

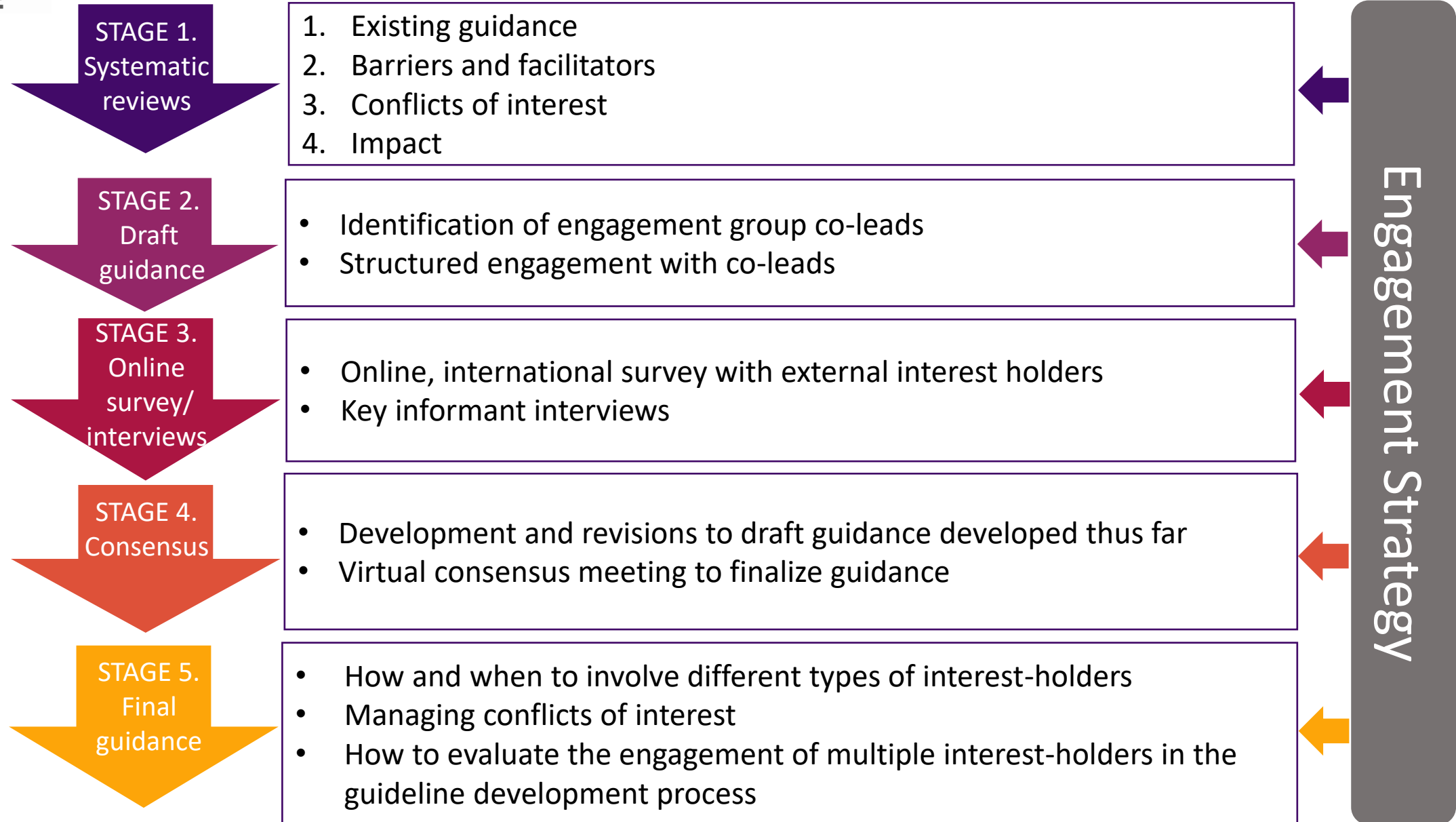


The GIN-McMaster Guideline Development Checklist Extension for Engagement

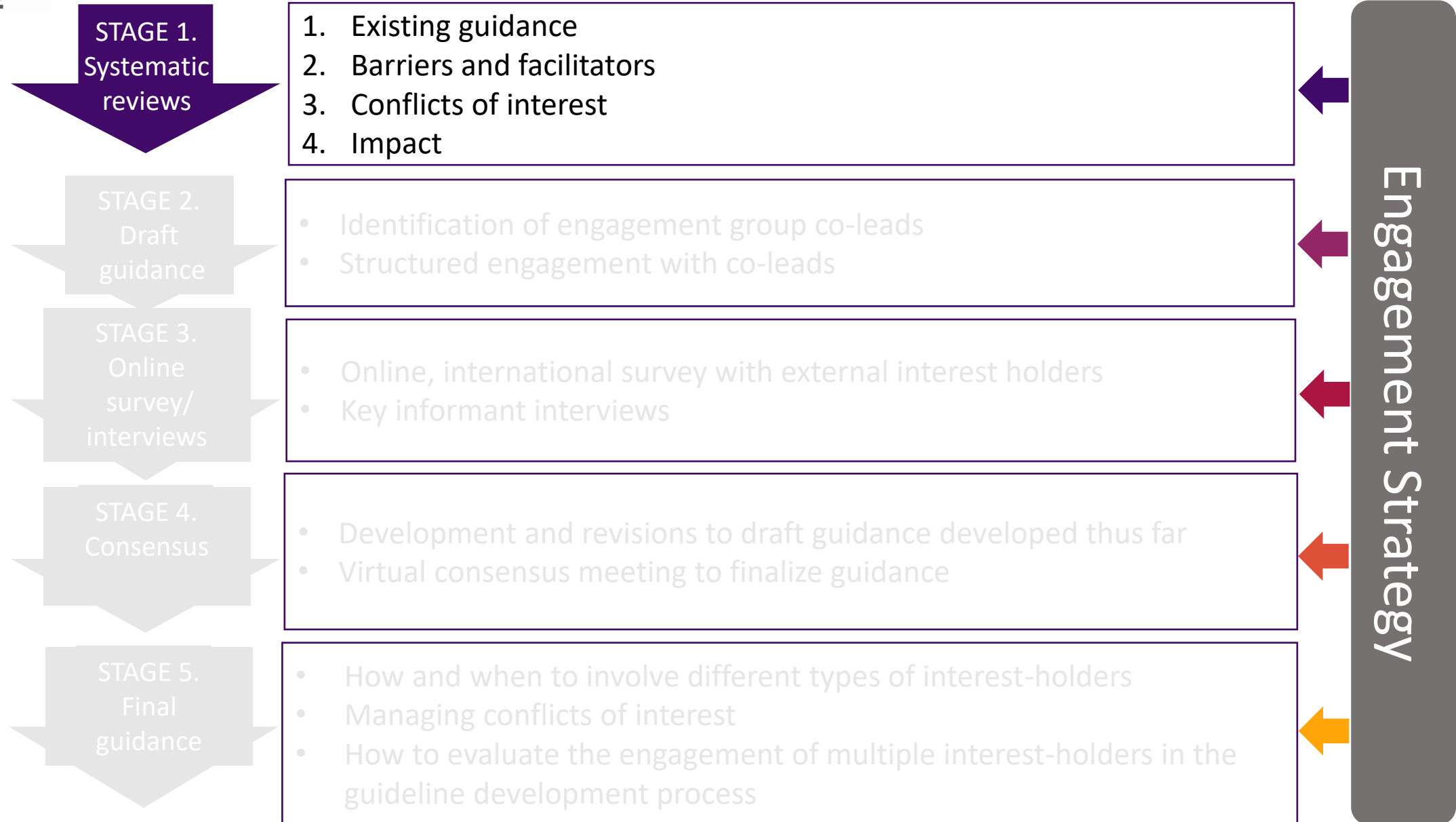
September 18, 2025

Joanne Khabsa, on behalf of the MuSE Consortium

MuSE-Guidelines Project Overview




MuSE-Guidelines Project Overview



Existing guidance

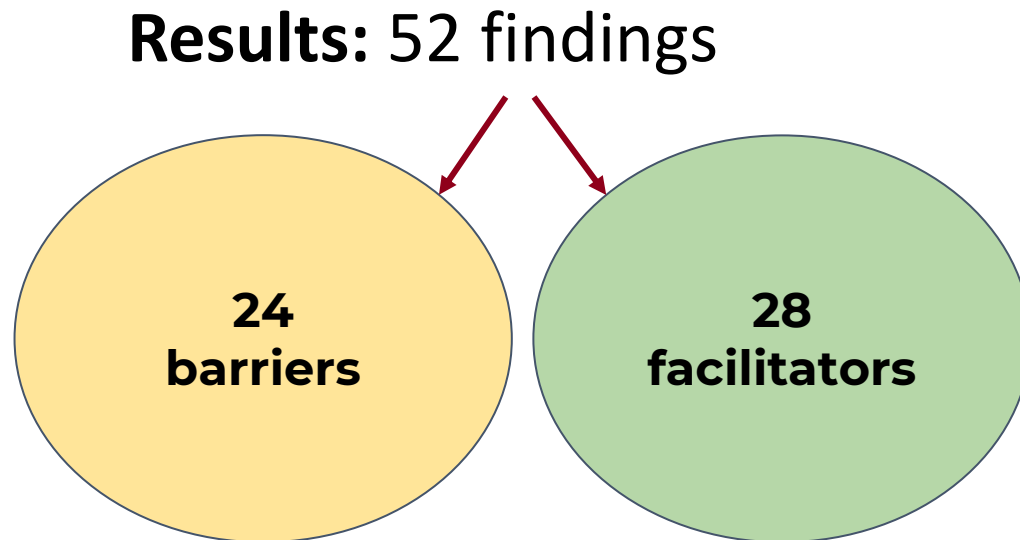
Guidance for engagement in health guideline development: A scoping review

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, Airtion 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.

Barriers and facilitators

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





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





Journal of Clinical Epidemiology
Volume 160, August 2023, Pages 147-150



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}  , Joanne Khabisa^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.

