Cochrane Rapid Reviews Learning Live webinar series:

Bridging the Gap - Involving Knowledge Users in Rapid Reviews

Cochrane Rapid Reviews Methods Group

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Disclosures

Financial competing interests:
ACT receives payment as the Co-Editor in Chief of the Journal of Clinical Epidemiology receives and a stipend as an Associate Editor for the Journal of Clinical Epidemiology; CG provides advice to Cochrane Response.

Academic competing interests:
ACT holds a Tier 2 Canada Research Chair in Knowledge Synthesis several grants to advance the science of knowledge synthesis/translation

ACT is the Nominated Principal Investigator of the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) Evidence Alliance

Other competing interests:
ACT (unpaid Associate Editor for Systematic Reviews and sits on the Editorial Board as an unpaid member for the BMC Medicine and JBI Evidence Synthesis journals). CG sits on the Editorial Board as an unpaid member for Cochrane’s Evidence Synthesis and Methods journal. CG is also an unpaid member of Cochrane’s Methods Executive and Co-convenor of the Cochrane Rapid Reviews Methods Group. MS is an unpaid Co-convenor of the Cochrane Co-Production Methods Group.
Today’s Session

➢ Aim is to increase understanding as to how to involve knowledge users (KUs) in rapid reviews (RRs)

Part 1. Setting the Foundation
• Key definitions to centre the discussion
• Context: Importance of involving KUs in RRs
• Opportunities during the review process to get KUs involved
• Other considerations

Part 2. Insights from the Experts
• Case Example
• Offer insights on considerations when involving KUs in RRs (fireside chat)

Part 3.
• Open discussion/questions
Part 1. Setting the Foundation
Poll Question

What level of experience do you have involving knowledge users (key stakeholders) in the production of rapid reviews or systematic reviews?

1. I am at the beginner level (no experience)
2. I am at the intermediate level (some experience)
3. I am a pro and could lead this webinar
Cochrane Rapid Review

Definition:

‘A type of evidence synthesis that brings together and summarises information from different research studies to produce evidence for people such as the public, healthcare providers, researchers, policymakers, and funders in a systematic, resource-efficient manner. This is done by speeding up the ways we plan, do and/or share the results of conventional structured (systematic) reviews, by simplifying or omitting a variety of methods that should be clearly defined by the authors.’

*Developed with the input of patient and public partners as part of a collaborative Priority Setting Partnership on rapid reviews (led by Evidence Synthesis Ireland).¹-³
Knowledge User

Definition:

• A knowledge user is defined as an individual who is likely to use research results to make informed decisions about health policies, programs and/or practices.

• It can more broadly imply an individual or group who may be responsible for or affected by health-related and healthcare-related decisions that research can inform.

• The term KU includes, for example, clinicians and their professional associations, healthcare policy-makers, patients, caregivers, patient groups, researchers, government agencies and the public.

• The main goal of KU involvement in health research is to co-produce or co-create evidence that is relevant and useful for making real-world healthcare decisions, ultimately to increase the uptake of evidence into practice.
Importance of Knowledge Users

• Active KU involvement is widely accepted to enhance the quality, relevance, and impact of health research.

• National strategies in many countries emphasize the importance of involving KUs in all research activities, including primary research and evidence synthesis [e.g. Canada (SPOR), UK (James Lind Alliance/INVOLVE), US (PCORI)].

• For RRs, each KU group (patient and public partners, healthcare providers, and policy-makers) offers a unique perspective to inform goals, objectives, questions, outcomes, and interpretation of findings.

• Close collaboration with KUs is crucial to ensure feasibility and relevance in the context of timely decision-making for RRs.

• One study suggests that when KUs are involved in RRs, it has a considerable impact on study results, making them more relevant to patients and policy-makers (Feldmann 2019).4
Knowledge Users & Rapid Reviews

• RRs have gained traction in the field of evidence synthesis, as they offer a quicker alternative to traditional SRs, which can be time-consuming and resource-intensive, making RRs valuable in situations where rapid decision-making is required.

• Proven useful, for example, in emergent situations, for time-sensitive clinical decisions, and rapid guideline development

• Formal involvement of knowledge users (KUs) is often limited, omitted or not reported in the conduct of RRs (Feldmann 2019; Garrity 2020).

• Based on systematic reviews, there are potential ways to involve KUs in reviews to varying degrees.

