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Rapid Reviews Methods Series: Involving patient and public partners, healthcare providers and policymakers as knowledge users

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Abstract

Rapid reviews (RRs) are a helpful evidence synthesis tool to support urgent and emergent decision-making in healthcare. RRs involve abbreviating systematic review methods and are conducted in a condensed timeline to meet the decision-making needs of organisations or groups that commission them. Knowledge users (KUs) are those individuals, typically patient and public partners, healthcare providers, and policy-makers, who are likely to use evidence from research, including RRs, to make informed decisions about health policies, programmes or practices. However, research suggests that KU involvement in RRs is often limited or overlooked, and few RRs include patients as KUs. Existing RR methods guidance advocates involving KUs but lacks detailed steps on how and when to do so. This paper discusses the importance of involving KUs in RRs, including patient and public involvement to ensure RRs are fit for purpose and relevant for decision-making. Opportunities to involve KUs in planning, conduct and knowledge translation of RRs are outlined. Further, this paper describes various modes of engaging KUs during the review lifecycle; key considerations researchers should be mindful of when involving distinct KU groups; and an exemplar case study demonstrating substantive involvement of patient partners and the public in developing RRs. Although involving KUs requires time, resources and expertise, researchers should strive to balance 'rapid' with meaningful KU involvement in RRs. This paper is the first in a series led by the Cochrane Rapid Reviews Methods Group to further guide general RR methods.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Formal involvement of knowledge users (KUs) is often limited, omitted or not reported in the conduct of RRs. 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.

WHAT THIS STUDY ADDS

⇒ This study discusses the importance of involving KUs (ie, patient and public partners, healthcare providers and policy-makers) in developing RRs, provides detailed steps on how and when to involve KUs, including patient and public involvement, and offers suggestions that research teams should consider to facilitate their involvement.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Those producing RRs for decision-making purposes should consider how best to include various KUs as involvement will enhance the relevance and applicability of RRs. Meaningful KU involvement requires time, resources and advanced planning, given the condensed timelines of RRs.

Introduction

This paper is the first in a series led by the Cochrane Rapid Reviews Method Group to further guide general RR methods.[1 2 3] In healthcare, rapid reviews (RRs) are a practical evidence synthesis tool used to synthesise evidence for decision-makers more quickly. RRs streamline or omit certain systematic review (SR) methods to produce evidence in a resource-efficient manner, accelerating the process compared with traditional SR methods or other types of evidence synthesis.[4] Ideally, RRs should be designed to maximise relevancy for key end-users,[5] who use the research derived from them to inform choices and decisions. In healthcare, there is now widespread acceptance and use of RRs among clinicians, health system managers, policy-makers, patients and members of the public.[6–10]

For RRs, the term 'knowledge user (KU)' refers to an individual who is likely to use the knowledge generated through research to make informed decisions about health policies, programmes or practices.[11] It can more broadly imply an individual or group who may be responsible for or

affected by health-related and healthcare-related decisions that these reviews can inform.[11 12] Therefore, the term KU includes but is not limited to, clinicians and their professional associations, healthcare policy-makers, patients, caregivers, patient groups, government agencies and the public.[13] The main goal of KU involvement in health research is to coproduce evidence that is relevant and useful for making real-world healthcare decisions, and to increase the uptake of evidence into practice.[14]

RRs are often commissioned by governments, health system decision-makers, international organisations and other groups when urgent or timely decisions are required, and sometimes because of resource limitations, namely funding.[15 16] Those who have undertaken RRs for urgent and timely decision-making purposes understand that by their very nature, they often necessitate close collaboration between decision-makers usually as commissioners of the RR and researchers.[17] However, one study found that formal KU consultation is often limited, omitted or not reported in the conduct of RRs.[18] In this study, based on a sample of 103 RRs, although two-thirds reportedly targeted policy-makers and key KUs as the intended audience, less than one-third of these same reviews reported engaging with KUs directly to discuss and review content for relevance and clarity. Moreover, only 6% of these RRs reported including patients as KUs in the RR process.[18] As evidenced from SRs, there is a range of ways to potentially involve KUs in RRs and to varying degrees.[19] However, involving KUs takes time and resources, and involvement can be overlooked during an accelerated review process.

Over the last number of years, seminal RR guides have been developed, each with a different focus (eg, health policy and systems research[20] public health[21]) and an emphasis on the importance of involving key KUs in the RR process. More recently, Cochrane also developed guidance that provides recommendations for conducting RRs.[22] One of the first recommendations outlined in the guidance is to involve key KUs to set and refine the question, eligibility criteria and the outcomes of interest. Further, Cochrane RR guidance recommends consulting with a broad group of KUs throughout the process to ensure research is fit for purpose and to discuss any necessary post-hoc changes that may occur as the RR progresses.[22] This recommendation aligns with Cochrane's recently adopted framework of KU involvement, of which a key premise is coproduction of reviews alongside patients and carers.[23] Nonetheless, existing RR guidance lacks detailed steps on how and when to engage KUs, including patients and public partners, in RRs. This article, therefore, discusses the importance of KU involvement, highlights potential ways to engage users and details stages of KU involvement in the RR process. This paper is the first of a collaborative, multiple-part series, led by the Cochrane Rapid Reviews Methods Group to provide comprehensive guidance on RR methods for all those interested in RR methodology.

The importance of involving KUs in the RR process

The involvement of KUs has been described as an iterative process of actively soliciting a broad range of interests to create a shared understanding and making relevant, transparent, and effective decisions.[24] It is now widely accepted that active KU involvement is beneficial to the quality, relevance and impact of health research.[25] Bringing together multiple KUs in a transparent, equitable and evidence-based way has driven national strategies in many countries to ensure involvement in all research activities relevant to both primary research and evidence synthesis.[26–29]

Specific to RRs, typically patient and public partners, healthcare providers and policy-makers are the key KU groups involved. Healthcare providers contribute clinical expertise to RRs, and deliver care directives that may be derived from RRs. Policy-makers are decision-makers, who shape the rules and regulations that govern our health and may contribute policy-relevant aspects (eg, care delivery, access, costs) to RRs. Finally, patient and public partners contribute lived experiences of a health issue. Therefore, each KU group brings a unique perspective to inform the goals and objectives of RR, and their involvement aims to ensure that their respective perspectives are reflected in the RR questions, outcomes measured and interpretation of findings.

Close collaboration is essential in the context of RRs. It allows opportunities for KUs to interact meaningfully throughout the process, ensuring the RR is feasible (ie, involvement that helps focus the scope and conduct of the RR making it more doable) and that results are relevant in the context of timely decision-making.[5] Although few efforts have directly reported the effects of KU involvement in RRs, a recent study, which included a small select sample of RRs (n=30), found that 13 (43%) RRs identified involved KUs.[30] Of these, 11 review authors surveyed confirmed that KU involvement had considerable effects on the study results, thereby making the RR more relevant to patients or policy-makers.[30]

As the ultimate end-users of research evidence stemming from RRs, it is essential to highlight the significance of patients (often referred to as patient partners) and members of the public as key KUs. Research suggests that individuals who are engaged in their health are more likely to achieve better health outcomes.[25 31] Although examples of patient and partner involvement in SRs exist,[32–34] involving patient and public partners in evidence synthesis is often limited or overlooked primarily due to a lack of guidance and promising ways to effectively engage them in the design and conduct of evidence synthesis.[35] To date, patient and public partner involvement in RRs has also been limited[18 30] and requires innovative ways to feasibly involve patients in planning, expeditious conduct and knowledge translation of such reviews.[36]

Because RRs is an evolving field, currently there is limited evidence to draw on to inform KU involvement. However, there is movement in the field. A recent priority setting partnership determined the top 10 unanswered research questions for RRs.[37] Ranked highest was how to determine the best approaches to identify people or groups that will use the results of RR, and how they can have meaningful involvement in the various stages of a review. Also, highly ranked was determining how underserved stakeholder groups (eg, ethnic minorities, socioeconomically disadvantaged) and stakeholders from under-represented jurisdictions (eg, countries of different income levels) can best be identified and have meaningful involvement in RR. Therefore, KU involvement in RRs is an important area of interest as determined by researchers and KUs.

Ways and levels of involving KUs in RRs

At the outset, research teams should review the ACTIVE (Authors and Consumers Together Impacting on eVidencE) framework, which describes the range of methods and approaches for involving KUs in SRs.[38] The ACTIVE framework outlines a continuum of KU involvement from receiving information about a review to leading the initiation and completion of a review. By extension, this framework could support RR authors in planning how to involve KUs at the different stages of the review process. There are opportunities to engage KUs at the1) preplanning, 2) initiation and planning stages, 3) during the conduct, and 4) at the end of RR (see table 1 adapted from).[39] Practically, the extent of involvement may entail several touch points if KUs are included in a more integrated approach as team members.[19 39 40]

Table 1 Stages of KU involvement in rapid reviews (RRs)

(1) Preplanning of the RR	(2) At the initiation and planning of the RR	(3) During conduct of the RR	(4) At the end of the RR
Provide input in: ► Identifying priority areas for RRs ► Developing a KU recruitment and involvement strategy ► Codeveloping an engagement policy or plan together with KUs ► Conceptualising review topics prior to stage (2) ► Planning for KU involvement for a specific RR ► Facilitate developing relationships between other KUs and researchers	Provide input in: ► Defining the research question ► Prioritising and defining outcomes of interest ► Developing or reviewing the protocol ► Setting or providing input into the eligibility criteria ► Providing seed studies to facilitate search efforts ► Providing key terms to include in the literature search	► Selecting studies, whether by screening studies for including or providing input about whether specific studies meet eligibility criteria ► Extracting data, whether identifying data elements for extraction or participating in the data extraction itself ► Providing input into data analysis or synthesis of results ► Providing interpretation of results and findings most relevant to them ► Drafting or reviewing the resulting report	► Developing key messages and other knowledge translation activities including: ► Writing or reviewing a plain-language summary or other product (eg, infographic, video) ► Promoting the RR with other patient/public partners and other KUs (eg, social media, talks or presentations)

KU, knowledge user; RR, rapid review.

1. At the preplanning stage of a RR, KUs can be involved in determining topic relevancy and identifying priority areas for a review. Consider implementing a formal priority-setting exercise for those KU groups with many topics in contention for a RR. KUs can help to identify representatives of several groups and can facilitate establishing additional KU relations. KUs may also be instrumental in the preplanning and conceptualisation of a RR. In consultation with KU partners, agree on a plan that will work with what a researcher can offer that aligns with the KUs' expectations and skill set.
2. At the initiation and planning stage of a RR, KUs can be involved in helping define the review objectives, including the RR questions. They can assist by reviewing the planned approach as part of the protocol. They can also provide input on the inclusion criteria. KUs can also support the literature search by providing a list of seed articles and key terms that should be considered. The SelecTing Approaches for Rapid Reviews tool was developed to aid review authors in planning the most suitable approach when conducting a RR[41] and is something research teams could consider using to seek KU input in a structured way. The tool provides a series of questions the research team goes over with the RR commissioner to elicit the RR's purpose and context, the questions to be answered, and how the RR will be conducted and used.
3. During the conduct of a RR, the process of including KUs is similar to SRs. They can take an active role in helping to screen, select and extract articles. Even if not directly participating in screening or extraction, soliciting their input on certain studies for inclusion or assisting in identifying potentially relevant studies or data extraction items is worthwhile. Although it is not common for KUs to be directly involved in data analysis or synthesis of the results, a key opportunity is to have them check the results and interpretation of findings to see if they make sense. Although most KUs would not be directly involved in drafting the resulting report, they may be involved in reviewing the draft, identifying key findings and developing or reviewing the implications of findings to ensure that they are relevant to the intended audiences.
4. At the end of a RR, KUs can play an important role in knowledge translation activities. They can be involved in developing key messages, plain language summaries and other dissemination activities. KUs can also help draft evidence summaries used in knowledge brokering or participate in communication strategies targeting social media platforms (eg, Facebook, Twitter). Importantly, KUs, alongside researchers, can advocate for findings to be shared in relevant circles in the health systems community to ensure findings reach their intended audiences, including relevant decision-makers.

As with SRs, there are various modes of engaging KUs in RRs,[19] and each RR can employ a combination of different methods during the review lifecycle (see figure 1). Considering the time pressure in a RR, specific modes (eg, workshops, interviews) may be more beneficial for RRs with a few months or more timeline. 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.

Other considerations when involving KUs in RRs

If undertaking RRs, there are other considerations that teams should bear in mind if involving KUs. As detailed in table 2, among these is ensuring all team members are prepared for collaboration by securing necessary resources,[42] through skills development and practice of all team members, including KUs[43] and in an equitable manner.[44 45] It is also important to develop a KU engagement plan,[46] especially if working within tight timelines, as it will ensure a clear understanding of mutual expectations throughout the RR. KUs may require resources and training (including an onboarding session) to participate meaningfully in the review process. Any additional training will likely need to be tailored to the needs of the individual KUs involved. Further, providing information on the policies and procedures, including a compensation policy, is important to show recognition and appreciation of patient and public partner contributions.[47]

Another consideration is the importance of highlighting the patient and public perspectives of the evidence as part of a RR report or summary, as this aims to bring these voices closer to that of health policy decision-makers. KU involvement in the RR process should also be reported in the methods section of the review so it is clear and transparent how they contributed to the process.[48]

Recognising any potential barriers KUs may experience and strategising solutions in advance to manage these is critical. Therefore, at the outset, RR teams are encouraged to discuss with KUs what could hinder their involvement. For example, because

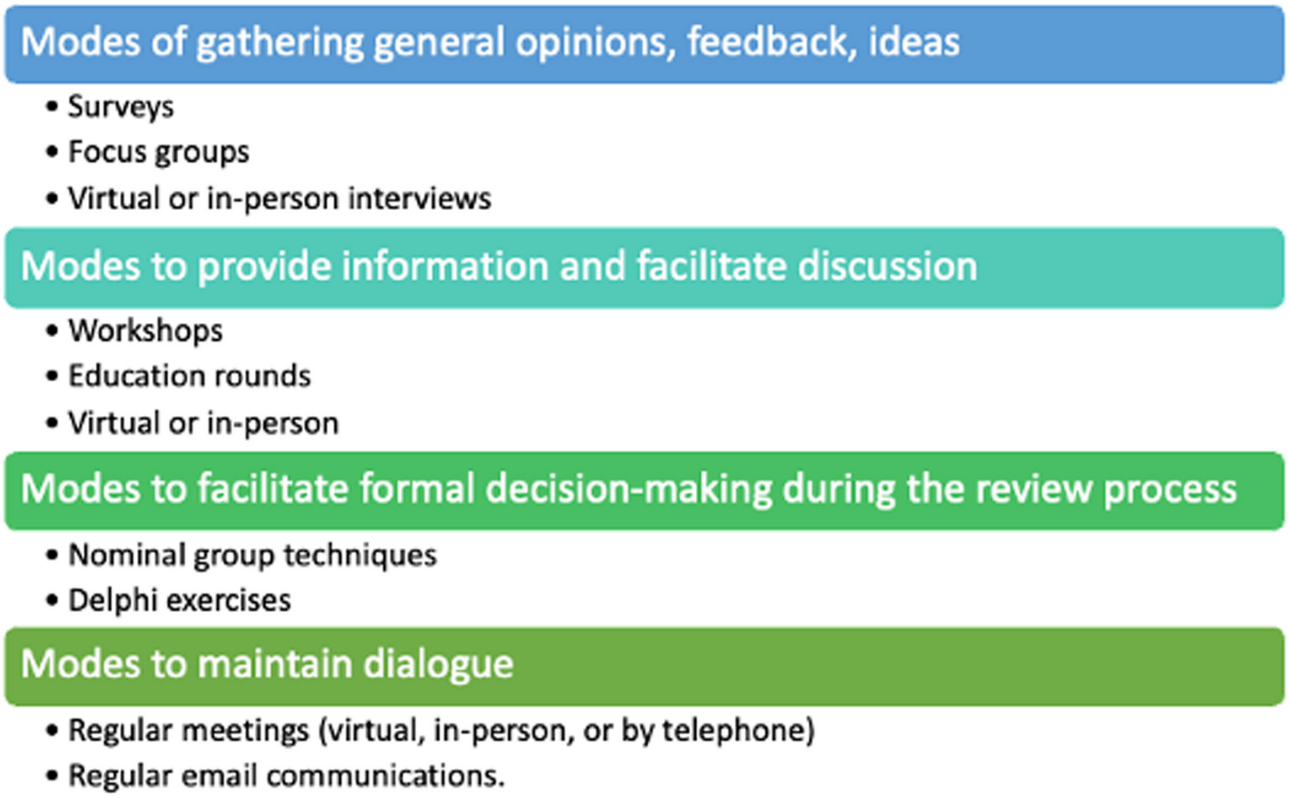

Figure 1 Modes of involving knowledge users.

the time to conduct a RR is a potential barrier to meaningful KU involvement, consider developing KU partnerships before conducting a RR. Therefore, when the need to address a question of urgency arises, teams could approach KUs who may be interested in being involved at the ready. Although not possible to anticipate all barriers ahead of time, be proactive in monitoring for issues that arise at the outset and throughout the process and address issues swiftly so timelines are not hindered. Furthermore, ensure that the condensed RR timelines are communicated in advance, allowing KUs to determine if the time commitment works for them.

The feasibility of KU involvement will be based on many factors and will range from project to project. Although undertaking the full spectrum of KU involvement may be possible in certain circumstances, this is not expected for all RRs. For example, the rapidity and demands of completing a RR on time may necessitate involvement at the lower end of the spectrum rather than at the higher end with full involvement throughout the process. Varying degrees of involvement along the spectrum is not necessarily problematic. However, ideally, the aim should be to strive for involvement towards the higher end of the spectrum to the extent possible. Regardless, KU involvement needs to be planned, with clear objectives and purpose, to ensure it is meaningful and not just a token effort. Last, RR research teams must also evaluate KU involvement by gathering the perspectives of KUs and researchers. It will provide a more holistic assessment of the inclusion of KUs to ensure everyone involved learns from the experience, to ensure tokenism is avoided and that future KU processes are refined as needed. Various evaluation tools can be adapted for use with RRs.[49–51] (See table 2 for additional details on these collective considerations).

Case examples

There are examples that illustrate iterative and collaborative multisectoral KU involvement processes in generating RR evidence to inform decision-making.[52–54] These examples serve as a reference for researchers who wish to involve KUs and develop impactful research evidence rapidly. In particular, we showcase a Canadian initiative, through the Strategy for Patient-Oriented Research (SPOR) Evidence Alliance, and in collaboration with the COVID-19 Evidence Network to Support Decision-Making, which mobilised meaningful involvement of patient partners and the public in developing COVID-19 RRs (see online supplemental file 1 for a brief description).[54] Not all RRs, particularly in low-income and middle-income countries,[55] will be adequately funded or resourced, thus making KU involvement less feasible. Nonetheless, this exemplar project is an example to learn from for planning and applying best practices for KU involvement in RRs.