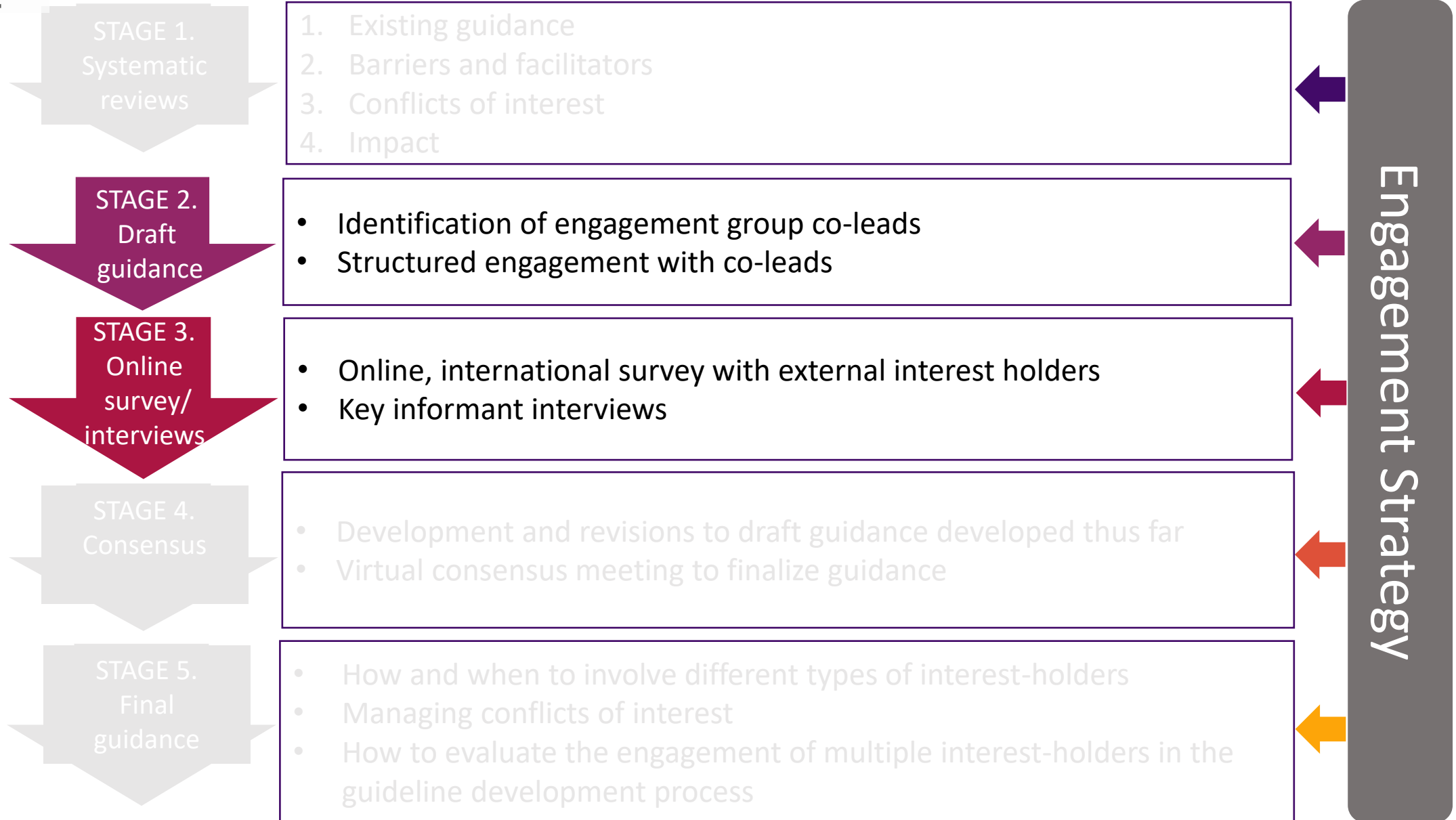


Impact of engagement

Outcome category 1: The research process	Outcome category 2: The research product	Outcome category 3: Interest-holders involved in research (individual level)	Outcome category 4: The relationship between interest-holders (partnership level)	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