• However, there is a lack of guidance on how and when to involve KUs meaningfully in RRs, given the demands of shorter timelines to complete them.
Knowledge Users & Rapid reviews

- RRs often necessitate the involvement of policymakers or decision-makers as commissioners of RRs; with healthcare providers often involved as experts as well as end-users.
- Patient and public partners play a crucial role as they are the ultimate end-users of research evidence from RRs.
- For meaningful patient and public partner involvement in RRs, which is lacking – we need to think about innovative approaches.

Recent priority setting initiative:

#1 What are the best approaches to identify people or groups who will use the results of a rapid review (e.g., stakeholders such as patients and the public, clinicians, policy makers), and how can they have meaningful (i.e., purposeful, relevant) involvement in planning and doing a rapid review, and in reporting and sharing the findings? (Priority III, Beecher C. 2023)³

*Cochrane Rapid Reviews Methods Guidance Recommendation 1: Involve knowledge users to set and refine the review questions, eligibility criteria, and the outcomes of interest, with consultation at various stages of the RR. (Garritty, 2021)¹
Knowledge Users in Rapid Reviews

- Cochrane Rapid Reviews Method Group is leading a series of papers in BMJ Evidence-based Medicine (EBM) to guide general RR methods.
- First paper discusses importance of involving KUs in developing RRs (Garritty 2023)\(^6\)
- Outlines opportunities to involve KUs in planning, conduct and KT, and various modes of engaging them during the RR life cycle.
- Offers suggestions that research teams should consider to facilitate their involvement.
## Ways of Involving Knowledge Users in RRs to Varying Degrees

<table>
<thead>
<tr>
<th>1) Pre-planning of a RR</th>
<th>2) At the initiation and planning of the RR</th>
<th>3) During Conduct of the RR</th>
<th>4) At the end of the RR</th>
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<tbody>
<tr>
<td>Provide help with:</td>
<td>Provide input in:</td>
<td>Actively participate in</td>
<td>Developing key messages</td>
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<tr>
<td>• Determining <strong>relevance of a topic</strong> and to identify priority areas for RRs</td>
<td>• Defining the research question and review objectives</td>
<td>screening, selecting and extracting articles or more commonly, provide input about whether <strong>specific studies meet eligibility criteria</strong>, <strong>identify data elements</strong> for extraction</td>
<td>and other knowledge translation activities including:</td>
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<tr>
<td>• Developing a KU recruitment strategy (they may know of others)</td>
<td>• Prioritising and defining outcomes of interest</td>
<td>Providing <strong>input into data analysis or synthesis</strong> by reviewing results</td>
<td>• <strong>Writing</strong> or reviewing a plain-language summary or other product (e.g., infographic, video)</td>
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<td>• Co-developing an engagement policy or plan</td>
<td>• Reviewing the planned approach or protocol</td>
<td>Providing <strong>interpretation</strong> of findings most relevant to them (put context around some of the findings)</td>
<td>• <strong>Promoting the RR</strong> with other KUs (e.g., social media, talks or presentations)</td>
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<td>• Conceptualising review topics prior to stage 2</td>
<td>• Setting or providing input into the eligibility criteria</td>
<td>• May also <strong>review the draft</strong> or <strong>draft a section of the report</strong> (e.g., key findings; implications of findings)</td>
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<td>• Planning for specific KU involvement</td>
<td>• Providing seed studies to facilitate search efforts</td>
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<td>• <strong>Fostering relationships between other KUs and researchers</strong></td>
<td>• Providing key terms to include in the literature search</td>
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Ways and Levels of Involving Knowledge Users in RRs

• At the outset, teams should review ACTIVE (Authors and Consumers Together Impacting on eVidencE) framework\(^7\), which describes the range of methods and approaches for involving different types of KUs in SRs.
  – Outlines a continuum of KU involvement from receiving information about a review to leading the initiation and completion of a review.

• By extension, this could support RR authors in planning and reporting KUs involvement at the different stages


![Figure 1: The ACTIVE framework of involvement in a systematic review](image-url)
Differing Modes of Involving Knowledge Users

- As with SRs, there are various modes of engaging KUs in RRs, and each RR can employ a combination of different methods during the review lifecycle.
- Considering the time pressure in a RR, specific modes (e.g., workshops, interviews) may be more beneficial for RRs with a few months or more time.
- On the other hand, for more urgent RRs conducted in less time, regular meetings and email communications or a short survey are probably easier to integrate into the process.

