



Engagement in Evidence Synthesis

Guidance for engaging with interest-
holders in evidence synthesis

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on behalf of the MuSE Consortium



What is the MuSE Consortium?

- Established in 2015
- International team of 180+ members 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-ES Team

Core Team

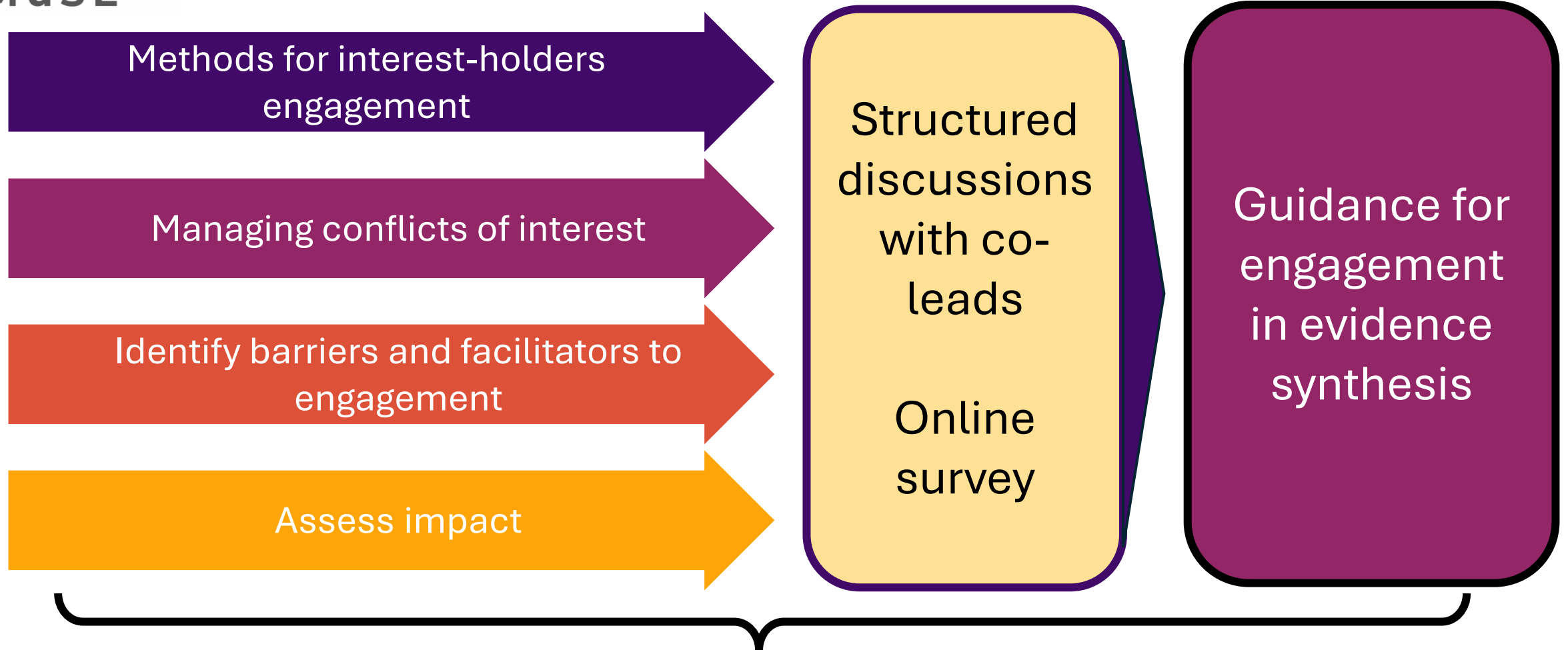
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MuSE-ES Interest-holder Co-leads

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MuSE-ES Project



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



Interest-holder Categories



Producers/commissioners
of evidence synthesis



Providers of care



Public



Payers of research



Payers of health services



Patients, caregivers, and
patient organizations

“groups with legitimate interests in the health issue under consideration. The interests arise and draw their legitimacy from the fact that people from these groups are responsible for or affected by health-related decisions that can be informed by research evidence” (Akl et al. 2024).



