



Engaging patient representatives in the identification and prioritization of Health Technology Assessment topics

[Impliquer les représentants de patients dans l'identification et la priorisation des sujets en évaluation des technologies de la santé]

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Article received:
18 July 2016

First response:
9 August 2016

Article accepted:
26 September 2016

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Abstract: Effective ways to incorporate the patient perspective in Health Technology Assessment (HTA) are needed. Embedded within a wider project that aimed to develop and evaluate interventions to engage patient representatives alongside with clinicians and managers in the conduct of a HTA, we sought to describe this process and its results on the identification and prioritization of HTA topics. Three steps of the HTA process were involved: 1) suggestion of HTA topics, 2) filtration and refinement of topics, and 3) prioritization of topics. Patient representatives, clinicians and managers from eastern and central regions of Quebec (Canada) were asked to suggest potential HTA topics in the field of cancer. In total, representatives of all stakeholder groups suggested 30 topics. A filtration and refinement process allowed formulating 12 HTA questions from these topics. Participants were then asked to attend a consensus meeting for prioritizing HTA topics. The top three priorities emerging from the prioritization meeting were: "group meetings with an interdisciplinary team in oncology (including community group representatives) in support for new cancer patients", "strategies to invite people to participate in cancer screening programs" and "teleconsultation for preliminary evaluation and follow-up of cancer patients in rural and remote areas". These priorities differed from those identified in the pre-meeting survey. Patient representatives, clinicians and managers had different perspectives on topics to prioritize but could find a consensus. Engaging patient representatives in different activities related to the identification and prioritization of topics appear to influence the final selection of HTA topics.

Keywords: patient involvement, hospital-based health technology assessment, identification and prioritization of HTA topics.

Résumé : Des moyens d'intégrer la perspective des patients dans l'évaluation des technologies en santé (ÉTS) sont nécessaires. S'inscrivant dans un projet de recherche plus large visant l'engagement des représentants de patients, cliniciens et gestionnaires dans la conduite d'une ÉTS, cette étude présente le processus d'engagement de représentants de patients dans l'identification et la priorisation des sujets en ÉTS et ses résultats. Trois étapes du processus d'ÉTS ont été abordées : 1) suggestion de sujets, 2) filtrage et raffinement, et 3) priorisation. Des représentants de patients, cliniciens et gestionnaires des régions de l'Est et du Centre du Québec (Canada) ont été interrogés pour proposer des sujets d'ÉTS dans le domaine du cancer. Trente (30) sujets ont été suggérés et 12 ont été retenus. Une rencontre a été organisée pour prioriser ces sujets et trois sujets ont été retenus : « rencontres de groupe avec une équipe interdisciplinaire pour soutenir les patients nouvellement atteints de cancer », « stratégies pour inviter les personnes à participer aux programmes de dépistage du cancer » et « téléconsultation pour l'évaluation préliminaire et le suivi des patients atteints de cancer en régions rurales et éloignées ». Ces priorités différaient de celles du sondage pré-rencontre. Les représentants de patients, les cliniciens et les gestionnaires avaient des perspectives différentes sur les sujets à prioriser, mais ont pu trouver un consensus. Impliquer les représentants de patients dans différentes activités d'identification et de priorisation des sujets d'ÉTS semble influencer la sélection finale des sujets qui feront l'objet d'une ÉTS.

Mots clés : implication des patients, évaluation des technologies de la santé en milieu hospitalier, identification et priorisation des sujets en ÉTS.

Introduction

Engaging patients in the selection of Health Technology Assessment (HTA) topics is perceived as particularly important to ensure a more patient-centered HTA [1, 2]. Patient engagement in HTA allows considering their needs and values in decision regarding health technologies, which could increase their relevance [3]. However, there are still numerous gaps in knowledge regarding effective ways to engage patients in HTA structures, activities and process [4-6].

Many HTA agencies worldwide have implemented processes to consult patients and/or the general public about potential HTA topics, usually by completing an application form on the HTA organization's website [2]. However, patients are mostly excluded from the prioritisation of HTA topics [2, 3]. One notable exception is the HTA program of the National Institute for Health Research in the United Kingdom that has developed an infrastructure to get patient input in the identification and prioritization of HTA topics [5, 6].

