McMaster University | Health Forum

Living Evidence Profile #9

Putting evidence at the centre of everyday life: Engaging citizens in asking questions and answering them

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[MHF product code: LEP 9d]

Context

- The Global Commission on Evidence to Address Societal Challenges (the Global Evidence Commission), which began in 2022 as a grassroots effort to improve the use of research evidence, prioritized action to put evidence at the centre of everyday life.
- To further understand the strategies that can be used to put evidence at the centre of citizens' everyday lives, the Global Evidence Commission consulted with subject-matter experts and citizen partners, including the Citizen Leadership Group and a series of citizen panels, and developed a list of five potentially promising strategies that could help to achieve this aim.
- This living evidence profile (LEP) addresses **strategy 4,** which focuses on engaging citizens in asking questions and answering them and includes a number of sub-strategies that could be used to enable the engagement of citizen partners as key contributors to all stages of the research process.
- These sub-strategies include creating websites where citizens can submit their questions to organizations funding research, having citizens engaged in prioritizing questions from all of those received, encouraging citizens to become partners in a research team to answer the question if the question requires new research, offering pathways to facilitate citizen-led research initiatives, and – if evidence is already available to answer the question – encouraging citizens to become partners in teams that are dedicated to summarizing existing evidence on the question.
- This LEP is the fourth in a series of five that collectively aim to examine what is known from the best-available evidence documents about the full list of strategies developed by the Global Evidence Commission for putting evidence at the centre of everyday life, including:
  1. make evidence-based choices the default or easy option (LEP 9a)
  2. make evidence available to citizens when they are making choices (LEP 9b)
  3. help citizens judge what others are claiming or find (and receive) reliable information on a topic (LEP 9c)
  4. engage citizens in asking questions and using new or existing evidence to answer them (this synthesis, LEP 9d)
  5. help health and social systems learn and improve rapidly and contribute to a society-wide transformation (LEP 9e).

Box 1: Evidence and other types of information

+ Global evidence drawn upon

Evidence syntheses and single studies selected based on relevance, quality and recency of search

+ Additional forms of evidence used

Qualitative insights

Evaluation

*** Additional notable features**

Prepared with input from two citizen partners

Question

What is the best-available evidence related to engaging citizens in asking questions and using new or existing evidence to answer them?

High-level summary of key findings

- We identified 88 evidence documents (57 evidence syntheses, 27 single studies and four protocols) across the four sub-strategies listed in the framework below related to engaging citizens in asking questions and answering them.
- The evidence showed that priority setting partnerships (PSPs) that bring together patients, families and caregivers, and healthcare professionals to set health research priorities have been an effective strategy for engaging citizens in research.
- The evidence documents included in our analysis emphasized that the engagement process should include notions of respect, equality and inclusion, and consider the specific type of research and phases of research that citizens or patients are engaged in.
- Despite the focus in the evidence documents identified, more approaches to engage citizens, such as websites where citizens can submit their questions to organizations funding research, still need to be explored.

Box 2: Approach and supporting materials

For this living evidence profile we engaged citizen partners, who read earlier drafts to ensure the summary of the evidence was presented with clear and understandable language from their perspective.

We identified evidence addressing the question by searching Health Systems Evidence, Social Systems Evidence, PubMed, Web of Science, ProQuest and EBSCOhost search. All searches were conducted in April 2024. The search strategies used are available upon request as a supplementary document. In contrast to evidence-synthesis methods that provide an in-depth understanding of the evidence, this profile focuses on providing an overview and key insights from relevant documents.

We searched for full evidence syntheses (or synthesis-derived products such as overviews of evidence syntheses) and protocols for evidence syntheses. We appraised the methodological quality of evidence syntheses that were deemed to be highly relevant using AMSTAR. AMSTAR rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. The AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to evidence syntheses pertaining to delivery, financial or governance arrangements within health systems or to broader social systems.

We anticipate completing a jurisdictional scan that will be included in the next update to this LEP.

A separate appendix document includes:
1) methodological details (Appendix 1)
2) details about each identified evidence synthesis (Appendix 2)
3) details about each identified single study (Appendix 3)
4) syntheses that were excluded in the final stages of review (Appendix 4)
5) references.

