approach would be most effective. According to the Ministry Working Group Report, 80% chose a central body within the Ministry. See Working Group Report, p. 22.

[884] MSSS. Unifier notre action contre le cancer, 2004, p. 16.

subsumed under a single central authority, that of a *National Cancer Control Director* that would be positioned within the Health Ministry.[885]

The Ministerial Cancer Working Group report stated that a number of conditions needed to be united for a successful modernization of cancer control in Québec. Cancer control efforts needed to be: (1) integrated to ongoing health system reforms; (2) associated with targeted investments; and (3) sustained with clear goals and outcome expectations. Finally, the capacity to monitor progress had to be put in place. It is for these reasons that the Ministerial Cancer Working Group recommended the creation of a Cancer Control Director position with the necessary authority and Ministry support to exercise effective leadership.[886] Three main goals were envisioned with the creation of the Cancer Director position:

1. Make accessible a full continuum of cancer services;
2. Report anually and publicly on observable cancer control progress in Québec;
3. Determine priority outcome targets to be included in performance agreements.[887]

The Ministerial Cancer Working Group also recommended that all human and budgetary resources within the Health Ministry that were specifically linked to cancer control (*en lien exclusif ou principal*) be placed under the authority of the Cancer Control Director, along with the following functions:

- Setting priority outcomes for cancer control and associated monitoring activities
- Clinical governance, including clinical practice guidelines, guidance for establishing individual cancer service plans, and organisational standards
- Quality assurance and monitoring, including the updating of the cancer registry and use of relevant information systems
- Provincial coordination of radio-oncology, hostels services, palliative and supportive care services, and collaborative links with volunteer organisations
- Coordination of the network, including the designation, accreditation, and oversight of cancer control teams.

The Working Group also recommended that all activities related to the planning, managing, and assessment of cancer screening programs should continue to be under the responsibility of the Public Health Branch, with the exception of the associated human resources, which would be under the Cancer Director. Results expected from these changes in governance would be:

- A clarification of the mandate and the responsibilities, as well as the authority line and the accounability links betwen local, regional and provincial cancer control actors
- A more coherent and simplified program administration
- Public transparency of the Cancer Control Program management

To this end, the Working Group proposed the following organizational structure:[888]

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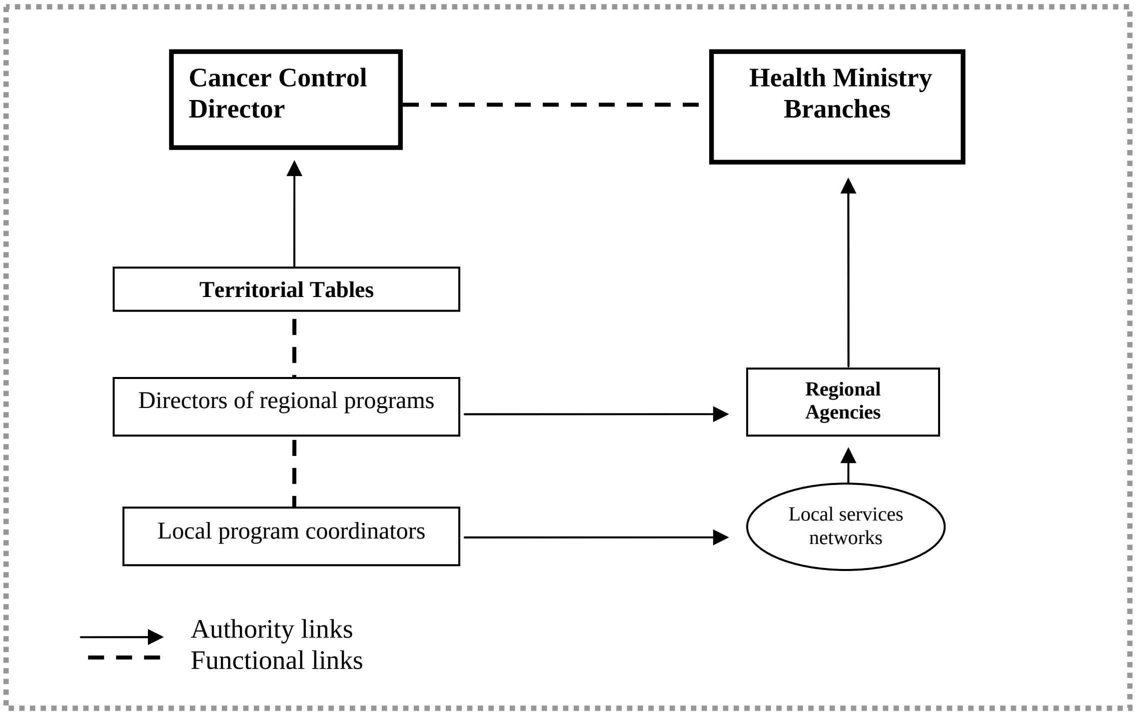
[885] MSSS. Unifier notre action contre le cancer, 2004, p. 4.
[886] MSSS. Unifier notre action contre le cancer, 2004, p. 9.
[887] MSSS. Unifier notre action contre le cancer, 2004, p. 4.
[888] MSSS. Unifier notre action contre le cancer, 2004, p. 40.

