

BACKGROUND

- Despite increases in involving patients/public/citizens in many areas within the health care system, there is limited evidence on the effect of such involvement in health care prioritization.
- Methods of public involvement in health care are inconsistently defined, particularly within the drug recommendation committees.
- Our research, and that of others, have identified the need for evaluating patient and public involvement in health care decision processes and outcomes in relation to committee objectives.

AIMS

- To test the sensibility of the Patient and Public Involvement Questionnaire (PPIQ), an instrument to measure public and patient involvement in the area of resource allocation decisions in drug reimbursement.

DEVELOPMENT OF THE PPIQ

Using a mixed methods design we developed questionnaire items as follows:

Phase 1: Item Generation

1. Interviews & Literature Review

- Key informant interviews were conducted with patient groups, past or present government employees, representatives from Ministries of Health, advisory committee members and industry representatives.
- We used a qualitative thematic approach to analyze the transcripts. The process was inductive and involved line-by-line coding.
- The items developed above were augmented by a literature review.¹

2. Development of Criteria

- Using information from steps 1 above we developed nine criteria against which patient and public involvement could be judged.¹
- Using these criteria we pooled together all items.

Phase 2: Item Refinement

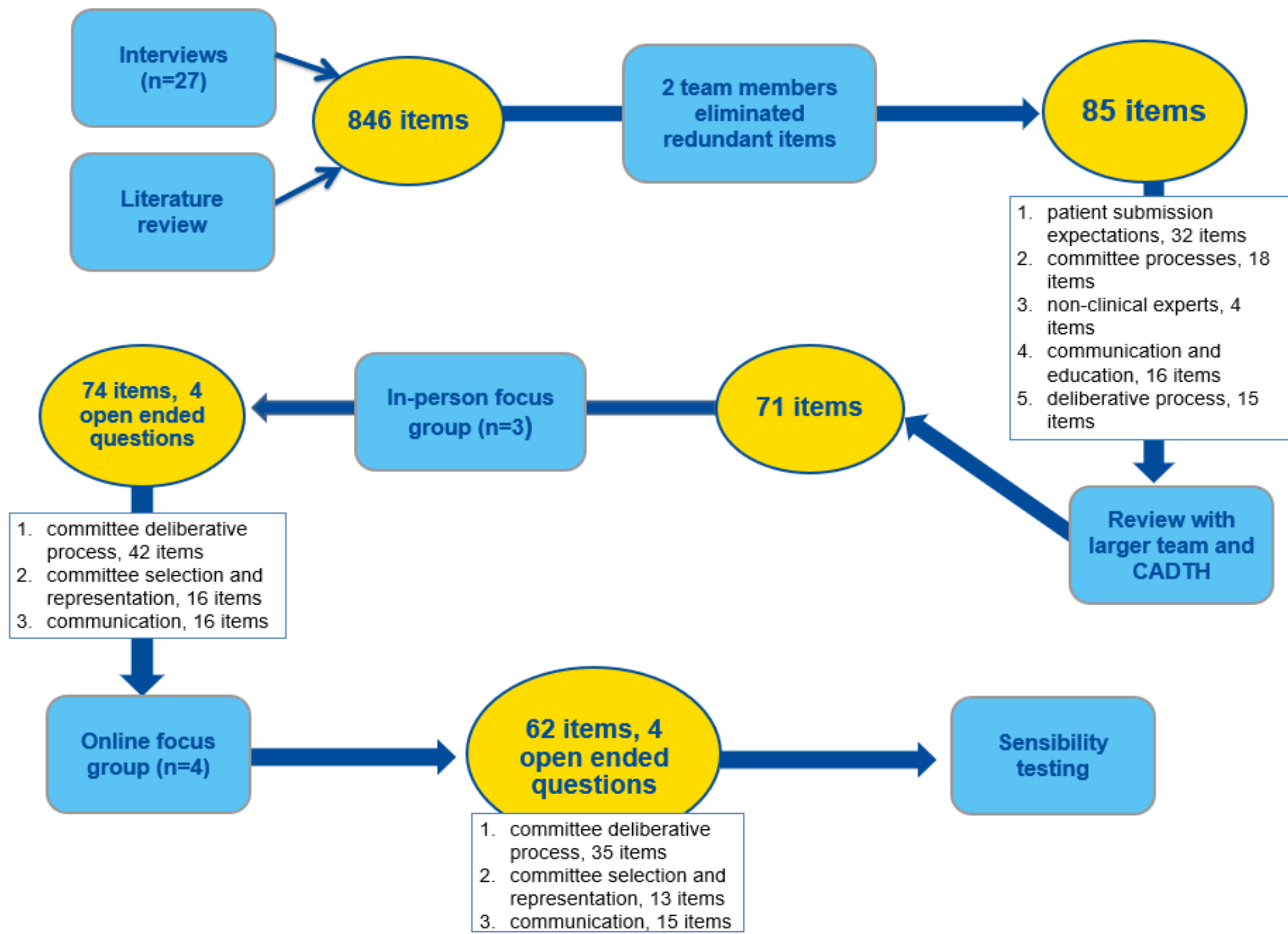
1. Team Feedback

- We reviewed the potential items with our team including our knowledge user partner, the Canadian Agency for Drugs and Technologies in Health (CADTH), ensuring that no items were missing.

2. Focus Groups

- We conducted two focus group sessions – one in-person and another online - to further refine the instrument.
- Elimination of redundant items, addition of missing items, and ensuring each criterion for judging effectiveness was adequately captured by the listed items.

Process of PPIQ: Item Generation and Refinement



METHODS

Sensibility Testing

- We surveyed and interviewed a purposeful sample of committee members, patient group representatives, and public drug plans employees across Canada and academic experts in decision making and public involvement techniques.
- We aimed to evaluate sensibility of the PPIQ. Sensibility testing for questionnaires is typically qualitative and based on the judgment of the end users.²
- We used Feinstein's components of sensibility: purpose and framework, overt format, face and content validity, and ease of use.²
- The sensibility questionnaire included eight questions, with a Likert scale measuring sensibility from 1 (poor) to 7 (excellent).

Analysis

- For the survey data, we summarized Feinstein's sensibility items using Measures of Central Tendency (Mean, Median, and Standard Deviation).
- We analyzed the interviews using a qualitative thematic approach consisting of line-by-line coding to develop categories that pertain to the Feinstein's criteria of sensibility.

RESULTS

Sensibility survey (n=21)