Framework to organize what we looked for

The strategy of engaging citizens in asking questions and answering them was categorized into four sub-strategies:

- creating a website where citizens can submit their questions to organizations funding research
- having citizens engaged in prioritizing questions from all of those received
- encouraging citizens to become partners in a research team to answer the question if the question requires new research, and offering pathways to facilitate citizen-led research initiatives
- if evidence is already available to answer the question, encouraging citizens to become partners in teams that are dedicated to summarizing existing evidence on the question.

We organize our findings around each sub-strategy, with a specific focus on what we know about the:

- benefits of the approach
- challenges/harms when using the approach
- costs and/or cost-effectiveness of the approach
- adaptations that must be made when using the approach
- views about and experiences with the approach.

What we found

For this LEP, we identified a total of 88 evidence documents (57 evidence syntheses, 27 single studies and four protocols) relevant to engaging citizens in asking questions and answering them. There are four sub-strategies identified under this approach. Below, Table 1 provides a high-level summary of our key findings, and the sections that follow provide a detailed description of our findings for each sub-strategy.

Table 1: What we know from identified evidence documents about engaging citizens in asking questions and answering them

	What does the evidence say about **strategy #4: Engaging citizens in asking questions and answering them**? And, in particular, what do we know about the: • **benefits** of the approach? • **challenges/harms** when using the approach? • **costs and/or cost-effectiveness** of the approach? • **adaptations** that must be made when using the approach? • **views about and experiences** with the approach?
Creating a website where citizens can submit their questions to organizations funding research	• No insights about benefits, challenges/harms, costs and/or cost-effectiveness, adaptations, or views about and experiences with the approach
Having citizens engaged in prioritizing questions from all of those received	• When the role of citizens or patients is explicitly discussed, and when citizens are adequately represented in priority-setting partnerships, it has the potential to improve the impact of research on patient outcomes **[benefits]** • A few challenges of priority-setting partnerships involving citizens include time constraints for reviewing background information to make informed decisions, balancing the tension between priorities of patients, caregivers and clinicians, and finding the appropriate degree of citizen involvement and representation of certain groups **[challenges/harms]** • Priority-setting approaches that have been identified as being successful in setting priorities with the engagement of patients are the Global Evidence Mapping approach (Australia), Dialogue Method (Netherlands), and Deep Inclusion Method/Choosing All Together (U.S.) **[adaptations]** • No key insights about costs and/or cost-effectiveness or views about and experiences with the approach

Encouraging citizens to become partners in a research team to answer the question if the question requires new research, and offering pathways to facilitate citizen-led research initiatives	• Some benefits of involving citizens and patients in research include the increased likelihood of incorporating life impact outcomes, citizen awareness and activism, and increased empowerment in study design **[benefits]** • Community-based participatory research has provided a promising opportunity for citizens of diverse racial backgrounds to participate in designing studies, data collection, recruiting participants and conducting interviews **[benefits]** • Challenges may consist of logistical issues with time and resources, added workloads to ensure that participation is informed, scientific discord and lay perspectives on research, and differences in knowledge and experience that can make communication and collaboration more difficult **[challenges/harms]** • The evidence indicates that there is a lack of uniformity in how citizen engagement in research is defined and the activities that citizens may be involved in **[challenges/harms]** • Having a menu of evidence-based public-engagement resources for researchers to choose from may be helpful for encouraging citizen engagement in answering a research question **[adaptations]** • AI technologies can be used to enhance patient engagement in research **[adaptations]** • Co-design and co-production in research require a strategy that is adaptable to the diverse expertise and knowledge of participants **[adaptations]** • No key insights about costs and/or cost-effectiveness or views about and experiences with the approach
If evidence is already available to answer the question, encouraging citizens to become partners in teams that are dedicated to summarizing existing evidence on the question	• Citizens can play several roles in the evidence-synthesis process, including coordinating and producing reviews, peer reviewing, spreading results and making reviews more accessible **[benefits]** • Evidence about the impact of citizen involvement in the evidence-synthesis process is limited and of low quality **[challenges/harms]** • There was no evidence on training for researchers to accommodate and understand the lived experiences and knowledge gained from citizen participants (e.g., Indigenous peoples) **[challenges/harms]** • Factors that can lead to successful citizen involvement in the evidence-synthesis process include providing sufficient time, training and resources for participation, having regular communication between participants and researchers, and fostering positive working environments **[adaptations]** • Equity and representation in the recruitment process were recommended **[adaptations]** • No key insights about costs and/or cost-effectiveness or views about and experiences with the approach

Key findings from included evidence documents

For the strategy of engaging citizens in asking questions and answering them, we identified 88 evidence documents (57 evidence syntheses, 27 single studies and four protocols). There were no evidence documents relevant to the sub-strategy of *creating a website where citizens can submit their questions to organizations funding research*, indicating another gap in the literature and/or the lack of exploration of this strategy as an option for making evidence available to citizens.

Sub-strategy 2: Having citizens engaged in prioritizing questions from all of those received

Seven evidence syntheses, 25 single studies and two protocols were identified as relevant to the second sub-strategy**.** One evidence synthesis and all single studies featured the James Lind Alliance (JLA) approach, or a variation inspired by the JLA approach, that provides a process to adopt PSPs that bring together interest holders representing patients, carers and healthcare professionals to set research priorities in a specific area of health.(1) Alongside an independent JLA advisor, the PSP gathers questions from interest holders, typically via a survey, and a short list of questions is created after a series of consultations with interest holders. The final stage of the PSP is a one-day workshop where up to 30 patients, carers and healthcare professionals come together to share their experiences and knowledge and jointly agree to the final top 10 most important questions for research, which the PSP will promote to researchers and funders. Given that interest-holder engagement is a key function of the JLA approach, most of the evidence documents featured interest holders' views and perspectives on prioritizing questions for research. Some health conditions of focus for research priorities in the evidence we identified included different types of cancer, dementia, type I diabetes, rare diseases in children and adults, and mental health conditions.(2-9)

Benefits of engaging citizens in prioritizing questions

It is worth noting that interest holders involved in the JLA approach include patients, carers and healthcare professionals; however, a few studies indicated that patients typically make up less than 20% of respondents.(10-12) When the role of citizens or patients is explicitly discussed, and when citizens are adequately represented in the survey stage of PSPs, it has the potential to improve the impact of research on patient outcomes.(11; 13-15) One study evaluating patient and public participation in a larger landscape of numerical aspects of clinical trials emphasized the importance of public participants having a trusting relationship with researchers, confidence in challenging researcher assumptions, and accessibility of information.(16) One evidence synthesis identified the Global Evidence Mapping approach (Australia), Dialogue Method (Netherlands), and Deep Inclusion Method/Choosing All Together (U.S.) as approaches in the priority-setting dimension of the health ecosystem that were successful in setting priorities that are inclusive, objectively based and specific to the priorities of interest holders engaged in the process.(17)

Challenges and potential harms of citizen engagement in prioritizing questions

PSPs have reportedly led to positive engagement with interest holders, but challenges have been highlighted in some of the evidence, including requirements of participants to review background information to make informed decisions, balancing the tension between priorities of patients, caregivers and clinicians, and finding the appropriate degree of citizen involvement and representation of certain groups (e.g., those of low socio-economic status) for each specific PSP.(1; 18-20) Several evidence syntheses describing patient engagement on a number of health research-prioritization exercises also highlighted that patient involvement is uncommon and that more resources should be invested in engaging patients and the public in priority setting.(21-23)

We did not identify any evidence documents that explicitly focused on costs and/or cost-effectiveness of the JLA approach or other strategies to engage citizens in prioritizing questions.

Sub-strategy 3: Encouraging citizens to become partners in a research team to answer the question if the question requires new research, and offering pathways to facilitate citizen-led research initiatives

For the third sub-strategy**,** we identified a large volume of evidence documents, specifically 47 evidence syntheses, two single studies and two protocols. Some of the evidence focused on defining what the engagement process can look like when citizens are involved in research. The evidence indicates that the engagement process should include notions of respect, equality and inclusion, and consider the specific type of research and phases of research that citizens or patients are engaged in (i.e., research in which citizen or patient perspectives are valued and prioritized).(24; 25) For example, one evidence synthesis found that Black and minority ethnic groups in North America are most often involved

in health and social-care research during the research-design phase.(26) In contrast, another evidence synthesis reported that public engagement was rarely considered at all in the design, administration or evaluation of patient feedback tools due to an assumption that professional and patient objectives are synonymous and patients do not have the capacity or desire to be involved.(27) The evidence documents identified found that there are numerous ways to describe approaches for engaging citizens as research partners; however, findings from these documents indicate that there is inconsistency in how citizen engagement in research is labelled and defined and the activities that citizens may be involved in, which can ultimately hinder engagement altogether.(28-31)

Benefits and enablers of citizen participation in research

To optimize citizen participation in research, the evidence indicates that communication, listening, tailored work approach and support, acknowledgement, accommodation and continuous evaluation are essential.(32; 33) Providing sufficient time, training and resources and developing a clear recruitment plan were also recommended enablers for patient and public involvement in research.(34) Some of the evidence focused on patient engagement in research on specific health conditions (e.g., dementia, intellectual disability, rare diseases) and highlighted specific enablers to engagement, including maintaining flexible meetings to account for changes in patients' circumstances over time, avoiding tokenistic involvement, and problem solving within the research team to accommodate patients' specific needs.(35-37) For citizen partners to have a positive experience and engage meaningfully in research, they must feel that their input is valued and will have an impact.(38) To gain public trust during citizen-engagement initiatives, one evidence synthesis suggests using focus groups, meetings, patient panels, public events and discussions to facilitate meaningful citizen participation.(39)

The evidence revealed several benefits of involving citizens and patients in research, including the increased likelihood of incorporating life-impact outcomes, citizen awareness and participation empowerment in study design.(40-43) Citizens and patients can also provide a valuable perspective that is more patient-oriented than researchers', even when there is considerable overlap in their valued outcomes.(44) There have also been reported benefits for older co-researchers such as psychological and social benefits, new learning, and activism and career opportunities.(45) In addition to increasing patient empowerment and skills, the evidence shows that research teams most often reported acquiring new skills or knowledge as a result of patient engagement.(46)

Challenges and potential harms of citizen participation in research

According to the available evidence, citizen co-researchers may experience some challenges when participating in research, including logistical issues with time and resources, added workloads to ensure that participation is informed, disagreement between medical experts and lay perspectives on research, and differences in knowledge and experience that make communication and collaboration more challenging.(29; 43; 45; 47) There can also be challenges for researchers to facilitate increased collaboration and ownership amongst interest holders, financing citizen-engagement initiatives, extending research timelines to accommodate engagement activities, and integrating patient insights into traditional evidence structure.(43; 48; 49) Language and cultural obstacles, lack of incentives for participation, and lack of resources were also reported as obstacles to engaging citizens in research.(50)

Approaches to support citizen participation in research

We identified several evidence documents that described approaches and initiatives to encourage and facilitate citizen participation in specific types of research. A growing number of frameworks and evaluation tools are available to support patient and public engagement in research, but there is evidence to suggest that most do not have strong theoretical foundations and have limited transferability.(51-53) Having a menu of evidence-based public-engagement resources for researchers to choose from may be helpful for encouraging citizen engagement in future research endeavours.

A few evidence documents addressed the engagement of children and youth in research. The experience-based co-design (EBCD) framework can be used as an approach to address the most commonly reported barriers of patient engagement in child, adolescent and youth mental health research (e.g., time restrictions, recruitment, generalizability), but a recent evidence synthesis found that use of the EBCD framework is very limited, highlighting the potential for this framework to be more impactful on improving mental health services for youth with increased use.(54) There was also a study that used the Public and Patient Engagement Evaluation Tool (using a Likert survey and open-ended questions) to collect the perspectives of an immigrant adolescent-advisory group on sexual and reproductive health needs of immigrant youth.(55) The research team found that the advisory group was constructive in informing sexual and reproductive health research, and members of the advisory group reported that an inclusive and supportive research environment encourages active participation and youth empowerment. Lastly, the involvement of disabled youth in research can also be a valuable asset, according to an evidence synthesis, if appropriate accommodations are made, including developing effective communication techniques, ensuring that sufficient support and funding is available for researchers, and using flexible methods that are adaptable to participants' needs and preferences.(56)

Evidence has indicated that there is very limited peer-reviewed literature describing initiatives to encourage patient engagement in drug development research and clinical trials.(57-59) One of the few evidence documents that addressed patient engagement in clinical trials described two decision aids that were used to disseminate sex/gender knowledge and build capacity for patient-oriented research beyond traditional decision aids.(60) Community-based participatory research (CBPR) has been suggested as a promising avenue to increase the diversity of racial representation in clinical trials through a participatory communication method that centres on effective dialogue between researchers and community members.(61) The elements of CBPR associated with positive outcomes are community-partner participation in a study advisory committee, data collection, development of interviews and participant recruitment. Another evidence synthesis examining patient engagement in drug development found that patients were most involved in designing studies where goals were already set, followed by finetuning details to make minor contributions.(62) Setting up research and development (R&D) programs displayed the lowest representation despite the greatest opportunity for impact.

A recent evidence synthesis on the use of co-production, co-creation and co-design in research on green spaces indicated that an engagement strategy that is flexible and adaptable to the diverse expertise, purpose and knowledge of participants is necessary to ensure clear and effective citizen participation.(63) While there is evidence that explores the different co-design and participatory methods that engage patients and the public in different types of research, there is limited and inconsistent formal evaluation of these methods.(64; 65) Research co-design processes and outcomes should be evaluated in order to learn from past experiences and reduce conflict between the needs of end users and the aims of research.(66)

Finally, there is strong preliminary evidence to suggest that patient and public involvement in healthcare research and caregiving can be enhanced through the use of artificial intelligence (AI)-assisted data collection and analysis techniques that can enable patients to be more active in their care, contribute to experiential insight, stay motivated to remain in treatment, and facilitate engagement with clinicians, other patients, or friends and family.(67) When considering the use of AI in research, public trust and willingness to share information through AI-assisted technologies is a major concern. Additionally, patient and public engagement in AI-assisted healthcare will need to consider the broader socio-political context of gendered, ethnic, racial, age-based, class-based and geopolitical inequalities that exist and their influence in shaping professional practice, information sharing between patient and care providers, and treatment of mental disorders.

There were no evidence documents that specifically focused on the costs and/or cost-effectiveness of citizen engagement in research.

Sub-strategy 4: If evidence is already available to answer the question, encouraging citizens to become partners in teams that are dedicated to summarizing existing evidence on the question

Three evidence syntheses were relevant to the sub-strategy of encouraging citizens to become partners in teams that are dedicated to summarizing existing evidence on the research question. Two evidence syntheses highlighted the potential for citizens to play several roles in the evidence-synthesis process, including coordinating and producing syntheses, peer reviewing, making syntheses more accessible and spreading results.(68; 69) Some concerns were identified by the evidence reviewed, particularly that there is a limited body of evidence and low-quality reporting on the impact of interest-holder involvement in the evidence-synthesis process.(68; 69) Addressing these concerns is important given that measuring any changes to the evidence-synthesis process due to citizen involvement will be critical to understanding the value of public participation in summarizing existing evidence. Success factors for patient and public involvement in synthesizing evidence recommended by the evidence included providing sufficient time and resources for research partners, providing sufficient training and support, developing a clear recruitment plan, having regular communication between researchers and about research parameters, and fostering positive working relationships.(34)

It is important to note that while several evidence documents under this sub-strategy specify the value in citizen engagement being in the lived experience that patients, community members, and their friends and families bring, no studies included recommendations on training the researchers to better accommodate these forms of knowledge and lived experience brought forth by participants. It is also worth noting the absence of Indigenous representation in the included studies. While equity and representation were recommended for recruitment, there is a gap in available evidence evaluating engagements of Indigenous communities in research endeavors.

None of the identified evidence documents specifically focused on the costs and/or cost-effectiveness of citizen engagement in teams that are dedicated to summarizing existing evidence.

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