MuSE-Guidelines Project Overview



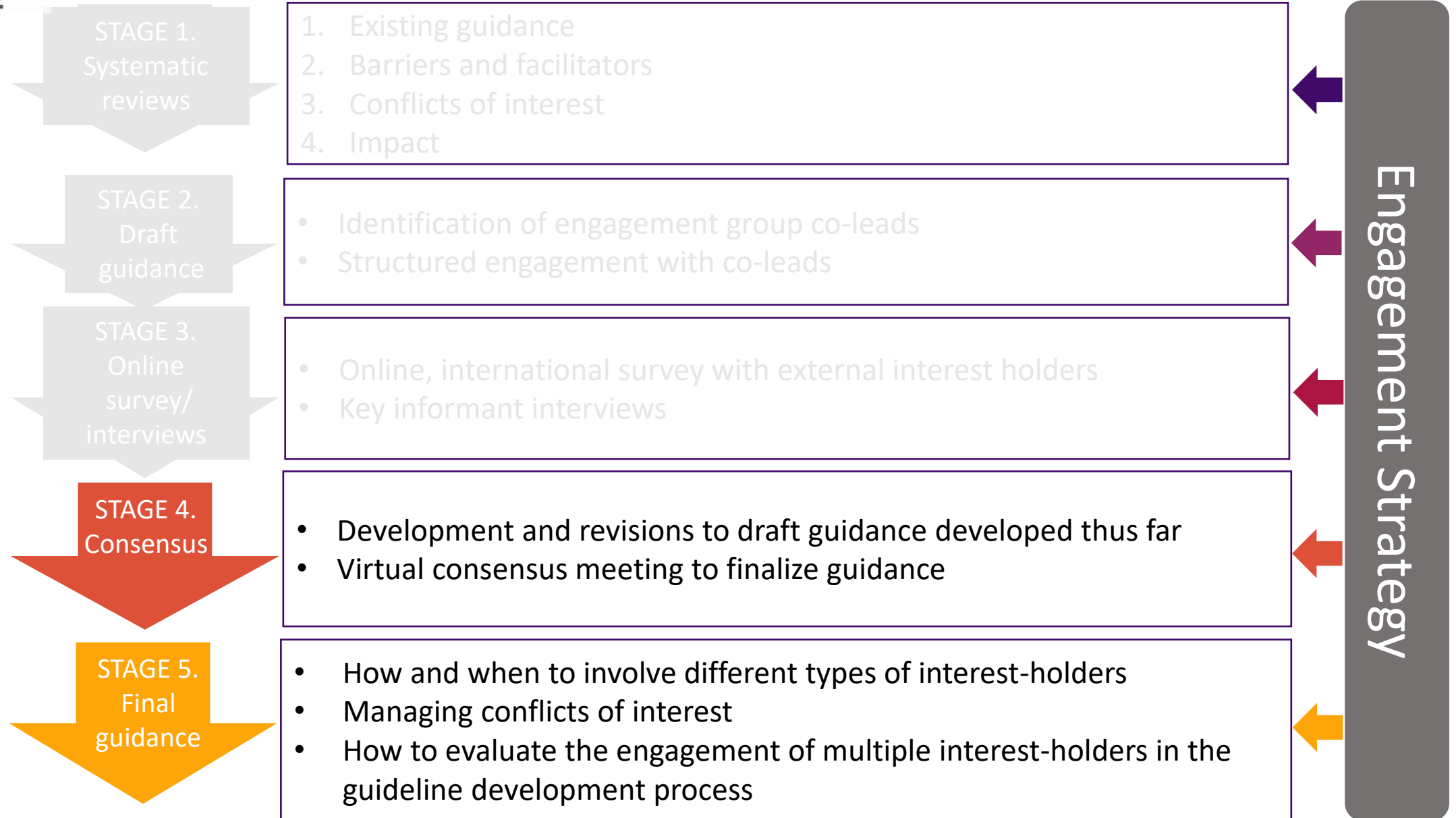


Engagement

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



MuSE-Guidelines Project Overview



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 