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Summary

- » There is growing recognition of the potential value of involving experts-by-experience in knowledge mobilisation. This scoping review synthesises the existing evidence on the role of experts-by-experience in knowledge mobilisation and policy research.
- » Two research questions are investigated: 1) What evidence, literature, tools, and guidance exist on the role of experts-by-experience in knowledge mobilisation?; 2) What does this tell us about when and how knowledge brokering organisations¹ can best draw on expertise-by-experience to inform and shape their work?
- » This review summarises key insights from 41 articles published over the last four years, highlighting the varied terminology used for 'experts-by-experience', with 14 articles focusing primarily on knowledge mobilisation.
- » The literature identifies six key rationales for involving experts-by-experience. In certain circumstances, it can: (a) be ethically appropriate; (b) enhance understanding of policy and research areas, particularly in scoping and priority identification; (c) result in more meaningful and valuable research; (d) empower those involved; (e) help build collective action; and (f) increase the impact of the research produced. However, it is important to note that most reviewed articles advocate for this approach and are written by authors who have employed it, often focusing more on research rather than knowledge mobilisation specifically.
- » Involving experts-by-experience may not be suitable for every project, but it is often effective in projects focused on mobilising knowledge for practice rather than policy.
- » Co-production was the most commonly used methodological approach, where experts-by-experience were involved from the initial planning stages of a project through to the dissemination of findings.
- » There were gaps in the literature regarding the practical and logistical dimensions of this work, such as the recruitment and remuneration of experts-by-experience. This represents an area for future research.
- » Fifteen articles explored the involvement of experts-by-experience, including challenges at the planning stage of a project related to time and funding constraints, recruitment, ethical considerations, and insufficient staff skills. Challenges in building effective working relationships and managing diverse views, perspectives, and expectations were also highlighted.

¹ Specifically, the Wales Centre for Public Policy, collaborating What Works Centres including Centre for Aging Better, Centre for Homelessness Impact and other What Works Centres and peer organisations.

Introduction

There is growing recognition that involving experts-by-experience in knowledge mobilisation and policy research has the potential to strengthen this work by both boosting diversity and inclusion in practice and enhancing the quality of outputs.

‘Members of the public use research and can act as trusted intermediaries; they can drive the mobilisation of findings to relevant groups to inform decision making and facilitate change.’

(Swaithes, 2024)

The aim of this scoping review is to bring together available evidence, guides, and toolkits about the potential and optimal role of experts-by-experience in knowledge mobilisation. The key questions guiding the review were:

1. What evidence, literature, tools and guidance exist on the role of experts-by-experience in knowledge mobilisation?
2. What does this tell us about when and how knowledge brokering organisations² can best draw on experts-by-experience to inform and shape our work?

This review was conducted to inform practice and policy within the What Works Network and peer organisations. It is one strand of an ESRC Policy Innovation Fellowship.

² Specifically, the WCPP, collaborating WWCs including Centre for Ageing Better, Centre for Homelessness Impact and Youth Futures Foundations, other What Works Centres and peer organisations.

About the ESRC Policy Innovation Fellowship

This ESRC Policy Innovation Fellowship aims to investigate the role of experts-by-experience in knowledge mobilisation within the What Works Network and beyond. It began in November 2023 and will complete in April 2025. Its goal is to provide more clarity about why, how and in what circumstances Knowledge Brokering Organisations can best involve experts-by-experience in their work, as well as clarity about the circumstances in which this may be inappropriate.

Led by Dr Rounaq Nayak, hosted by the Wales Centre for Public Policy, it is a collaboration with three other What Works Centres: Centre for Ageing Better, Youth Futures Foundation and Centre for Homelessness Impact. It is being advised by the Joseph Rowntree Foundation and supported by the Modern Slavery Policy Evidence Centre and the International Public Policy Observatory.

Current practice context

Lived experience as described by Chandler and Munday (2016) refers to personal knowledge gained through direct, first-hand involvement in everyday events'. Drawing on the expertise of individuals with lived experience is a well-established approach in healthcare research (e.g. Grindell et al., 2022; Cloke et al., 2023; Langley et al., 2018). More commonly known as 'patient and public involvement' or 'service-user involvement,' this approach ensures that research focuses on issues that are directly relevant to patients and the public. The 'Patient and Public Involvement Policy,' created by the National Institute for Health and Care Excellence (NICE), provides guidance on best practices. Additionally, the GRIPP2 (Guidance for Reporting Involvement of Patients and the Public) offers a framework for reporting such research (Staniszewska et al., 2017). This checklist aims to improve the quality, transparency, and consistency of the international patient and public involvement (PPI) evidence base, ensuring that PPI practices are grounded in the best available evidence. Recently, the National Institute for Health and Care Research (NIHR) published *How to Involve the Public in Knowledge Mobilisation* (NIHR, 2024), which provides practical advice on this topic, drawing on insights from both research and practice.

Advocates argue that, when conducted in the right circumstances, involving experts-by-experience in knowledge mobilisation and policy research can provide positive opportunities for those individuals while also improving the quality and impact of research outputs. This approach is widely used in applied social policy research and has more recently been adapted to knowledge mobilisation, particularly in the health sector but also in other areas.

Key concepts

Experts-by-experience



One approach to mobilising knowledge for policy making involves engaging individuals with lived experience of a particular policy issue in the process. There is an ongoing movement towards involving experts-by-experience in research that directly addresses their needs and experiences (Johnston et al., 2021). Beyond involving individuals with lived experience as research participants, some advocates call for their involvement as advisors, co-researchers, full partners, or in various other roles within the research process (Hawke et al., 2024). This shift emphasises drawing on the expertise of individuals with lived experience of a particular issue, rather than simply collecting lived experience evidence. The term 'experts-by-experience' can be used when the focus is on gathering expertise, rather than evidence. The Experts-by-Experience Employment Initiative defines experts by experience as:

'...people with direct, first-hand experience of issues and challenges (of the UK asylum or immigration system). Experts by experience are interested in activating their lived experience of the issues to help address unique needs, challenges, and injustices...'

(Experts-by-Experience Employment Initiative, 2024)

An important aspect of this definition is that it does not imply that experts-by-experience must necessarily share their personal stories, but rather that they use their experiences to provide valuable expertise. For the purposes of this scoping review, the definition of 'experts-by-experience' is:

'...individuals possessing both lived experiences and substantive engagement with policy, research, and institutional frameworks,'

This working definition refers to individuals who have developed expertise by actively combining their personal experiential knowledge of a policy issue (such as poverty, homelessness, or loneliness) with the experiences of others who have been similarly affected. The definition has been adapted from Beresford (2021) and Sandhu (2019). These individuals also engage with research, policy, or institutions to share their insights, aiming to inform policy and practice in meaningful ways. However, this definition has not yet reached consensus among participating What Works Centres (WWCs). A key point of debate centres around differing views on who qualifies as an expert-by-experience. One perspective suggests that experts-by-experience are those who actively integrate their own experiences with the collective knowledge of others impacted by the same policy issue. The alternative view holds that individuals with lived or ongoing experience of a policy challenge should be considered experts-by-experience, regardless of whether they have engaged in the integration of their experiences with others'.

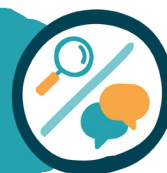
Key concepts

Knowledge Mobilisation



Knowledge mobilisation can be defined as ‘the reciprocal and complementary flow and uptake of research knowledge between researchers, knowledge brokers (those who do knowledge mobilisation) and knowledge users... in such a way that may benefit users and create positive impacts...’ (Social Sciences and Humanities Research Council of Canada [SSHRC], 2016). It aims to reduce the gap between research and practice while simultaneously strengthening the link between the two. Although other terms such as ‘dissemination’, ‘knowledge exchange’ and ‘knowledge translation’ are often used, knowledge mobilisation ‘indicates that this work requires specific effort, over time, working with others, and involves much more than telling people about research findings’ (Levin, 2013). According to Levin (2013), knowledge mobilisation is a cooperative, social task that requires active partnerships and cannot be achieved without the involvement of researchers, knowledge brokers, and knowledge users in a two-way process.

