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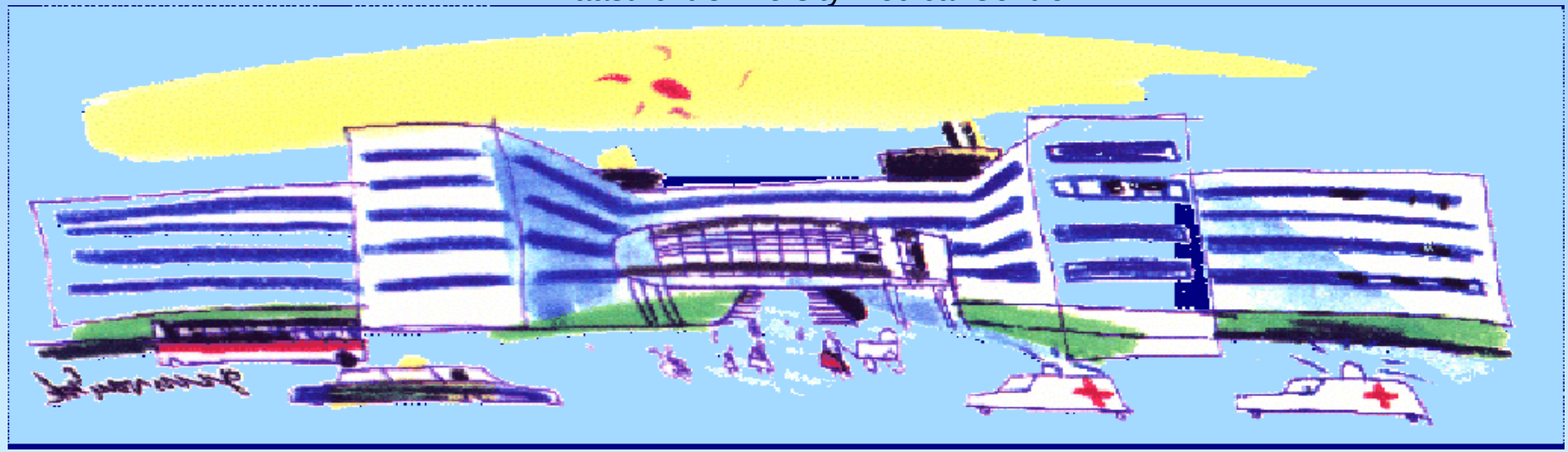
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Integrating evidence on patient preferences in health care policy decisions: are we up for it?

Outcomes beyond QALY symposium

November 16, 2012

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The **Patient-VIP study**: patient values in policy decisions

Background ‘Patient-VIP study’

- Increasing attention for consumer/patient preferences in health care decision-making
- Consideration mostly through direct patient participation (a ‘seat’ at the table)
- Systematic and explicit use of evidence from patient preference research (indirect participation) limited
- Suggests that there may be barriers for its use

What are preferences?

- Dictionary: the selecting of someone or something over another or others
- Psychology: individual's attitude towards a set of objects, typically reflected in an explicit decision-making process OR an evaluative judgment in the sense of liking or disliking an object
- Economics, the term preference refers to the set of assumptions related to ordering some alternatives, based on the degree of happiness, satisfaction, gratification, enjoyment, or utility they provide, a process which results in an optimal "choice" (whether real or imagined).
- Convergence in the view that patient preferences are (comparative) judgements made regarding the desirability of a range of health experiences, treatments options, or health states.
- The *subjective judgement* is what distinguishes preferences from factual descriptions of experiences, processes and (health) outcomes

Why consider patient preferences?

- Health behaviour is driven by preferences
- Patient preferences may differ from those of the general public:
  - patients may value the same things differently
  - patients may value different things
- Source of information for patient representatives in health care decision-making (empowerment)
- May enhance patient-centeredness of care and shared decision-making regarding preference-sensitive decisions

Overall:

- May improve the quality of decisions and increase efficiency
- Yields return on investments in patient preference research (otherwise why bother?)