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## Challenges to Involving Knowledge Users in Rapid Reviews

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<th>Challenge</th>
<th>Description</th>
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<tr>
<td>Lack of ‘know how’ to do it properly</td>
<td>If researchers lack the knowledge and strategies for effectively engaging KUs, they may results in tokenistic involvement, or, in some cases, they may even opt to forgo such involvement altogether.</td>
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<td>Lack of time</td>
<td>RRs usually have tight deadlines, which can make it hard to involve and work closely with KUs (not enough time to identify people or to properly prepare for their involvement; challenging to find meeting times that work for everyone and making sure everyone is available).</td>
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<td>Lack of funding to do this properly</td>
<td>RRs are frequently done with limited resources, and this can make it challenging to involve KUs and limit the ability to engage them meaningfully.</td>
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<td>Belief that involvement won’t work or will slow things down</td>
<td>Thoughts that KUs can make the process more complicated or slower. This might mean the need for more time and expertise to manage it properly.</td>
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<td>Lack of KU interest/belief views won’t matter</td>
<td>KUs might think they don’t have enough experience to get involved, that their thoughts won't really influence the review, or that the findings are already decided in advance.</td>
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Other Considerations

**Be Prepared**
(Become knowledgeable of KU engagement methods and start to think about necessary resources to involve KUs; be mindful of methods that promote equity, diversity and inclusion in RRs - see SPOR Evidence Alliance resources)

**Develop an Engagement Plan**
(Detailed plan is key for collaboration with KUs; include description of roles; training needs, logistics and resources required - see SPOR Evidence Alliance resources)

**Secure Required Resources**
(especially for patient partners who may need access to a computer, Internet, screening software; and possibly training to participate)

**Highlight the Patient and Public Perspectives**
(RR teams should consider including a separate section devoted to this as part of the RR report or summary; a means of getting the patient/public voices closer to that of health policy decision-makers)

**Report KU Involvement**
(Authors of RRs should describe all KU involvement in the methods section of the RR report/publication; consider using the GRIPP2 reporting checklist - international guidance for reporting patient/public involvement in research; also a checklist short form)

**Evaluate KU Involvement**
(From all perspectives including the KUs and those of the researchers; lessons to be learned from all sides; existing evaluation tools can be adapted for use with RRs)

**Anticipate Potential Barriers**
(And, monitor throughout the process to mitigate issues)
**Start early**
- Develop KU partnerships before conducting RRs (assist KUs to prioritize questions of urgency; recruit a roster; possibly train in advance)
- The earlier KUs are engaged, the more they will know about it and be able to effectively contribute

**Provide training**
- Assume that both researchers and KUs on the team will need some degree of training; in addition to experts and decision-makers; aim to engage >1 patient or public partner

**Compensation**
- For patient and public partners, provide fair compensation; reimburse for meeting and travel related expenses, etc.

Credit: https://sporevidencealliance.ca/about/policies-procedures/
A. **Cochrane Equity**: provides methodological guidance for considering equity for stakeholder engagement and for the review process - [https://methods.cochrane.org/equity/projects/evidence-equity/progress-plus](https://methods.cochrane.org/equity/projects/evidence-equity/progress-plus)


E. **Short form of the GRIPP2**: [https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0062-2/tables/2](https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-017-0062-2/tables/2)


- Other tools available that could be adapted for use with RRs as per BMJ-EBM paper (e.g., PEIRS-22 (short form); Public and Patient Engagement Evaluation Tool (PPEET) McMaster University)
Part 2. Real world example & an insights from the experts
Case Example from the Real World
(Description)

• The Strategy for Patient Oriented Research (SPOR) Evidence Alliance, in collaboration with the COVID-19 Evidence Network to support Decision-making (COVID-END) recognized the need for the patient and public involvement in COVID-19 rapid reviews (RRs) and in 2020, quickly mobilized to provide meaningful engagement opportunities for patients (referred to as citizen partners for COVID-END) in the production of RRs.