The use of knowledge to inform policy and practice is well-established, based on the premise that insights from research evidence can be distilled and applied to improve policy and practice solutions and solve problems (Tseng, 2012). For evidence-informed policy making, knowledge mobilisation between researchers and policy makers, potentially facilitated by knowledge brokers, is an essential part of the process. The What Works Network (WWN) is a collaboration of knowledge broker organisations (KBOs), comprising thirteen centres across the United Kingdom. The thirteen WWCs, including the Wales Centre for Public Policy, support policy making by making evidence accessible and understandable to policy makers. They engage in evidence synthesis and mobilisation to bridge the research-policy gap (GOV.UK, 2024).

Key concepts***Lived experience evidence vs lived experience expertise/experts-by-experience***

There is a distinction between drawing on lived experience evidence for knowledge mobilisation and actively involving experts-by-experience in the knowledge mobilisation process. This mirrors the difference between engaging experts-by-experience as research participants and working with them as ‘co-researchers’ or ‘peer researchers.’ Indeed, there are existing examples of systematic or scoping reviews that primarily draw on lived experience evidence (e.g. Peters et al., 2021; Golann et al., 2019), as well as examples of knowledge brokers collecting primary evidence from people with lived experience, where individuals have shared their stories or experiences through methods such as focus groups, surveys, or storytelling (e.g. Sovacool et al., 2021; Askew et al., 2022; Kanagasabai et al., 2023). However, drawing on expertise-by-experience in knowledge mobilisation projects involves working directly in partnership with experts-by-experience to inform, shape, or co-produce some or all elements of the work.

Experts-by-experience may contribute to various stages of agenda setting, such as identifying problems, determining project focus areas, and defining research questions. It is important to note that their involvement in agenda setting can occur at different levels. For example, experts-by-experience may participate in agenda setting at the strategic and governance level, influencing the direction of a knowledge brokering organisation, or they may focus on a specific policy issue, such as homelessness among recent prison leavers. Alternatively, their involvement may be limited to setting the agenda within a specific project, without contributing to agenda setting at higher organisational levels.

As much of the work of knowledge brokering organisations involves working with evidence from research, the role of experts-by-experience often includes elements of data synthesis, such as defining relevant search terms, screening evidence for relevance, and reviewing findings (e.g. Walker et al., 2021). Regarding the dissemination of findings, experts-by-experience can be involved in the production of outputs and may co-present at knowledge mobilisation events.

Guidelines for the involvement of experts-by-experience in knowledge mobilisation are well-established in healthcare research (NIHR, 2024), but such guidelines do not yet exist for knowledge mobilisation in other policy and practice fields, beyond the internal, unpublished policies and resources of individual knowledge broker organisations. As a result, there is a need to review existing evidence, drawing on guidance and best practices, to support KBOs in their efforts to involve experts-by-experience in knowledge mobilisation processes.

Method



This scoping review was designed using the five-stage approach developed by Arksey and O'Malley (2005). These five stages include: (1) formulating the research questions, (2) identifying relevant studies, (3) selecting eligible studies, (4) charting the data, and (5) collating, summarising, and reporting the results. At each stage, our approach was systematic and transparent, adhering to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) guidelines (Tricco et al., 2018). The review did not include a registered review protocol. A scoping (rather than systematic) review was chosen because the aim was to map the extent of knowledge and identify gaps in the literature, rather than analyse or inform guidelines (Lockwood et al., 2019; Pollock et al., 2021).

Search strategies and information sources

A search strategy was developed, piloted, and refined in consultation with all authors. Search terms included keywords related to three main concepts: (1) experts-by-experience; (2) knowledge mobilisation; and (3) type of literature/document. See Appendix 1 for a comprehensive list of search terms, which also includes alternative terminology used by other organisations for 'experts-by-experience.' This ensured that the search was broad enough to capture studies that might use different language to describe similar concepts. The following databases were searched in April 2024: Google Scholar, Scopus, ScienceDirect, Web of Science, PubMed, and Google. Several search strategies were tested by the first author to optimise the retrieval of citations known to the investigators and increase the likelihood that all relevant studies would be retrieved.

Inclusion Criteria

The review included all peer-reviewed journals, books, white papers, and reports relevant to the involvement of experts-by-experience in the knowledge mobilisation context. Due to resource constraints and the language limitations of the authors, only studies published in English between 2010 and 2024 were included. Studies published before 2010 were excluded, as they generally did not address the involvement of experts-by-experience in knowledge mobilisation. Eligibility criteria required that studies be within the domains of experts-by-experience involvement and knowledge mobilisation and contain one or more of the search terms in their title or abstract. Other exclusions included master’s theses, posters, informal literature surveys, and duplicate articles. All papers that met the inclusion criteria were reviewed. Table 1 outlines the inclusion criteria for articles to be included in the review.

Table 1: Inclusion Criteria

Inclusion Criteria
Published between 2010 and 2024
Published in English
Empirical studies, commentaries, reviews, protocols, conference abstracts, webpages, reports, book chapters
Involves experts-by-experience
Involves knowledge mobilisation
Responds to at least one aspect of the research questions

Study Selection

The results of the literature search were imported into the research collaboration platform, Rayyan, where the second author removed duplicate articles. Titles and abstracts were initially screened by the second author, and secondary screening was carried out by the co-authors. Publications identified as potentially relevant were retrieved in full text and screened by the second author. Any queries regarding the inclusion of articles were resolved through discussion and consensus among the authors.

Data synthesis

A data charting form was developed in Microsoft Excel and piloted by the authors. Pilot testing involved reviewing a representative sample of articles to identify missing or superfluous data. Basic study descriptive information was extracted into the Excel spreadsheet. This included article characteristics (authors, authors' country of affiliation, year, article type, scope/purpose of the article), rationale and approaches to engaging experts-by-experience, methods used in research projects, and barriers and enablers to utilising such an approach. Since this study did not aim to evaluate the strength of the studies or their methodologies, we did not use quality appraisal tools or meta-analysis techniques to assess the effectiveness of specific interventions (Chick et al., 2019). Data were narratively summarised based on the categories and themes extracted from the included articles.

Findings



Search results

The search results from the six databases yielded 481 potentially relevant citations. 48 duplicates were removed. After screening the titles and abstracts against the inclusion criteria, a further 332 articles were excluded, leaving 101 articles for full-text review. 41 articles met the eligibility criteria and were included in the final review. The results of the search and information extracted from these 41 articles are summarised in Appendix 2.

With a final set of 41 articles meeting the eligibility criteria, the next step was to explore these articles in the context of our two main research questions. Research Question 1 (RQ1) focuses on understanding the scale and nature of the existing evidence base concerning the role of experts-by-experience in knowledge mobilisation. This includes an analysis of where the research has been conducted, both geographically and in terms of policy areas, as well as the overall characteristics of the evidence base. Research Question 2 (RQ2) explores the specific roles that experts-by-experience play in knowledge mobilisation, examining the contexts in which their involvement is most effective. The following sections present the findings for each of these research questions.

RQ1: What evidence exists on the role of experts-by-experience in knowledge mobilisation?³

Article Characteristics

While only a minority of the papers reviewed focus on the role of experts-by-experience in knowledge mobilisation, rather than research itself, some of the findings and recommendations may be transferable to knowledge mobilisation processes. Most articles were published between 2020 and 2024 (n=36, 88%). Four (10%) were published between 2015 and 2019, and one (2%) was published earlier, in 2013.

Almost half of the articles were published in the UK (n=20, 49%), with a further nine (21%) from Canada, four (9%) from Australia, and three (7%) from the United States. Five (12%) articles were published in other countries, including Spain, Uganda, Greece, New Zealand, and South Africa.

Most of the articles were either empirical studies (n=14, 34%) or commentaries (n=15, 37%), published in academic journals. Other types of articles included protocols (n=3, 7%), reviews (n=3, 7%), reports (n=2, 5%) as well as one thesis, one book chapter, one conference abstract, and one webpage.

The most common area of expertise-by-experience was in healthcare issues (n=10, 24%). Other areas of expertise-by-experience included substance or alcohol addiction (n=3, 7%), racial discrimination (n=2, 5%), mental health issues (n=5, 12%), dementia (n=3, 7%), poverty (n=3, 7%), climate change issues (n=4, 9%), young people with adverse lived experiences (n=2, 5%), and education (n=2, 5%). Other lived experience expertise, where only one article was eligible for each, included human trafficking, homelessness, autism, and domestic violence. Four articles (10%) focused on lived experience expertise in general, such as a commentary on the involvement of experts-by-experience in knowledge mobilisation.