Khabisa^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^{jj}, 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).

[illegible]

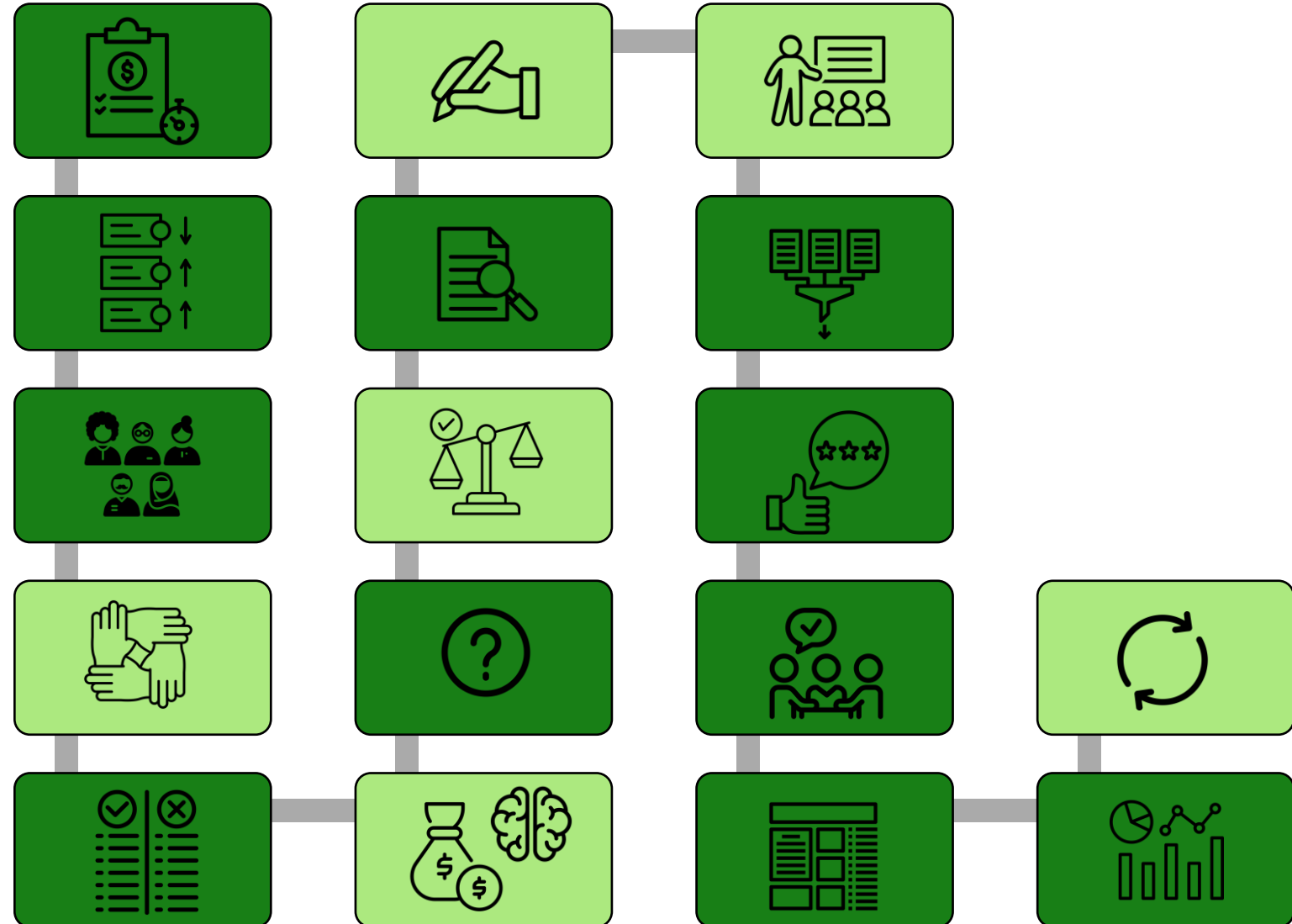
GIN-McMaster Guideline Development Checklist