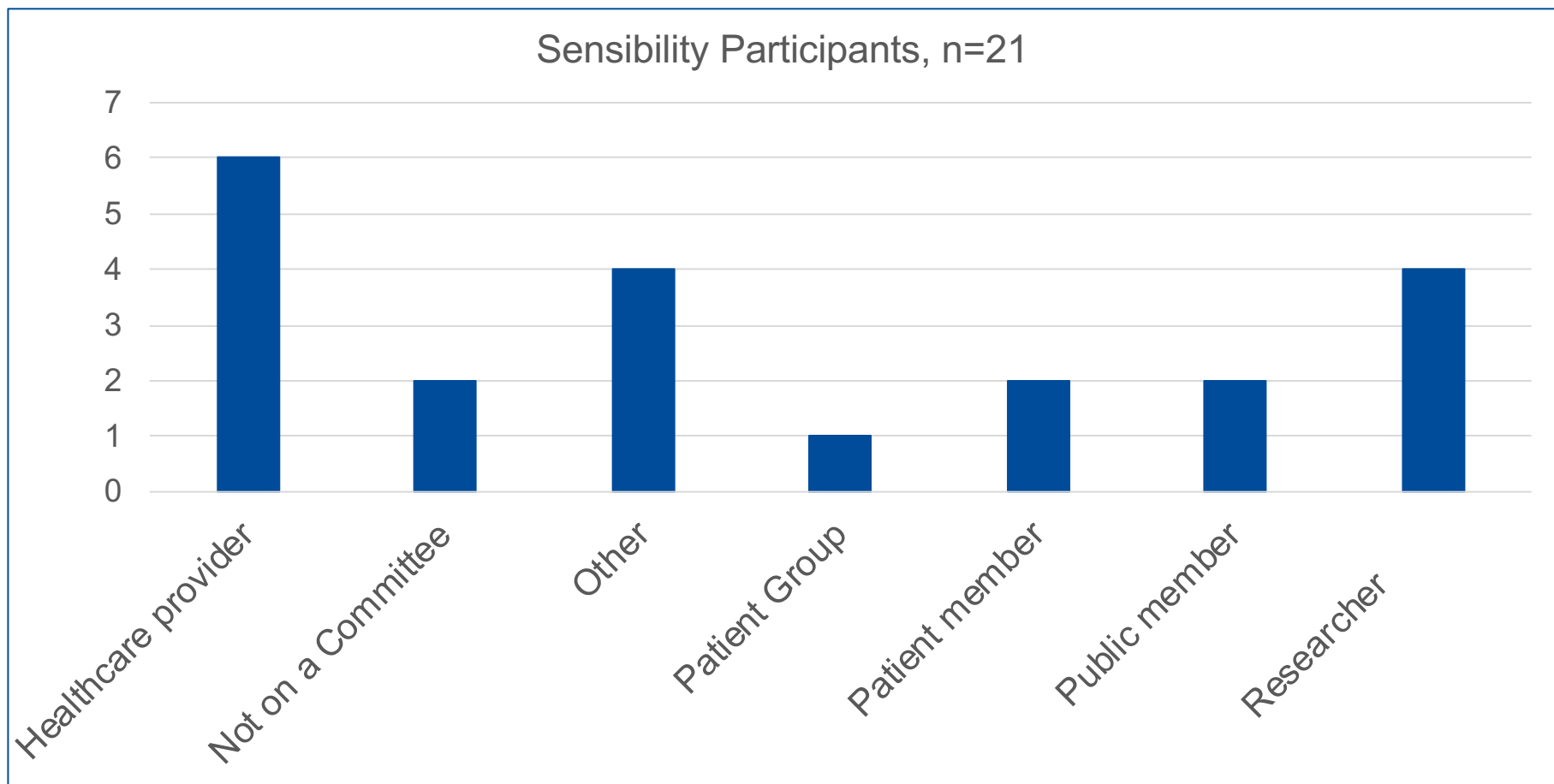


Figure 1: Majority of respondents were employed in paid work, while two respondents were retired. Two respondents were not part of a committee but had academic experience evaluating public and patient involvement.

Description	Average Response
Please rate the questionnaire (PPIQ) in terms of clarity and simplicity.	5.60 ± 0.86
Were the questionnaire (PPIQ) instructions adequate?	6.05 ± 0.65
Is the way in which the questions (in the PPIQ) were presented confusing to you?	5.40 ± 0.92
Please rate the amount of time taken to complete this questionnaire.	5.47 ± 1.31
To what extent do you think this questionnaire examines public involvement in decision making?	5.38 ± 1.73
How many of the items are crucial or necessary, and how many are redundant or unnecessary?	5.32 ± 1.83
Do you think that there are important areas (gaps) that should be included in a measure of successful public involvement that have not been included?	5.16 ± 1.38
Do you think the response scale provided in the questionnaire allows you enough choice for your responses?	6.0 ± 1.33

Table 1: Participant responses to sensibility questionnaire. Each question included a Likert scale (1-7) with higher scores relating to higher sensibility. Mean and standard deviation were calculated for each question.

Sensibility Interviews (n=14)

1. Overall strengths of the PPIQ, include:

- Face Validity: "I think the questions are ... [written] in a very easy to understand language. And ... they would resonate with people" (INT 10).
- Comprehensive: "I thought that it was really thorough. And I thought that it did a really good job asking about people's thoughts on the public and patient involvement process from many different perspectives" (INT 3).