Although all articles involved some form of knowledge mobilisation, this was not always the primary focus. Fourteen (34%) of the articles primarily relate to knowledge mobilisation, eight (20%) to policy making, three (7%) to practice, and the remaining 25 (60%) focus on research that does not directly relate to knowledge mobilisation, policy, or practice, for example Co-producing *Rapid Research: Strengths and Challenges from a Lived Experience Perspective* (Machin et al., 2023).

³ The research question has been shortened for the purpose of the subheading.

Table 2: Article characteristics

Characteristic		Count	%
Year of publication	2020–2024	36	88%
	2015–2019	4	10%
	2010–2014	1	2%
Country	United Kingdom	20	49%
	Canada	9	21%
	Australia	4	9%
	USA	3	7%
	Other*	5	12%
Type of Document	Commentary (published in academic journal)	15	37%
	Empirical Study	14	34%
	Protocol	3	7%
	Scoping / Systematic / Literature review	3	7%
	Report	2	5%
	Other **	4	9%
Type of lived experience	Healthcare issue	10	24%
	Mental health issues	5	12%
	Climate change issue	4	10%
	Dementia	3	7%
	Poverty	3	7%
	Racial discrimination	2	5%
	Substance or alcohol addiction	2	5%
	Youth	2	5%
	Education	2	5%
	Other***	4	10%
	Non-specified	4	10%
Primary focus	Knowledge Mobilisation	14	34%
	Policy making	8	20%
	Practice	3	7%
	Research	25	60%

* South Africa, Spain, New Zealand, Uganda, Greece

** Thesis, Book Chapter, Conference Abstract, Webpage

*** Human Trafficking, Homelessness, Autism, Domestic Violence

RQ1***Terms and definitions for experts-by-experience***

Although the WCPP and some other What Works Centres use the term 'experts-by-experience' to describe individuals with lived experience involved in research and knowledge mobilisation projects, it is not the most widely used term in the broader literature. The articles in this scoping review identified a variety of terms used to describe experts-by-experience. These included:

- 'lived experience experts'
- 'patient co-researchers'
- 'public and patient involvement'
- 'service-user'
- 'peer collaborators'
- 'survivors'
- 'lived experience consultants'
- 'lived experience researchers'

Terms such as 'patient co-researchers,' 'patient and public involvement,' or 'service-user' were commonly used in health-related knowledge mobilisation projects (e.g. Hughes et al., 2024; Walker et al., 2021; Campbell et al., 2021). The term 'survivors' was used by LEAP, the Lived Experience Advisory Panel (Human Trafficking Foundation, 2023). In their annual report, this term was used interchangeably with 'lived experience experts,' 'lived experience consultants,' and 'experts by experience.' 'Lived experience researchers' was the term used for those in a Mental Health Policy Research Unit (Machin et al., 2023). Other terms included 'people with lived experience of' specific issues, such as homelessness (Campbell et al., 2021), and 'peer collaborators,' for instance in a project working with people with dementia (Reid et al., 2023). It was more common for articles to define 'lived experience' rather than the term used for the experts themselves.

A small number of articles offered specific definitions. Lived experience experts were defined as:

'...individuals, their caregivers and family members directly impacted by (an issue) whose diverse and personal knowledge gives each individual the unique ability to translate lived experience into meaningful system change'

(Santaella, 2023, p. 4)

This definition highlights that not only the individuals who directly experience an issue can be considered experts, but also caregivers and family members of those individuals. A second definition from the literature describes lived experience researchers as:

'...people with personal experience of mental health issues and involvement in research'

(Machin et al., 2023, p1)

Although definitions were not always explicit, it became apparent from reading the articles that, in most cases, experts-by-experience referred to those impacted by an issue who were engaging in research or knowledge mobilisation projects in some capacity. Whether or not researchers and organisations define expertise as requiring prior engagement with policy, practice, or research was unclear. The articles revealed a mixture of individuals involved in projects who were currently living with, or had previous lived experience of, particular issues. This was most often determined by the purpose and focus of the article. For example, articles on dementia or autism often involved those currently living with these conditions, as did many healthcare-related articles. In contrast, articles focusing on mental health issues or trauma more often involved individuals with previous lived experience.

RQ2: When and how can knowledge brokering organisations best draw on lived experience expertise to inform and shape our work?

When to draw on lived experience expertise

One of the aims of this review was to gain a better understanding of the circumstances in which it is likely to be useful, ethical, and appropriate to draw on lived experience expertise in knowledge mobilisation activities.

The evidence reviewed provided limited information about when, or under which circumstances, it may be best to use this approach. In their opinion piece on 'integrating' youths with mental health issues in data synthesis, Beames et al. (2021, p. 2) state:

'The aims of reviews and types of interpretations that ensue may determine whether integration is appropriate. Recommendations that have direct relevance for individuals and groups in the community, for example those geared toward programme development, service delivery, and clinical practice, may be more likely to align with the lived experience lens.'

This article highlights that the involvement of experts-by-experience may not be appropriate in every project, but often works well in projects aimed at mobilising knowledge for service delivery and practice improvement.

There was a lack of information in the articles explaining when it may be best to draw on expertise-by-experience in knowledge mobilisation specifically related to policy. However, there were examples of projects that utilised this approach for policy purposes, such as: working with citizens to co-design energy and climate policy recommendations, part of which involved mobilising knowledge (Willis et al., 2024); co-developing policy guidelines with community activists on conducting ethically safe HIV molecular epidemiology (Cholette et al., 2023); and producing community-led alcohol policy, where people who use alcohol were central to the knowledge mobilisation and policy development process (Bailey et al., 2023).

It was possible to draw on evaluative information provided in many of the articles to understand when it may or may not be appropriate to involve experts-by-experience in projects:

- Funding constraints: Initially, funding constraints may determine when it is appropriate to involve experts-by-experience in a project (Fitzpatrick et al., 2023). Sufficient flexibility within funding arrangements is necessary to allow for co-production approaches (Hawke et al., 2024).
- Time constraints: As many projects face time limitations, this approach may only be appropriate when there is sufficient time to do it well. This includes allowing enough time to build trusting relationships between researchers or knowledge brokers and experts-by-experience (Machin et al., 2023).
- Staff capacity and training: One article highlighted the importance of ensuring staff have the necessary experience and skills to adopt a participatory approach effectively and ethically (Hugh-Jones et al., 2024).
- Avoiding tokenistic involvement: To avoid tokenistic involvement, it is important to have clarity regarding the purpose of involving experts-by-experience in a project (Walker et al., 2021).

RQ2

The value of involving experts-by-experience

Although information on when and in which circumstances it may be best to involve experts-by-experience was sparse, the rationale for involving individuals with lived experience in the knowledge mobilisation process was highlighted in the majority of articles. This rationale often linked closely to the value of engaging in such an approach. Thirty articles (70%) explained their rationale for involving experts-by-experience in knowledge mobilisation, and 26 articles (60%) outlined the value of such an approach. The findings from the data can be categorised into six themes related to the potential for:



***Increased
ethical
legitimacy
of work***



***Opportunities for
empowerment***



***The production
of more valuable
and meaningful
outputs***



***Building
collective
action***



***More effective
scoping
and priority
identification***



***Greater impact on
policy and practice
and ultimately
communities***

Increased ethical legitimacy of work



One argument for involving experts-by-experience in knowledge mobilisation is that such an approach can promote greater inclusion and diversity, thereby enhancing ethical standards (Beames et al., 2021). It has been suggested that individuals with lived experience have a 'moral right' to be involved in research relevant to their experiences (Grindell et al., 2022), highlighting the importance of allowing them to contribute to issues that directly affect them, in an inclusive manner (Santaella et al., 2023). As Fitzpatrick et al. (2023, p. 2) note:

'those from marginalised groups, have the right to participate in research, policy making and service design that seeks to represent them and/or address their interests'

The involvement of experts-by-experience can promote ownership and give voice to those often excluded from narrative authority, helping to address inequalities (McQuaid et al., 2021). As Cloke et al. (2023, p. 3) emphasise, involving those with lived experience helps to rebalance power dynamics by:

'respecting and valuing the knowledge they [key partners] bring to discussions'.

