

Introducing the patient's perspective in health technology assessment at the local level: A qualitative study of HTA producers and hospital managers

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Overview

- Introduction
- Description of the research project
- Objectives
- Methods
- Results
- Discussion - conclusion

Introduction

Creation of local HTA units in University hospitals in the province of Quebec:

- Decentralization of HTA in order to better meet the needs of local decision makers
- Hospital-based HTA aims at supporting managers and clinicians for decision making regarding the introduction and utilisation of healthcare technologies and interventions

Introduction

Patient/public involvement in HTA:

- Rationale: Patients provide 'experiential' evidence for the HTA process; they are the direct beneficiaries of health technologies
- They provide valuable information about the impact, benefits and unwanted effects of technologies
- Could allow more accurate assessment of the real value of health technologies

Introduction

- General consensus on the need for more patient-centered HTA, but how?
- Recent implementation of local health HTA units in university hospitals in Quebec: unique opportunity to foster an increased participation of patients in HTA

Research project

Introducing the patient's perspective in HTA at the local level, funded by the CIHR Knowledge-to-Action program

- Goal: To explore how the patient perspective could be introduced into the structures and activities of local HTA units
- Participatory approach: decision-makers collaborate in the elaboration of research objectives and the interpretation of results

Objectives

1. To synthesize international experiences with patient and public involvement in HTA activities
2. To explore actual practices and perceptions of HTA producers, hospital managers and patient representatives regarding the incorporation of the patients perspective in hospital based HTA activities
3. To produce a consensual framework that could guide interventions for involving patients in HTA activities at the local level

Methods

- Semi-structured interviews conducted with HTA producers and hospital managers from the Province of Quebec
- A conceptual tool was used to clarify dimensions of patient involvement and develop the interview guide
- The interview guide explored:
 - Respondents' current practices and perceptions with respect to patient involvement in HTA
 - Preferences regarding the type and level of patient involvement
 - Perceived barriers and facilitators to involving patients in HTA activities
 - Perceived conditions for successful patient involvement

Methods

- Interview guide sent before the interviews
- Verbatims were analysed using NVivo software (5 first transcripts coded by 2 people independently)
- A workshop with researchers to validate initial analysis of data (expert verification) and to contribute to the final analysis

Type of mechanism and level of involvement	Phases in the HTA process							
	Selection of evaluation subjects		Evaluation				Final report and recommendations	
	Submitting assessment requests	Prioritizing requests	Elaborating evaluation plan	Collecting evidence (literature)	Contextualizing or collecting new data	Analysing and synthesising results (First version of report)	Discussing and approving of report	Making recommendations
on face awareness)	Mechanism to inform and raise patients awareness							
ion face opinions influence)	Mechanism to collect primary data							
	Mechanism which allows patients to provide comments							
	Mechanism which allows patients to appeal a decision							
ion face to as)	Mechanism which allows patients to collaborate							
	Mechanism which allows patients to be partners							
	Mechanism which							

Results

- 21 semi-structured interviews
 - 18 with individual respondents + 3 with two participants
 - Total of 24 participants from three regions (Montréal, Québec, and Sherbrooke)
- Participants' characteristics:
 - 14 HTA producers, including directors of HTA local units
 - 8 Hospital managers
 - 2 Clinicians
- Interviews lasted 57 min. on average (29 to 93 min.)

Results

Why include the patient ?

- For a better assessment of the impact of technologies by including the experience of the patient
- To understand the impact of technologies on the patient, particularly undesirable effects, and safety
- To improve care and services, by considering the patient's needs, expectations, and values
- To have a more complete and contextual understanding, especially useful when formulating recommendations
- To encourage patient responsibility and autonomy, and humanization of care
- To facilitate implementation, adoption and acceptance of a technology or a type of intervention

Results

Obstacles:

- Lack of knowledge and tools
- The UETMIS organization was not quite ready: evaluation is recent in these hospitals
- Concerns about delays and more work
- Concerns that there would be a focus on less important issues
- Bias and industry lobbies
- Difficult to include patient information in final report

Results

Methods for introducing the patient's perspective:

- Literature review: social, psychological, quality of life, ethics
 - *Consultation: As part of research, collect patient information
 - Participation: collaboration
 - *Direct participation in the evaluation: patient as partner
- * The two main types used in HTA local units in Quebec

Results

The technology or issue which can benefit from patient consultation:

- When the technology is used by the patient or has an impact on the patient (ex. insuline pump; telehomecare; readaptation in the community; diagnostic tests)
- Intervention type (the way care is organized or that a technology is used)
- Ethical issues or what is understood during patient consent
- Implementation, acceptance, or feasibility issues
- The degree of uncertainty associated with a technology

Results: consultation

Barriers	Facilitators or strategies
Time constraints, complexity (ethics committee)	Choose questions, the consultation objectives and the analytical dimensions carefully
Lack of financial and human resources (limited hospital budget)	<ul style="list-style-type: none">• Pool resources in organizations and share tools• Obtain additional financial resources
Quality standards may sometimes come into question with qualitative studies	Use personnel with solid qualitative background and rigorous methodology
Difficulty recruiting patients	Recruitment through: 1) patients' associations, 2) clinicians, 3) users' committee
Patient sampling	Try to obtain a variety of perspectives
Integrating the patient perspective in the final report	

Results

Patient participation in evaluation: When?

- When developing the evaluation plan: the research/evaluation questions, dimensions, issues
- When discussing the preliminary report and writing the recommendations
- Diffusion of evaluation report and knowledge transfer

Results: Participation

Barriers	Facilitators or strategies
Difficult to recruit patient representatives who are interested, competent and available	<ul style="list-style-type: none">• Recognize the value of the patient perspective and provide feedback• Give public information on HTA activities• Select participants according to criteria
Patient sampling issues	Strive for a variety of perspectives rather than a representative sample
Major demands on participants	Define expectations and the role of participants carefully
Some participants may be militants	Select participants who are neutral
Lack of familiarity with the scientific approach or with HTA	<ul style="list-style-type: none">• Training and support• Select participants with an interest in and knowledge of the technology/service (a plus)• Avoid acronyms and use plain language

Results: Participation (cont.)

Barriers	Facilitators or strategies
Lack of effective participation by patient representatives	<ul style="list-style-type: none">• Minimum number of participants: 2• Selection:<ul style="list-style-type: none">• previous education and experience (for ex., work in a group or participation in meetings)• Ability to understand, good judgement, listening skills, respect, self-confidence• Explain their role so that they feel valued and competent• Preparation, training and support• Meeting facilitation: use of common language, presence of a facilitator, etc• Keep the same representatives so that they increase their skills
Lack of tools which provide support to the participant	Use models for citizen participation in other fields

Results

Criteria for successful participation:

- Criteria concerning impact:
 - The added value in the final product (report and recommendations)
 - Influence on decisions
 - Adoption of recommendations which were related to the patient perspective
 - Indicators related to reception
 - Improvement in the understanding of technology (in the short term) and evaluation (in the long term)
- Criteria related to the process such as participant satisfaction

Discussion

- Informants agreed on the relevance of the patient perspective in HTA, but there are very few projects in this area
- With the diversity of HTA projects, it is difficult to develop a typology of health technology issues linked to participation methods
- Type of involvement and who should be involved: linked to the specific phase of the HTA process:
 - For topic selection and prioritization: participation of the service users (« general patients ») who have a broader perspective
 - For data collection and contextualization: consultation of « specialist patients » who have a direct knowledge of the health issue

Discussion

- Patient consultation can be more complex than anticipated: for HTA, explore different approaches
- Direct participation in evaluation: no consensus on its utility or pertinence; a need to document its real impact
- Collaboration with patient “specialists”: still to be explored

Conclusion

- This study explored various experiences and perceptions of HTA in Québec: clarification of different types of possible implication, obstacles, and strategies to overcome problems
- Promote the use of common vocabulary and a provincial network for this area
- At the current time, patient participation is still an hypothesis rather than a practice; more trials and evaluation are needed
- There is a need to develop and adapt strategies which fit with HTA objectives and available resources in local level

Questions and comments?

Muito obrigada!

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