Conclusions

A challenge to KU involvement in RRs is a lack of clarity about what it is and how to put it into practice. There are many ways producers of RRs can engage key KU groups ranging from receiving information about the RR or the results of the RR through to leading a RR and varying degrees in between. For meaningful involvement, those producing RRs for decision-making purposes should consider how best to include various KUs, starting with open dialogue, grounded in the premise that involvement enhances the relevance and applicability of reviews in the decision-making process,[5] and as similarly demonstrated for scoping reviews.[56] KU involvement will require time and resources with engagement at several potential time points during a RR. Involvement is, therefore, an essential component of a project plan from the outset and should be incorporated into timelines.[40]

Table 2 Other consideration when involving knowledge users (KUs) in rapid reviews (RRs)

Other considerations when involving knowledge users in rapid reviews (RRs)	
Prepare for collaboration	► At the outset, RR teams need to identify the necessary resources for involving KUs (eg, appropriate funds, human resources and staffing, access to training and equipment).[42] ► Knowing effective communication strategies is key to ensuring a cohesive team environment, as is having the background knowledge to facilitate meaningful involvement. ► RR team members may need training on KU engagement frameworks, specific methods and mechanisms to include a range of KUs within a RR. In addition, equity training is encouraged to ensure that the team respects the principles of equity, diversity and inclusion. ► When starting a RR, consideration should be given to starting the process with a self-reflective exercise to ensure the research is undertaken with an equity, diversity and inclusion lens.[44] Also available is methodological guidance for considering equity for RR stakeholder engagement and for the review process.[45]
Develop an engagement plan	► A detailed engagement plan is the foundation of your collaboration with KUs especially if working within tight timelines.[46] ► A description of KU roles can serve as the basis for discussion with your KUs, ensuring that they align with their expectations and skills and planned level of involvement. ► The plan should also consider training needs, logistics such as communication, reimbursement for expenses and compensation.[42] ► Acknowledgement of KUs (eg, as coauthors, mentioned in acknowledgements) and their own preferences as to whether they wish to be acknowledged should be in the plan. ► The plan should provide information on the policies and procedures in place, including a compensation policy, to show recognition and appreciation of patient and public partner contributions.[47]
Required resources and knowledge user training	► KUs may require training to participate meaningfully in the review process. An onboarding session with KU partners is an excellent opportunity to provide basic training on RRs and ascertain if more is needed. ► If KUs would like to learn more about RR methodology or wish to be involved in methodological tasks such as data extraction, the research team must discuss if they can do so within the team, or if they can fund external training. ► KUs, especially patient/public partners, may require resources such as a computer, access to the Internet and screening software, and possibly training to use these resources to participate in the RR process. ► Training should be tailored to the needs of the individual KUs involved and will depend on the engagement plan.
Highlight the patient and public perspectives	► ● RR teams should consider including a separate section devoted to the 'patient and public perspectives of the evidence' as part of the RR report or executive summary. ► ● Patient/public partners can advise on how research might impact one's health beyond an academic or policy or decision-making audience and is a means of getting the patient/public voices closer to that of health policy decision-makers.
Reporting knowledge user involvement	► Authors of RRs should describe all KU involvement in the Methods section of the RR publication. ► Consider using the GRIPP2 reporting checklist, which provides international guidance for reporting patient and public involvement (PPI) in health and social care.[48] This tool aims to improve the quality, consistency and transparency, helping to ensure the PPI in practice is based on the best evidence to improve reporting.
Anticipate barriers	► Some KUs may experience challenges surrounding digital literacy, accessibility issues (eg, access to research materials in an accessible format) and transportation costs. ► Efforts should also be made to mitigate potential power imbalances that are inherent when KUs collaborate with researchers such as a 'leave your title at the door' policy and by encouraging activities that allow researchers and KUs to learn about each other outside of their roles on the team (eg, shared interests, experiences). ► The team needs to be open to the lived experiences of the KUs involved and KUs integrated as members of the team.[44] ► Time to conduct a RR is also a potential barrier to meaningful KU involvement. As such, RR teams should consider developing KU partnerships before conducting RRs (eg, assist KUs to prioritise questions of urgency, recruit a roster of patient/public partners and provide training in advance). ► Ensure that the condensed RR timelines are communicated in advance, allowing KUs to determine if the time commitment works for them. Involvement of KUs may need to be tailored to match individual KU capacity.
Evaluation	► Existing evaluation tools can be adapted for use with RRs.[38 49–51] For example, National Institute of Health Research guidance describes four tools (ie, impact log, the cube framework, Public Involvement Impact Assessment Framework guidance and the Realist Evaluation).[49] ► The Patient Engagement in Research Scale,[51] and the Patient Engagement Evaluation tool[50] can also be used, with the latter used to evaluate engagement in an SR. ► Evaluating KU involvement, both from the perspectives of the KUs and those of the researchers, is essential in advancing KU involvement methods and could serve as an important indicator when assessing a RR's broader outputs and impact.
*When involving KUs in RRs, it is important to establish a process to proactively monitor issues that may arise at the outset of the review and throughout with the flexibility to make any necessary adjustments to facilitate the completion of the RR in a timely manner.	

For RRs, a key tension exists when balancing 'rapid' with meaningful involvement, and for some RRs, involving KUs may not be feasible. However, the downside of not doing this, or not doing it well, is a RR that may be less relevant or impactful, or require more dissemination effort after completion to improve uptake. On the other hand, working directly with KUs during a RR should be an opportunity to kick-start the process of discussing practice or policy implications and implementation considerations and may lead to longer-term research collaborations. Thus, there are many potential upsides to involving diverse KU groups in developing RRs. Ultimately, involving KUs in RRs should serve as a mechanism to ensure that research better meets the needs of those whose lives the research affects.

Patient and public involvement

A patient partner (MS) was a key member of the author team. MS provided input on the research question based on their priorities, experience and preferences, and contributed to the design of the article. MS was involved at all stages of the cocreation of this manuscript, from writing key components of the patient involvement section, to offering constructive input on the entirety of the article and writing this statement. MS will be involved in a

dissemination plan to share the article with her extensive global patient and public involvement networks in a manner that is relevant to them and meets their needs for this information.

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Supplemental File 1.

Exemplar project – Involving knowledge users (KUs) in rapid reviews[51]

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

The main challenges of this knowledge user involvement are:

(1) Tight timelines that are difficult for both the researchers and their KU partners, as time to develop the partnerships is limited and the window of opportunity to provide feedback is tight;

(2) RRs where involvement at the initial stage is limited because the commissioner has prescribed a specific question, which did not provide space for suggested modifications; and

(3) Little time for training of both the research team and the partners.

It is of vital importance to be transparent about the challenges and to allow the KU partners to make their own decisions about whether they are willing to work under these conditions as well as offer solutions to the challenges when possible.

Key enablers have been:

(1) A SPOR Evidence Alliance 10-hour training program to prepare 24 patient and public partners to meaningfully engage with Canadian researchers conducting RRs by providing basic knowledge of evidence synthesis and, specifically, RRs as well as addressing the unique challenges of patient and public involvement in the production of rapid evidence during the COVID-19 pandemic (note: all patient and public partners who took the course have been engaged across 18 projects since June 2021);

(2) Available resources for RR teams (e.g., a patient/public partner request form, webinars highlighting RR engagement, appreciation policy co-developed by patient and public partners);

(3) Contact people from the SPOR Evidence Alliance and COVID-END collaborating with researchers to "match" patient/public partners and follow up on lessons learned; and

(4) Sharing best practices through webinars and workshops.

Further information is available at:

https://sporevidencealliance.ca/resources/webinars/

https://sporevidencealliance.ca/resources/for-researchers/

A list of completed projects is available at:

https://sporevidencealliance.ca/key-activities/covid-19-evidence-synthesis/

* Noted that patient/public partner names are listed for each RR