Patient and public engagement in health technology assessment: Update of a systematic review of international experiences

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Overview

- Background
- Objective
- Methods
- Results
- Discussion
- Conclusions
The importance of involving patients and the public in different health domains, including health technology assessment (HTA), is recognized and supported in many jurisdictions.

Patient and public involvement (PPI) in HTA emerged as an imperative for more informed, transparent, accountable, and legitimate decisions about health technologies.
Rationale for involving patients in HTA

- Patients (including family and informal care givers) are directly affected by a health condition
- They can bring a unique perspective on experiences, attitudes, beliefs, values, and expectations regarding health technologies
- Taking into account the patient perspective could contribute to more relevant technologies and improve adherence
Rationale for involving the public in HTA

- As tax payers, citizens should be involved in decisions regarding the healthcare system
- In a democracy, they have the right and the duty to participate in decisions for the common good
- Considering their perspectives can ensure fairness and transparency in health resources distribution
But...

- Many questions remain about the best strategies for involving patients and the public into the structures and activities of HTA agencies...
- Why, when, who, how?
- Does it worth the effort?
Objective

- To update a systematic review (published in 2011) on patient and public involvement in health technology assessment
Methods

Search strategy

- Literature search in eight databases
- Years covered: 2009-2016
- Other literature identified through citation tracking of included studies
- Abstracts and titles screened by 1 reviewer and checked by another
Methods

Study selection criteria

- *Type of publication*: Paper describing empirical research. Editorials, reviews, commentary pieces and opinion articles were excluded.
- *Types of participants*: Patients, carers, consumers, members of the public (*i.e.* citizens)
- *Types of interventions*: The study had to describe, in whole or in part, any experience of patient or public involvement in the field of HTA.
- Selection made by 2 independent reviewers
Methods

Data extraction

- Country, methods, participants
- HTA approach and activities
- Conceptual framework or model
- Evaluation of PPI in HTA
- Effects or impacts of PPI on HTA processes, stakeholders’ perceptions, and decisions
Study selection flow

- Records identified through database searching (n = 5965)
- Records after duplicates removed (n = 707)
- Records screened (n = 4762)
- Records excluded (n = 4734)
- Fulltext articles assessed for eligibility (n = 23)
- Articles included in synthesis (n = 21 describing 20 studies)
Preliminary results

20 studies included

Country where studies were conducted:
- Canada (n=6); Australia (n=3); Germany (n=3); Finland (n=2); United Kingdom (n=1); Italy (n=1); Spain (1); South Korea (n=1); Multi-country (n=2)

Year of publication:
- 2014-2016 (n=12)
- 2010-2013 (n=8)
- Before 2010 (n=24)
Preliminary results

Overview of the identified studies

- **Who is involved:**
  - Citizens (n=6)
  - Patients/services users (n=6)
  - Both citizens and patients (n=8)

- **Type of involvement:**
  - Consultation (n=19)
  - Information/communication (n=13)
  - Participation (n=5)
Preliminary results

Impact of PPI on stakeholders’ perceptions

- Influence on elements of discussion in the HTA and recommendations (focus on care rather than technology)
- Including the public in HTA could enhance transparency and reduce conflict of interest
- Influence the selection of priority HTA topics (e.g. preferences for prevention or early diagnosis, targeting younger people, and rural populations)
- Enable healthcare decision makers to consider specific implications (e.g. access, patient important endpoints) of the introduction of a new technology
Preliminary results

- Impact on clinical interventions (examples)
  - Suggestion of other alternatives that could reduce the use of restraint and seclusion
  - Suggestion to educate healthcare professionals in order to develop an empathetic approach in communicating with patients
  - Development of a tool to assist healthcare professionals and patients in decision-making regarding treatment options
# Preliminary results

## Facilitators
- Organisational context
  - Receptivity of other stakeholders during meetings
  - Reference person for patient participants
  - Providing documents and training in advance
  - Support from patient groups
- Political context
  - Educational program for patients and patient organisations
- Community context
  - Collaboration of patient groups in the recruitment

## Barriers
- Organisational context
  - Patients and citizen may feel ill equipped with the task
  - Small number of patient representatives on the committee limits their influence
  - Time and efforts needed (unworkable deadlines)
- Decision-making context
  - Difficult to find patients who have experienced several treatments for the same condition
  - Online consultation forms not appropriate for all patients
Discussion

- The number of studies on PPI in HTA has increased in recent years
- Many of them (6) were conducted in Canada
- First study from an emerging country (South Korea)
- Patient and public are still mostly consulted than directly involved in the HTA process
Discussion

- Some indication that PPI can impact the HTA process and clinical interventions, but evidence is limited
- Maybe due to lack of preparation of HTA producers on how to integrate their perspectives
- Evaluating PPI impact in HTA remains a major methodological challenge
Study limitations

- Gray literature not directly considered (only when referenced in included studies)
- No consultation of international experts in the field
- Other reviews were excluded (but their references were checked)
- Only studies with empirical data were included (descriptive reports of experiences not considered)
Conclusions

- Findings from this update are mainly consistent with those of the previous systematic review.
- Despite the increased number of published studies, evaluation of PPI in HTA is still limited.
Conclusions

- Studies are needed to assess the effectiveness of different strategies for engaging patients and the public in HTA.
- Studies are also needed to assess the impact of PPI on the HTA process, recommendations, and outcomes.
Questions and comments? Thank you!

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