Program managers



Principal investigators
(& their research teams)



Peer review editors



Product makers



Policymakers



What is “meaningful engagement”?

“the planned, supported, and valued involvement of team members in the research process within a positive environment in which they contribute and have a rewarding experience”

- Lewis et al., 2024

“the planned, supported and valued involvement of patients in the research process within an interactive team and positive research environment that facilitates effective contributions by patients or their surrogates to help to produce important outcomes while benefiting the patients or their surrogates”

- Boden et al., 2021



What is “meaningful engagement”?

A study from 2018 assessed perspectives of patients, family members, and informal caregivers about meaningful engagement and identified four themes that help make engagement meaningful: Research environment, Expectations, Support, Value

Black et al., 2018

Current study, led by Lili Zeidan

- Aims to describe what constitutes meaningful engagement in guideline development and the factors affecting its meaningfulness



MuSE-ES Guidance

Desirability

Consider the value of engagement for your project

Summary of guidance:

- reflect on whether engagement adds value to your project

Feasibility

Consider whether engagement is practical and achievable

Summary of guidance:

- consider the feasibility of engagement given resources and context.
- consider the teams expertise, time available, training, funding and other required resources

Who

Who should we engage in evidence synthesis?

Summary of guidance:

- review the perspectives offered by the TIPs
- consider equity principles which includes diversity of representation, strategies to ensure equitable practices, and strategies for selection, and recruitment.

When

When in the evidence synthesis will you engage interest-holders?

Summary of guidance:

- consider each step of evidence synthesis and the potential role of interest-holder engagement at each step

How

How will you engage interest-holders?

Summary of guidance:

- consider the level of control over decisions, and the approach to engagement

Reporting & Evaluation

How to report and evaluate engagement in evidence synthesis

Summary of guidance:

- consider tools and resources for reporting engagement
- consider methods for evaluating engagement, including the impact of engagement



Assessing feasibility

Authors need to consider:

- The experience, expertise, timelines, funding, and networks available to them
- Whether there is institutional support for engagement
- Whether the team would be able to use resources for
 - Training and recruitment
 - Connecting with interest-holders
- Whether the timeline can be modified
- Whether minimal engagement would be appropriate (e.g. top and tail approach)



How do you choose individuals to engage?

Consider factors such as:

- Ability/willingness to represent interest-holder group
- Commitment/time capacity
- Expertise/experience
- Potential conflicts of interest
- Inclusivity
- Training, support, and funding needs
- Barriers for engagement
- Accessibility requirements



When does engagement typically occur in the review process

Scoping review of methods of engagement

- 42% of the 272 evidence syntheses used a “**top and tail**” approach
 - Top and tail included the steps of **setting the scope** and **defining the review questions** (during protocol development) as well as **interpreting the results**
 - Most common (14%) at the stages of interpretation of findings and data synthesis
- 13% reported engagement “throughout” or “within” the review process
 - We have examples of successful engagement throughout all steps of the review, including technical steps
- In 25% engagement was unclear
 - Better reporting is required



Common barriers to engagement

- Time
- Recruitment of interest-holders including representative and diverse individuals
- Funding/compensation needed to pay some interest-holders, particularly patients/public.
- Human resource needs – coordination of engagement is time consuming and logistically challenging.
- Knowledge/experience of methods of engagement
- Lack of understanding or knowledge about evidence synthesis
- Power imbalances and tokenism
- Academic research is slow and we lose team members/interest over time.



Key messages

1

Engage early –
during protocol
development

2

Be clear about
expectations,
roles, decision-
making power

3

Use accessible,
two-way
communication

4

Build in feedback
loops

5

Evaluate and
reflect on the
engagement
process



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Levels of engagement

Levels of decision-making:

Contributing	provide views, feedback, opinions, experiences
Influencing	provide data or information which can directly influence the evidence synthesis but without direct control over the decisions
Controlling	work in partnership with researchers making decisions and/or controlling aspects of the evidence synthesis
Leading	initiate the synthesis and have responsibility for carrying out and completing it