

MuSE Working Group 3 Update

May 2019

Plans to develop guidance for multi-stakeholder engagement in guideline development are moving according to projected timelines ([attached- project overview](#)). We want to provide you with a brief update on the project and invite you to get involved!

1. Personnel updates

Jennifer Petkovic is away on maternity leave; Pearl Atwere will be performing her duties until she returns in September 2019. Pearl has worked previously on evaluating consent documents and has experience conducting and evaluating systematic reviews.

2. Overall study protocol

Thank you for all the feedback we've received since the overall study protocol was circulated for comment. This protocol lays out the plan for the entire MuSE Project. A call was put out in late 2018 inviting MuSE members to contribute to the protocol's development. Members who responded to this call (self-selection) worked together on its development, which has gone through several iterations. We are now finalizing the article to be submitted to Implementation Science in May 2019.

3. Systematic reviews update

Four systematic reviews are underway examining the literature on stakeholder engagement and guideline development. The topics are:

- a. Existing guidance on stakeholder engagement in guideline development
- b. Barriers and facilitators to stakeholder engagement in guideline development
- c. Impact of stakeholder engagement in guideline development
- d. Conflicts of interest in stakeholder engagement in guideline development

The systematic review titles are provisionally accepted by the Campbell Collaboration's Knowledge Translation Methods Group. A comprehensive systematic search was executed for all four reviews. Full text screening is complete and we are proceeding with tagging each included study to the appropriate review(s). The four review protocols are still in development and will be circulated to members who have previously expressed interest in contributing to specific reviews for input before submission to the Campbell Collaboration for peer review. The goal is to complete the four reviews by the end of 2019.

4. MuSE key definitions

We had the opportunity to gather some of the MuSE project members for a face-to-face meeting in early April in Ottawa when members were in town for another event. The objective of the meeting was to discuss some key concepts used in the MuSE project. Definitions for stakeholder, engagement, guidance, guideline, equitable engagement and levels of engagement were discussed. Where needed, modifications and clarifications were presented. Attendees also provided valuable input to the logic model. The input from this meeting was used to revise the overall study protocol. Please see the [attached meeting agenda, list of attendees, and meeting minutes](#) for additional information.

5. MuSE Evaluation Framework

Peter Tugwell, Vivian Welch and Alison Riddle met with Sophie Staniszewska (Professor of Health Research in the Patient and Public Involvement and Patient Experiences Programme, RCN Research Institute, Warwick Medical School) in Montreal to discuss the way forward for the development of an evaluation framework for the MuSE study. Sophie has agreed to dedicate a portion of her time to the development of the MuSE stakeholder engagement evaluation framework. The objective of the evaluation framework will be to assess the processes and impact of the MuSE study's engagement of its own multiple stakeholders throughout the four-year study. Our vision is to co-produce the evaluation framework and its products with a Patients and Public Advisory Council. We will look for key points in the MuSE study process to capture and evaluate the processes/impact of our approach to stakeholder engagement in the study. The study's logic model will help to guide what we want to evaluate. We expect the evaluation framework to help us capitalize on the contributions of our diverse stakeholders that will serve as a complement to (and critically challenge) our literature review findings, and inform the development of our overall guidance.

6. MuSE Patients and Public Advisory Council

The MuSE study would like to establish a more systematic method for engaging our patients and public members. Consequently, we are in the process of establishing a Patients and Public Advisory Council for the project. More details will follow, but we welcome any input/suggestions from our members to inform the development of this important body.

7. Public Health Agency of Canada (PHAC) Innovation Guideline Hub

Peter Tugwell, Alison Riddle and Pearl Atwere met with Gregory Traversy, Alejandra Jaramillo Garcia and Rachel Rodin from PHAC to discuss potential opportunities for MuSE to collaborate with the Guidance Innovation Hub (iHub) at PHAC. The iHub is set up with a vision to be a trusted source of scientifically robust and relevant guidelines and knowledge implementation tools to serve Canadians. The goal is to provide leadership and coordinated support while building PHAC's capacity to support guideline development, acceptance and use.

One of iHub's key deliverables is to collaborate with stakeholders external to PHAC, which MuSE can contribute to. Potential areas for collaboration are developing methods for incorporating patient/public perspectives into guidelines and engaging patients/public in the guideline development process. While GRADE is helpful, it needs to be improved when used for non-preventive scenarios. With PHAC's commitment to collaboration, there is a possibility for funding for a consensus meeting. Next steps with PHAC are:

- a. PHAC to provide MuSE with the names of the various (6) guideline groups and a summary of the work each group does to tailor/facilitate engagement
- b. MuSE to provide PHAC with the specific stakeholder groups for each item in the 18-step framework
- c. PHAC to provide MuSE with their current practice with each stakeholder group around the 18-steps
- d. MuSE to provide PHAC with current protocols for input/comments; how is MuSE doing in terms of asking questions that are relevant to guideline developers?
- e. MuSE to provide PHAC with timelines for each of MuSE stages to facilitate feedback

Other MuSE Working Group Updates

WG1 – A paper on 'Engaging Patients and Other Non-Researchers in Health Research: Defining Research Engagement' led by Lori Frank has been conditionally accepted and in second review with the editor at Journal of General Internal Medicine.

WG2 – A paper on 'Practical guidance for involving stakeholders in health research' led by Tom Concannon has been published in the March 2019 edition of the Journal of General Internal Medicine (Concannon, T.W., Grant, S., Welch, V. et al. J GEN INTERN MED (2019) 34: 458.

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