

Development of the GIN-McMaster Guideline Development Checklist Extension for Engagement

September 18, 2025

Joanne Khabsa, on behalf of the MuSE Consortium



Disclosure

- Member of the MuSE Consortium and co-author of several MuSE publications
- Aligned with the movement that engaging interest-holders is valuable in science and policy



What is the MuSE Consortium?

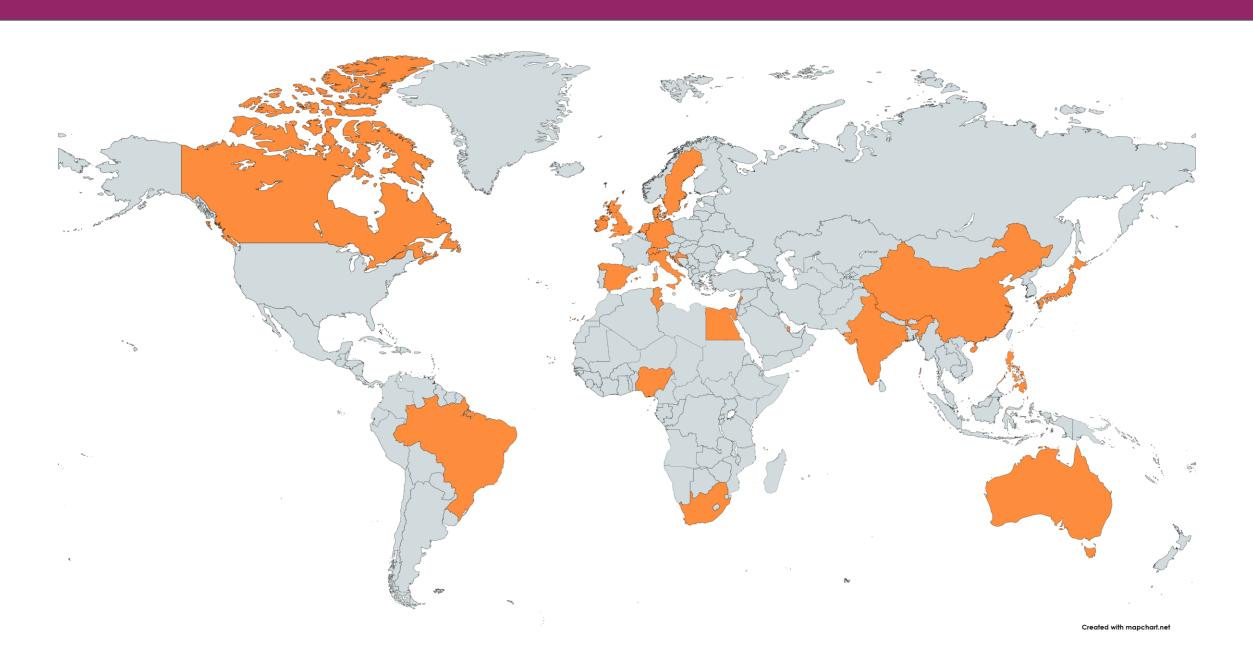
- Established in 2015
- Has grown to a 180+ member international team across
 26 countries from diverse contexts and backgrounds
- Common interest in advancing methods for engagement in research and guidelines



Engagement in guideline development (2018-2024)

Engagement in evidence synthesis (2021-2026)

MuSE Consortium





Stakeholders > Interest-holders

- Continued use "stakeholder" can be disrespectful
- The MuSE Consortium proposes "interest-holder" instead
 - Informed by survey and extensive discussion





Objective

 To describe the methods for the development of the Guidelines International Network (GIN)-McMaster Guideline Development Checklist (GDC) Extension for Engagement



MuSE-Guidelines Project Overview

STAGE 1. Systematic reviews

- 1. Existing guidance
- 2. Barriers and facilitators
- 3. Conflicts of interest
- 4. Impact

STAGE 2. Draft guidance

- Identification of engagement group co-leads
- Structured engagement with co-leads

STAGE 3.
Online
survey/
interviews

- Online, international survey with external interest holders
- Key informant interviews

STAGE 4. Consensus

- Development and revisions to draft guidance developed thus far
- Virtual consensus meeting to finalize guidance

STAGE 5. Final guidance

How and when to involve different types of interest-holders

ngagement Strategy



Interest-holder Categories









Providers of care

Payers of health services



Patients, caregivers, and patient organizations

Groups with legitimate interests in the health issue under consideration; people from these groups are responsible for or affected by healthrelated decisions that can be informed by research evidence.