It is crucial, however, that this rationale for involving experts-by-experience does not result in tokenistic forms of engagement. This democratic rationale is dependent on the specific circumstances in question and the methods used, as discussed in more detail later in this report.

The production of more valuable and meaningful outputs



A common rationale across the articles for involving experts-by-experience in knowledge mobilisation is the potential for producing more meaningful and higher-quality outputs. Knowledge and experience are central to policy research, and the literature indicates that when a policy area is discussed early with a group of citizens, the resulting policy is typically more robust (Willis et al., 2024). This approach is said to increase the accountability and transparency of outputs (Walker et al., 2021), improving their quality and relevance (Redman et al., 2021), and ensuring alignment with the needs of those intended to benefit.

The broader depth of evidence gained from lived experience can strengthen the reliability and validity of outputs (Hughes et al., 2024) and often leads to increased trust in the findings (Beames et al., 2021). However, it is important to note that none of the articles in this review specifically measured the impact of these outputs for knowledge mobilisation.

More effective scoping and priority identification



Many articles highlighted the value of involving experts-by-experience in knowledge mobilisation, specifically in the initial stages of a project, was valuable in establishing priority areas and focal points for evidence synthesis and knowledge mobilisation (e.g. Flynn, 2023; Santaella et al., 2023; Hughes et al., 2024; Human Trafficking Foundation, 2024; ASPE, 2022; Beames et al., 2021; Sinclair et al., 2023). As Langley et al. (2017, p. 334) describe:

‘A need to better understand contextually specific processes, that are difficult to describe without understanding the who, where, what and why.’

Involving experts-by-experience at the outset can provide a better understanding of focus areas, ensuring that research and knowledge mobilisation address the key issues that are most relevant to those most affected. It also allows for a critical exploration of professional and institutional blind spots and barriers (Phipps et al., 2021). Sinclair et al. (2023) worked with experts-by-experience to identify the top ten priorities for building evidence for research, policy, and clinical practice for autistic adults with alcohol or other substance use disorders. They noted that involving experts-by-experience helped to better identify concerns and pinpoint the key policy, research, and clinical questions that should be addressed, as those affected by a problem are best positioned to highlight and delineate it. A steering group consisting of a variety of key partners, including those with lived experience of autism, was part of a priority-setting partnership:

‘This PSP [priority-setting-partnership] identified key priorities for research, policy, and practice, to facilitate the much needed evidence base in this area.’ (p. 6)

This suggests that involving experts-by-experience in the development of a project adds real value in terms of understanding and sharing these priority areas.

Opportunities for empowerment



Articles evaluating the involvement of experts-by-experience in knowledge mobilisation often included evaluations of the process from the perspective of the experts-by-experience themselves. Many individuals reported a general sense of empowerment from taking an active role in knowledge mobilisation projects. This sense of empowerment was attributed to:

- the opportunity to influence policy (Tremblay & Jayme, 2015)
- an increased sense of inclusion and belonging (Reid et al., 2023)
- increased self-efficacy (ASPE, 2022)
- strengthened community connectedness and more social and emotional support (ASPE, 2022)
- enhanced self-confidence (Tremblay & Jayme, 2015)

One article by Campbell et al. (2021) used a community-based participatory research approach to engage individuals with lived experience of diabetes and homelessness in two projects: concept mapping to choose a research focus (gathering expertise) and photovoice⁴ to explore access to healthy food while homeless (gathering evidence). Throughout the projects, all members evaluated their experience. One expert-by-experience shared the following reflection following their involvement:

‘It made me feel that my story was important. We were involved in choosing the topics that were important to us and being able to share our stories with the other members of the committee. It was an empowering experience knowing that I was not alone.’ (p. 7)

⁴ Photovoice is a research method that uses photography to document and communicate people’s experiences and concerns – Wang, C., & Burris, M. A. (1997). Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment. *Health Education & Behavior*, 24(3), 369–387.

Building collective action



The literature suggests that involving experts-by-experience in the research process can foster collective action, particularly within the research itself, enhancing collaboration and improving the capacity to address key social issues. Many articles featured a 'research team' that included a diverse range of partners (e.g. Reid et al., 2023; Appleton et al., 2023; Fitzpatrick et al., 2023), such as advocates, patients, clinicians, researchers, policy makers, and health system innovators (McCloskey et al., 2021). This intersectoral collaboration among a variety of key partners can promote and be supported by a culture of co-production.

Co-production

Co-production is a collaborative model of research that includes key partners such as patients, the public, donors, clinicians, service providers, and policy makers. It is a sharing of power, with partners and researchers working together to develop the agenda, design and implement the research, and interpret, disseminate, and implement the findings (Redman et al., 2021).

Some articles argued that utilising a multi-experiential or multi-perspective approach helps address the complexities of issues more collaboratively, fostering collective responsibility (Flynn, 2023). Involving experts-by-experience can help develop more dynamic and adaptive community-academic partnerships, with the potential to foster mutual trust, respect, and solidarity. One example of this collaborative approach to knowledge mobilisation is demonstrated in Vancouver's Alcohol Knowledge Exchange Project (Bailey et al., 2023, p.1), where:

'regular meetings of stakeholders brought together peers who used beverage and non-beverage alcohol, shelter and harm reduction service providers, public health professionals, clinicians, and policymakers, to improve system-level capacity to reduce alcohol-related harm.'

This project demonstrated how a community of practice, involving not only those with lived experience of alcohol use but also other relevant partners (such as researchers and knowledge brokers), can bring together diverse perspectives and foster collective responsibility for initiating and driving systems change.

Greater impact on policy and practice and ultimately communities



Many articles suggested that engaging experts-by-experience in knowledge mobilisation improves the relevance and practical impact of the conclusions drawn from research. Fitzpatrick et al. (2023, p. 1739) suggest that the involvement of experts-by-experience leads to 'more effective transfer of evidence into practice', highlighting the potential for wider and more effective research dissemination and translation (Beames et al., 2021). This is achievable through the co-creation of knowledge transfer between a range of key partners. By focusing on the social relations of research, a recognition of and confrontation with power becomes central, with the interests and needs of those being researched prioritised above those of the researchers (Fitzpatrick et al., 2023). This focus on the needs and priorities of those being researched can lead to more relevant outputs, potentially enhancing practical impact. This is particularly important for knowledge brokers, as the transfer of evidence is a core aspect of their work.

This rationale for involving experts-by-experience was especially relevant in health-focused articles, where there is often a strong commitment to improving service user experience. These articles emphasised how involving the end user of a product or service in knowledge mobilisation projects is likely to improve that product or service for the 'user' (Willis et al., 2024).

RQ2

Approaches to involving experts-by-experience

One aim of this review was to gather information about how experts-by-experience are involved in knowledge mobilisation processes. Collectively, the articles revealed that involving experts-by-experience as early as possible in a project, or at least considering this early on, is often the most effective approach (e.g., Hughes et al., 2024; Thom et al., 2022; Machin et al., 2023). Engaging experts-by-experience during the planning stages provides a clearer starting point and helps inform scoping and issue identification, ensuring the focus is relevant and meaningful to those affected. This co-productive approach can help avoid tokenistic involvement, where experts-by-experience are engaged for a minor aspect of the project without substantial input into the design and strategy, potentially leading to performative rather than substantive engagement.

A co-productive approach to knowledge mobilisation (and research projects that include elements of knowledge mobilisation) can involve a wide variety of models, methods, and techniques. Those utilised in the articles reviewed are explained in more detail below:

Co-productive approaches



Co-production approaches involve experts-by-experience from the initial planning stages of a project through to dissemination and evaluation. Power and ownership of co-produced research are shared between researchers and key partners. Co-design and co-creation are variations of this approach, where experts-by-experience may be involved in planning, developing aims, and acquiring funding (e.g., Hawke et al., 2024), as well as evidence synthesis (e.g., Walker et al., 2021), writing publications (e.g., Hughes et al., 2024), and planning or contributing to knowledge mobilisation events such as conferences (e.g., Aguzzoli et al., 2024).