Editorials

Discrete choice experiments in health care

NICE should consider using them for patient centred evaluations of technologies

In many publicly provided healthcare systems, limited resources coupled with unlimited demand result in decisions having to be made about the efficient allocation of scarce resources. This raises questions of how services should be provided (for example, how should patients with cancer be treated? should central clinics, which reduce waiting time but increase travel time for patients, be introduced?) through to the optimal provision and the financing of health care (for example, how should we pay doctors to encourage them to work in remote and rural areas? what would encourage nurses to return to the labour market?). Given the lack of a market for health care, economics techniques inform such decisions.[1] One approach adopted by and further developed in health economics over the past decade is discrete choice experiments.[2 3] In this issue Sculpher et al use this approach to consider patients' preferences in the treatment of prostate cancer (p 382).[4]

Discrete choice experiments are an attribute based measure of benefit[2] that is based on the assumptions that firstly, healthcare interventions, services, or policies can be described by their characteristics (or attributes) and secondly, an individual's valuation depends on the levels of these characteristics. For a review of the stages involved in conducting discrete choice experiments and the information they provide, see Ryan and Farrar[3] as well as the paper by Sculpher et al in this issue.[4]

Although limited research has been conducted in this area and future research is clearly important (which is the case for all economic evaluation techniques, including those used in the QALY framework), experience from other areas such as the valuation of environmental goods and services implies that we can be optimistic.

Given the role of the National Institute for Clinical Excellence (NICE) in making recommendations concerning optimal treatments, can it make use crete choice experiments? The institute is increasing pressure to take account of patients' ences. To date systematic consideration of such ences has been limited. Typically public preferer required to elicit quality weights in the paradigm.[10] This is not enough since patier value outcomes differently to the public and ha erences over aspects of care beyond QALYs.[9 11]

NICE plans to have a patient centred evalu technologies in addition to the current assessn clinical and cost effectiveness. Using the appr discrete choice experiments allows the integr patients' values on all aspects of care in one m We will be able to see how patients trade d health outcomes as well as process type att alongside each other. Valuation of process and outcomes from the patients' perspective may w to conclusions that conflict with the recommen of the cost per QALY approach. This is more

Papers p 382

Source: Mandy Ryan, British Medical Journal, 2004

International Journal of Technology Assessment in Health Care, 23:1 (2007), 30–35.
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Patient-based health technology assessment: A vision of the future

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Johns Hopkins Bloomberg School of Public Health

Background: In conjunction with other important movements in contemporary medicine, including evidence-based medicine (EBM), health technology assessment (HTA) has promoted a culture of critical evaluation. Despite this impact, institutional and methodological challenges are associated with HTA. For example, only in recent years has HTA attempted an open dialogue with patients; however, this is normally done by giving them a "seat" at the HTA decision-making table, rather than by more scientific means.
Objectives: The aim of this study was to develop a working definition of patient-based HTA, to identify the current barriers to adopting a patient-based model, and to formulate a vision of how a patient-based HTA could be used to promote patient empowerment and patient-centered care.
Results: In the ideal setting, a patient-based HTA would promote patient knowledge by providing access to information and promoting an informed dialogue between patients and their healthcare professionals. To implement a patient-based HTA, the focus must turn to the patient's issues and incorporate each patient's unique perspective and preferences. Processes must change to increase patient participation in all levels of HTA and aim to promote empowered patients who can make informed decisions.
Conclusions: Present-day HTA is broad and has numerous stakeholders, with none so

Aim of study

To investigate whether, and if so, how and what type of evidence on patient preferences can be integrated in health care decision-making in The Netherlands regarding pharmaceuticals.