In Australia, Lopes et al. [7] have studied the involvement of various stakeholders, including patient organizations, in decisions related to public funding for new health technologies. They found that the engagement process was not optimal both from the perspective of patient organisation representatives and advisory committee members. While not specifically in HTA, the study conducted in Canada by Boivin et al. [8] reports how engaging patients in priority setting for healthcare improvement has improved consensus between patients and professionals regarding priorities at the community level.

Danner et al. [9] report another example of patient engagement in the HTA process in Germany. They applied the analytic hierarchy process for the elicitation of patient priorities regarding treatment endpoints in the case of antidepressant treatment, and found that this method was well suited to provide a quantitative dimension of patient preferences in HTA.

However, little information is available on effective methods that could be applied specifically to account for the patient perspective in the early phases of HTA, which comprise the identification of HTA topics to be evaluated by a HTA organizations and their prioritization.

Objective

This study is part of a larger project [10] that aimed to develop and evaluate interventions for engaging patient representatives, alongside with clinicians and managers, in the early phases of the HTA process. The present paper describes the process and results of patient engagement activities in the identification and prioritization of HTA topics in the field of cancer.

Methods

Context

This study was developed and carried out through a collaborative project with knowledge users from the hospital-based HTA unit of the CHU de Québec (a large university hospital in Quebec, Canada) and the HTA roundtable of the Integrated University Health Network of Université Laval (IUHN-UL) that involves six health regions of Eastern and Central Quebec.

This study comprised three steps of the HTA process that are described in details below: 1) suggestion of HTA topics, 2) filtration and refinement of the suggested topics, and 3) prioritization of topics. For each step, we provide a description of the participants as well as the methods used.

Suggesting HTA topics

We sent an invitation to suggest HTA topics related to cancer to clinicians working in the field of cancer, healthcare managers, and community groups supporting people with cancer from the IUHN-UL area. The chief executive officers of health and social services agencies and the regional coordinators of oncology services provided a list of 75 names of clinicians and health managers. We identified 25 community organisations located in the IUHN-UL area through a website of community resources

in oncology. We sent an e-mail invitation to potential participants with an attached document that presented the background of the project, its aims, its steps and a brief description of HTA. Participants could suggest topics through a web form or in a form attached to the email that they could send back to us. We provided instructions and specific examples on the form. We also invited participants to spread this message in their network so that all interested persons (including patients or informal caregivers) could participate in this consultation. We asked participants to indicate whether they were patient, informal caregiver, representative of community group, clinician or manager. We sent two email reminders to all, except for the community groups for which one of these reminders was made by telephone.

Filtration and refinement processes

Following the example of the NIHR HTA program in the United Kingdom [5] we filtered the suggested topics. The filtration and refinement processes were undertaken independently by the two managers of the HTA unit (MC and MR) to select topics that could be relevant to the HTA program. They pooled their recommendations, which were then validated by a research team member (BC) who works in the field of cancer.

Prioritizing topics

Preparation of vignettes

We prepared vignettes of about 1.5 pages of text for each topic retained in order to give preliminary information on the evaluation question (background, technology, population affected and context, overview of the research on the topic) to those who would participate in the consensus meeting for prioritization. At the end of each vignette, the HTA question was summarized using the PICO question-formulation tool (Population, Intervention, Comparator, and Outcome). We sent these vignettes to two experts – a clinician and a representative of a community group – for comments.

Recruitment of participants for the consensus meeting

We held a consensus meeting to prioritize topics retained after the filtration step. In the research protocol, we had projected to organize three groups to cover the different categories of regions, and a final meeting with representatives of participants of each previous meeting. Given the limited number of participants and their dispersion on a vast territory, we decided to bring everyone together in a single and more convenient group.

We recruited participants for the consensus meeting from the same lists used in the previous step. They were clinicians, health managers and representatives of community groups in cancer. An email and a reminder were sent to inform them about this consensus meeting and to invite them to participate.

Preparatory documents

We sent four preparatory documents to participants 14 days prior to the meeting. These documents included the agenda of the meeting, the list of the 12 retained HTA topics, a vignette for each of them, and a consent form. Before attending the meeting, we asked participants to answer a questionnaire on their perceptions about the priority of each topic on a 4-points Likert scale (1: high priority; 2: moderate priority; 3: low priority; 4: no priority). To help participants in their judgement, we proposed six prioritization criteria, based on those used by the HTA unit of CHU de Quebec-University Laval, that we popularized and presented on the top of the questionnaire. These six criteria assessed the potential of the topic to: 1) improve health outcomes and patient satisfaction; 2) support best clinical practice; 3) increase accessibility to care; 4) prevent the occurrence of health problems; 5) optimize resource allocation or healthcare organization; and 6) increase knowledge on interventions for which there is uncertainty or conflicting evidence regarding security, efficacy or applicability.

We also asked participants to identify the four topics they considered to be their top priorities.

Consensus meeting

The consensus meeting began with a welcome address and a presentation of the study, followed by a briefing session about HTA. We applied a method inspired by the nominal group process to reach consensus about topics to prioritize [11-13]. This process involves multiple iterative rankings, by groups of increasing size, and allows participants to influence the process without the pressure to conform to individual viewpoints. Participants in a nominal group are asked to first record their ideas individually, and then to share, discuss, and listen about ideas in group, and finally to judge or vote on the ideas independently [12]. The nominal group process is a recognized qualitative consensus method when little is known about a topic and participants may have diverse opinions [13].

The first prioritization exercise allowed the two groups to select four topics. The second exercise, done with all participants, allowed retaining of six topics. The last prioritisation exercise was individual: each participant was given a number of tokens equivalent to the number of topics that emerged from the previous rounds of prioritization. Participants had to distribute these tokens among the different topics in a way that reflected their relative priority for them.

Results

Suggesting topics

Figure 1 illustrates the identification and priority setting process. In total, 20 different participants proposed 30 topics. Two participants proposed 3 topics together, and one participant proposed one topic after consulting other people involved in cancer in the region. Topics came from participants from five out of the six regions targeted. Representatives of community organizations proposed 7 topics, clinicians 10 topics, and managers or planning officers

of the regional agencies 13 topics.

Suggested topics concerned home support and post-treatment support (4 topics); oral chemotherapy (3); breast cancer screening (3); screening for distress and psychosocial support (3); specialized palliative care (3); information or decision support tools for patients (2); interventions on patient lifestyles (2); use of information and communication technology (2); organization of services in oncology (2); community organizations (2); and other topics (4), such as means to invite the population for screening, and support group for newly diagnosed patients with an interdisciplinary team.

Filtration and refinement of topics

The filtration step and the refinement of HTA topics allowed us to formulate 12 questions from proposed topics (see Table 1 and Figure 1). Many topics that were proposed did not match the mandate of the HTA unit, as they were more related to program or large-scale services evaluation, or concerned research questions.

Prioritizing topics

Preparation of vignettes

We created vignettes for the 12 topics retained, which were revised by two experts, including a content expert and a representative from a community group. The latter provided commentaries mostly on the importance of the patient's perspective on the topics. Some minor changes were made on a few vignettes from this review.

Participants

Thirteen people agreed to participate in the consensus meeting and completed the pre-meeting questionnaire (see Figure 1). However, two of them were prevented from taking part in the meeting because of an unexpected event. Thus, 11 people attended the meeting, including two people living in remote areas who participated through videoconferencing. Five participants were representatives of community groups, three were clinicians and three were health managers.

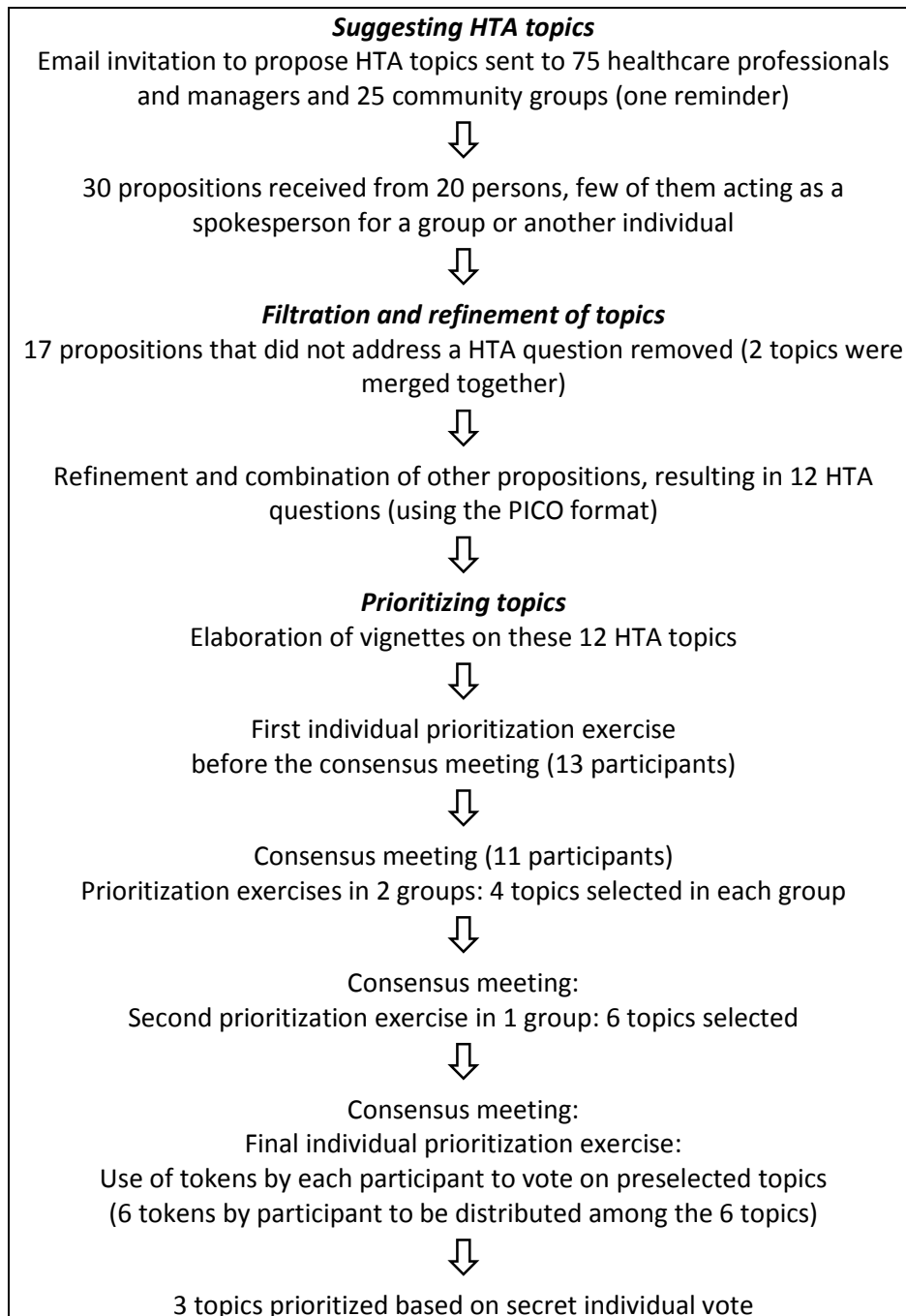


Figure 1: The identification and priority setting process

Pre-meeting survey results

The findings reported here concern the 11 respondents who participated in the meeting. The first priority topic that emerged from this survey was: “What is the best time to refer patients with advanced cancer to the palliative care team, and to raise patients’ and their family’s awareness to this approach?”. This topic received the

highest overall score on the first part of the survey (Likert scale) and was the topic found in the top four priorities of the greatest number of participants (5/11). Two topics came in second position: “Is early nutritional intervention recommended for cancer patients who have to receive chemotherapy and/or radiation therapy?”

Table 1: List of eligible HTA topics (not in a specific order)

1	Is offering a program that promotes healthy living to patients in remission of their cancer reduces the risk of recurrence and improves their health and quality of life, and which form should it take?
2	What are the best strategies to invite people to participate in cancer screening programs for which there is an effective treatment?
3	Should we include magnetic resonance imaging (MRI) as breast cancer screening test for women at high risk or who have high breast density?
4	Should teleconsultation be recommended for the preliminary evaluation and monitoring of patients in rural and remote areas in clinical oncology?
5	What are the benefits of group meetings facilitated by an interdisciplinary oncology team in support for new cancer patients?
6	Which distress screening tool should be used for patients with cancer?
7	What are the most effective ways to provide information before surgical treatment of breast cancer about the intervention and its effects?
8	Should early nutritional intervention be recommended for cancer patients who have to receive chemotherapy and/or radiation therapy?
9	Which means of communication should be used to support patients in the management of side effects of chemotherapy at home?
10	Should systematic psychosocial follow-up be offered after treatments against cancer?
11	Which support interventions should be offered to caregivers of a cancer patient?
12	What is the best time to refer a patient with advanced cancer to the palliative care team and to raise patient and family awareness of this approach?

and “What support interventions should be offered to caregivers of a cancer patient?”. These topics were prioritized by the largest number of patient representatives. The first of them also received the highest score on the first part of the survey from this group.

Consensus meeting

Figure 1 shows the flow of the HTA topics identification/prioritization process and the number of topics at each step. Participants were asked to reach a consensus on the topics to prioritize, first in two small groups and then in the large group. Figure 2 shows the topics prioritized in each of the two small groups, and the results of the last prioritisation exercise done through individual secret vote.

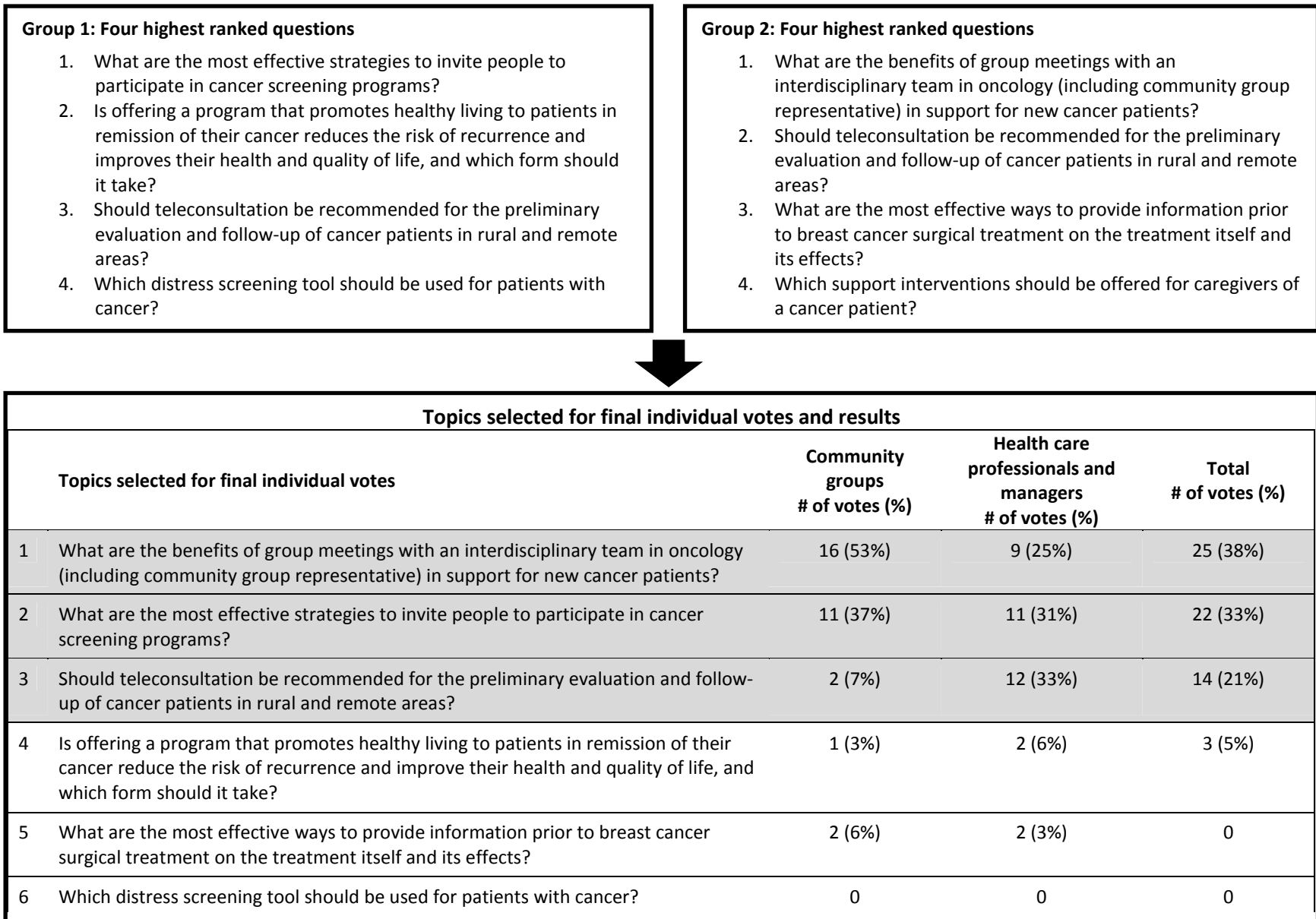
As shown in Figure 2, the first prioritized topic – What are the benefits of group meetings with an interdisciplinary team in oncology (including community group representatives) in support for new cancer patients? – received strong support from patient representatives. The second topic –

