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Involving patients in early stages of the HTA process: a participatory research project

Marie-Pierre Gagnon,^{1,2*} Bernard Candas,³ Marie Desmartis,¹ Marc Rhainds,⁴ Martin Coulombe,⁴ Geneviève Asselin,^{4,5} Daniel La Roche,⁴ Johanne Gagnon,^{1,2} France Légaré^{1,5}

1 Quebec University Hospital Research Centre, Québec, Canada

2 Faculty of Nursing, Laval University, Québec, Canada

3 National Institute of Public Health, Quebec, Canada.

4 HTA Unit, CHU de Québec-Université Laval, Québec, Canada

5 Faculty of Medicine, Laval University, Québec, Canada

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Background

- The selection of HTA topics, which includes identifying and prioritizing HTA questions, is a constant challenge for decision-makers
- Patient and public involvement (PPI) in the selection of HTA topics makes it possible to counterbalance the value judgments and preferences brought by variety of stakeholders (e.g. scientists, health professionals)
- More likely to be relevant to them and adapted to their needs

Background

- The cancer field generates a vast array of questions and issues that encompass the full range of services and health policies, ranging from primary prevention, treatment, and expansive drug provision to palliative care.
- Thus PPI in HTA in the cancer field appears particularly relevant.

Objective

To describe and evaluate the process and the results of interventions aiming to involve patient representatives alongside health professionals and managers in the identification and prioritization of HTA topics in the cancer field

Methods

- A collaborative study with knowledge users from the HTA Unit of the CHU de Québec and the HTA Roundtable of the Integrated University Health Network of Université Laval

Methods

- Involvement strategies included
 - Consultation about potential HTA topics in the cancer field
 - Consensus meeting to reach agreement on top priorities
- Evaluation of the prioritization activity
 - Based on a qualitative approach
 - semi-structured interviews (11) and observation of the prioritization meeting
 - Analysis of prioritized topics
 - at the end of the meeting vs. before the meeting
 - according to the categories of stakeholders

Selection process and results

Suggestion of topics

- Email invitation to propose HTA topics sent to 75 clinicians and health managers + 25 community groups
- 30 proposals received from 20 different participants, some of them formulated after consulting other people

Filtering of topics and creation of vignettes

- 17 proposals that did not address the HTA program
- Honing of other proposals: 12 HTA questions
- Creation of vignettes for these 12 HTA topics

Prioritization exercise

- Pre-meeting survey (13 R)
- Consensus meeting (11 participants):
 - First prioritization exercise in 2 groups: 4 topics selected
 - Second exercise in 1 group: 6 topics selected
 - Final individual exercise: 3 topics emerged

Results – Suggestion of HTA topics

- 30 proposals received (including 7 from community groups)
- 12 HTA topics developed (vignettes)
- 40% of topics were usable (12/30)
- 29% of topics suggested by patient representatives (2/7) were usable

Results – Pre-meeting survey

- First priority topic:
"What is the best time to refer patients with advanced cancer to the palliative care team and to raise their awareness and the awareness of their family concerning this approach?"
- Two topics in second position:
"Is early nutritional intervention recommended for cancer patients who need to receive chemotherapy and/or radiation therapy?"

"What support interventions should be offered to caregivers of a cancer patient?"

Prioritization meeting: process

Welcoming address and presentation of the study



Briefing session about HTA



Prioritization exercise in two groups:
four topics selected in each group



Prioritization exercise in one group:
six topics selected



Final individual prioritization exercise: use of chips equivalent to the number of topics selected. Participants distributed the chips among the six topics in such a way as to reflect their relative priority for them.

Results – HTA priorities emerging from the consensus meeting

	Topics prioritized and individual votes	Community group Nb of votes (%)	Health care professional and manager Nb of votes (%)	Total Nb of votes (%)
1	What are the benefits of group meetings with an interdisciplinary team in oncology (including a community group representative) as regards providing support for new cancer patients?	16 (53%)	9 (25%)	25 (38%)
2	What are the most effective strategies used to invite people to participate in cancer screening programs?	11 (37%)	11 (31%)	22 (33%)
3	Should teleconsultation be recommended for the preliminary evaluation and follow-up of cancer patients in rural and remote areas?	2 (7%)	12 (33%)	14 (21%)
4	Would offering patients in cancer remission a program to adopt healthy lifestyle habits reduce the risk of recurrence and improve their health and quality of life? And what form should this program take?	1 (3%)	2 (6%)	3 (5%)
5	What are the most effective ways to provide information prior to breast cancer surgical treatment concerning the treatment itself and its effects?	2 (6%)	2 (3%)	0
6	Which distress screening tool should be used for patients with cancer?	0	0	0

Results of interviews

Perceptions of the prioritization process

The diversity of participants (from the healthcare network and the community sphere) and of regions

- provided complementary perspectives on patient trajectory and raised awareness of different regional realities
- enabled rich exchanges that allowed participants to gain an overview on the topics to prioritize

But...

Various types of regions made it difficult to select topics relevant to all settings (5/11)

Results of interviews

Perceptions of prioritization process

- Vignettes
 - Participants appreciated receiving them 10 days before the meeting to get ready for the meeting
- Briefing session about HTA
 - enabled participants, especially participants from community groups, to learn the basics of HTA
 - provided a better understanding of the whole process, and the place of this prioritization activity
- Consensus method for prioritization
 - allowed everyone to express his or her point of view, and hear the views of others while not preventing them from maintaining their positions

Results of interviews

Prioritization criteria

- Criteria varied according to the type of participant
 - Community group representatives tended to favour topics related to patient support (emotional, practical, etc.)
 - Clinicians and managers tended to favour topics linked to their clinical area or their management issues

Criteria were different because, as a manager, I had a certain vision concerning deficiencies, performance, and access, while they [representatives of community groups] were more involved in patient support ... Interview # 2

Results of interviews

- Criteria varied according to different regional realities:
 - Participants tended to favour an assessment that would lead to subsequent actions in a given context and thus have a real impact on patients in their regions (e.g. teleconsultation for remote regions)

Results of interviews

Input of patient organizations

- Perspectives on the life of patients outside the hospital and on the support provided by the community and their families
- Often represented the voice of vulnerable and isolated patients
- Problem of “representativeness” of patients on such a committee = not easy to solve, as noted by one participant

Discussion

This study provides knowledge about the effects of involving various stakeholders in the selection of HTA topics and the impact of these strategies on the selection of HTA topics.

Discussion

- Difficulties in recruiting enough participants for the prioritization committees as originally planned
- Preparatory activities appreciated and perceived as useful
 - Distribution of vignettes 10 days before the meeting allowed participants to be well prepared
 - HTA briefing session: a prerequisite for participating in such an activity

Discussion

Impact of the consensus meeting

- Allowed participants from diverse sectors and regions to share their knowledge and experience
- Provided a better understanding of the topics to prioritize
- Feasibility of the follow-up of recommendations = important criterion influencing priority of HTA topics
- Input of representatives of community groups
 - provided perspectives on the life of patients outside the hospital and on the support provided by community and family
 - could give voice to the most vulnerable patients

Conclusion

- Involving patient representatives in early steps of HTA is feasible
- Patient representatives and caregivers have different perspectives from managers on topics to prioritize but could reach a consensus
- Involving patient representatives in the selection process of HTA topics could modify the topics prioritized



Thank you!

Contact: marie-pierre.gagnon@fsi.ulaval.ca

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