Patients, caregivers, and
patient organizations



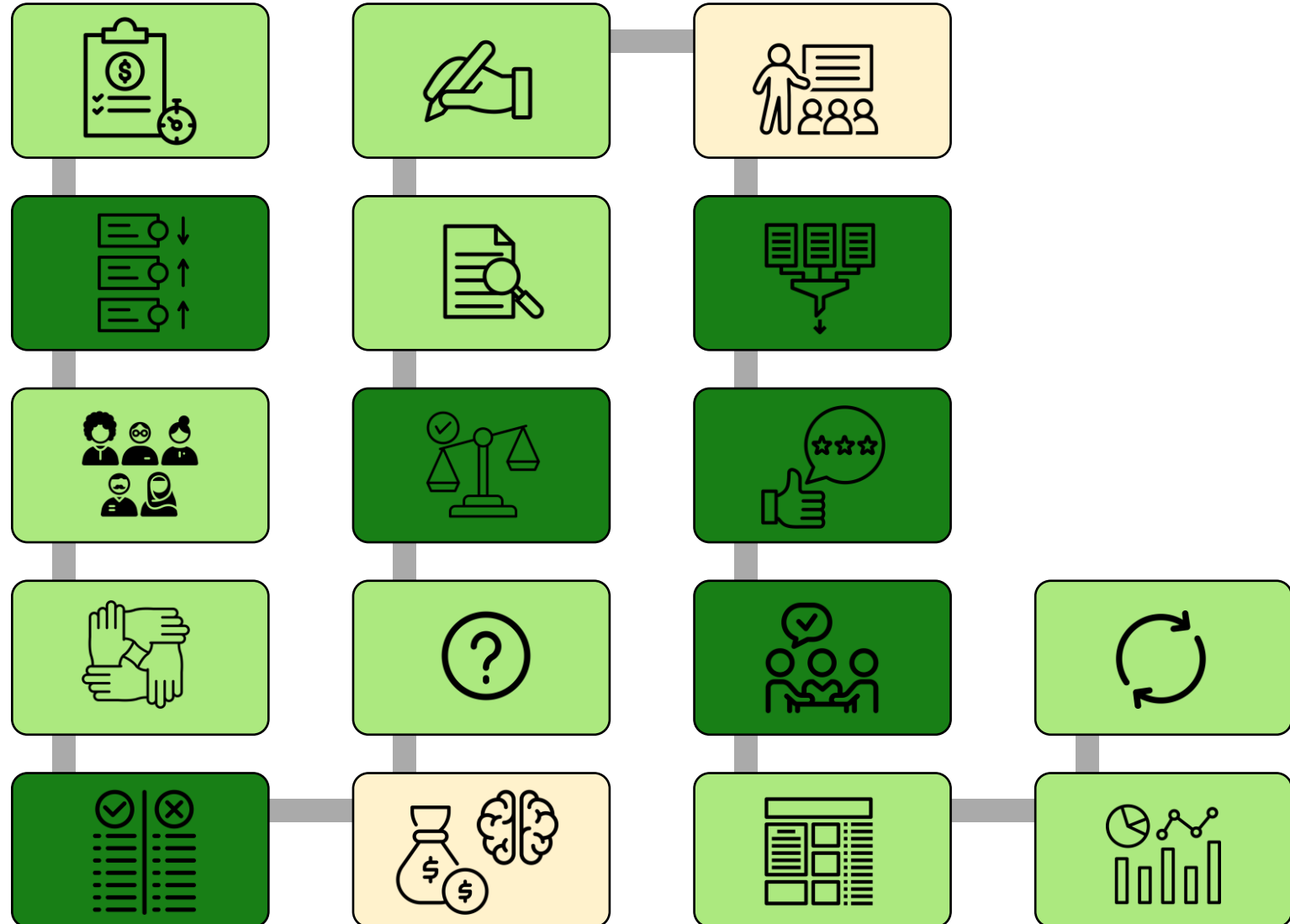
Public



GIN-McMaster Guideline Development Checklist



Policymakers



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)



We would like to hear from you!





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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