Program managers



Principal investigators (& their research teams)







Peer review editors

Product makers

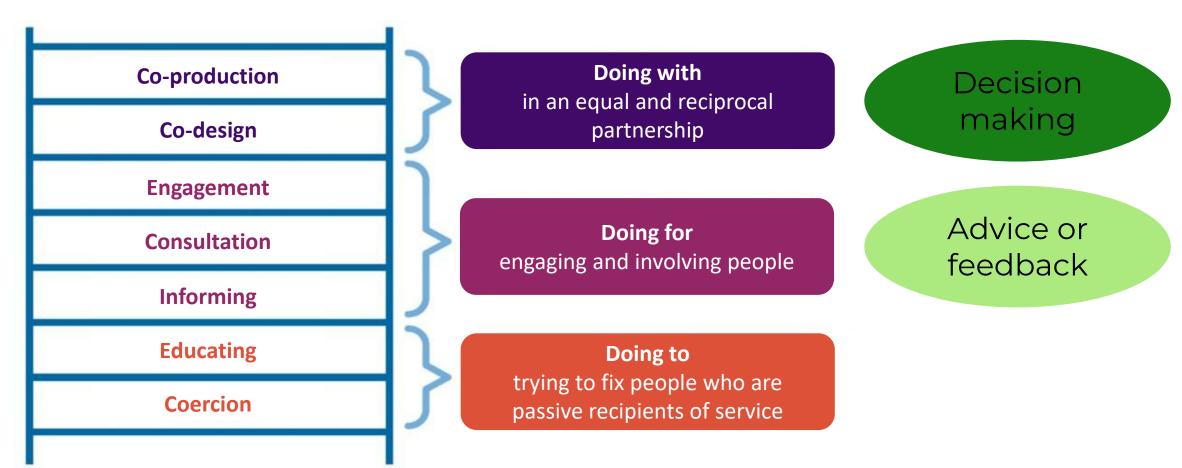


Levels of engagement

 Defining engagement = an approach intended to gather input or contribution from partners toward the development of a guideline, completion of any stages of a guideline, or dissemination, uptake or evaluation of a guideline and its recommendations



Levels of Engagement



Arnstein's ladder of participation



Levels of Engagement

Decision making Interest-holders actively contribute as an "equal voice" with other members of the Guideline Panel in decision-making about guideline activities

Advice or feedback

Opinions, perspectives, experiences, or values are sought and considered by the guideline development team



Key issues

- Definitions, roles, and settings
- Stakeholder identification and selection (Roses Parker et. al)
- Levels of engagement
- Evaluation of engagement
- Documentation and transparency
- Conflict of interest management

Petkovic et al.

Research Involvement and Engagement (2023) 9:2

https://doi.org/10.1186/s40900-023-00433-6

Research Involvement and Engagement

RESEARCH

Open Access

Key issues for stakeholder engagement in the development of health and healthcare guidelines

Jennifer Petkovic^{1,2*}, Olivia Magwood^{1,3}, Lyubov Lytvyn⁴, Joanne Khabsa⁵, Thomas W. Concannon⁶, Vivian Welch^{1,7}, Alex Todhunter-Brown⁸, Marisha E. Palm^{9,10}, Elie A. Akl^{11,12}, Lawrence Mbuagbaw^{13,14,15,16,17,18}, Thurayya Arayssi¹⁹, Marc T. Avey²², Ana Marusic²³, Richard Morley²⁴, Michael Saginur²⁵, Nevilene Slingers²⁸, Ligia Texeira²⁹, Asma Ben Brahem³⁰, Soumyadeep Bhaumik³¹, Imad Bou Akl³², Sally Crowe²⁷, Laura Dormer²⁶, Comfort Ekanem²⁰, Eddy Lang²¹, Behrang Kianzad³³, Tanja Kuchenmüller³⁴, Lorenzo Moja³⁵, Kevin Pottie^{36,37}, Holger Schünemann^{38,39} and Peter Tugwell^{40,41,42,43}



Engagement Strategy in MuSE

Feb 2020

1st meeting with core team, including guideline developers and other interestholders

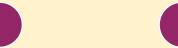
(Ottawa, Ontario)

Feb 2021

Large group meeting to discuss overall plan and any key issues (online)

2022-2023

Interview guides for interest-holders developed with coleads; interestholders interviewed about draft guidance













2020-2021

Recruited co-leads
Individualized
meeting
Invited to larger
group meetings

Sept 2022

Meeting with core team and co-leads during GIN (Toronto, Ontario)

May 2023

Consensus
meetings to ensure
alignment and
consistency across
groups and any
discrepancies and
key issues

