Supplemental Materials for

Engaging cancer patients in clinical practice guideline development: a pilot study

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Listing of Supplemental Material(s):

Supplemental Appendix 1: Model 1 talking points for the HRM orientation teleconference with patient representatives

Supplemental Appendix 2: Model 2 working group survey
Supplemental Appendix 1: Model 1 talking points for the HRM orientation teleconference with patient representatives

1. Introduction
   • Introduce everyone on the call
   • Thank patients for their participation

2. Review of the Terms of Reference Document
   a) Purpose of the Project
      • Research study
      • Testing different models of patient engagement in practice guideline development
      • One of the models being tested is having patients as active members of a Working Group
   b) Why patient representative input is valuable
      • Ensures patient preferences and opinions are considered in the development of recommendations
      • Recommendations help health care professionals, researchers and policy makers make decisions that influence patient care
   c) Meetings
      • Working Group meets over the phone
      • HRM will schedule all Working Group meetings
      • Meetings will be held once/month (on average)
   d) Estimated timeline
      • Explain to patients what the current timeline for the project is
   e) Evaluation
      • Short survey half-way through the project and then again when project is complete
   f) Confidentiality
      • Patients not obligated to talk about cancer experience
      • They can share as much or as little information about their personal experiences
      • Ask patients if they’re okay with having their contact information (i.e., email) shared with the Working Group members
      • Patients must refrain from sharing information that’s received through participation in this project
      • Guideline documents remain confidential until the guideline becomes available to the public
   g) Conflict of Interest form
      • CCO COI form has been signed
      • Remind patients that they will also be asked to sign a PEBC COI form, which is specific to this project
   h) Stepping Down
      • This study is a volunteer activity
      • Patients can stop participating at any time, for any reason

3. Practice Guideline Development Process
   • Ask patients if they have any questions about the practice guideline development process. If they need a reminder, refer to the notes below
   a) Select Topic and write a project plan
      • Patients are likely to review a project plan, which outlines the roles of the Working Group members, the selection criteria for the systematic review and the literature search plan, the practice guideline review process, strategies for dissemination and implementation, and the timeline
b) **Search for research evidence**  
- Systematic process to find and select research evidence that is relevant to the guideline topic and questions  
- Patients not actively involved in this stage

c) **Assess the quality of the research evidence**  
- Working Group assesses the quality of the research evidence (i.e. Were the studies well designed and conducted? Did the researchers provide clear descriptions of the participants and the interventions? Are the results biased?)

d) **Write recommendations and draft a practice guideline document**  
- Working Group considers the quality of the research evidence, the context in which recommendations are to be applied, benefits and harms (patient input), and values and preferences (patient input)

e) **Reviews of the guideline**  
- Reviewed by experts  
- Patients also asked to provide feedback  
- Working Group considers all feedback and makes necessary changes

f) **Dissemination and Implementation**  
- Guideline is distributed and put into practice

4. **Questions or Concerns**  
- Ask patients if they have questions about their role, or about how it differs from the role of other Working Group members
Supplemental Appendix 2: Model 2 working group survey

INSTRUCTIONS

The questionnaire is composed of several statements. Please indicate your level of agreement with each statement and check only one box for each statement. Please provide additional feedback in the comment boxes provided throughout the questionnaire. All information you provide will remain confidential. Thank you very much for your participation!

Consultation Group activity: Final evaluation – Model 2

| The purpose of this patient engagement pilot test was clearly explained to me. | Strongly agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
| Patient input was valuable to the Working Group and was relevant to the practice guideline topic. | | | | |
| The final practice guideline document encompasses the patient perspective. | | | | |
| Including patients as consultation group members resulted in the creation of a higher quality practice guideline. | | | | |
| I am interested in receiving input from a patient and caregiver-specific consultation group again in the future. | | | | |

Open-ended questions:

1. Please identify any improvements that could be made for future practice guideline development projects that involve patient engagement.

2. 

3. What is/was the best thing about receiving input from a consultation group consisting solely of patients, survivors and/or caregivers?

Additional comments: