

The GIN-McMaster Guideline Development Checklist Extension for Engagement

September 18, 2025

Joanne Khabsa, on behalf of the MuSE Consortium



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 Draft guidance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- Development and revisions to draft guidance developed thus far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
- Managing conflicts of interest
- How to evaluate the engagement of multiple interest-holders in the guideline development process

ngagement Strategy



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Engagement Strategy



Existing guidance





SYSTEMATIC REVIEWS Open Access

Guidance for engagement in health guideline development: A scoping review

Jennifer Petkovic Alison Riddle, Lyubov Lytvyn, Joanne Khabsa, Elie A. Akl, Vivian Welch, Olivia Magwood, Pearl Atwere, Ian D. Graham, Sean Grant, Denny John, Srinivasa Vittal Katikireddi, Etienne V. Langlois, Reem A. Mustafa, Alex Todhunter-Brown, Holger Schünemann, Airton T. Stein, Thomas W. Concannon, Peter Tugwell ... See fewer authors

- 16 papers providing guidance for at least one of our interest-holder groups for at least one stage of guideline development
- Australia, Denmark, the Netherlands, the UK, and the USA, and international (countries not specified)
- Guidance was mostly available for patient engagement (15/16 papers) and healthcare providers (9/16 papers)
- We did not identify guidance for payers of health research or for editors of peer-reviewed journals.



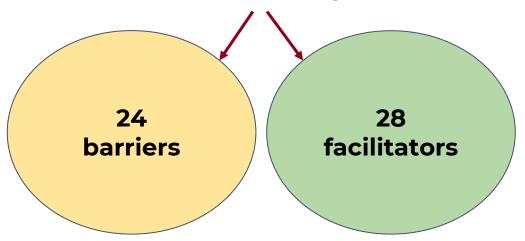
GIN-McMaster Checklist Topics	PATIENTS	PUBLIC	PROVIDERS	PRINCIPAL INVESTIGATORS	POLICYMAKERS	PRODUCT MAKERS	PROGRAM MANAGERS	PAYERS OF HEALTH RESEARCH	PAYERS OF HEALTH SERVICES	PEER REVIEW EDITORS
1: ORGANIZATION, BUDGET, PLANNING AND TRAINING	12 studies (Adams 2022; Bjorkqvist 2021; Chalmers 2017; Duff 1996; English 2017; Fretheim 2006; GIN- Public; Kelson 2012; Khodyakov 2020; Kunz 2012; MacLennan 2017; Wedzicha 2011)	2 studies (Wedzicha 2011; GIN- Public)	5 studies (Adams 2022; Fretheim 2006; GIN-Public; Kelson 2012; MacLennan 2017)	2 studies (Adams 2022; Kunz 2012)	1 study (Fretheim 2006)		2 studies (Adams 2022; Fretheim 2006)		1 study (MacLennan 2017)	
2. PRIORITY SETTING	6 studies (Armstrong 2017; Chalmers 2017; Fretheim 2006; GIN- Public; Grant 2021; MacLennan 2017)		2 studies (Fretheim 2006; MacLennan 2017)		1 study (Fretheim 2006)		1 study (Fretheim 2006)		1 study (MacLennan 2017)	
3. GUIDELINE GROUP MEMBERSHIP	5 studies (Adams 2022; Armstrong 2017; Duff 1996; GIN-Public; Grant 2021	2 studies (Armstrong 2017; GIN- Public)	4 studies (Adams 2022; Kunz 2012;MacLennan 2017; Rapu 2005)	1 study (Adams 2022)		1 study (Kunz 2012)				
4. GUIDELINE GROUP PROCESSES	6 studies (Chalmers 2017; Eccles 2012; Duff 1996; GIN- Public; Kelson 2012; Khodyakov 2020)	2 studies (GIN-Public; Kunz 2012)	2 studies (English 2017; Rapu 2005)	1 study (English 2017)	1 study (English 2017)	1 study (Kunz 2012)				
5. TARGET AUDIENCE AND TOPIC SELECTION	5 studies (Armstrong 2017; Duff 1996; Fretheim 2006; Grant 2021; Kelson 2012)	1 study (Armstrong 2017)	1 study (Fretheim 2006)		1 study (Fretheim 2006)		1 study (Fretheim 2006)			
6. CONSUMER AND STAKEHOLDER INVOLVEMENT	7 studies (Adams 2022; Chalmers 2017; Duff 1996;Eccles 2012; GIN- Public; MacLennan 2017; Wedzicha 2011)	2 studies (GIN-Public; Kunz 2012)	3 studies (Adams 2022; Eccles 2012; Rapu 2005)	1 study (Adams 2022)		1 study (Eccles 2012)			1 study (Eccles 2012)	
7. CONFLICTS OF INTEREST CONSIDERATIONS	2 studies (Armstrong 2017; Grant 2021)									
8. QUESTION GENERATION	2 studies (Armstrong 2017; Grant 2021)	2 studies (Armstrong 2017; GIN- Public)								
9. CONSIDERING IMPORTANCE OF OUTCOMES AND INTERVENTIONS	4 studies (Armstrong 2017; Grant 2021; Khodyakov 2020; MacLennan 2017)	1 study (Armstrong 2017)								
10. DECIDING WHAT EVIDENCE TO INCLUDE AND SEARCHING FOR EVIDENCE	2 studies (Armstrong 2017; Fretheim 2006)		1 study (Fretheim 2006)		1 study (Fretheim 2006)		1 study (Fretheim 2006)			
11. SUMMARIZING EVIDENCE AND CONSIDERING ADDITIONAL INFORMATION	2 studies (Armstrong 2017; MacLennan 2017)	1 study (MacLennan 2017)	1 study (MacLennan 2017)						1 study (MacLennan 2017)	
12. JUDGING QUALITY, STRENGTH OR CERTAINTY OF A BODY OF EVIDENCE	2 studies (Armstrong 2017; Grant 2021)	1 study (Armstrong 2017)								
13. DEVELOPING RECOMMENDATIONS AND DETERIMING THEIR STRENGTH	4 studies (Armstrong 2017; Grant 2021; Kelson 2012; Khodyakov 2020)	1 study (Armstrong 2017)								
14. WORDING OF RECOMMENDATIONS	4 studies (Armstrong 2017; Grant 2021; Kelson 2012; Khodyakov 2020)	1 study (Armstrong 2017)								
15. REPORTING AND PEER REVIEW	3 studies (Fretheim 2006; GIN	2 studies (GIN Public; Kunz 2012)	1 study (Fretheim 2006)		1 study (Fretheim 206)	1 study (Kunz 2012)	1 study (Fretheim 2006)			
16. DISSEMINATION AND IMPLEMENTATION	6 studies (Armstrong 2017; Duff 1996; Fretheim 2006; GIN Public: Grant 2021; MacLennan 2017)	1 study (Fretheim 2006)	1 study (Fretheim 2006)		1 study (Fretheim 2006)		1 study (Fretheim 2006)			
17. EVALUATION AND USE	2 studies (GIN-Public; MacLennan 2017)	1 study (Kuriz 2012)								
18. UPDATING	2 studies (Armstrong 2017; Grant 2021)									



Barriers and facilitators

 Qualitative evidence synthesis of 34 studies; findings mapped to GIN-McMaster Guideline Development Checklist

Results: 52 findings





Barriers and facilitators

Examples of barriers

Challenges **identifying** "representative" patients to engage in guideline development.

Power imbalances between patients and providers of care in guideline development groups may promote unequal influence in decision-making.

Interest-holder engagement may be limited by a **lack of technical skills** in reviewing or judging the certainty of scientific evidence.

Examples of facilitators

Recruit **knowledgeable and experienced** interest-holders, with a focus on **diverse perspectives, roles, and personal characteristics**.

Enlist a **skilled moderator/chair** to manage group dynamics.

Provide **training** to empower interest-holders and improve self-efficacy and confidence in guideline development skills. Training should focus on evidence-based methods such as evidence synthesis and evidence-to-decision frameworks.



Conflicts of interest

- 10 included studies
- **Types of COI:** financial (e.g., industry funding) and non-financial COI (e.g., patient's opinion affected by that of their treating physician)
- **Prevalence of COI**; 44% of advocacy and professional organizations submitting public comments to CDC draft guidelines reported receiving funding from the industry (1 study)
- Impact of COI; association between industry funding of interest-holders' organizations and their support to the guidelines and specific recommendations (1 study)
- 2 studies reported that patients' own experiences of the condition represent 'vested' or 'inherent' interests that may bias their views



Conflicts of interest



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Commentary

A new taxonomy is proposed for defining the interests of stakeholders' representatives in health research: the case of guideline development

Elie A. Akl ^{a b} $\stackrel{\triangle}{\sim}$ $\stackrel{\boxtimes}{\sim}$, Joanne Khabsa ^c, Holger J. Schünemann ^{b d}, Eve Tomlinson ^e, Roses Parker ^f, Peter Tugwell ^g, Thomas W. Concannon ^{h i}

• We argue that patients' experiences should not be considered as COI; but as non-conflicting interests ("legitimate interests") that should be reflected in the final recommendations.



Impact of engagement

•	Outcome category 2: The research product		The relationship between	Outcome category 5: The community or society
Changes to any of the stages and activities	Changes to the final report, publication or other output directly related to the evidence synthesis	Changes or impacts experienced by the interest-holders	Changes or impacts which influence the relationship between people and how they work together	Broader impacts which extend beyond the research project and influence community or society, such as the health system or academic systems



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Engagement

Characteristics	N Co-leads	N Survey Responses				
Patients	2	70				
Public	3	26				
Providers	3	30				
Program managers	3	7				
Principal investigators	3	20				
Payers/of health services	2	2				
Policymakers	2	5				
Payers of research	1	4				
Peer review editors	4	27				
Product makers	3	4				



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ORIGINAL RESEARCH

The GIN-McMaster Guideline Development Checklist extension for engagement

Jennifer Petkovic^{a,1,*}, Olivia Magwood^{b,1}, Thomas W. Concannon^c, Elie A. Akl^{d,e}, Joanne Khabsa^f, Lyubov Lytvyn^e, Vivian Welch^{g,h}, Marc T. Aveyⁱ, Soumyadeep Bhaumik^{j,k}, Angus Gunn^l, Ana Marusic^m, Lawrence Mbuagbaw^{n,o,p,q,r,s}, Zachary Munn^t, Marisha E. Palm^{u,v}, Danielle Pollock^w, Michael Saginur^x, Imad Bou Akl^y, Thurayya Arayssi^z, Asma Ben Brahem^{aa}, Tammy Clifford^{bb,cc}, Laura Dormer^{dd}, Comfort Ekanem^{ee}, Regina Greer-Smith^{ff}, Chris Huzzey^{gg}, Behrang Kianzad^{hh}, Christine Laineⁱⁱ, Eddy Lang^{ij}, Kevin Pottie^{kk}, Lorenzo Moja^{ll}, Richard Morley^{mm}, Nevilene Slingersⁿⁿ, Ligia Texeira^{oo}, Pauline Campbell^{pp}, Stephanie Chang^{qq}, Leonila F. Dans^{rr}, Jeanne-Marie Guise^{ss}, S. Vittal Katikireddi^{tt}, Anneliese Synnot^{uu,vv}, Janice Tufte^{ww}, Holger Schünemann^{xx}, Peter Tugwell^{g,yy,zz,aaa,bbb}



General principles for engagement

- 1. Interest-holders are **groups with legitimate interests** in the health issue under consideration.
- 2. Guideline developers should **plan** for meaningful engagement of interest-holders throughout the guideline development process.
- 3. The selection of representatives of interest-holder groups should **consider the** representativeness and diversity of membership.
- 4. Guideline developers should have a process for the **management of the COI** of the representatives of the interest-holder groups.
- 5. Guideline developers should **accommodate** interest-holders to participate in the topics of the guideline development process they are interested in and eligible for according to this guidance.
- 6. Guideline developers should assess the need for, develop, and deliver appropriate **capacity strengthening** activities to interest-holders in relevant technical skills (e.g., in systematic reviews, consensus building approaches).

	Patients + Public	Payers of Research	Payers / of health services	Peer review editors	Policy- makers	Product makers	Pls	Program managers	Providers
1.Organisation, budget, planning									
2.Priority Setting									
3.Guideline group membership									
4.Guideline group processes									
5.Identifying Target Audience and Topic Selection									
7.Conflict of Interest Considerations									
8.(PICO) Question Generation									
9.Considering Importance of Outcomes and Interventions, Values, Preferences and Utilities									
10.Deciding what Evidence to Include and Searching for Evidence									
11.Summarizing Evidence and Considering Additional Information									
12.Judging Quality, Strength or Certainty of a Body of Evidence									
13.Developing Recommendations and Determining their Strength									
14. Wording of Recommendations and of Considerations of Implementation, Feasibility and Equity									
15.Reporting and Peer Review									
16.Dissemination and Implementation									
17.Evaluation and Use									
18.Updating									