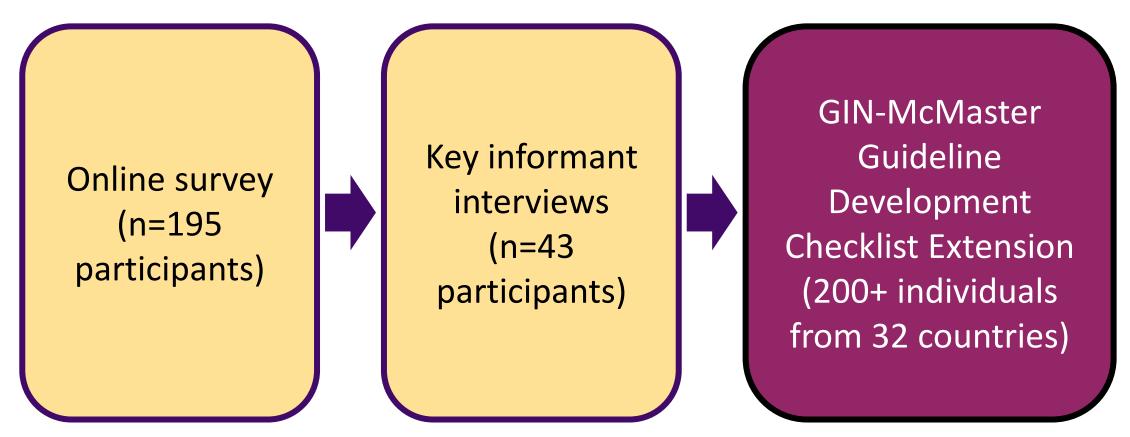
(online)

Open callouts to MuSE consortium to:

Join systematic reviews, participate in surveys and interviews



MuSE Guidelines Project Overview



Engage with interest-holders throughout the project (feedback & decision-making)



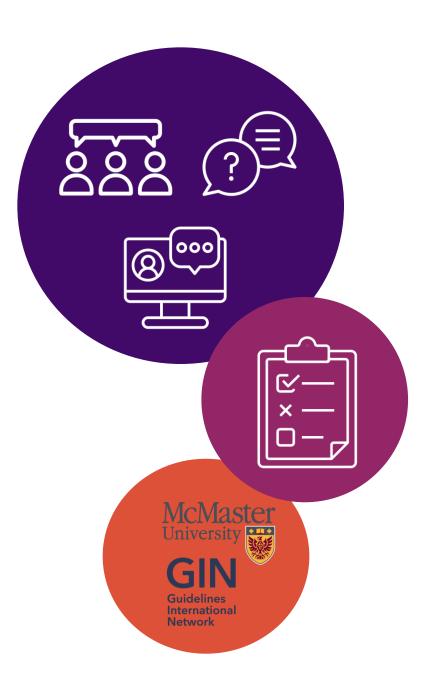
Engagement Strategy Challenges

- Considering all 10 interest-holders
- Thoroughness vs pragmatism
- 10 interest-holders and 18 topics framework in the survey
 - Poor completion rates of the survey due to the length → difficult to complete, difficult to analyze
- Some interest-holders may not have had extensive guideline development experience, and the 18 topics are very detailed
- Product makers: COI
- Program managers: Hard to define, different scopes of practice depending on context
- Policy makers: Not readily available



Strengths

- Multiple reviews (methods, barriers and facilitators, COI, impact) and multiple processes to obtain input (interviews, surveys, meetings)
- Interest-holders gave direct feedback on how and when they wanted to be involved
- Purposive sampling of co-leads (international, high and middle/low income settings)





Limitations

- No formal evaluation of engagement strategy we used to develop the guidance
- Difficult to engage certain interest holders due to access and timing (2020-2022)
- Consortium participants were committed to engagement, and may not represent those interested in engagement; critical perspectives may be missing



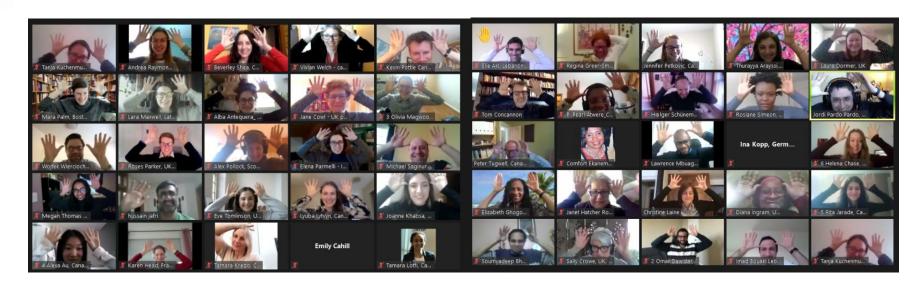


Key messages about the development

- 1. Consider the 10 interest-holder groups
- 2. Developing a consortium takes time
- 3. Ongoing connection is important
- 4. Use multiple sources to fill gaps in published literature
- 5. Multi-group processes require time and being adaptable



Thank you!





Follow MuSE for more information: @GuidelinesMuSE

https://theoche.ca/muse-news

Coordinator

Jennifer Petkovic, PhD jennifer.petkovic@uottawa.ca