

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

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# Overview

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- Background
- Objective
- Methods
- Results
- Discussion
- Conclusions

# Background

- 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...

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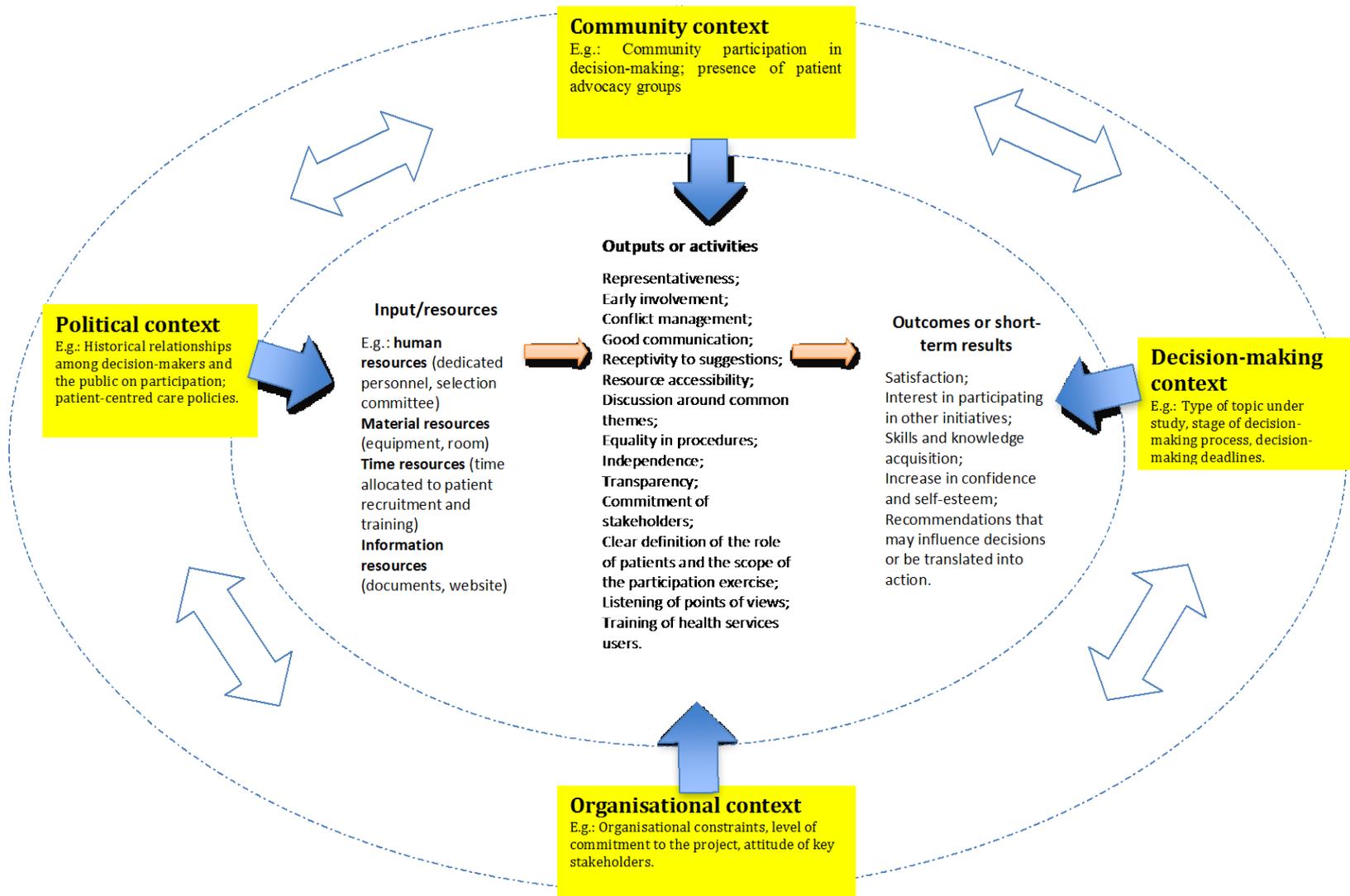
- Many questions remain about the best strategies for involving patients and the public into the structures and activities of HTA agencies...
- Why, when, who, how?
- Does it worth the effort?