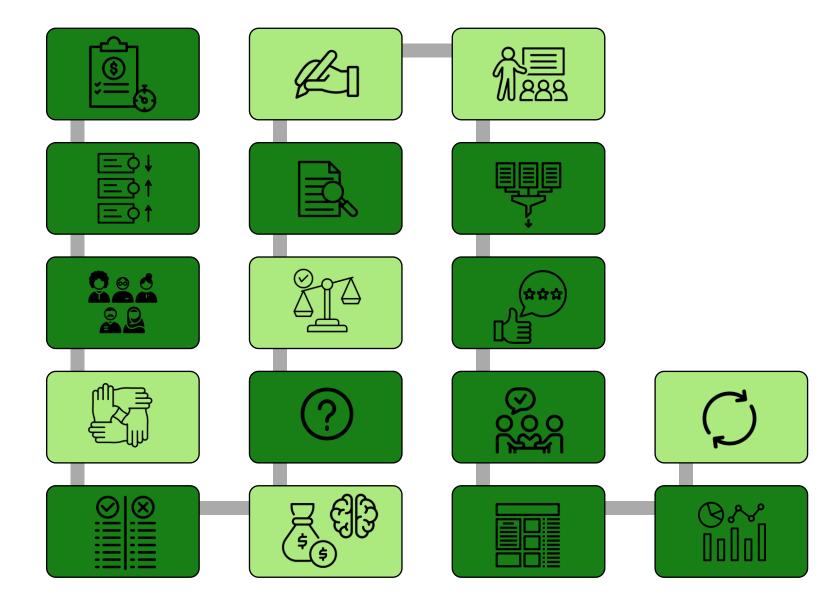


GIN-McMaster Guideline Development Checklist



Patients, caregivers, and patient organizations

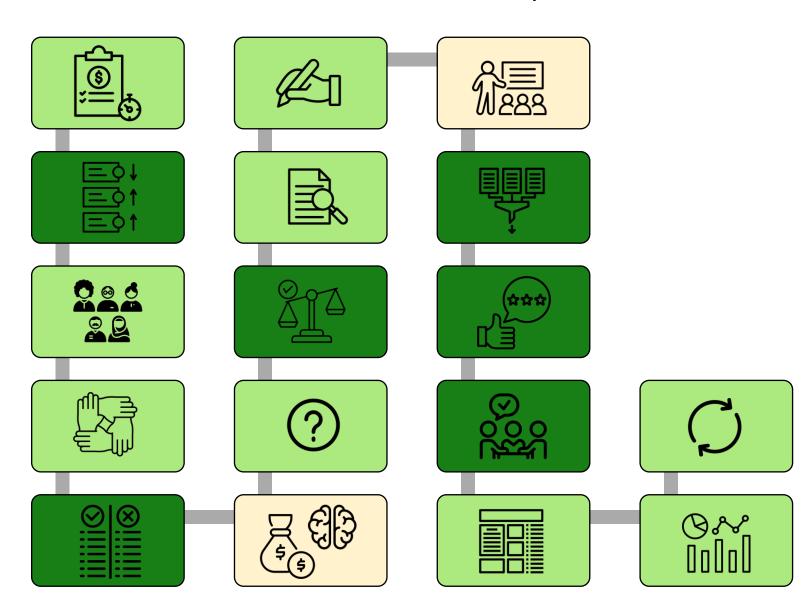






GIN-McMaster Guideline Development Checklist







Strengths

- Interest-holders gave direct feedback on how and when they wanted to be involved
- Multiple reviews (methods, barriers and facilitators, COI, impact) and multiple processes to obtain input (interviews, surveys, meetings)
- GIN-McMaster Checklist is widely accepted and being used to develop other extensions
- Context discussion to facilitate flexible (not prescriptive) use of the tool
- Discussions spurred multiple additional research questions and projects





Limitations

- Challenge of presenting comprehensive information without overload
- Literature featured certain interest-holders more often (e.g., patients)
- Guidance may not work for every situation
- Not pilot tested (aspirational framework)







Key takeaways

- 1. Plan early
- 2. Consider the 10 interest-holder groups and level of engagement (advice/feedback, decision-making)
- 3. Not all groups need to be engaged in the same way
- 4. Report your methods
- 5. Consider a tool to measure and report impact

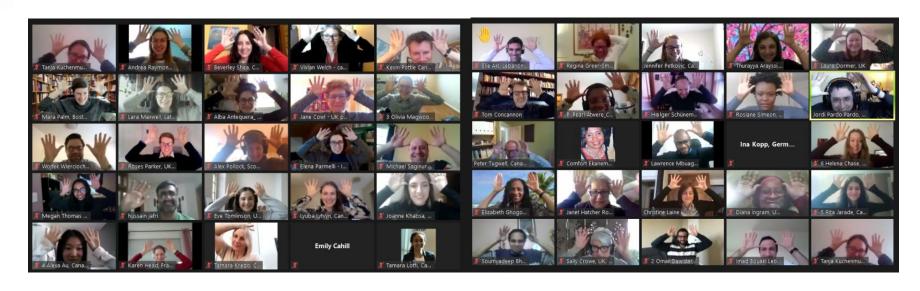


Next steps

- 1. RIGHT-MuSE extension
- 2. Defining meaningful engagement
- 3. Engagement in ES



Thank you!





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