In most studies, experts-by-experience were brought together to participate as a group, rather than as individuals. They sometimes formed working groups, which included a combination of experts-by-experience, researchers, facilitators, and other key partners (e.g., Appleton et al., 2023; McCloskey et al., 2021; Santaella et al., 2023). This group was sometimes referred to as the 'project team' (e.g., Reid et al., 2023). Often, these co-production approaches were made possible by working closely with pre-existing advisory groups or panels (e.g., LEAP, 2023) or by conducting some form of participatory research. Participatory research, as a method, involves working closely with community members, key partners, and those with lived experience of an issue to conduct research and explore opportunities for change. These participatory methods will now be discussed in more detail.

Participatory methods



Within a co-productive approach to knowledge mobilisation, participatory methods are often used, where key partners engage in various research activities, allowing them to be equal partners in the research and knowledge exchange process. A variety of participatory methods were used in the articles reviewed, aiming to establish a balance of power between experts-by-experience, professionals, researchers, and knowledge brokers. To establish research priorities, Priority-Setting Partnerships (PSPs) were described in two articles. Participatory action research or community-based participatory research were the most cited approaches for involving experts-by-experience in knowledge mobilisation projects, with variations of these terms, including 'participatory approach,' 'participatory stakeholder process,' 'participatory methods,' and 'participatory design.' Other approaches included Equity-focused Intersectoral Practice (EquiP), collective making, and Collaborative Implementation Groups (CIGs). The table below highlights the key elements of each of these participatory methods:

Table 3: Participatory methods utilised in reviewed articles

Approach	Definition	Article references	Pros	Cons
Priority-setting partnerships	Often includes a steering committee of relevant partners to jointly identify research priorities. In the health sector, this can involve patients, carers, and clinicians.	Freebairn et al., 2022; Sinclair et al., 2023	Ensures research is relevant and aligned with community needs.	Time consuming to reach consensus.
			Promotes collaboration among key partners.	Challenges in balancing power dynamics among partners.
Participatory action research	An approach to research that emphasises the participation and action of communities affected by the research. It involves researchers and participants working together to understand and improve a problematic situation.	Lazarus, 2018; Freebairn et al., 2022; Tremblay & Jayme, 2015	Empowers participants and encourages active involvement.	Requires significant time and commitment from participants.
			Produces actionable, context-relevant outcomes.	Potential for biased results if participants do not represent the broader community.
Community-based participatory research	Equitably involves community members, researchers, and other key partners in the research process, recognising the unique strengths each brings. The aim is to combine knowledge and action to create positive, lasting social change.	Campbell et al., 2021; Reid et al., 2023; Cholette et al., 2023; Willis et al., 2024, Powell et al., 2013; McEwan et al., 2022	Equitable partnerships promote mutual respect and shared ownership.	Complexities in managing diverse partner expectations.
			Results in community-driven, sustainable solutions.	Difficulties in maintaining long-term community engagement.
Equity-focused knowledge translation	A new methodology that merges participatory research principles with the strategic inclusion of lived experiences. This approach helps different sectors focus on the contextual factors contributing to specific issues.	Phipps et al., 2021	Incorporates diverse voices into the research process.	Requires careful planning to ensure fair representation.
			Helps contextualise research findings inclusively.	Limited scalability due to context-specific, tailored approaches.
Collective making	A specific approach to share, mobilise, and activate knowledge, closely linked to co-design.	Langley et al., 2018	Encourages creativity and allows for diverse forms of knowledge sharing.	Requires resources and skills in facilitation and design.
			Creates a shared sense of ownership and connection to outcomes.	May be challenging to scale beyond local or community-level initiatives.
Collaborative Implementation Groups	A group of diverse partners who meet to discuss research and exchange knowledge, with an emphasis on interactive and collaborative peer/co-learning.	Clove et al., 2023	Facilitates continuous feedback and knowledge exchange.	High dependency on active participation.
			Enhances learning among partners with varied expertise.	Logistical challenges, such as scheduling regular meetings, may hinder continuity.

Research activities



Through these participatory methods, a wide range of activities can be co-facilitated, developed, or participated in by experts-by-experience. Experts-by-experience were often brought together with other key partners and members of the research team as working groups, who met throughout the life cycle of a project to discuss and make decisions at each stage of the research process (see Case Study 1 below). For example, concept mapping, a visual method that presents concepts as shapes with relationships shown by arrows, was used by people experiencing homelessness and diabetes to develop research and action aims (Campbell et al., 2021). Other activities included art, theatre-based activities, and creative workshops (e.g., Grindell et al., 2022; MacGregor et al., 2022; Phipps et al., 2021). These creative activities were used to co-create or co-design aspects of the research, with some projects focusing on planning knowledge mobilisation. In projects involving evidence synthesis, the involvement of experts-by-experience included developing search strategies, data extraction, analysis, and writing up (Walker et al., 2021). The articles highlighted how traditional research activities can be reimaged to be more inclusive for experts-by-experience. For instance, in a project connecting policy making with the lived experiences of girls in Uganda, the research team:

'explore how research-led applied arts can advance participatory methodologies... engaging girls meaningfully within the research process, and knowledge exchange processes that connect policy-making with their lived experiences'

(McQuaid, et al., 2020, p. 1)

Knowledge mobilisation outputs



Experts-by-experience can help shape dissemination and communication strategies as part of knowledge mobilisation efforts. Examples of this include co-authoring papers (Hawke et al., 2024), adding personal commentaries to conclusions in published papers (Appleton et al., 2023), developing public factsheets to share findings with students in schools (Lazarus, 2018), and creating visualisation tools, such as interactive web dashboards to rate meal options from three kindergartens (Cámara-Menoyo et al., 2024). One project team involving experts-by-experience co-developed easy-to-understand policy guidelines on conducting ethically safe HIV research (Cholette et al., 2023), and another developed an initial proposal for a policy package for home energy decarbonisation (Willis et al., 2024).

In addition to helping shape published outputs, experts-by-experience can also contribute to events, conferences, and symposiums, which are key components of knowledge mobilisation (see Case Study 2). This may involve planning presentations or verbally presenting findings. Communication strategies included presenting stories and projects about living with dementia (Aguzzoli et al., 2024) and delivering educational sessions for stakeholders regarding chronic kidney disease (Hughes et al., 2024).

As mentioned previously, while the articles included in this study involved at least one aspect of knowledge mobilisation, it was often not the primary focus of the project. One of the key elements of the work carried out by What Works Centres is mobilising knowledge. Below are two case studies highlighting the involvement of experts-by-experience in knowledge mobilisation.



Involvement of experts-by-experience in knowledge mobilisation: Case Study 1

Bridging the Chasm between Pregnancy and Health across the Life Course

(McCloskey et al., 2021) was a two-year project, launched in 2018 in North America. The project brought together patients, advocates, providers, researchers, policymakers, and systems innovators with the overall aims to: 1) form a network of diverse members to collectively create an Agenda for Research and Action to Bridge the Chasm, bringing together all forms of expertise, and 2) set the stage for the policy, research, and practice changes needed to create a coherent, holistic, and equitable healthcare system and experience for all birthing people across the life course.

Phase 1 involved recruiting a Stakeholder Engagement Leadership Council (SELC), which included members from community and advocacy organisations and academic partners. This group began by conducting a systematic review of the literature. In Phase 2, a 2-day conference engaged a diverse network of partners (advocates, patients, clinicians, researchers, policy experts, and healthcare innovators) to co-create the outline for the National Agenda for Research and Action. Each organisational member of the SELC invited constituents to ensure equal participation across all partner groups. In Phase 3 (Year 2), 70 members (a mix of conference attendees and new recruits) formed six working groups. Each working group held five conference calls over five months, advancing the agenda through a consensus process to create: 1) a problem statement, 2) a synthesis of findings based on an analysis of peer-reviewed and grey literature and key informant interviews, and 3) a ranked list of strategic priorities for the Agenda for Action and Research to Bridge the Chasm.





Involvement of experts-by-experience in knowledge mobilisation: Case Study 2

In 2024, Hawke et al. published **Discussing the gaps in the science and practice of lived experience engagement in mental health and substance use research: results of knowledge mobilization activities**. Based on a scoping review conducted with people with lived experience (PWLE) of mental health and substance abuse, two knowledge mobilisation events were held in Toronto in 2023 to translate the findings to end users and gather feedback. These events brought together 55 attendees, including PWLE, research staff, family members, lead scientists, research trainees, and individuals with multiple perspectives. The events were developed with the support of a Lived Experience Advisory Group and were publicised through the team's contacts, knowledge user newsletters, and social media posts.

The first event (22 attendees) was held in person at the Centre for Addiction and Mental Health (CAMH), and the second event (33 attendees) was virtual. After a brief presentation of the scoping review, facilitated discussions combined large group discussions with smaller breakout groups. Facilitators included a scientist, a PWLE, and patient and family engagement coordinators. Discussions focused on attendees' perspectives on the findings and their views on the most urgent areas of PWLE engagement. After the events, feedback was synthesised narratively from participant and facilitator notes and reported back to a Lived Experience Advisory Group for feedback and discussion.

When evaluating their experience, experts-by-experience highlighted the need to improve communications, relationships, rapport, and power dynamics. They emphasised the importance of clearly explaining research concepts, actively listening, authentically valuing PWLE perspectives, compensating PWLE for their work, and fostering consistent, ongoing engagement. They also stressed the need to involve individuals from a diverse range of racial, cultural, age, gender, and mental health/substance use backgrounds.



Recruitment



An important aspect of how to involve experts-by-experience in knowledge mobilisation is understanding the recruitment process. Two main approaches to recruiting experts-by-experience were identified in the literature: a) working with pre-existing lived experience advisory groups or community-based organisations, and b) recruiting individuals from various sources to form a new group of experts-by-experience, specifically for a particular project. For projects involving pre-existing advisory groups, some researchers collaborate with gatekeeper organisations, such as LEAP (Human Trafficking, 2023). Others have their own established networks, for example, the Mental Health Policy Research Unit (Appleton et al., 2023) and the Eastside Illicit Drinkers Group (Bailey et al., 2023). For projects that recruit individuals to form a new group, there is generally little detail about the recruitment process. Articles tend to summarise their recruitment strategy with statements such as:

‘A stakeholder working group...was assembled for the review’

(Appleton et al., 2023, p. 3)

‘multi-disciplinary working groups have been created’

(Santaella et al., 2023, p. 7216)

When lived experience advisory groups or community-based organisations were involved, the details of the recruitment process were particularly sparse. Projects that did not involve pre-existing groups often provided more detail about the recruitment process. Methods used included distributing flyers in homeless shelters (Campbell et al., 2021), care homes, libraries, community centres, and health centres, as well as advertising on local radio (Reid et al., 2023).

‘The project was advertised widely, including through the project website and social media, and relevant information was hosted by the Society for the Study of Addiction’

(Sinclair et al., 2023, p. 2)

There is a clear gap in evidence regarding the specifics of recruitment. More research is needed to highlight the challenges and opportunities for improvement in the recruitment process, as the substantial cost implications for involving experts-by-experience in projects could, if not recognised in funding processes, become a barrier to meaningful involvement.

Sites of involvement



There was little information in most of the articles regarding where engagement with experts-by-experience took place. In the articles that did provide details, examples included a community space in a local park for people with lived experience of homelessness and diabetes (Campbell et al., 2021). This venue was chosen because it was familiar to all participants and within walking distance. Other examples included meetings held online, in university buildings (Cloke et al., 2023), or in care homes where the participants lived (Reid et al., 2023). Some work with experts-by-experience also took place during organised walks (Aguzzoli et al., 2024) for those with lived experience of dementia or during longer, four-day retreats (Phipps et al., 2021) involving those with lived experience of housing inadequacy, held in a rustic lodge, far from everyday responsibilities. While the locations varied, the articles highlighted the importance of ensuring that venues were accessible and that experts-by-experience felt physically and psychologically comfortable in those spaces.

Duration and frequency of involvement



The duration and frequency of involvement of experts-by-experience in knowledge mobilisation varied widely. Project teams, including experts-by-experience, often met multiple times, for example, in bi-weekly meetings or workshops over an average of six months (Campbell et al., 2021; McQuaid et al., 2021), a series of eight one-day workshops over a 12-month period (Cloke et al., 2023), or four full-day workshops over 18 months (Hugh-Jones, 2024). Timings and frequencies differed for each project, with no overriding patterns emerging, other than the common feature of meetings held at various points during the project. These regular meetings facilitated a co-productive approach. A key point emphasised across the literature was the importance of allowing sufficient time to establish relationships with experts-by-experience before the research begins. When time constraints existed, insufficient time to build these relationships often resulted in tokenistic involvement (Walker et al., 2021).

Remuneration



Remuneration is another important element of how to involve experts-by-experience, and knowledge brokers may seek to understand this process. The importance of remuneration was highlighted across the literature, with one article stating:

‘There must always be remuneration. Co-working is not a one-off exercise, but instead is a culture’

(LEAP, 2023)

However, the details of remuneration policies or processes were only mentioned in a minority of studies (e.g., Campbell et al., 2021; Bailey et al., 2023; Thom et al., 2022; Walker et al., 2021). The remuneration summarised in these articles ranged from providing food vouchers or coffee shop gift cards to a \$10 stipend or a \$20 honorarium per meeting (Campbell et al., 2021). One article suggested that compensation for experts-by-experience should be commensurate with the rates offered to other experts, such as those engaged based on their expertise as practitioners or researchers (ASPE, 2022).

In addition to financial compensation via direct hourly payment, stipends, or honoraria, some organisations also consider providing other benefits and resources to facilitate experts-by-experience engagement. These include incentives such as childcare, mental health services, funding for travel, conference participation, and continuing education (ASPE, 2022). However, the sources of funding used by organisations to remunerate experts-by-experience were not disclosed in the articles reviewed.

RQ2

Challenges and opportunities

The literature highlighted several potential challenges or barriers to involving experts-by-experience in knowledge mobilisation projects, as well as suggesting enablers or opportunities for improvement. This area of literature provides knowledge brokers with insights into best practices and guidance on how to shape their own work involving experts-by-experience. These challenges and opportunities for improvement are explored below.

Challenges



Fifteen articles (35%) discussed the potential challenges of involving experts-by-experience in projects. These challenges fall into two broad themes: a) challenges at the planning stage of a project, and b) challenges in building effective working relationships. Several subthemes emerged within these two major themes, as highlighted in the table below:

Table 4: Challenges at the planning stage of a project

Subtheme	Explanation / Example	Reference
Time constraints	Projects involving experts-by-experience can take longer than more traditional approaches. Often, there is insufficient time allocated to effectively involve experts-by-experience in a project.	ASPE, (2022), Walker et al. (2021), Fitzpatrick et al., (2023), Machin et al., (2023)
Funding constraints	Securing funding for co-production projects can be difficult, as the funding application requires methodology planning, which typically occurs after experts-by-experience have been recruited.	Fitzpatrick, et al., (2023), Machin et al., (2023)
Ethical approval	There are uncertainties about whether proposals developed through co-design will be implemented, as well as concerns that involving experts-by-experience could negatively impact scientific rigour.	Campbell et al., (2021), Hawke et al., (2024)
Recruitment	Knowledge brokers and researchers may lack knowledge about methods for recruiting experts-by-experience.	Campbell et al., (2021), Willis et al., (2024)
Insufficient skills in participation	Knowledge brokers and researchers may also have insufficient experience or skills in participatory methods involving experts-by-experience.	Hawke et al., (2024), Walker et al., (2021)

Table 5: Challenges in building effective working relationships

Subtheme	Explanation / Example	Reference
Power imbalances	A potential conflict arises from power imbalances between academics or knowledge brokers and experts-by-experience. Some research teams recognised this as difficult to manage.	Thom et al., (2022), Grindell et al., (2022), Cloke et al., (2023), Machin et al., (2023)
Managing different perspectives	Uncertainty exists around how to manage or resolve differences in opinions or perspectives, for example, between members of a project team or working group.	Fitzpatrick et al., (2023), Walker et al., (2021)
Language barriers	Language barriers often exist between experts-by-experience and other project team members, such as when English is a second or third language or when academic jargon is misunderstood.	Camara-Menoyo et al., (2024), Fitzpatrick et al., (2023)
Managing expectations and concerns	Challenges can arise when the role of experts-by-experience is unclear, or when insufficient information is provided regarding their participation.	Hugh-Jones, et al., (2024), Walker et al., (2021)
Lack of time to build trusting relationships	There is typically insufficient time to build the trusting relationships necessary for truly shared power in effective co-creation, often leading to a tokenistic approach.	Machin et al., (2023), Hawke et al., (2024)

Opportunities for improvement



Eighteen articles (42%) discussed factors that help enable the involvement of experts-by-experience in knowledge mobilisation. Most of these enablers, or opportunities for improvement, responded to the challenges outlined above regarding the effectiveness of working relationships between project team members. Four broad areas for improvement emerged from the literature:



Taking the time to invest in mutually respectful relationships



Utilising a co-production approach



Ensuring clear communication



Reflective and informed practice

It was clear from the literature that building effective working relationships with experts-by-experience takes time. This involves maintaining clear communication throughout, ensuring that different opinions and perspectives surrounding an issue are heard and recognised. A co-production approach, supported by appropriate skills, knowledge, and training, facilitates these effective working relationships. These four areas for improvement will now be discussed in more detail:

Taking the time to invest in mutually respectful relationships



The importance of building mutually respectful relationships was a common feature across the literature, with suggestions that successful involvement of experts-by-experience requires trust between all parties and respect for the different expertise brought by various partners. Flynn (2023, p. 2) highlights how:

‘respect, mutual understanding [between researchers and experts-by-experience], and researcher responsibility provide a foundation for effective [involvement of experts-by-experience in] knowledge mobilisation’

A practical example of how to build relationships and facilitate ongoing contact with experts-by-experience comes from Campbell et al.’s (2021) project, where individuals with lived experience of homelessness were provided with prepaid mobile phones. This helped overcome a key practical and financial barrier to relationship-building and communication. Another example of how to build positive relationships was in a study protocol by Hugh-Jones et al. (2024, p. 5) who planned to:

‘conduct online engagement meetings with adolescents to begin to build positive relationships, to understand their motivations, needs, expectations and concerns about participation and how we can mitigate any perceived risk and optimise their ability to contribute.’

This example underscores the importance of early engagement and relationship-building to enable more effective later involvement in projects.

Ensuring clear communication



One risk identified in the literature was the inability of knowledge brokers or researchers to 'guarantee' that policy change would result. While knowledge brokers and researchers often emphasise the value of participation opportunities in terms of enabling enhanced 'voice' and the potential for positive societal change, these outcomes cannot be guaranteed, leading to the possibility of disappointment among experts-by-experience. To manage this, the literature recommended that clear communication at all stages of a project is vital. This involves agreeing on ways of working and creating clear descriptions of everyone's roles.

'Honest discussions about what can and cannot be done are a key element of effective participation...and upfront agreement about basic principles such as mutual respect, openness, and reciprocity...'

(Redman et al., 2021).

The same article discussing the future of co-production discusses how knowledge brokers can improve communication by developing shared expectations, such as agreeing on who determines priorities and owns the information. To aid communication further, visual tools and prompts can be employed. In a study investigating creative co-design to facilitate knowledge mobilisation in healthcare (Grindell et al., 2022), analysis of 14 projects revealed that drawing and making activities allowed individuals to articulate their experiences more easily. Creative and visual tools led to enhanced engagement and innovation. It was also helpful in some research projects to use a design researcher, who could plan the workshops and produce a co-created output, facilitating activities that were accessible to all (e.g., Grindell et al., 2022).

Utilising a co-production approach



As highlighted in the section of this report discussing approaches to involving experts-by-experience, there was widespread agreement in the literature that co-production is a favourable approach. Co-production involves engaging experts-by-experience from the initial stages of a project through to dissemination activities. This bottom-up approach affirms all voices in each part of the project (Lazarus, 2018).

One article reflected on the co-production of the 'Co-Creating Safe Spaces' project (Fitzpatrick et al., 2023). Safe spaces are peer-led alternatives to hospital emergency departments, specifically co-designed with people who have lived experience of emotional distress or suicidal crises, offering safe, accessible, recovery-oriented support. The aims, methodology, and methods of the project were guided by the values and principles identified in the initial co-design of the safe spaces. These included respect, inclusion, choice, transparency, safety, lived experience-led, and valuing each person's experience and expertise. By holding a co-design workshop that brought together the core group of researchers and key partners, the authors were able to:

'establish shared values and principles for working together as a group (e.g., power-sharing, language and communication, authorship policy),' (p. 1741)



Reflective and informed practice

The final opportunity for improvement was encouraging and enabling reflective practice, informed by relevant guidance. Researchers commented on the importance of building their personal capacities through regular meetings and reflections on their practice:

‘Building our own capacities as researchers was instrumental to our preparatory work. We held regular meetings, reflected on the practical and ethical dimensions of our work, practiced our facilitation roles, and participated in local events’

(Phipps et al., 2021, p. 3)

One way project facilitators can improve the quality of experts-by-experience involvement is by drawing on existing guidelines around this approach. One article in this review (Walker et al., 2021) describes and reflects on the methods of involving young people with lived experience in a complex evidence synthesis. In their article, they refer to the guidelines produced by INVOLVE (2015) titled *Public Involvement in Research: Values and Principles Framework*. These guidelines present six values and principles to be followed when involving those with lived experience in research: respect, support, transparency, responsiveness, fairness of opportunity, and accountability. These principles can also be extended to the involvement of experts-by-experience in knowledge mobilisation projects. Walker et al. (2023) utilise these guidelines in their study to address some of the challenges discussed above:

1. Respect: Researchers, research organisations, and the public respect each other’s roles and perspectives.
2. Support: Researchers, research organisations, and the public have access to practical and organisational support to involve and be involved.
3. Transparency: Researchers, research organisations, and the public are clear and open about the aims and scope of involvement in the research.
4. Responsiveness: Researchers and research organisations actively respond to the input of public members involved in research.
5. Fairness of opportunity: Researchers and research organisations ensure that public involvement in research is open to individuals and communities without discrimination.
6. Accountability: Researchers, research organisations, and the public are accountable for their involvement in research and to the people affected by the research.

While focused on research practice, these guidelines may also be relevant for knowledge mobilisation projects involving experts-by-experience, and they align closely with the opportunities for improvement explored in this report.

Conclusion



This scoping review synthesised the existing evidence on engaging individuals with lived experience expertise in knowledge mobilisation and policy research. It aimed to answer the following research questions:

1. What evidence, literature, tools and guidance exist on the role of lived experience participation in knowledge mobilisation?
2. What does this tell us about when and how knowledge brokers can best draw on lived experience expertise to inform and shape our work?

One key aim of this review was to explore evidence regarding the value of involving experts-by-experience in mobilisation and policy research. The data provided six clear rationales for engaging with experts-by-experience: a) it is ethically appropriate; b) it provides a better understanding of research areas, particularly in scoping and priority identification; c) it results in more valuable and meaningful research; d) it is empowering for the experts-by-experience who take part; e) it helps to build collective action; and f) the research produced could have a greater impact. While this does not necessarily mean that knowledge brokers should always use this approach, the purpose and value of engaging in such an approach in certain circumstances was evident across the literature reviewed.

However, it is important to highlight that the articles included in this review were written by authors who have either used or advocate for this approach. Consequently, the review reflects the perspectives of those who support this method, rather than the views and practices of a broader range of knowledge brokering organisations. Additionally, many of the articles discussed research cases rather than knowledge mobilisation processes specifically.

Methodologically, the literature provided substantial information for knowledge brokers considering how to engage with experts with lived experience. Community-based participatory research or participatory action research were the most commonly used methodological approaches in the projects reviewed. Although there was limited information about the circumstances in which it may be beneficial to involve experts-by-experience in knowledge mobilisation for policy or practice, one consistent view across the literature was that experts-by-experience should be involved as early as possible in the project process. This co-production approach is closely linked to the rationales for engaging with individuals with lived experience expertise, as it helps establish knowledge mobilisation priorities and research questions by involving those directly affected by an issue.

This review also highlights the lack of published literature on the recruitment and remuneration of experts-by-experience. While a small number of articles provided details regarding their recruitment and/or remuneration strategies, general guidance and recommendations for knowledge brokers considering this approach remain limited. The review underscores the need for greater detail regarding recruitment and remuneration strategies in future published work.