- Ease of Use: "I think it flowed well... it didn't feel like it was leading me anywhere. Which is important, right? It was clear and logical" (INT 8).

2. Areas of improvement for the PPIQ, include:

- Improve distinction between public and patient because they represent different perspectives: "The patient ... They're the user. And of course maybe the cost is not so important ... But from a societal perspective ... the cost is important. Especially [for] those who manage ... the resources, they have to make ... tough decisions" (INT 1).
- Ease of Use (length of survey): "If it was relevant to me, yeah, then I would do it. But otherwise I might give up... I might just go tick, tick, tick... It would have to resonate, and the person would have to be engaged" (INT 10).
- Formatting: Many respondents also requested less response options and a status bar to highlight progress within the survey.

DISCUSSION

- Findings from the sensibility survey and interviews illustrate good sensibility for the PPIQ based on Feinstein's criteria in terms of clarity, lack of redundancy, and comprehensiveness.
- Next steps will include performing validity and reliability testing with 50 committee members of drug reimbursement committees across Canada.
- The PPIQ will help to evaluate current levels of patient and public involvement, indicate areas where such involvement can be strengthened, and help decision makers to address concerns about equity, ethics, and justice in the context of drug reimbursement committees in Canada.

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ACKNOWLEDGEMENTS:

Thank you to all study participants.

This research is funded by:

