McMaster University | Health Forum

Living Evidence Profile #9

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

8 December 2025

[MHF product code: LEP 9d]

Appendices

Appendix 1: Methodological details

We use a standard protocol for preparing living evidence profiles (LEP) to ensure that our approach to identifying research evidence is as systematic and transparent as possible in the time we are given to prepare the profile.

Engaging subject matter experts and citizen partners

Citizen partners were engaged after drafts of the living evidence profile report were completed to offer feedback and propose changes that help with clarity.

Organizing framework

To structure our searches for evidence to include in this LEP and to structure our analysis and the presentation of our findings, we drew on an organizing framework developed through the efforts of the Global Commission on Evidence to Address Societal Challenges (the Global Evidence Commission) following consultations with subject-matter experts and citizen partners, guidance from the Citizen Leadership Group, and from the views and experiences elicited through a series of citizen panels held in October 2022. This organizing framework categorized the range of strategies for supporting citizens to use evidence in everyday life into five overarching strategies. This LEP focuses on one of those strategies, namely **engaging citizens in asking questions and answering them**, which consists of 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.

Identifying research evidence

In April 2024, we searched for evidence syntheses (and protocols for evidence syntheses underway) and for single studies relevant to all five strategies developed by the Global Evidence Commission in six databases: Health Systems Evidence, Social Systems Evidence, PubMed/MEDLINE, EBSCOhost, ProQuest and Web of Science. The detailed search strategies for each of the sub-strategies are available upon request.

We retrieved 4,299 total studies across all databases searched. Covidence software was used to coordinate screening with our team of researchers. After duplicates were removed, we assessed 3,304 for eligibility based on a review of titles and abstracts and deemed 478 potentially eligible for inclusion. The detailed search strategies for each of the sub-strategies are available upon request.

For the 612 studies that were considered relevant to strategy 4, a single member of the research team assessed the full text of each study, which resulted in a further 512 being removed, and a final set of 99 studies deemed eligible for the analysis. The team used a dedicated virtual channel to discuss and iteratively refine inclusion/exclusion criteria throughout the process, which provided a running list of considerations that all members could consult during the first stages of assessment. Several studies were removed during the final stages of analysis, which have been listed in Appendix 4.

We excluded documents that did not directly address the research question and the organizing framework. We were unable to extract key findings from documents that were written in languages other than Chinese, English, French, Portuguese or Spanish, or were not able to be translated to English via Google applications. We provided any documents that made it to full-text screening and did not have content available in these languages in Appendix 4 containing documents excluded at the final stages of reviewing.

Assessing relevance and quality of evidence

We assessed the relevance of each included evidence document as being of high or low relevance to the research question and sub-strategies of the organizing framework.

Two reviewers independently appraised the methodological quality of the included evidence documents using AGREE II. We used three domains in the tool (interest holder involvement, rigour of development and editorial independence) and classified guidelines as high quality if they were scored as 60% or higher across each of these domains. Disagreements were resolved by consensus with a third reviewer if needed. AMSTAR rates overall methodological quality on a scale of 0 to 11, where 11/11 represents an evidence synthesis of the highest quality. High-quality evidence syntheses are those with scores of eight or higher out of a possible 11, medium-quality evidence syntheses are those with scores between four and seven, and low-quality evidence syntheses are those with scores less than four. It is important to note that the AMSTAR tool was developed to assess evidence syntheses focused on clinical interventions, so not all criteria apply to those pertaining to health-system arrangements or to economic and social responses. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, an evidence synthesis that scores 8/8 is generally of comparable quality to another scoring 11/11; both ratings are considered 'high scores.' A high score signals that readers of the evidence synthesis can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the evidence synthesis should be discarded, merely that less confidence can be placed in its findings and that the evidence synthesis needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1): S8.)

Preparing the profile

Each included document is cited in the reference list at the end of the LEP. For each included evidence synthesis and single study, we prepared a small number of bullet points and an overarching declarative statement of the findings, alongside additional study characteristics (e.g., date of last search, methodological quality, study jurisdiction). Findings from all the evidence documents are then used to summarize key messages in the profile report. Protocols and titles/questions have their titles hyperlinked, given that findings are not yet available.

Appendix 2: Details about each identified evidence synthesis

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
Sub-strategy 1: Creating a website where citizens can submit their questions to organizations funding research (Search 1, Search 2, Search 3) *Total syntheses: 0*	No evidence syntheses identified						
Sub-strategy 2: Having citizens engaged in prioritizing questions from all of those received (n=7; two protocols) (Search 1, Search 2, Search 3)	Deliberative and consultative public and patient engagement approaches have been found to be successful in health ecosystem priority setting, such as James Lind Alliance (JLA) Priority Setting Partnerships (U.K.), Global Evidence Mapping (Austalia), Dialogue Method (Netherlands), and Deep Inclusion Method/Choosing All Together (U.S.), and at the preparation phase for health research (1) • Ethical considerations need to take into account the high risk of tokenism across all patient-engagement opportunities, the allocation of time to engage patients in the research design stage, and the need for plain-language knowledge sharing with patients • Evaluation of patient engagement activities is also critical to underscore the value of patient and public priority setting in decision-making exercises	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	April 2017	No	None identified
	Interest holders most frequently asked to identify research priorities are doctors, patients, academics/researchers, nurses, allied healthcare professionals, family members, friends and carers, and overall, only 9% of the research priority setting projects identified emphasized the importance of interest holders and actively involved them (2)	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	January 2021	No	None identified
	Patient engagement was noticeably absent in this review of research priority setting in kidney disease, but initiatives that did involve patients showed that symptom and treatment burden, maintaining quality of life, impact on lifestyle, and treatment decision-making are of central concern to patients (5)	High	No	3/9 (AMSTAR rating by McMaster Health Forum)		No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	Children and parents should be given more opportunity to engage in research priority setting in paediatric research as evidence shows there is very limited engagement of these groups (6)	High	No	6/9 (AMSTAR rating by McMaster Health Forum)	September 2019	No	None identified
	While research priority-setting approaches in childhood chronic diseases cover many discipline areas (e.g., cancer, neurology, endocrine/metabolism), patient and caregiver involvement is uncommon and specific methods for prioritizing research topics often lack clarity (7)	High	No	3/9 (AMSTAR rating by McMaster Health Forum)	October 2016	No	None identified
	Interventions incorporating participatory planning, inclusion (of marginalized groups), transparency, and accountability (PITA) mechanisms are effective in engaging service users in low- and middle-income countries and improving meeting attendance, contributions to community funds, and general knowledge about services in comparison to standard service delivery (3)	Low	No	8/11 (AMSTAR rating by McMaster Health Forum)	2018	No	• Socio-economic status
	A steering group, including patients, carers and healthcare professionals, was established using the JLA approach to systematically review survey results to prioritize uncertainties relevant to emergency medicine (4)	Low	No	2/9 (AMSTAR rating by McMaster Health Forum)	2022	No	None identified
Protocol	Developing a toolkit to improve resident and family engagement in the safety of assisted living: Engage-A interest holder-engaged research protocol (8)						
Protocol	What are the most important unanswered research questions on rapid review methodology? A James Lind Alliance research methodology Priority Setting Partnership: The Priority III study protocol (9)						
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 (n=47)	Life impact outcomes are more likely to be represented in "core outcome sets" (COS) that have been developed with patients or their representatives than COS without patient participation (10)	High	No	3/9 (AMSTAR rating by McMaster Health Forum)	March 2021	No	None identified
	Studies reveal several benefits of patient involvement in rare diseases research (e.g., increased quality and relevance of studies, increased public awareness of rare diseases), but few describe methods for measuring impacts and effectiveness (11)	High	No	3/9 (AMSTAR rating by McMaster Health Forum)	September 2021	No	None identified
	Definitions of patient engagement in research often lack clarity, but should include notions of inclusion, respect and equality in the interactions between patients and researchers (12)	High	No	5/9 (AMSTAR rating by	December 2018	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
(Search 1, Search 2, Search 3)				McMaster Health Forum)			
	Studies exploring patients participating as co-researchers in health research suggest that mere collaboration efforts may take more priority than knowledge outcomes and quality of methodological standards, indicating that the type of research that patients participate in should be considered (13)	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	October 2016	No	None identified
	Evidence of effectiveness of patient and public involvement in health research in low-income and middle-income countries (LMICs) remains limited, but it suggests increased relevance to the community, empowerment of participants and alterations in study design (14)	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	December 2017	No	None identified
	Many frameworks for supporting patient and public involvement in research have been developed (including power-focused, priority-setting, study-focused, report-focused and partnership-focused frameworks), but they have limited transferability (15)	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	December 2018	No	None identified
	There is a growing number of evaluation tools available to support patient and public engagement in research and health-system decision-making, but most tools do not have strong theoretical foundations and have not been tested for reliability (16)	High	No	6/9 (AMSTAR rating by McMaster Health Forum)	February 2016	No	None identified
	Benefits for older co-researchers included psychological and social benefits, new learning and activism and career opportunities, but challenges included workloads, difficult relationships and dissatisfaction with level of involvement (17)	High	No	6/9 (AMSTAR rating by McMaster Health Forum)	October 2017	No	None identified
	Black and minority ethnic group involvement in health and social care research is most often during the research design phase and least in data analysis and interpretation (18)	High	No	5/10 (AMSTAR rating by McMaster Health Forum)	April 2016	No	• Race/ethnicity/ culture/ language
	A socioecological model can inform what needs to be done to support the engagement of citizens living in vulnerable circumstances in research or policymaking (19)	High	No	1/9 (AMSTAR rating by McMaster Health Forum)	Sept 2021 (Year of publication)	No	• Socio-economic status • Race/ethnicity/ culture/ language
	Recommendations for best practice for patient and public involvement in evidence synthesis and systematic reviews are provision of sufficient time and resources, developing a clear recruitment plan, provision of	High	No	7/9 (AMSTAR rating by	August 2023	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	sufficient training and support, and fostering positive working relationships (20)			McMaster Health Forum)			
	The Experience Based Co-Design (EBCD) framework is not commonly used to guide patient engagement in child, adolescent and youth mental health care research, as most studies followed less than half of the framework, even though study barriers most commonly reported could be addressed by the EBCD, such as time restrictions, recruitment and generalizability; most studies used a participatory or co-design approach for engagement (21)	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	November 2023	No	None identified
	Methods to measure or evaluate citizen engagement in health research include audits, focus groups, interviews, frameworks and surveys, which are often used in combination and commonly evaluate perceived empowerment, impact, respect, support and value, but there remains a need for standardized guidelines on evaluating citizen engagement in research due to variations of terms and core principles (22)	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	December 2022	No	None identified
	Facilitators and barriers to the involvement of older care-home residents in research include social factors, skills, resources, care-home organization, and the organization of the research, while flexibility in research designs, processes and ways of practising can enable residents to have meaningful involvement (23) • Residents were involved in smaller scale participatory research as collaborators, and in larger studies as advisors and consultants • The reporting of patient and public involvement varies, and it is difficult to evaluate the impact of involving care-home residents on the research outcomes	High	No	3/9 (AMSTAR rating by McMaster Health Forum)	May 2016	No	• Personal characteristics
	Recommendations for involving disabled children and young people in research include 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; however, more needs to be done to involve those with non-verbal communication (24) • Few details were reported about disabled children and young people's involvement in studies and the quality of evidence was low	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	July 2015	No	• Personal characteristics (age, disability)
	Most patient feedback tools in psychiatry are designed, administered and evaluated from the professional perspective only, as existing tools assume patients do not have the capacity or desire to be involved, therefore future patient feedback tools should be co-produced, and the purpose of patient feedback be re-evaluated (25)	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	April 2019	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	Principles were identified and assessed for optimizing patient and public involvement (PPI), of which working in equal partnership and sharing information were considered the most essential, while communication, listening, support, acknowledgement, accommodation, continuous evaluation and tailored work approach were also considered essential (26) • Consensus on principles was defined as 75% or greater agreement; the Delphi technique was used to attain consensus of expert opinion • 22 PPI experts identified through the social and professional networks of the research team were invited to take part through advertisements distributed through the Patients Association, Lived Experience Network and Developers of User and Carer Involvement in Education network	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	September 2017	No	None identified
	Specific strategies to engage persons with dementia in research included relationship building, defining involvement and roles, accounting for the individual, ensuring clear and inclusive communication, providing training, support and funding, offering updates on study progress, acknowledging contributions, maintaining flexible attitudes, planning dementia-friendly meetings, and acknowledging that circumstances of involvement and participation can change over time with dementia (27) • There is insufficient research to demonstrate the impact of patient engagement on dementia research – both on research processes and outcomes, and on persons with dementia • Barriers to engagement (on behalf of researchers) were time and costs of engagement activities, protecting anonymity of participants, adapting to sharing control over decision-making, negotiating research ethics boards, and finding representative individuals and groups to engage • Barriers to engagement for people with dementia included research complexity, lack of training and experience, and distress	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	November 2018	No	None identified
	Eight recommendations were developed for patient research partner (PRP) involvement in research working groups, including group leadership being responsible for appropriate representation of the patient perspective; PRP being given the opportunity to be involved throughout multiple parts of the research process, adapting involvement based on project scope; and providing tailored support and information for PRP to optimize participation and collaboration (28)	High	No	2/9 (AMSTAR rating by McMaster Health Forum)	January 2016	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	• Recommendations were extracted from 18 articles and were incorporated in Outcome Measures in Rheumatology (OMERACT) organization research						
	Facilitating co-research with people with intellectual disability requires pre-planning, training of co-researchers in research and team working, flexibility and problem solving within the research team to accommodate the needs of working adults with intellectual disability, and ethical considerations such as striving for equality within the research team, avoiding tokenistic involvement, respecting the autonomy of co-researchers and safeguarding their dignity (29) • Co-research with people with intellectual disability was predominantly facilitated within research exploring health and social care delivery • Less than half of the protocols reported PPI (42.8%), and in several instances, involvement only occurred for consultative/advisory purposes • Co-researchers were either independent or groups of people with intellectual disability from established third-sector organizations/networks	High	No	7/9 (AMSTAR rating by McMaster Health Forum)	September 2018	No	• Personal characteristics (disability)
	Evidence for the extent, quality and impact of PPI in antimicrobial drug development research has not yet appeared in peer-reviewed literature (30)	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	February 2018	No	None identified
	Patients with requisite skills and experiences should be integral in research development and healthcare technology assessment, acting as informed participants in co-leading trial development and execution (31) • Active patient involvement in designing oncology clinical trials can lead to improved recruitment strategies and more patient-centred outcomes, development of patient-friendly resources, improved patient experience, and higher adherence to trial intervention • Challenges to patient involvement are logistical issues with time and resources, scientific discord and lay perspectives on research, and integrating patient insights into traditional evidence structure • Barriers can be addressed through patient education, the creation of standardized frameworks for patient involvement, and dedicated efforts to ensure diversity in patient representation across demographic factors	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	September 2023	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	The current prevalence of patient engagement in patient-oriented interventional research is very poor, with 23 of 2,777 trials reporting activities engaging patients, highlighting a need for best practices of engagement and a standardized manner of reporting engagement (32) • Patient-oriented research (POR) is research informed by patients and is centred on what is of importance to them, including patients as an integral part of the research process from conception to dissemination and implementation	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	May 2018	No	None identified
	The most commonly reported patient engagement (PE) strategies in paediatric health research include qualitative methods, such as focus groups, meetings, interviews and working groups, used at different stages of the research process; however, further work is needed to test the degrees of effectiveness of these strategies (33) • The term patient is used as "anyone who has personally lived the experience of a health issue as well as their informal caregivers, including family and friends" • Inconsistent terminology (e.g., interest holder engagement, consumer participation, patient and public involvement, participatory research) plagued this body of literature and clarity is urgently needed • Navigating power differences, time and money were commonly reported challenges	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	November 2019	No	• Personal characteristics
	While minimal, patient and interest holder engagement in research on rare diseases was usually conducted to identify patient-centred research agendas, and input was obtained through workshops, focus groups, interviews or Delphi methods (34) • The most effective approaches to engagement have not been well defined • Patient-centred research agenda support included selecting study outcomes, providing input on study design, and identifying strategies for increasing enrollment	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	August 2014	No	None identified
	Most studies in a review of preclinical laboratory research engaged patients at the education or priority-setting stages, with the most frequently reported benefit being 'providing a mutual learning opportunity,' and reported barriers including differences in knowledge and experience making communication and collaboration more challenging (35) • A variety of patient partners were engaged including patients, community members, members of patient organizations, family members, caregivers and friends	High	No	6/9 (AMSTAR rating by McMaster Health Forum)	August 2021	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	• Engagement activities included information sharing and roundtable discussions, contribution in planning and conducting priority-setting focus groups or surveys, and subsequent transcription and analysis of discussions • Five included studies described patient-partner contribution in planning and conducting priority-setting focus groups or surveys and subsequent transcription • Levels of engagement (awareness, inform, consult, involve, collaborate, empower) are not mutually exclusive and patient partners can be engaged at multiple levels within one research project						
	Researchers in LMICs are incorporating patient-oriented research in their research; however, there is a need for improved reporting practices in published articles, and the use of frameworks to guide patient-oriented research (36) • Barriers to POR included financial challenges, and gaps in patient involvement in their care • Engaging patients brought about unforeseen needs of researchers to facilitate increased collaboration and ownership amongst interest holders, but also added extra costs and extended timelines	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	January 2023	No	None identified
	There is very little surgical research reporting on PPI in surgical research, and the quality is low; of eight articles describing PPI in surgical trials, none accounted for how PPI was conceptualized (37) • Articles described PPI in surgical trials to improve the identification of research topics, study design, recruitment, retention and data collection • Training and support for patients, their involvement in dissemination, and a critique of the limitations of PPI were not reported	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	February 2015	No	None identified
	A 10-year systematic review found a large increase in the number of community-based participatory research (CBPR) related studies and studies related to racial and ethnic representation in research, and the elements of CBPR associated with positive outcomes were community partner participation in a study advisory committee, data collection, development of interviews, and participant recruitment (38) • CBPR is a participatory communication method that centres on effective dialogue between researchers and community interest holders with the goal of creating an equitable partnership for health and social change	High	No	4/10 (AMSTAR rating by McMaster Health Forum)	August 2022	No	• Race/ethnicity

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	• CBPR is still a promising avenue to increase the diversity of racial representation in clinical trials, although the rigor of application of these methodologies should be improved						
	For patient partners to have a positive experience and engage meaningfully, they must feel that they belong in research, with perceived impact on research being a key factor in this (39) • Authors generated a list of recommendations to enable positive patient partner experiences from research findings • Through a better understanding of patient engagement, future research teams will be able to improve on current methods, which will ultimately lead to health research of better quality	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	October 2022	No	None identified
	Health researchers have differing reactions to patient engagement (PE) in research, from being supportive, questioning its value, or being resistant, and researchers' first good experiences with PE bring more enthusiasm to further PE initiatives, while training patient partners is seen to reduce power balances and barriers in the research process (40) • Five general themes inductively emerged from the analysis: the understanding of PE and the motivations, contexts, attitudes and practical aspects of PE that are central to researchers	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	April 2023	No	None identified
	Parent advisory groups were engaged in structured activities to rank outcomes of young children with autism spectrum disorder, revealing that parents focused on outcomes through a different perspective than researchers, despite considerable overlap in valued outcomes (41) • Parents' perspective reflected a 'social model' of disability, while early evaluation studies focused on a 'medical model' categorized by deficit, rather than measuring outcomes appropriate to interventions that are designed to support parents in managing their child's everyday life, functioning and well-being	High	No	2/9 (AMSTAR rating by McMaster Health Forum)	April 2018	No	None identified
	Children and their families were less represented in studies than other interest holders, and a research agenda aligned with making children and their families equal partners alongside other interest holders may lead to improved satisfaction, improved patient-centred research, and improved quality of care in the future (6)	High	No	6/9 (AMSTAR rating by McMaster Health Forum)	September 2024	No	None identified
	While partnerships between research and communities can foster a co-learning environment, engaging communities in health service research on dengue control in Indo-Pacific region indicate that priority setting, communication, lack of incentives for participation, and lack of resources were obstacles (42)	High	No	6/9 (AMSTAR rating by McMaster Health Forum)	October 2023	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	• Interest holder groups engaged included local government, project-related health staff, local health services staff, community leaders, local communities/residences/general public, heads of households, community health volunteers, schoolteachers, and schoolchildren						
	Informed and improved use of co-production/co-creation/co-design through effective study evaluation could reduce conflict between needs of end users and aims of research in studies of green spaces; however, this review found that roles of citizen participants were not always clarified, and a lack of clear participation appraisal made it unclear as to whether citizens were co-creators of a solution or an intervention (43) • Participants included academic researchers/scientists, practitioners/experts, decision-makers/governmental agencies, and citizens • Co-approach studies should recruit a wider array of interest holders, particularly non-professionals and end users, and promote interactions among them • Organizations often deem non-professionals as unreliable, which makes institutional/policy support a barrier to interest holder engagement • The review found that the absence of inter-sectorial communication further strained the relationships between citizens and decision-makers and it also caused incompatibility between interest holders, raising the needs for adequate communication means or facilities to smooth the inter-relationships • An engagement strategy that is flexible and adaptable to the diverse expertise, purpose and knowledge of participants is necessary	High	No	5/11 (AMSTAR rating by McMaster Health Forum)	November 2022	No	None identified
	Researchers worked with Clinical Trials Ontario and other key interest holders to make two decision aids – one for patients and one for investigators – which deliver sex/gender knowledge and information about patient-oriented research beyond traditional decision aids used for health screening or treatment decisions (44) • Initial findings of literature review before tool development were reported at a patient-oriented research consultation workshop attended by interest holders (including patient partners/investigators/decision-makers from the Strategy for Patient-Oriented Research (SPOR) chronic disease networks) • A subsequent engagement sought to establish key concepts, principles, and areas for patient engagement and sex/gender	High	No	3/9 (AMSTAR rating by McMaster Health Forum)	2017	No	• Gender/sex

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	knowledge/uptake in clinical trial research; and disseminate knowledge about the POR tools developed by the project team in the previous phase (co-delivered by investigators and patient partners) • Patients, investigators and shareholders gave positive feedback on the user friendliness and separation (patient- and investigator-centred) of the tools						
	Health research findings on evidence co-design evaluation or outcomes were presented to an interest holder panel to interpret and critique, after which a consensus meeting was conducted to agree upon a co-design evaluation framework to be used in planning, process and review of co-design initiatives (45) • The interest holder panel included consumers, healthcare professionals and researchers • The framework used a tree metaphor to represent the processes and people in the co-design group (below-ground), underpinning system- and people-level outcomes beyond the co-design group (above-ground) • The framework highlights potential consumer involvement in dissemination, data analysis, data collection, study design, and agenda/priority-setting • Interest holders are frequently engaged in research but if research co-design processes and outcomes are not evaluated, there will be limited learning from past experiences	High	No	2/9 (AMSTAR rating by McMaster Health Forum)	2024	No	None identified
	A two-part framework was developed to optimize patient and service user engagement (PSUE) in research, consisting of 1) integral PSUE components including patient and service user initiation, reciprocal relationships, co-learning and re-assessment and feedback, and 2) sources describing PSUE at several research stages, within three larger phases: preparatory, execution and translational (46) • Due to the non-comparative, observational and/or non-empirical nature of available literature, the framework of PSUE engagement is built from sometimes disconnected and insufficiently tested or reported literatures	High	No	4/10 (AMSTAR rating by McMaster Health Forum)	2013	No	None identified
	There is an increasing interest in pediatric patient engagement, but a lack of uniformity about the definition of pediatric patient engagement as well as clear information for clinicians can hinder engagement (47) • Patients were most often asked to express their views on questions from daily clinical care, and the individual interview was the most used method	High	No	2/9 (AMSTAR rating by McMaster Health Forum)	February 2021	No	• Personal characteristics

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	• Engagement of pediatric patients generally increases with age						
	Common positive impacts of patient and family engagement in child health research on patient and family partners were empowerment and gaining skills, and similarly, research teams most often reported acquiring new skills or knowledge (48) • Patient and family partners and researchers agree that evaluating impact is key to determining whether the proposed benefits of engagement are in fact being produced and how researchers, patients and families can best work together • Systematic and standardized evaluation of engagement is needed to understand how, when and why to engage patients and families	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	2021	No	None identified
	There is strong preliminary evidence to suggest that data-intensive technologies can enhance PPI in research and caregiving, but public engagement on AI-assisted mental health care will need to include debates on the broader socio-political context and its influence in shaping professional practice and treatment of mental disorders (49) • Using AI for early detections of mental health concerns can further entrench gendered, ethnic, racial, age-based, class-based and geopolitical inequalities • Data collection and analysis techniques could enable patients to take an active role in their care through self-monitoring, contributing experiential insight, maintaining motivation and adherence to treatment, or facilitating engagement with clinicians, other patients, or friends and family • Patient and public trust is a major concern, and chatbots or digital reporting may increase willingness to share information; they may also complicate relationships and information sharing between patient and care provider	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	December 2020	No	• Race/ethnicity/ culture/ language • Socio-economic status • Age • Gender/sex • Place of residence
	PE initiatives in drug development consisted of consulting, involving and partnering with patients in fine-tuning details, designing studies, and setting up research and design (R&D) programs (50) • The most involvement of PE was in designing studies where goals were already set, followed by finetuning details to make minor contributions, and setting up R&D programs displayed the lowest representation despite the greatest opportunity for impact • It is necessary to distinguish between different types of PE in order to understand consequences of choices regarding depth and intensity of PE	High	No	4/9 (AMSTAR rating by McMaster Health Forum)	April 2021	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	Patient and public involvement and engagement (PPIE) in the design and conduct of implementation research can lead to enhanced cultural appropriateness and sustainability, but there is little formal evaluation of the use of PPIE and inconsistent (51) • This scoping review evaluated how patients and the public have been involved in implementation research, the reported impact of patient and public involvement, and the reported benefits and challenges of patient and public involvement in implementation research • Co-design and participatory methods that include feedback sessions, committee representation and roundtable discussions were most commonly used by researchers to consult with patients and the public • Most of the included studies reported that engaging community members in the design and implementation of community-based programs and trials led to enhanced cultural appropriateness and increased the likelihood of sustainability • There was little formal evaluation of the use of PPIE and inconsistent, and often absent, reporting of PPIE activities and barriers and enablers	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	March 2023	No	None identified
	While there is still a lack of consistent conceptualization of 'co-design,' recommendations for carrying out research co-design include training end-users in research skills, having researchers and end-users communicate regularly, setting clear expectations for end-users, and assigning rules to all parties involved in co-design (52)	High	No	9/9 (AMSTAR rating by McMaster Health Forum)	January 2019	No	None identified
	A list of six best practices for use of peer models in engagement was created: 1) recognizing the complex relational and social issues inherent in the process, 2) attending logistical and structural details, 3) focusing on partnership, 4) considering benefits to peers and community, 5) sharing decision-making and power, and 6) highlighting benefits through comprehensive description (53) • Peer models are a dimension of engagement composed of insider "lay" community members who often share some combination of ancestry, context, language, values/norms, experience and/or proximity with a project's target population • Common background and experiences serve as a foundation of peer support, modelling, empathy and information, which foster a sense of trust and credibility for establishing shared frameworks for communication and partnership	Low	No	2/9 (AMSTAR rating by McMaster Health Forum)	June 2017	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
	• Peers can be engaged in different levels: advisory (advisory boards and steering committees), employment (data collection and screening), and as partners (leading and decision-making in the project)						
	There are four key forms of citizen engagement in transitions research: 1) envisioning sustainable futures, 2) local transition implementation, 3) revealing public perceptions, and 4) developing participatory methods to facilitate transitions; however, participation of citizens in this research is rare (54)	Low	No	2/9 (AMSTAR rating by McMaster Health Forum)	June 2021	No	None identified
	The quality of reporting on PPI in cancer research is lacking and could be strengthened through critical reflection of the PPI process (55) • PPI was mostly reported at the early stages of research (definition and prioritization of research topics and the development of recruitment strategies), and needs to be integrated more broadly into the entire process	Low	No	5/9 (AMSTAR rating by McMaster Health Forum)	April 2017	No	None identified
	Patient, family, and community advisory councils (PFACs) engage communities in healthcare research through individual projects, but evidence on their impact and outcomes is lacking, and there are very few randomized control trials or studies to guide strategies for engagement through PFACs, highlighting a need for standardized measuring tools for PFACs and an opportunity for PFAC members to contribute to future systematic reviews (56)	Low	No	6/10 (AMSTAR rating by McMaster Health Forum)	September 2016	No	None identified
	The current reporting of PPI in orthopaedic surgery randmized controlled trials is poor and of low quality, but this may be due to medical editorial guidelines causing a practical barrier to reporting (57) • Some editorial guidelines have shaped PPI reporting in research through requiring authors to submit PPI declarations • Of only two studies involving PPI, one did not report methods, and the methods reported by the other were routing clinical consultation and trial steering group participation	Low	No	6/9 (AMSTAR rating by McMaster Health Forum)	2020	No	None identified
Protocol	Patient-Oriented Research Competencies in Health (PORCH) for patients, healthcare providers, decision-makers and researchers: Protocol of a scoping review (58)						
Protocol	Recognizing patient partner contributions to health research: A mixed methods research protocol (59)						
Sub-strategy 4: If evidence is already available to answer the question, encouraging citizens	Consumers can play various roles in organizations undertaking systematic reviews (e.g., coordinating and producing reviews, peer reviewing, making reviews more accessible, spreading the results), but there is limited evidence about the impact of their involvement in systematic reviews (60)	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	June 2015	No	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations
to become partners in teams that are dedicated to summarizing existing evidence on the question (n=3) (Search 1, Search 2, Search 3)	Providing sufficient time and resources, developing a clear recruitment plan, providing sufficient training and support, and fostering positive working relationships are key success factors for patient and public involvement in evidence synthesis (20)	High	No	7/9 (AMSTAR rating by McMaster Health Forum)	February 2022	No	None identified
	There is a growing body of evidence on interest holder involvement in systematic reviews, but the quality of reporting is generally very poor (61)	High	No	5/9 (AMSTAR rating by McMaster Health Forum)	2016	No	None identified

Appendix 3: Details about each identified single study

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
Sub-strategy 1: Creating a website where citizens can submit their questions to organizations funding research	No single studies identified			
Sub-strategy 2: Having citizens engaged in prioritizing questions from all of those received (n=25)	The top research priorities for childhood chronic complex disease (CCD) include improving diagnosis and treatment access, addressing social inclusion and stigma (e.g., in healthcare, school, employment settings), understanding the mental health impacts of CCD, and reducing the treatment burden, while also focusing on the need for better accommodations and support for young people with visible and invisible disabilities (62)	High	*Publication date:* 2023 *Jurisdiction studied:* Australia *Methods used:* James Lind Alliance (JLA) priority-setting methodology	None identified
	Young cancer patients and their families face major gaps in information (e.g., post-treatment impacts, fertility, lifestyle choices), communication (e.g., the timing and delivery of information), and service provision (e.g., coordination of psychological and long-term care services) (63)	High	*Publication date:* 2021 *Jurisdiction studied:* United Kingdom *Methods used:* JLA priority-setting methodology	None identified
	The top research priorities in pediatric hospital medicine included improving care models for children with medical complexity, supporting families (e.g., mental health support, shared decision-making), addressing the unique needs of children with developmental disabilities, and exploring alternatives to prolonged hospital stays (i.e., home-based care) (64)	High	*Publication date:* 2022 *Jurisdiction studied:* Canada *Methods used:* JLA priority-setting methodology	None identified
	Mental health was the top research priority for child and family health, with interest holders (i.e., caregivers and healthcare professionals) identifying key gaps in areas like healthcare navigation, screen time and diet/nutrition, while also highlighting challenges in interest holder engagement (e.g., underrepresentation of diverse populations) and the need for better knowledge translation (65)	High	*Publication date:* 2023 *Jurisdiction studied:* Canada *Methods used:* A modified JLA priority-setting methodology	None identified
	The James Lind Alliance (JLA) priority-setting approach was used to survey metastatic breast cancer (MBC) patients, caregivers and clinicians to identify unanswered questions on MBC and reach consensus on the top 10 research priorities; patients represented nearly half (49%) of participants surveyed (66)	High	*Publication date:* September 2019 *Jurisdiction studied:* Canada	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
			Methods used: Survey and workshop (JLA priority-setting approach)	
	People with lived concussion experience, including patients and caregivers, were surveyed to identify unanswered questions about concussions and their top 10 research priorities were agreed upon at a priority-setting workshop; the main themes of questions identified focused on early and accurate diagnosis, effective concussion symptom management and prediction of poor outcomes (67)	High	*Publication date:* June 2023 *Jurisdiction studied:* Canada *Methods used:* Survey and workshop (JLA priority-setting approach)	None identified
	Through a survey and workshop, patients caregivers and health professionals identified the top research questions and priorities to improve the lives of people with dysphagia from the U.K., which included questions on the identification, assessment and nature of dysphagia, cost-effective strategies to manage dysphagia, service provision, and the role of speech and language therapists (68)	High	*Publication date:* January 2022 *Jurisdiction studied:* United Kingdom *Methods used:* Survey and workshop (JLA priority-setting approach)	None identified
	A list of the top 10 questions regarding the processes and effects of diet- and exercise-related type 1 diabetes (T1D) interventions was developed by patients, caregivers and healthcare providers of people living with T1D in a research priority-setting exercise; focus areas of these research questions were lifestyle factors and exercise modifications that maintain short-term glycaemic control (69) • Meaningful dialogue between patients, caregivers, healthcare providers and researchers cultivated trusting relationships between researchers and people with relevant lived experience	High	*Publication date:* 2020 *Jurisdiction studied:* Canada *Methods used:* Mixed methods (Scoping review and qualitative survey)	• Place of residence • Gender/sex • Race/ethnicity/ culture/language • Personal characteristics associated with discrimination (e.g., age, disability)
	Patient and public partners felt that their involvement in the numerical dimensions of clinical trials can enhance the transparency and quality of trials while strengthening partners' technical capacities, and participants most frequently reported that patient and public participation should be prioritized in setting non-inferiority margins and the thresholds used to identify clinically meaningful differences, interpretation and dissemination of trial findings, and discerning the cost-effectiveness of interventions (70) • The identified facilitators of patient and public participation in the numerical dimensions of trials included empathetic, trusting relationships with researchers; partners' confidence in challenging researcher assumptions; the accessibility of number-	High	*Publication date:* 2021 *Jurisdiction studied:* Ireland and United Kingdom *Methods used:* Focus groups and an online priority-setting meeting drawing upon the James Lind Alliance methodology	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
	related communication by researchers; and partners' understanding of and interest in numerical dimensions			
	Based on shared reflections of senior nurse and midwife scholars that focused on identifying community nursing-related research priorities, inclusive community engagement was facilitated by professional diversity among researchers, use of snowball sampling and other forms of targeted recruitment, culturally responsive data collection, and intentional facilitation of meetings (71) • The virtual nature of engagement had strengths (e.g., reduced costs and travel time) and limitations (e.g., relational impacts, interest holders without technological access)	High	*Publication date:* 2022 *Jurisdiction studied:* England, United Kingdom *Methods used:* Shared reflection through consultations	• Place of residence • Race/ethnicity/culture/language • Gender/sex • Socio-economic status • Personal characteristics associated with discrimination (e.g., age, disability)
	Participation of patients, caregivers and healthcare professionals in research priority exercises on uncertainties related to dementia care was found to have broadened the scope of research priority setting by drawing attention to the need for evidence surrounding the organization and delivery of care for people living with dementia (72) • The identified research priorities related to the key supportive features of dementia care (e.g., effective interventions and best practices for supporting care partners) • Importantly, the questions identified by participants were deemed uncertainties solely if related high-quality, recent systematic reviews did not exist	High	*Publication date:* 2015 *Jurisdiction studied:* United Kingdom *Methods used:* Survey (James Lind Alliance approach)	None identified
	Patients, caregivers and healthcare providers identified the top-ranked research priorities related to uncertainties of hypertension management, which pertained to the lifestyle habits, treatments and educational tools that can support hypertension management, including for specified subgroups (e.g., Indigenous peoples) (73) • Patients tended to ask questions related to psychosocial challenges (e.g., anxiety) in hypertension management, while healthcare providers tended to highlight uncertainties regarding communication, education and the monitoring of blood pressure	High	*Publication date:* 2017 *Jurisdiction studied:* Canada *Methods used:* Survey (James Lind Alliance approach)	• Race/ethnicity/culture/language
	Research priorities of pediatric patients, caregivers and clinicians surrounding pediatric inflammatory bowel diseases (IBD) were identified, including research exploring the long-term effects and treatment of IBD alongside the transition to adult care; the top three questions related to the causes of IBD, how it can be prevented, and the role of diet in IBD management (74)	High	*Publication date:* 2019 *Jurisdiction studied:* Canada *Methods used:* Survey (James Lind Alliance approach)	• Personal characteristics associated with discrimination (e.g., age, disability)

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
	• A notable methodological limitation was the underrepresentation of certain groups (e.g., those of low socio-economic status) due to time, geography and other constraints			
	Prioritized questions identified by patients, caregivers, researchers and healthcare providers related to factors that can improve the outcomes and satisfaction of patients who receive anesthesia for surgery and the patient data that should be collected to understand their experiences with anesthesia alongside their outcomes (75) • The authors concluded that patient engagement in research priority setting has the potential to improve the impact of research, including on patient outcomes	High	*Publication date:* 2020 *Jurisdiction studied:* Canada *Methods used:* Survey (James Lind Alliance approach)	• Gender/sex • Personal characteristics associated with discrimination (e.g., age, disability)
	After identifying research priorities related to rare musculoskeletal diseases, patients, caregivers and healthcare providers agreed on questions related to prevention, treatment, prognosis, care and support, and self-management, emphasizing the progression of rare metabolic bone disease and long-term management (76) • Certain groups (e.g., men and people minoritized by way of ethnicity) were underrepresented in the survey; likely, patients with the most severe conditions were underrepresented	High	*Publication date:* 2020 *Jurisdiction studied:* United Kingdom *Methods used:* Survey (James Lind Alliance approach)	• Gender/sex • Race/ethnicity/culture/language
	The top three uncertainties identified by patients, caregivers and healthcare professionals surrounding breast reconstructive surgery related to the long-term outcomes of fat grafting for breast reconstruction, the effect of breast reconstruction timing on clinical and psychological outcomes, and how various forms of breast reconstruction affect quality of life (77) • The involvement of patients, caregivers and healthcare providers allowed a diverse array of surgery-related uncertainties to be uncovered; notably, patients and caregivers tended to highlight uncertainties related to the surgery's appropriate timing as well as the procedure's short- and long-term outcomes • The relatively small size of the sample, alongside the inclusion of only U.K. citizens, hinders the generalizability of the study's findings	High	*Publication date:* 2022 *Jurisdiction studied:* United Kingdom *Methods used:* Survey (James Lind Alliance approach)	None identified
	In this study that sought to identify patients', caregivers' and community nurses' research priorities for informing the practice of community nursing, 18 research questions were prioritized, with the top three questions focused on how community nurses can better address the complex health needs of patients with comorbidities, promote self-care and shared care among patients and care partners, and support home management of acute illness (78)	High	*Publication date:* 2022 *Jurisdiction studied:* England, Kingdom *Methods used:* Survey (James Lind Alliance approach)	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
	• The involvement of people accessing community nursing services was observed to have enabled the identification of pertinent issues • A key strength of the study was its inclusion of diverse patient, caregiver and community nurse groups (e.g., those of different ages and residing in varied geographical regions), which likely enhances its transferability within England and globally			
	An analysis of a Priority Setting Partnership for Anaesthesia and Peri-operative Care brought together responses from almost 2,000 patients, caregivers, and clinicians, and affirmed that service users prioritize different aspects of research compared with those prioritised by clinicians (79) • For patients and carers, the experience of care matters as much as its effectiveness • The survey was more effectively targeted towards clinicians than patients and carers; moreover, we did not attempt to measure the effectiveness of the strategies used to advertise and promote the priority setting partnership surveys to relevant interest holders	High	*Publication date:* September 2017 *Jurisdiction studied:* United Kingdom *Methods used:* Survey and interest holder meeting, JLA Priority Setting	None identified
	According to PRioRiTy II, a Priority Setting Partnership was successful in bringing together the public (including patients), clinicians and researchers to identify unanswered questions around retention in randomized trials (80) • Members of the PSP agreed by consensus on a prioritized list of those unanswered questions that will be used to inform future research • Of the survey respondents, 20% (n=174) were patients or members of the public • Patient involvement is believed to improve trial design and delivery • These results can contribute to reducing research waste and ensuring the voice of key interest holders is reflected in research to improve retention	High	*Publication date:* October 2019 *Jurisdiction studied:* United Kingdom and Ireland *Methods used:* Online surveys, in-person meeting with interest holder representatives, JLA Priority Setting	None identified
	The Cochrane Airways priority-setting group (CAPSG) was convened from healthcare professionals and citizens living with airways disease and used survey data to prioritize key systematic review questions for further research, reporting a positive experience overall (81) • Engaged interest holders with lived experiences of respiratory diseases and partners from professional bodies	High	*Publication date:* July 2022 *Jurisdiction studied:* Various (multilingual survey in English, Russian, Spanish) *Methods used:* Interest holder group, online survey, PICO	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
	• Meetings were conducted over Zoom • Study designers received some constructive suggestions for running future CAPSG meetings • The main tension highlighted was that the process is complicated, and a lot of background information is needed to make informed decisions • Some CAPSG members would have preferred formal scoping of the questions earlier in the process		development, JLA Priority Setting	
	Interest holder participants were engaged in a priority-setting exercise through an online survey to identify broad topic uncertainties on fecal incontinence, followed by priority-setting workshop activities, and exploring highest ranking topics through participant-led, neutrally facilitated group discussion (82)	High	*Publication date:* May 2022 *Jurisdiction studied:* United Kingdom *Methods used:* Literature review, interest holder group, online survey	None identified
	Youth and parents were engaged equally as part of a project team and steering committee to oversee a priority-setting partnership, co-produce knowledge translation activities, identify areas of participation, and engage as co-authors (83)	High	*Publication date:* April 2022 *Jurisdiction studied:* Canada *Methods used:* JLA priority-setting approach	None identified
	The acute care of older patients' priority-setting partnership convened an interest holder partnership group and identified relevant patient and advocacy organizations, consulted each interest holder organization to survey their membership, and involved each organization in a ballot process for prioritizing the resulting list of unanswered questions (84)	High	*Publication date:* May 2015 *Jurisdiction studied:* United States *Methods used:* Multiple interest holder organizations, online survey, JLA Priority Setting	None identified
	Anyone in the U.K. was eligible to participate in a survey that identified uncertainties about physiotherapy while partner organizations, steering group members, and the Chartered Society of Physiotherapy (CSP) promoted the survey through a range of advertisements to members in online and paper publications, social media, through professional and patient networks, and in clinical settings (85) • 510 participant responses were included, only 36 of which were members of the public	High	*Publication date:* July 2019 *Jurisdiction studied:* United Kingdom *Methods used:* Evidence review, survey, JLA Priority Setting	None identified

Dimension of organizing framework	Declarative title and key findings	Relevance rating	Study characteristics	Equity considerations
	The Trac-Stroke project is a priority-setting approach that brought together a user group (patients with stroke, their caregivers and various health personnel) by invitation to develop an online survey to gather and analyse research needs, and prioritize a top 10 list of research needs for communication and collaboration in transitional care for patients with acute stroke (86)	High	*Publication date:* May 2022 *Jurisdiction studied:* Norway *Methods used:* Online survey, Priority setting partnership approach, JLA Priority Setting (inspired by)	None identified
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 (n=2)	Dialogue formats giving citizens a more active role and a greater say in research policy or research funding appear to be the preferred approach (87)	High	*Publication date:* September 2021 *Jurisdiction studied:* Europe *Methods used*: Qualitative, quasi-experimental study	None identified
	An immigrant adolescent advisory group was constructive in informing sexual and reproductive health research teams, and members of the advisory group reported that an inclusive and supportive research environment encourages active participation and youth empowerment (88) • Data were collected using the Public and Patient Engagement Evaluation Tool, consisted of a Likert survey and open-ended questions, and analyzed in accordance with the Patient Engagement in Research (PEIR) framework	High	*Publication date:* October 2022 *Jurisdiction studied:* Canada *Methods used:* Public and patient engagement evaluation tool	• Immigrant status (social capital – relationships and networks)
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	No single studies identified			

Appendix 4: Documents that were excluded in the final stages of review

Document type	Hyperlinked title
Sub-strategy 1 (none identified)	
Sub-strategy 2	
Single study	Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership
Sub-strategy 3	
Review	Consumers' and health providers' views and perceptions of partnering to improve health services design, delivery and evaluation: A co-produced qualitative evidence synthesis
Review	Patient involvement in a scoping review of patient-oriented machine learning research
Single study	TelereHUB-CHILD: An online integrated knowledge translation tool to optimize telerehabilitation evidence-based practices for children with disabilities and their families
Single study	Understanding patient partnership in health systems: Lessons from the Canadian patient partner survey
Sub-strategy 4	
Article	Rapid reviews methods series: Involving patient and public partners, healthcare providers and policymakers as knowledge users

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