

CONTEXT

- 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.

OBJECTIVES

- To develop an instrument to measure public and patient involvement in the area of resource allocation decisions in drug reimbursement.

METHODS

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

Phase 1: Item Generation

1. Interviews

- 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.

2. Literature Review

- The items developed above were augmented by a literature review.<sup>1</sup>

3. Development of Criteria

- Using information from steps 1 and 2 above we developed nine criteria against which patient and public involvement could be judged.<sup>1</sup>
- 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.

3. Team Feedback

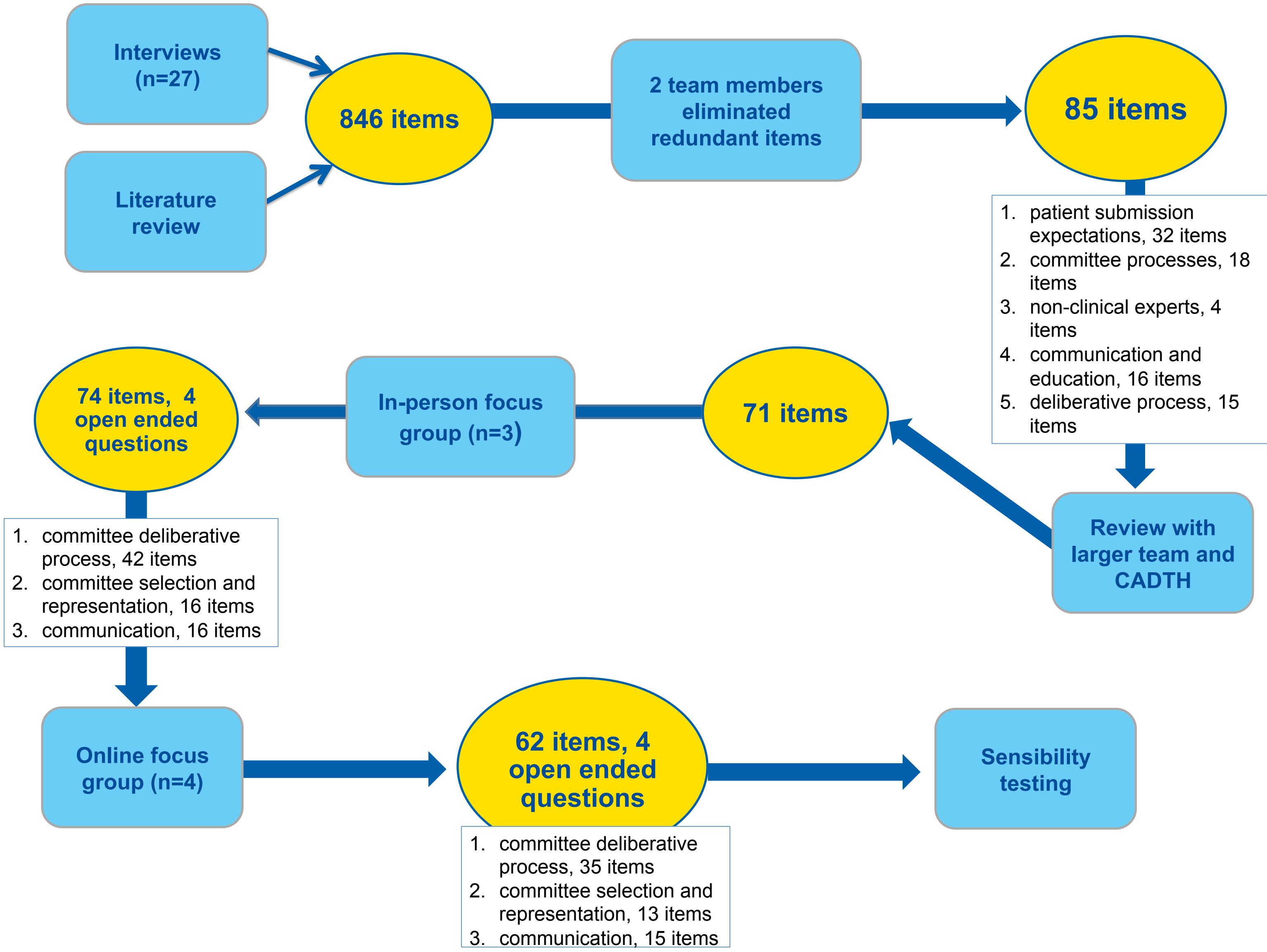
- The revised questionnaire was shared with the research team and CADTH for additional feedback.

4. 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 used Feinstein’s components of sensibility: purpose and framework, overt format, face and content validity, and ease of use.

