Co-constructing recommendations with patients and health professionals

Lambert L1, Boothroyd L1, Azzi L1, Collette C1, Brouillard P1, Pomey M-P2, Fournier M1, Grégoire A1, Ganache I1, Brière A1, Bogaty P1,3, Racine N4, de Guise M1

1. Institut national d’excellence en santé et en services sociaux (INESSS), Montréal, 2. Université de Montréal, 3. Quebec Heart and Lung Institute, Québec, 4. Réseau québécois en cardiologie tertiaire et Montreal Heart Institute, Montréal.

BACKGROUND
The Cardiovacular Evaluation Unit of the Institut national d’excellence en santé et en services sociaux (INESSS) received a ministerial mandate to evaluate the pertinence of implantable cardioverter defibrillator (ICD) replacement. The decision-making process about replacement or revision of an ICD must be patient-centered as well as clinically appropriate. We engaged both clinicians and patients in a multi-method approach to formulate recommendations about structures and processes that facilitate shared and informed decision-making.

METHODS

KNOWLEDGE MOBILIZATION FOR CLINICAL GUIDELINES DEVELOPMENT
• Multidimensional knowledge approach
• Based on collaboration and interactions with stakeholders
• Iterative and continuous mode of knowledge production
• Dynamic and multidirectional exchange process

KNOWLEDGE APPROPRIATION AND TRANSFER

EXPERIENTIAL DATA

“...As an epidemiologist, I deal with numbers. The patient’s committee brought home that each number is a human being.”

- Researcher

“We are here as experts-patients, and it was really helpful to hear and talk with others, because they lived a similar experience.”

- Patient

“Integrating the perspective of patients in the development of a health technology evaluation report is one way to allow ethics to live in this report, by giving a voice to those the most directly affected by the device being analysed.”

- Ethical

SCIENTIFIC DATA

Systematic review of the scientific literature concerning ICD replacement (2010-2017):

Clinical guidelines
Systematic reviews
Primary studies
Qualitative studies

DEVELOPMENT OF RECOMMENDATIONS

• Two rounds of consultation by email with sharing of de-identified comments amongst all members of the group
• One joint in-person meeting

CONTEXTUAL DATA: PROVINCE-WIDE FIELD EVALUATION

CONCLUSION
This multi-method approach enriched our interpretation of literature and ‘real world’ data and facilitated identification and prioritization of important themes. Seven of eleven recommendations were directly linked to the patient experience. Recommendations focused on multi-disciplinary, integrated follow-up of patients and best practice for incorporating patient wishes and life objectives.

Partnership with both patients and clinicians added a new and energizing dynamic to our evaluation and recommendation processes.

Acknowledgements
We would like to thank all the patients and clinical experts for their participation in this project.

Disclosures
I have not had an affiliation (financial or otherwise) with a commercial organization that may have a direct or indirect connection with the content of my presentation.

Contact information
laurie.lambert@inesss.qc.ca