Focus on *coverage decisions* and *clinical practice guideline development*

Project group/ -advisors

Health Care Insurance Board
Bert Boer, Annika van Velden

Dutch Association of Medical Specialists
Teus van Barneveld

Dutch Council for Quality of Health Care
Dunja Dreesens

Patient(s)/representatives
Cees Smit, Hans van Laarhoven

Leiden University Medical Center
Anne Stiggelbout (LUMC)

Maastricht University Medical Center /Maastricht University
Cecile Utens (postdoc), Trudy van der Weijden (co-projectleader), Manuela Joore (co-projectleader)

Research questions

1) What type of evidence and how is evidence on patient preferences currently considered in health care decision-making, either in The Netherlands or abroad (Study 1)?
2) What are barriers to and facilitators for considering evidence on patient preferences in health care decision-making regarding pharmaceuticals, and how can these barriers be resolved and facilitators enhanced (Study 2)?
3) What could be a decision framework for the integration of evidence on patient preferences in health care decision-making regarding pharmaceuticals (Study 3)?
   - integration in established decision processes
   - taxonomy for patient preference research

Work definition

- In this study, the term preference is broadly defined as **the value attached by patients to (aspects of) health (care services)**.
- Aspects of health care services may include both (health-related) outcomes and process features.
- With this work definition

  1) we are not a priori excluding specific conceptualizations and/or measurement techniques and

  2) we are not a priori confining the evaluative space to health-related outcomes only, but extend it with outcomes beyond health and process.

Sub-study 1: scoping review

Research questions:

- To what extent are results of patient preference research currently integrated in coverage decisions and guideline development
- What are the ideas and opinions regarding the use of and requirements for research on patient preferences for health care decision-making

Methods:

- Document/website search
- Review of selected guidelines
- Pubmed search (snowballing method)



Results scoping review

- In coverage decisions research on patient preferences has no formal role yet.
- In clinical practice guidelines the role of research on patient preferences is limited.
- Many terms relating to ‘preferences’
- Several barriers put forward regarding the use of results of research on patient preferences and values in health care policy-making

Source: Cecile Utens et al. Poster presented at ISPOR Berlin Nov 3-7, 2012

Related terms

Values? **Quality of life?**
Acceptability? UTILITY?
Attitudes? Perception?
Experience? Satisfaction?
Needs? Wishes?
Concerns? Beliefs?



Related terms in guidelines

- Prostate carcinoma

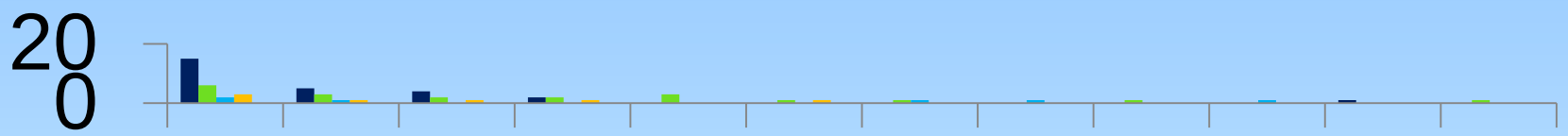


Figure 1. Number of references with term related to preferences or values in title - per guideline

Source: Cecile Utens et al. Poster presented at ISPOR Berlin Nov 3-7, 2012

Barriers



- Lack of conceptual clarity (what are preferences and how to measure)
- Validity issues (violations, distortions and biases)
- Evidence retrieving and synthesis (paucity of research, diversity in research methods, transferability/generalisability of preferences)
- Normative (public versus patient values, outcomes beyond QALY)
- Organisational (place and weight in established decision-making processes)
- Stakeholders' knowledge, attitudes and skills

Sub-study 2



Qualitative study

Aim:

- To explore ideas and opinions of broad group of stakeholders with respect to:
  - taxonomy for patient preference research
  - barriers and facilitators for integration of patient preference research in health care policy decisions
  - ways to enhance facilitators and resolve barriers

Method:

In depth semi-structured interviews with about 15-20 stakeholders (HTA researchers, patient representatives, policy-makers, guideline developers) with member checking

Interview scheme

- What comes up in your mind if you think about the term preferences?
- What is your experience with using research on patient preferences in coverage decisions/ guideline development?
- Do you see a role for research on patient preferences in coverage decisions or guideline development (barriers, facilitators, conditions for use: where, how, under which circumstances)?
- What is your experience with measurement of preferences?
- What would be the requirements for research on patient preferences (how, at what phase, in whom, preferences for what)?