RESULTS

Process of Item Generation and Refinement



Sensibility Testing

1. Sensibility survey (n=21)

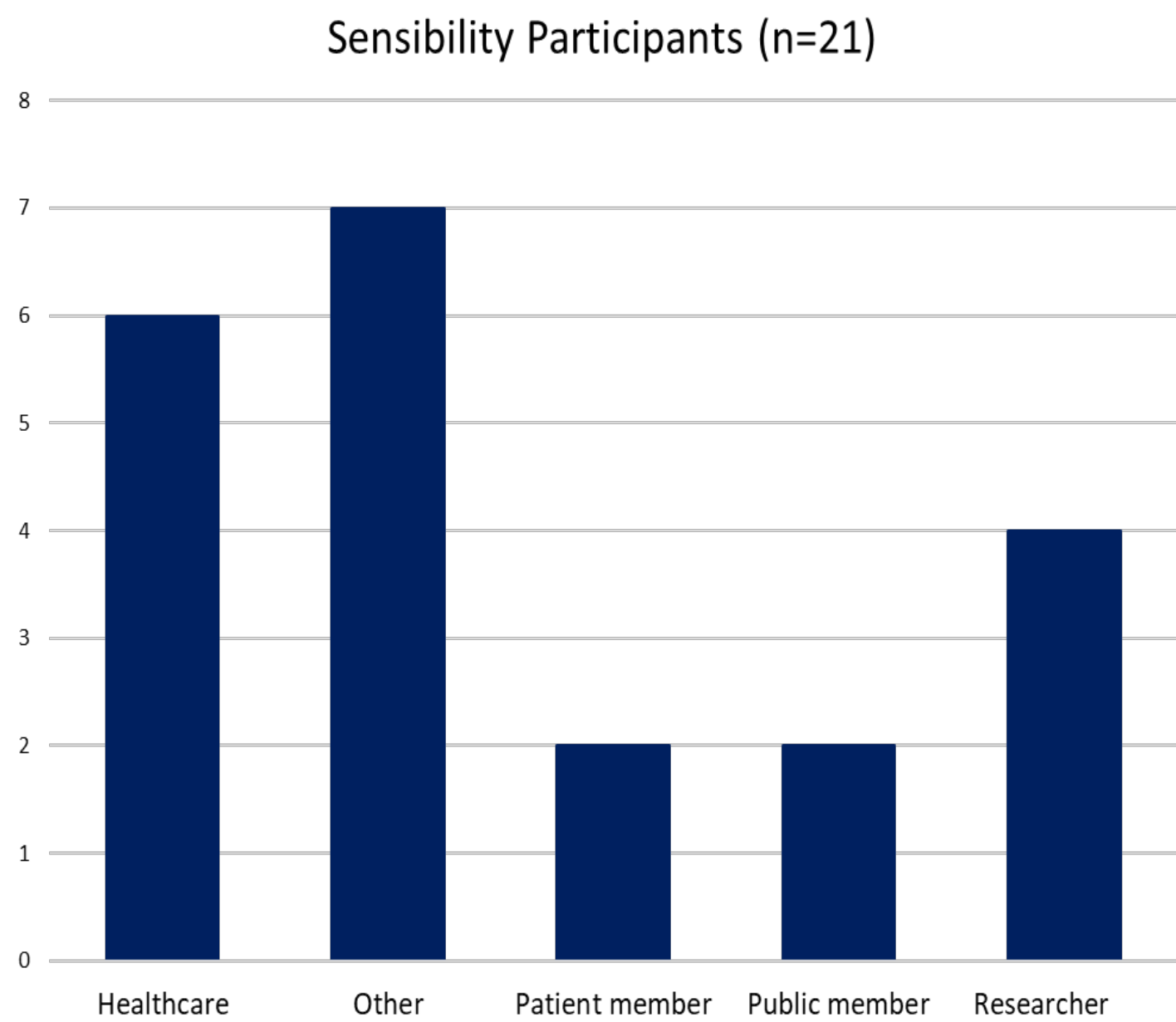


Figure 1: Majority of respondents were employed in paid work, while two respondents were retired. Two respondents were not part of a committee but had academic experience evaluating public and patient involvement.

Description	Average Response
Please rate the questionnaire in terms of clarity and simplicity	Good (5.63)
Were the questionnaire instructions adequate?	Excellent (6.10)
Is the way in which the questions were presented confusing to you?	Moderately (5.42)
Please rate the amount of time taken to complete this questionnaire	Acceptable (4.63)
To what extent do you think this questionnaire examines public involvement in decision making?	Acceptable (5.55)
How many of the items are crucial or necessary, and how many are redundant or unnecessary?	Few Unnecessary (5.32)
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?	Minor Gaps (5.22)
Do you think the response scale provided in the questionnaire allows you enough choice for your responses?	Excellent (6.0)

2. Interviews (n=14)

- Overall most participants thought that the questionnaire were:
  - Clear
  - Comprehensive
  - Addressed the overall purpose and
  - Appropriate
- Areas of improvement identified were as follows:
  - Improve definition surrounding public and patient
  - Redundant items
  - Better identify the purpose up front
  - Shorten, if possible
  - Less response option, if possible
  - Formatting, include a bar which identifies how far along one is in 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 users.
- We anticipate the PPIQ, will be used to identify the extent to which committees are meeting the criteria of patient and public involvement.
- 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.

REFERENCES:

Rosenberg-Yunger, Zahava R.S., and Ahmed M. Bayoumi. "Evaluation Criteria Of Patient And Public Involvement In Resource Allocation Decisions: A Literature Review And Qualitative Study." International Journal of Technology Assessment in Health Care, vol. 33, no. 02, 2017, pp. 270–278., doi:10.1017/s0266462317000307.

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