

Patient Stakeholder Group

MuSE

Reflections from Richard Morley and Maureen Smith

What have Richard and Maureen been up to?

- We provided feedback on the definition of the patient stakeholder group. We see three distinct stakeholder groups: patients, carers/families, patient advocates/organizations.
 - Steps refer to stakeholders and consumers
- Our first thought was to engage with patients to prepare for this meeting and how best to do this
- We worked with Jennifer and team to design a survey to seek feedback on the 18 steps and individual items: opinion on engagement (mandatory, desirable, unimportant) and the degree of engagement (provide feedback/advice, participate in decision-making, should not be engaged)
 - Survey is currently undergoing ethics review

Definition of “patients”

- Depending on the guideline topic, carers and families could be surrogates for patients and, essentially, their “voice” (e.g. young children, patients with cognitive impairments, etc.)
- Perspectives of carers and families can differ from patients and should be considered separately. They are not a substitute for patient perspectives.
- Patient advocates/organizations can bring a broader perspective, especially for populations and sub-populations who are more difficult to engage with

Matrix challenges/issues

- Only certain items in a step are relevant
 - *Step 1 - Organization, Budget, Planning and Training Plan and prepare for training and support that will be required for those involved in the guideline development process (e.g. conflict of interest related education or training for guideline panel members, teaching sessions for patients to be involved in the guideline group, etc.)*
- Needs to be adaptable. Many of the parameters are clearly defined by the organization requesting the guideline. Impacts on patient engagement for this step. How do you acknowledge when it is not doable while maintaining it as important when feasible?
- Step 5 - Identify your target audience - patients not listed in primary or secondary audience (e.g. public health measures for COVID)

ESSENTIAL PATIENT STAKEHOLDER ENGAGEMENT

- Early in process
- Assess training needs
- Provide training/support
- Priority setting (including topic generation for guidelines)
- Selection of outcomes
- Identify patient needs
- More than one patient stakeholder representative
- Use a variety of tools to engage with patient stakeholders (surveys, focus groups, etc.)
- Negotiate level of engagement - not dictate
- Open consultation period
- Plain language summaries, accompanying decision aids

The big questions

- How do you create a checklist that is realistic, yet forward thinking? Aspirational?
- How do you adapt the checklist to encompass the wide array of guidelines and unique needs?
- Will this MuSE work be seen as a model for stakeholder collaboration?