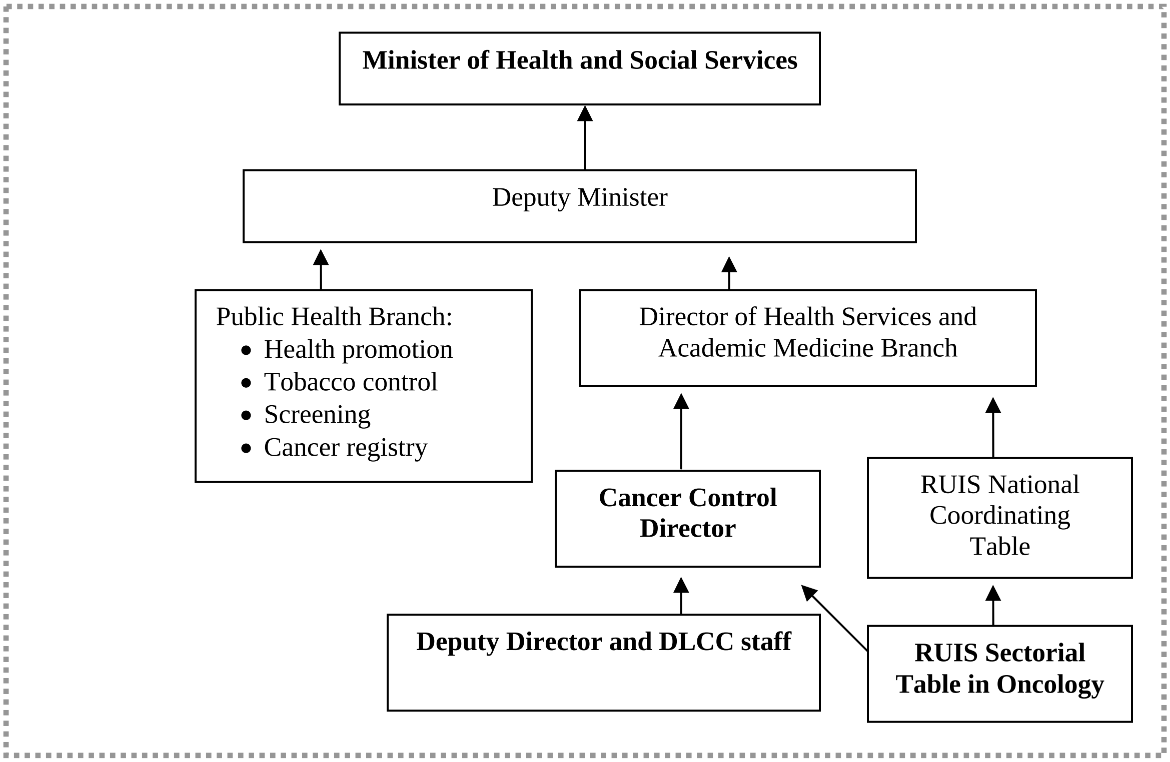
Figure 6. Ministerial cancer working group proposal for a unified governance



The third wave of governing structure: Health Ministry – Direction de la lutte contre le cancer (DLCC, 2004-)

In April 2004, the government established the DLCC. Shortly thereafter, the CQLC and the CCLCQ were abolished.[889] The Cancer Director was appointed in October 2004, and began its duties in January 2005. Also in January 2005, a RUIS Sectorial Table in oncology was created that would be presided by the Cancer Director.

Figure 7. Cancer control governance in Québec since 2005[890]



Based on these findings, it appears that the Cancer Director and DLCC are positioned under the Director of the Health Services and Academic Affairs Branch, which would be in continuity with the previous governance configuration as regards its level of authority.

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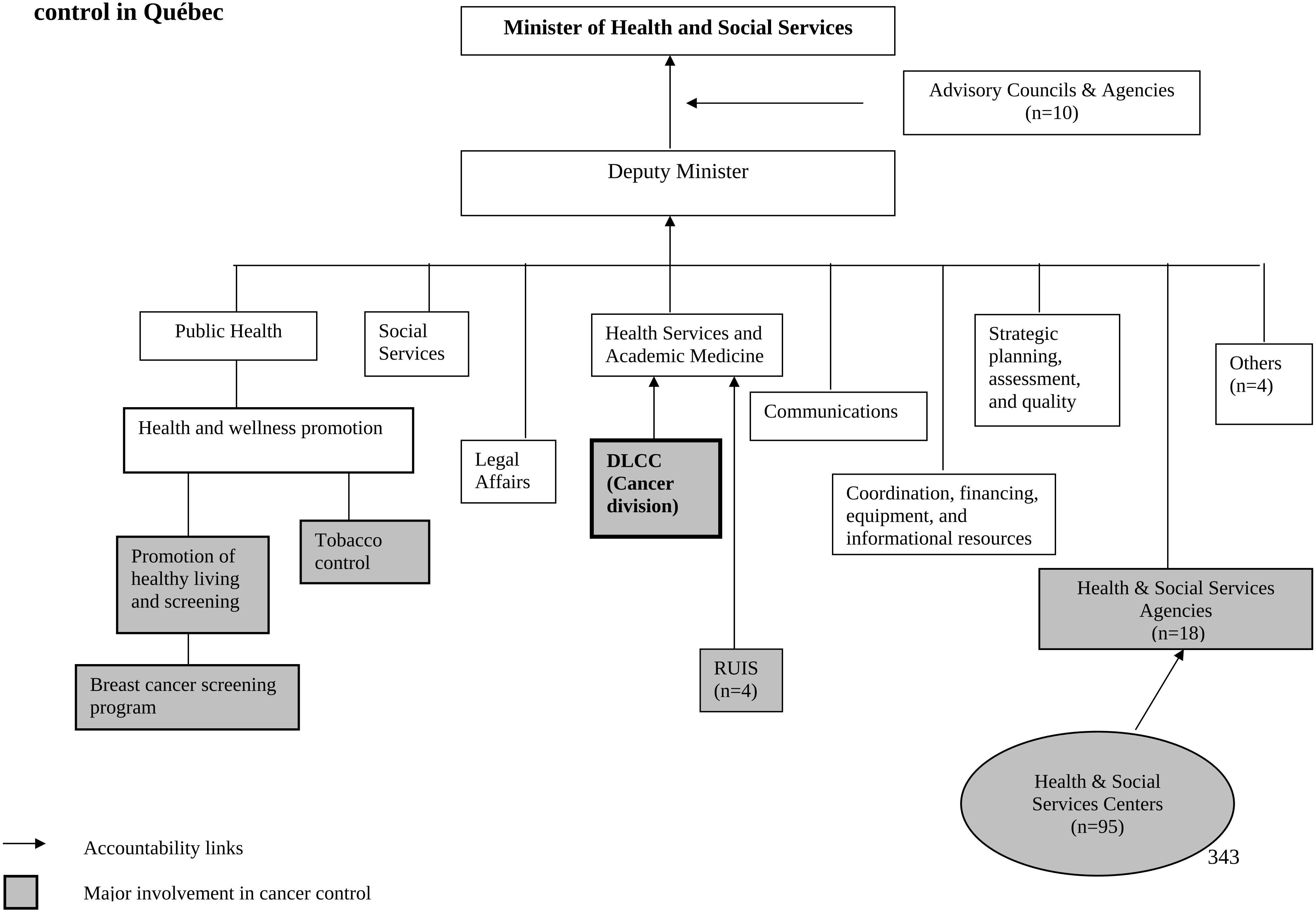
[889] Loutfi A. (Cancer Director) Bilan de la réorganisation de la lutte contre le cancer au MSSS. Powerpoint presentation to the second annual forum of the Coalition Priorité Cancer au Québec, April 22, 2005. Available at: http://www.fqc.qc.ca/coalition/forum2005.asp.

[890] Based on the Plan d'organisation administrative du Ministère de la santé et des services sociaux, March 2006, and on a Table from MSSS. DGSSMU – Direction des affaires universitaires, January 2007.

Appendix 9G: Organizational chart of Québec Ministry of Health and Social Services with a focus on cancer control

Health Ministry and cancer control in Québec



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