What are the most effective strategies to invite people to participate in cancer screening programs? – received equal support from patient representatives, clinicians and managers, and the third topic – Should teleconsultation be recommended for preliminary evaluation and follow-up of cancer patients in rural and remote areas? – was mostly preferred by managers and clinicians. However, the three topics prioritized in the pre-meeting survey – best time to refer patients with advanced cancer to the palliative care team; early nutritional intervention for cancer patients receiving chemotherapy and/or radiation therapy; and support interventions for caregivers of a cancer patient – were not reflected in the priorities emerging as a result of the consensus meeting.

Discussion

The present paper described the process and results of activities for engaging patient representatives alongside with clinicians and managers in the identification and

Figure 2: HTA priorities emerging from the consensus meeting



prioritization of HTA topics. Overall, we observed that it was possible to engage patient representatives in the HTA process and it was well received. We also observed that patient representatives, clinicians and managers had different perspectives on HTA topics to prioritize. Nevertheless, their input could be considered equally during the consensus meeting. The results bring us to make two main observations.

First, our findings indicate that prioritized topics following the consensus meeting were different from those prioritized individually through the pre-meeting survey. The short introductory training that provided a better understanding of the different aspects to consider in HTA and the deliberation process that allowed rich exchanges between participants are possible explanations for the differences between individual and group prioritization.

Second, although it is not possible to clearly isolate the impact of engaging patient representatives on the identification and prioritization of HTA topics in this study, their influence was noticeable in the selection of priority HTA topics, especially through the modification of some of the topics. The variation between HTA topics prioritized individually through the survey and those resulting from the consensus meeting is a particularly interesting finding from this study. A potential hypothesis could be that combining the diverse perspectives of patient representatives, clinicians and managers brings a more complete understanding of the various dimensions that should be considered in HTA, thus probably leading to prioritizing a topic with greater potential impact. However, qualitative studies are needed to understand what influences decision making regarding HTA topics from different stakeholder groups. It would also be important to evaluate different interventions in order to identify the best ways to integrate patient input in the early steps of HTA.