Sub-study 3



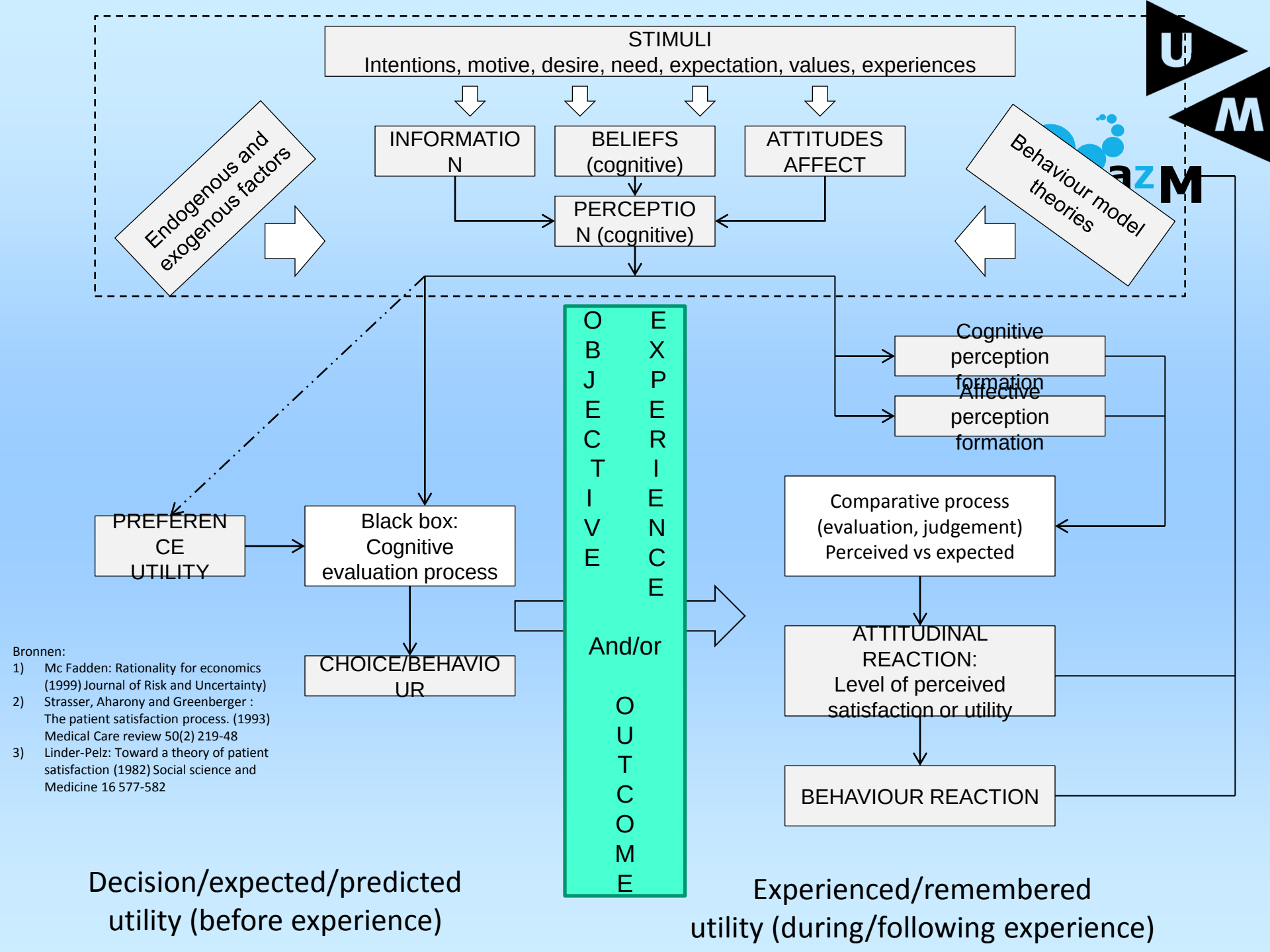
Aim: development decision framework

Methods:

- Will be based on qualitative study
- Two expert meetings for prioritizing and validation of topics and recommendations in draft(s)
- Nominal group technique
- Development of concept tool
- Face en content validity

So, what is needed?

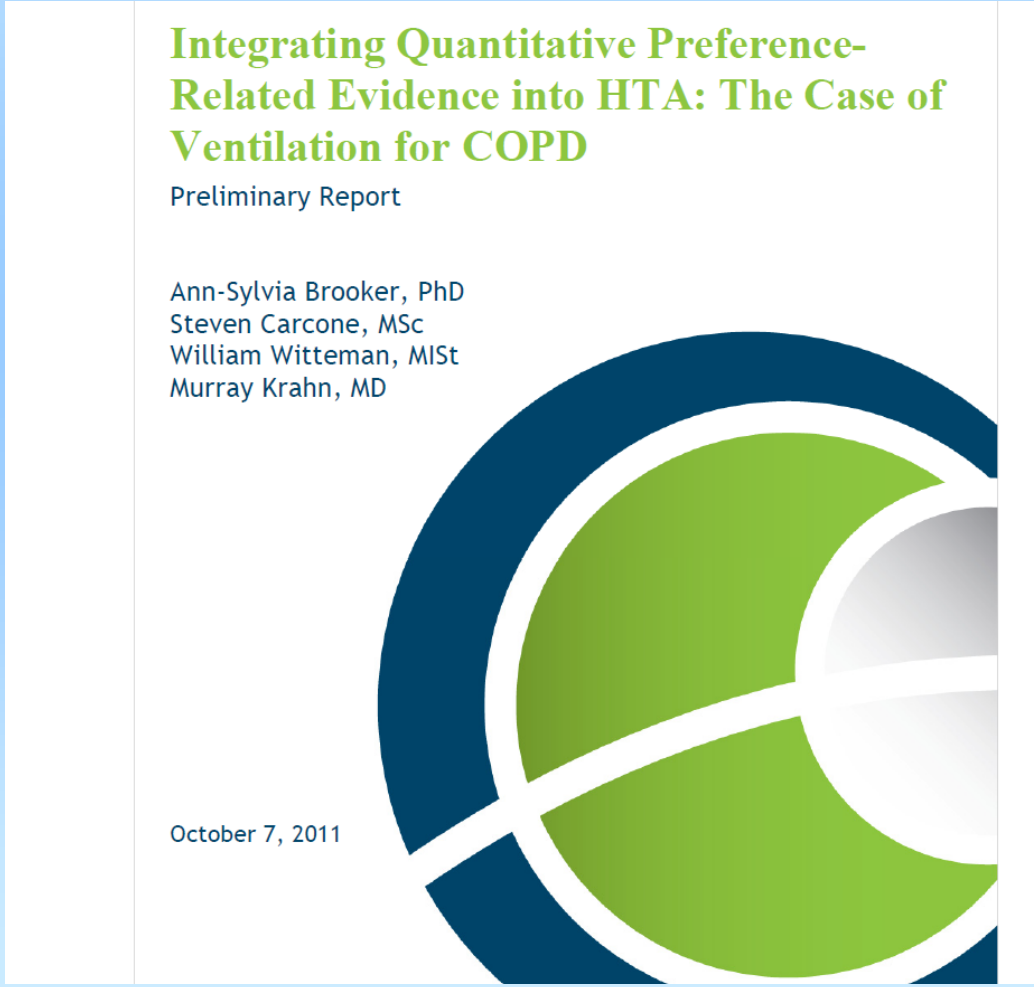
- Taxonomy for defining and conceptualizing preferences
- Overview of existing methods for measurement of preferences (e.g. see Ryan, 2001)
- Requirements for research on patient preferences (population, comparative, research setting, …)
- Methods for evidence retrieving, appraising, and synthesis
- Strategy for incorporation in existing procedures



Bronnen:

1) Mc Fadden: Rationality for economics (1999) Journal of Risk and Uncertainty)
2) Strasser, Aharony and Greenberger : The patient satisfaction process. (1993) Medical Care review 50(2) 219-48
3) Linder-Pelz: Toward a theory of patient satisfaction (1982) Social science and Medicine 16 577-582

Searching for evidence



Integrating Quantitative Preference-Related Evidence into HTA: The Case of Ventilation for COPD

Preliminary Report

Ann-Sylvia Brooker, PhD
Steven Carcone, MSc
William Witteman, MISt
Murray Krahn, MD

October 7, 2011

Our objective was to include studies that pertained to the values, beliefs, attitudes, perspectives and preferences of COPD patients regarding ventilation (either MV or NIV) and that used quantitative methods. An iterative process was used to develop search terms pertaining to patient preferences. We developed a large list of possible search terms based on our knowledge of the literature, by examining key papers in the patient preference literature and by consulting with experts in the area. In this study, we used the term 'patient preference research literature' to include research pertaining to: patient view; patient value; patient perception, patient acceptability; patient participation; patient satisfaction, decision aid, decision tool; and patient perspective (See Appendix A for complete list).

Using the evidence

Health Technology Assessment International
An International Society for the Promotion of Health Technology Assessment

'Patients' perspectives in HTA: a route to robust evidence and fair deliberation'