# Objective

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

# Analysis framework



# Methods

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## 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

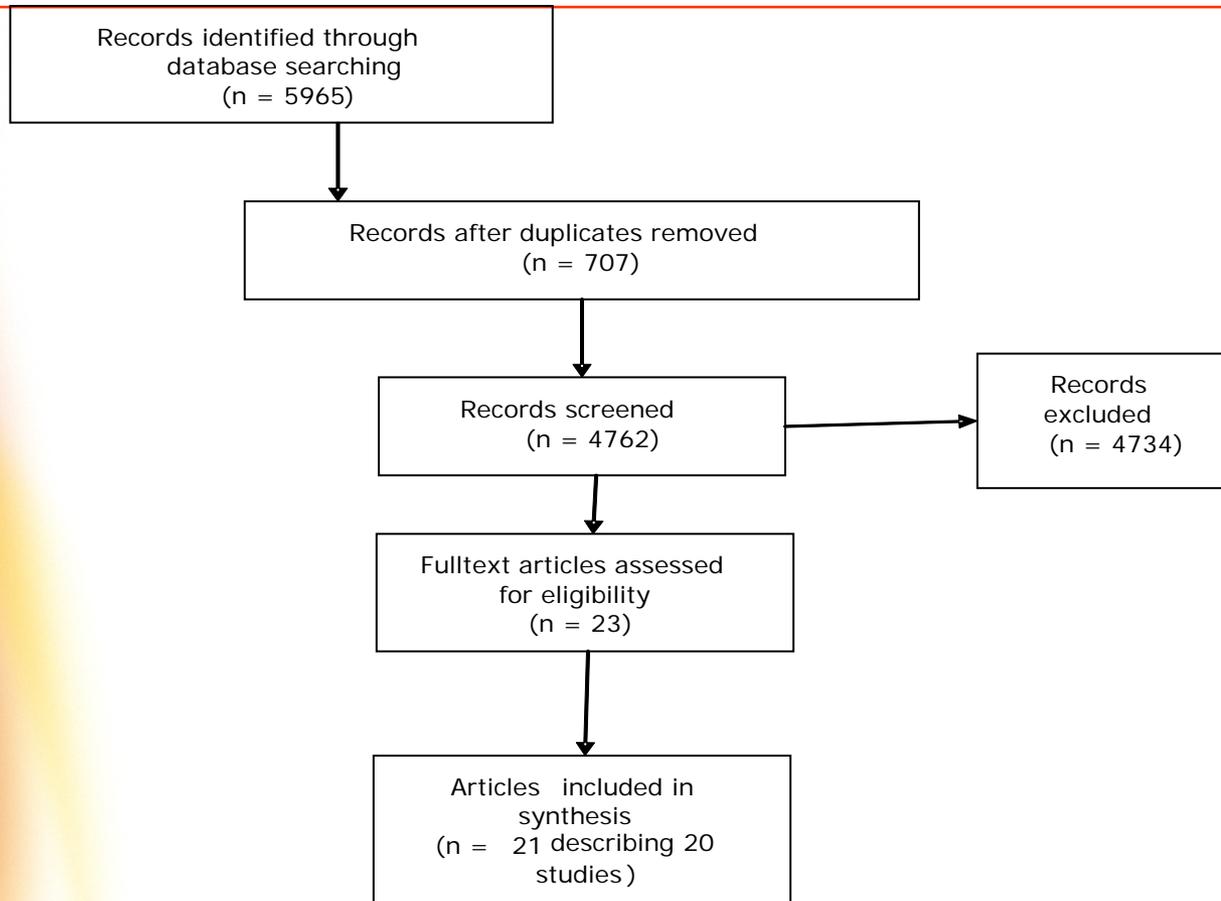
# Methods

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## 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



# 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

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- 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

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- 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

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- 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

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- 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

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- 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

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- 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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