In the present study, we chose to identify potential patient representatives

through organized support groups. We did not target individual patients because it could be difficult for these people to have sufficient distance from their lived experience and individual concerns. Thus, patient representatives came mainly from community organizations supporting people with cancer. They were linked to peer networks and were able to talk about diverse groups of cancer patients by having a good knowledge of the issues and experiences of the members of their organization. Individual patients could be engaged at other stage of the HTA process (the evaluation phase, for instance), contributing with their experience on living with a disease and on the effects of procedures or treatments on their life. For instance, a study in Germany used the analytic hierarchy process approach for quantifying patient preferences in the prioritization of patient-relevant endpoints for the assessment of antidepressant treatments [9].

We also chose to target support groups in the field of cancer and not general patient or consumer organizations because the HTA topics were specific to cancer. As shown in the study by Lopes et al. [7], umbrella patient organizations can have a different perspective than patient organization representatives. Community support groups are considered as legitimate representatives of patients because they have a good knowledge of the issues and experiences of the members of their organization and are able to easily get information from them [14].

As this study was a first attempt to engage patient representatives in the early steps of HTA, we used a collaborative approach based mostly on descriptive qualitative methods. Due to the small number of participants and the exploratory nature of this study, we did not apply formal quantitative methods in the prioritization process such as multi criteria decision analysis (MCDA) or discrete choice experiment (DCE). Thus, it is likely that the results of the individual prioritization of HTA topics have been influenced by participant's

first impression based on personal experience or values rather than an informed reflection process. In order to minimize this bias, participants were proposed a set of criteria used in HTA to consider in their evaluation. Moreover, all suggested topics were assessed during the consensus meeting without considering their initial priority score from the individual questionnaire. The modified nominal group process brought participants to reflect on their preferences and discuss in groups of increasing size, which allows reducing social influence and control of particular individuals over the discussion. The final vote regarding priority topics was secret and allowed participants to choose one up to six priority topics. These methods can be considered rigorous and valid for the prioritization process undertaken given the exploratory stage of the project [13]. For instance, in the field of HTA, Wortley et al. [16] applied a modified nominal process to identify the most important factors in determining whether public engagement in HTA should be undertaken.

Other methods to engage consumers in prioritization of HTA topics include the use of a citizens' jury, such as the example described by Menon and Stafinsky [15]. They used a random sampling method to select 16 representatives of the general population. This method can precede patient representative engagement when considering technologies targeting various health conditions simultaneously. A systematic review identified eight different methods used to elicit public preference in healthcare priority setting, the most common being DCE [17]. Another example of prioritization method is the analytic hierarchy process approach applied in the Danner et al. study for quantifying patient preferences in the prioritization of patient-relevant endpoints for the assessment of antidepressant treatments [9]. However, there is less information available on methods for involving patient representatives in priority setting.

Menon and Stafinsky [2] highlighted the importance of training patient and public

representatives on HTA committees to enable them to contribute significantly to the discussion. In the present study, we provided participants with vignettes on pre-selected HTA topics written in a popularized language and validated by patient representatives prior to the consensus meeting. We also provided a short introduction on HTA before the meeting, which helped patients get more familiar with HTA and thus contribute more significantly to the discussions.

Conclusion

This study aimed to describe the process and results of activities engaging patient representatives, alongside with clinicians and managers, in the identification and prioritization of HTA topics, a subject understudied in the current literature. As our findings suggest, engaging patient representatives in different activities related to the identification and prioritization of topics appear to influence the final selection of HTA topics. This influence ensures that the needs and values of patients are considered in the HTA process and ultimately, could direct HTA towards a more patient-centered approach.

Acknowledgements

We would like to thank Geneviève Asselin for her participation in the preparation of vignettes, the Consortium de recherche en oncologie clinique du Québec and the Fondation québécoise du cancer for their revision of vignettes. Special thanks also to the participants to the various stages of this project. MPG is Tier 2 Canada Research Chair on Technologies and Practices in Health. FL is Tier 1 Canada Research Chair in Shared Decision Making and Knowledge Translation.

Funding

This study was funded by a Knowledge to Action grant from the Canadian Institutes of Health Research (CIHR; grant #201210KAL-289993-KAL-CFBA-111141).

Conflicts of interest

The authors declare that they have no conflicts of interest.

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