“Whenever a theory appears to you as the only possible one, take this as a sign that you have neither understood the theory nor the problem which it was intended to solve.”

The Logic of Scientific Discovery, 1959
Sir Karl Popper

born 1902 in Vienna

died 1994 in London

Austrian and British philosopher

Professor at the London School of Economics

He is considered one of the most influential philosophers of science of the 20th century

Patient Focused Decision-Making in HTA

Key Questions

■ How are patients involved in the HTA-Systems?

■ To which extent is MCDA today part of the current HTA processes?
Patient Focused Decision-Making in HTA
Systematic Review from 2016


Patient Focused Decision-Making in HTA
Systematic Review - Results

- Broader view  
  **Public AND Patient involvement in HTA**
  
  53 HTA agencies, 34 countries

- Research questions
  - How are HTA organizations involving public and patients?
  - How are they doing this in terms of approaches, specific mechanism
  - With are the results? What are the barriers or facilitators?

- Public and patient involvement approaches (n = 13)
- Goals and rationales for public and patient involvement (n = 5)
- Evidence of public and patient involvement effectiveness (n = 2)
- Public and patient involvement feasibility (n = 0)

Patient Focused Decision-Making
Canada

- Patient Involvement
  CADTH’s first Call for Patient Input was issued in May 2010

- CADTH Common Drug Reviews (CDR)
  CADTH’s pan-Canadian Oncology Drug Review (pCODR)

- British Columbia *Your Voice* Program

- Ontario *Patient Evidence Submission*

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Patient Focused Decision-Making in HTA
England & Wales

- Participation at each strand of NICE’s work
  - Public Board Meetings
  - Scoping Process
  - Advisory Committees (i.e. Technology Appraisal Committee)

- NICE’s Public Involvement Programme (PIP)
  - developing and supporting opportunities to involve patients, carers, service users and the public in NICE’s work

- June 2016
  - Myeloma UK has awarded a research grant to NICE
  - to fund a two year exploratory study
  - Myeloma UK is a registered charity since 1997

- Project
  Methods for patient-centred decision making on the availability of new treatments (Lead: Prof Sarah Garner, NICE)

Patient Focused Decision-Making in HTA
Belgium

- Belgian Healthcare Knowledge Centre
- KCE REPORT 195C
  Models for Citizen and Patient Involvement in Health Care Policy. Part I: Exploration of their feasibility and acceptability

- Excellent methodological framework based on concepts
  International Association for Public Participation (IAP2)

- Different levels of involvement according to different decisions
  - for priority setting in the allocation of scarce health care resources: citizen representation
  - for reimbursement decisions of new treatments: patient representation


Patient Focused Decision-Making in HTA
Germany

- G-BA Coordination Committee of Patients Representatives
  - in total 220 patient representatives involved in G-BA subcommittees

- Institute for Quality and Efficiency in Health Care (IQWiG)
  - Written comments to benefit assessments (direct)
  - Hearings (PRO) (via Coordination Committee of Patients Representatives)
  - Patient’s perspective in benefit assessments (via questionnaire)
IQWiG initiated a study on Analytic Hierarchy Process (AHP) to integrate patients’ views into HTA.

**Topic:** Diagnosis of major depression

Rating of preferences with respect to the importance of different endpoints of antidepressant treatment

**Recommendations:**

AHP useful in HTA to give a quantitative dimension to patients’ preferences for treatment endpoints


**Patient Focused Decision-Making USA**

- **Patient Preference Initiative**
  
  "While patient representatives participate in many of the FDA’s advisory committees, […] the FDA has never had a committee that was wholly focused on patients."

- **Center for Biologics Evaluation and Research (CDER)**
  
  - Working on integrating qualitative data into review processes

- **Center for Devices and Radiological Health (CDRH)**
  
  - Working on quantitative approach
  - Pilot project on medical devices (weight-loss device)
  

- **Final Guidance in effect October 23, 2016**
  
  "FDA encourages medical device manufacturers to voluntarily include in their premarket submissions information on Patient Preference Information (PPI)"

http://www.fda.gov/Drugs/InformationOnDrugs/ucm446680.htm


Patient Focused Decision-Making in HTA

Conclusion

Patients' perspectives

- Considering patients' perspectives is increasingly essential as healthcare systems move toward more patient-centred approach

- This trend is part of broader political context of consumer protection

- However, the majority of HTA agencies lack systematic evaluation on:
  - structures
  - impact
  - facilitators and barriers of patient involvement

MCDA in HTA

- Technical
  MCDA techniques can support a broad variety of decision problems in HTA

- Political
  - transparency of the preference-elicitation process
  - involvement of ALL stakeholders into the value-assessment process
  - increasing the legitimacy of decision process

- Lack of familiarity with the diversity of MCDA techniques

- No sufficient methodological guidance how to
  - design
  - conduct and
  - implement MCDA a part of HTA