• Initiative brought together a group of willing Canadians, most of whom had never been engaged in evidence synthesis products and some who were engaging as public partners for the first time.
Expert Insights (A fireside chat)
Cochrane Co-Production Methods Group

Launched September 2023 at Cochrane Symposium
Co-Convenors: Alex Todhunter-Brown, Richard Morley, Maureen Smith

Founding Members:
Richard Morley - Cochrane
Jo Thompson Coon – Exeter University
Lyuba Lytvyn - McMaster University
Vivian Welch – Campbell Collaboration
Catherine Marshall – Cochrane Board
Annie Synnott – Monash University
Jack Nunn - Consumer Network Executive
Rebecca Rees - University College London, UK.
Maureen Smith – Cochrane Consumer Network Executive
Alex Todhunter-Brown – Glasgow Caledonian University
Rachel Plachcinski - Consumer Network Executive
Jennifer Petkovic - University of Ottawa
Ana Beatriz Pizarro – Cochrane Consumer Network

Helen Bulbeck - Consumer Network Executive
Sophie Staniszewska – Warwick University
Nicole Pitcher -- Cochrane volunteer
Biljana Macura - Stockholm Environment Institute
Zoe Jordan - The University of Adelaide
Danielle Pollock The University of Adelaide-
Andrea Tricco – Unity Health
Kate Boddy - University of Exeter Medical School
Chantelle Garrity - University of Split
Ursula Griebler - Danube University Krems
Dominic Ledinger - Danube University Krems
Brigitte Piso - Danube University Krems
Barbara Nussbaumer-Streit - Danube University Krems
Additional Resources:

https://training.cochrane.org/ACTIVE

https://training.cochrane.org/involving-people
Poll Question

Now that you have some additional information on involving KUs in rapid reviews, how likely is it that you will include them in your future rapid reviews?

1. Very likely
2. Likely
3. Neutral
4. Unlikely
5. Very Unlikely
6. I will NOT include them
Aim to minimize barriers to involvement:

- Preparation and training is key
- Clear communication of timelines and expectations is critical
- Build trust - take time to establish mutually respectful relationships
- Be transparent - make everyone aware of all relevant information
- Acknowledge differing and/or conflicting priorities and perspectives
- Be aware of possible power imbalances
- Aim to avoid tokenism; make involvement as meaningful as possible

Create a positive, inclusive environment:

- Be open and genuine, enthusiastic, curious with your KUs
- Share information, ideas and experiences
- Listen actively, invite others to talk and be respectful when there are differing opinions
- Summarize/paraphrase to check for understanding
- Acknowledge KU contributions (e.g., co-authors, acknowledgments; as they prefer)

Credit: https://sporevidencealliance.ca/about/policies-procedures/
Summary

• Putting KU involvement into practice for RRs can be challenging.
• Various ways and degrees to which RR teams can engage key KU groups in the production of RRs.
• KU involvement should start with planning, open dialogue and be integrated into the project plan and timelines.
• For RRs, a key tension exists when balancing ‘rapid’ with meaningful involvement; some cases, involving KUs might not be possible.
• Key upside of involving KUs during RRs is that it can kick-start discussions on practice, policy, and implementation, and foster research collaborations.
• Bottom line - effective KU involvement is vital for meaningful and impactful RRs.
Upcoming Cochrane Rapid Reviews Learning Live webinar series:

- **Tuesday 14 November 2023, 09:00 UTC**  
  **Literature search in rapid reviews**  
  Irma Klerings, Information specialist, Department for Evidence-based Medicine and Evaluation, University for Continuing Education Krems.

- **Tuesday 12 December 2023, 09:00 UTC**  
  **Team considerations, study selection, risk of bias and data extraction in rapid reviews**  
  Barbara Nussbaumer-Streit, Co-director, Cochrane Austria and Researcher, Department for Evidence-based Medicine and Evaluation, Danube University Krems. Co-convenor of the Cochrane Rapid Reviews Methods Group

- **Thursday 25 January 2024, 15:00 UTC**  
  **Evidence synthesis and certainty of evidence ratings in rapid reviews**  
  Gerald Gartlehner, Professor of Clinical Epidemiology & head of the Department of Evidence-based Medicine and Evaluation, Danube University Krems, Austria. Co-convenor of the Cochrane Rapid Reviews Methods Group

- **Wednesday 28 February 2024, 14:00 UTC**  
  **How to do a rapid qualitative review**  
  Professor Andrew Booth, Professor in Evidence Synthesis, Sheffield Centre for Health and Related Research (SCHARR), University of Sheffield.

- **Tuesday 12 March 2024, 09:00 UTC**  
  **How to do a rapid scoping review**  
  Fiona Campbell, Senior Lecturer in Evidence Synthesis, Institute of Population Health Sciences and Innovation Observatory, Newcastle University.

[https://training.cochrane.org/cochrane-rapid-reviews-learning-live-webinar-series](https://training.cochrane.org/cochrane-rapid-reviews-learning-live-webinar-series)
Part 3. Open Discussion
Thank you!

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References