Javier Gracia, Spain

Helle Ploug Hansen, Denmark

Alessandra Lo Scalzo, Spain

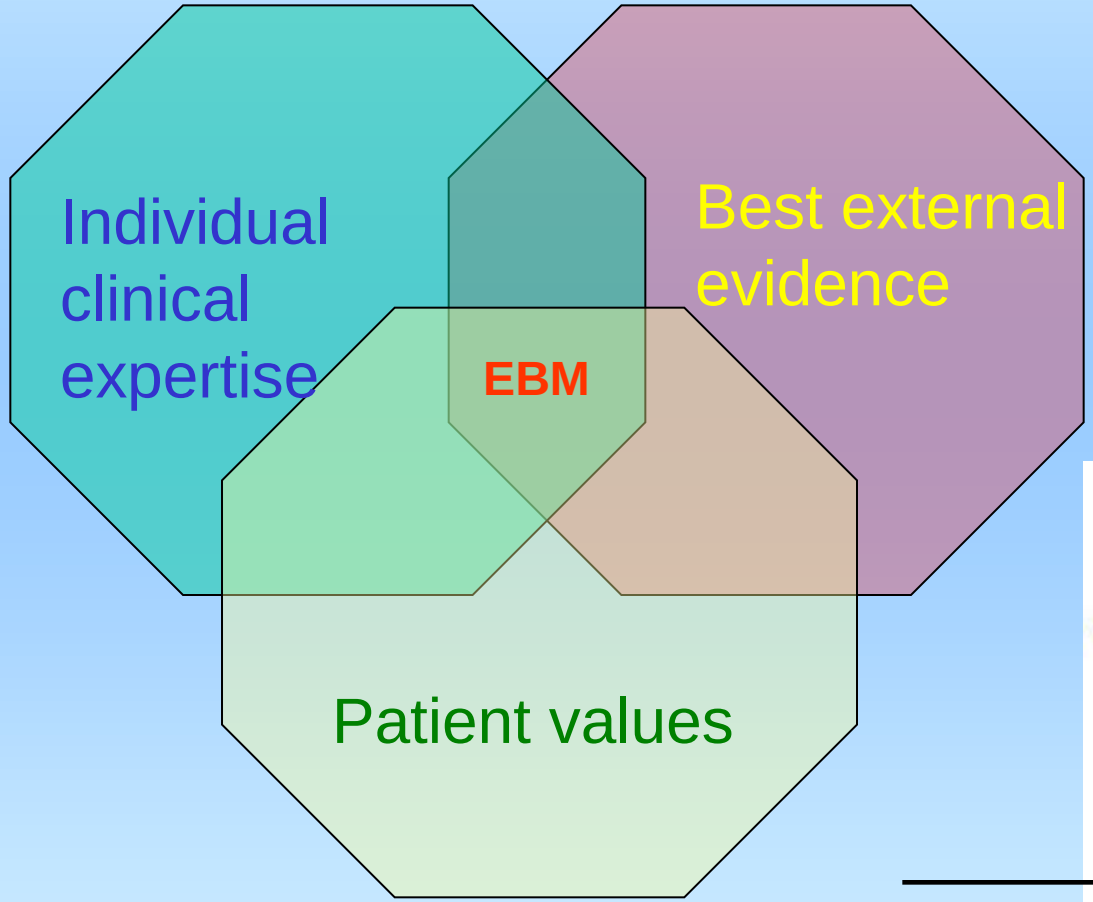
Jean Mossman, Health Equality Europe



Antoine Boivin, Canada

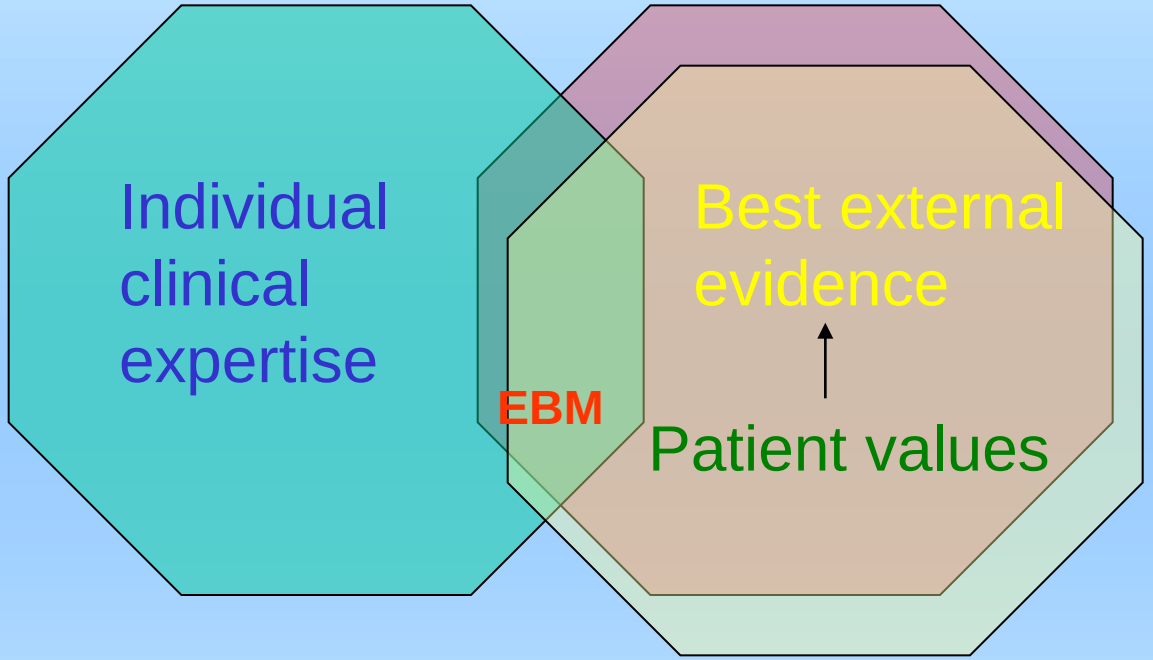
Ann Single, Australia

Evidence Based Medicine





Paradigm shift?



Possible ways to integrate patient preferences (coverage)

Assessment phase:

Necessity criterion

- Patient preferences: how much is the technology wanted, fulfilment of needs and wishes

Cost-effectiveness criterion:

- Patient valuation of health outcomes instead of/additional to public values (Q in QALY; may not be different from public values)
- Patient valuation of outcomes beyond/including/conditional on health ('Well-being' Adjusted Life year; WALY)

Extra criterion:

- Patient preferences for 'whatever is relevant'

How to weigh: MCDA

Appraisal phase: *part of 'other, 'not quantifiable' arguments*

Think big, start small, move fast?

- Resolve all barriers before considering patient preferences?
- Where to start?
- Are you up for it?

