

Integration of knowledge for fair and reasonable decisions :
focus on issues and best practices for users & citizens participation

Capturing the citizen's voice: from aspiration to reality

An UK citizen (and health economist) perspective

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Fair and reasonable : decisions and decision-making

- All decision-making involves the processing of factual (*objectively verifiable*) and subjective (*value-based*) information
 - The distinction can sometimes be blurred
- Some (but not all) nations/societies may espouse decision-making systems that are open and accessible
 - The decisions that are reached may result from such a “fair” process but can still be judged to be unreasonable by significant proportions of citizens
- Is it fair/reasonable that health (social) care be privileged ?
 - Where does that leave other welfare provision (or other policy areas) ?

The (muffled) voice of user / citizens

Community
Health Councils
(CHC)
1973 - 2003

- Reviewed NHS performance and provided advice to ministers.
- Had a legal duty to represent the views of the public and advocate for patients.

Public
Involvement
Forums (PIFs)
2003 – 2008.....

- Independent patients' forum to monitor, inspect every NHS provider unit

Healthwatch
England
2015 -

- Independent consumer champion for health and social care
- Locally based – national network

NICE Citizens Council

- Established 2002 to ensure that the views of those who fund the NHS are incorporated into the decision-making process
- Advisory board comprised of representative sample of the public
- Meets twice yearly
- Agenda largely set by NICE
- Topics reviewed include
 - What should NICE take into account when making decisions about clinical need?
 - Should NICE and its advisory bodies take into account the severity of a disease when making decisions?
 - In what circumstances should NICE recommend interventions where the cost per QALY is above the threshold range of £20-30,000?

NICE in context

- NHS reorganisation
- Cost containment
 - Drugs a “soft” target in the 1990s
- Health economics

- Arms-length decision-making reduces score for political embarrassment
- Evidence-based, independent scientists are now culpable



Sarah Boseley, *Health Correspondent*

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Anti-flu drug Relenza rejected for NHS

Pharmaceutical industry threatens legal action as winter 'life-saver' fails to pass fast-track assessment for general prescription

Relenza flu drug

Finance

Health economics :

Shining a light or blinding us with science ?

- **Systematic analytic framework**
- Agnostic / evidence led
- Established academic discipline
- Do the incremental costs justify the improved benefits?
 - QALYs & ICERs

- **Methodological minefield**
- Access / technical asymmetry
 - Impedes use by naïve users/citizens
- Relies on cognoscenti
- Lacks consensus on key elements
 - Measuring value of health benefits

Making a difference : Searching for evidence

- Do changes to the decision-making process lead to improvements in the quality of resulting decisions ?
- Has the existence of a Citizen Council and/or its deliberations changed anything ?
- Does NICE make better decisions ?
- Is the process of decision-making rendered more palatable ?
- If we cannot provide evidence to address such questions then we must rely on belief

Keep “politics” out of politics ?

STRIKE OUT



POLITICS

VOTE NON-PARTISAN

POLITICS KILLS CIVIC ENTERPRISE! DEFEND OUR CITY HALL! KEEP OUT THE PARTY 'YES' MEN WHO SEEK TO SEND OUR COUNCILS INTO WARRING POLITICAL GROUPS!

Clip Out and Take To Polls
NON-PARTISAN CANDIDATES!

ALABAMA	
BRADDOCK, BRUCE	X
JORDAN, JAMES L.	X
LEWIS, DONALD	X
PERDUE, ALAN	X

ARIZONA	
BLAZEK, JAMES	X
CHAPMAN, ALAN	X
DELUCA, JOHN W.	X
REAGAN, JOHN	X

FLORIDA	
FRY, BOB C.	X
WILLIAMS, L. ALAN	X
SMITH, MARY	X

CARD ESSENTIALLY NEEDED FOR ELECTION DAY, WED., DEC. 15---PHONE MAILING T131



Keep Religion OUT of Politics



FEFRE.ORG FREEDOM FROM RELIGION FOUNDATION