Through the review, it was possible to identify potential barriers to and enablers of involving experts-by-experience in knowledge mobilisation and policy research. Common challenges included those related to project planning, communication, and power imbalances. To overcome these barriers, the articles highlighted specific enablers, mostly in response to communication challenges. When planning such an approach, adequate time for relationship-building and appropriate training are essential considerations for knowledge brokers.

In summary, this desktop review highlights the growing literature on involving experts-by-experience in knowledge mobilisation, particularly within the health sector. Most articles explored examples of knowledge mobilisation for practice, with a high degree of participation from experts-by-experience. The articles shared rationales for the value of involvement, but there were fewer concrete examples of how this value was realised. The review also demonstrated the potential for involvement in all stages of the knowledge mobilisation process, particularly at the scoping stage. By identifying the challenges in utilising such an approach and the opportunities to overcome these challenges, it was possible to determine when and how it may be most appropriate for knowledge brokers to draw on expertise-by-experience in their work.



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Appendix 1: Search Terms

Experts-by-Experience	“lived experience” OR “experts by experience” OR “deliberative mini-publics” OR “community mentor” OR “direct experience” OR “participatory” OR “co-design” OR “co-production” AND
Policy Research and Knowledge Mobilisation	“policy research” OR “knowledge mobilisation” OR “mobilisation of knowledge” OR “knowledge brokering” OR “evidence-based policy” OR “evidence-informed policy” OR “knowledge exchange” OR “participatory knowledge mobilisation” OR “equitable knowledge mobilisation” OR “knowledge co-creation” OR “collective making” OR “evidence synthesis” AND
Type of literature / document	“good practice” OR “tools” OR “best practice” OR “guidance” OR “guides” OR “practice synthesis” OR “approaches” OR “design features”

Appendix 2: Table of Articles

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
Aguzzoli et al., (2024)	Empirical study	To describe “Walking the Talk for Dementia,” an initiative aimed at empowering people with dementia, enhancing understanding of dementia, and inspiring collaborations.	This initiative involved 300 participants from 25 nationalities, including people with dementia, care partners, clinicians, policy makers, researchers, and advocates, for a 4-day, 40 km walk through the Camino de Santiago de Compostela, Spain. A 2-day symposium after the journey provided novel transdisciplinary and horizontal structures, deconstructing traditional hierarchies.	Both the walk and the 2-day symposium aimed to provide knowledge exchange opportunities to enhance understanding, reduce stigma, and promote more comprehensive and empathetic dementia care and research.	The ‘Walking the Talk for Dementia’ initiative was part of a multi-partner consortium to expand dementia research.
Appleton et al., (2023)	Scoping review	To identify models that improve social circumstances across eight life domains for people with serious mental health conditions. This work was conducted in collaboration with a group of expert stakeholders, including people with lived experience of accessing mental health services.	A scoping review of existing international literature was conducted, and an expert consultation was held to identify models of support aimed at improving social circumstances across eight life domains for people with serious mental health conditions. This informed the iterative development of a conceptual framework to describe and categorise broad approaches in support models for serious mental health conditions, with the framework being refined through discussions with a stakeholder working group, including experts by experience, service providers, and academic experts.	A conceptual framework was developed that distinguishes sources and types of support to improve the social circumstances of people with serious mental health problems, providing a framework to guide future service development and evaluation.	Conducted by the NIHR Policy Research Unit (PRU) in Mental Health.

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
ASPE, (2022)	Webpage	A webpage linking to materials prepared by ASPE as it leads work on how federal agencies and programmes can meaningfully and effectively engage people with lived experience.	The webpage links to a document titled: Methods and Emerging Strategies to Engage People with Lived Experience.	Many of the projects and initiatives conducted by ASPE focus primarily on mobilising knowledge, e.g. 'National Youth in Transition Database Reviewers'	ASPE: Office of the Assistant Secretary for Planning and Evaluation.
Bailey et al., (2023)	Commentary	To highlight experiences in producing community-led alcohol policy through the Vancouver Alcohol Strategy, with particular attention to the ways in which people who use alcohol themselves were central throughout the policy development process.	The Eastside Illicit Drinkers Group for Education, an affiliate group of the Vancouver Area Network of Drug Users, convened a regular meeting of stakeholders, termed a 'community of practice' to bring together peers who used beverage and non-beverage alcohol, shelter and harm reduction service providers, public health professionals, clinicians, and policy makers to improve system-level capacity to reduce alcohol-related harm. The discussions that followed from these meetings were transformed into the Vancouver Alcohol Strategy, a comprehensive, harm reduction-oriented policy framework for alcohol harm reduction.	The <i>Alcohol Knowledge Exchange</i> project was a knowledge mobilisation initiative, with its primary aim being to develop a policy framework for alcohol harm reduction.	Project conducted by the Eastside Illicit Drinkers Group for Education

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
Bandola-Gill et al., (2023)	Review	To determine the range and nature of the use of the term 'knowledge co-production' across diverse literatures, in order to clarify its conceptualisation.	A systematic search of the Web of Science was performed via a query designed to capture literature likely focusing on co-production. Each document was manually examined for relevance. Citation network analysis was then used to 'map' this literature by grouping papers into clusters based on citation link density. The top-cited papers within each cluster were thematically analysed.	This research identified five meanings of co-production, one of which was boundary management. This focuses on the usability of knowledge, with the main focus being on structures that support the increased use of scientific knowledge in policy settings, addressing the observed gap between the production of evidence and its use in policy making.	Research conducted by the University of Edinburgh.
Beames et al., (2021)	Commentary	To identify the gap and build a case for the appropriate integration of lived experience in future data syntheses.	Across the commissioned projects discussed in this opinion piece, research teams used unique applications of lived experience perspectives. This included involvement in making decisions about the project (e.g., research questions), defining the review process, reviewing evidence, analysing and synthesising evidence, and reporting and dissemination.	The focus of this opinion piece is to build a case for the involvement of lived experience experts in data syntheses, a key method used by knowledge brokers to initiate the mobilisation of knowledge.	Produced by the University of New South Wales.

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
Camara-Menoyo et al. (2024)	Empirical study	To present and evaluate the co-design process of a Food-Water-Energy (FWE) nexus visualisation tool for stakeholders engaged with pre-school education in Słupsk, Poland, by designing a digital artefact and implementing a learning process to co-produce knowledge through the co-creation of a visualisation tool.	The process followed a User-Centred Design for Science Communication approach, consisting of four stages: 1) Foundations; 2) Software Development; 3) Transdisciplinary Team Review; and 4) Evaluation. Each stage was implemented through a series of activities, including bi-weekly meetings between the local partners in Poland and the visualisation team in the UK.	The visualisation tool co-created in this project was used to mobilise knowledge about the environmental costs associated with public food catering.	Part of the 'Creating Interfaces' transdisciplinary project.
Campbell et al. (2021)	Empirical study	To describe the process and challenges of conducting a participatory research project, highlighting the experiences of both patient co-researchers and academic researchers in diabetes health service research.	People with lived experience of homelessness and diabetes were recruited as patient co-researchers, asked to commit to attending biweekly meetings. Two research projects were conducted: concept mapping to choose a research focus, and photovoice to explore access to healthy food while homeless. A convergent mixed-methods design was used to evaluate their experience.	The <i>Photovoice</i> project (about accessing healthy food while homeless) was presented at local hospitals, research institutes, public exhibition spaces, and national conferences, including Diabetes Canada, Canadian Alliance to End Homelessness, and the North American Primary Care Research Group.	Research conducted by the University of Calgary.

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
Cholette et al., (2023)	Protocol	To engage community activists living in Nairobi, Kenya, in a knowledge exchange process through the CIPHR Project (Community Insights in Phylogenetic HIV Research). This community-based participatory approach aims to (1) explore the possibilities and limitations of HIV molecular epidemiology for key population programmes, (2) pilot a community-based HIV molecular study, and (3) co-develop policy guidelines for conducting ethically safe HIV molecular epidemiology.	Create a series of discussion forums where local community activists can critically engage with, adjudicate, and reinterpret expert scientific knowledge through an iterative process, taking place in a series of critical discussion workshops.	This protocol outlines plans to co-produce lay technical summaries of molecular methods and existing data to iteratively explore the possibilities and limitations of using findings from molecular analyses to inform network-based interventions. Lay expert knowledge will then be disseminated via presentations and local discussion forums, offering the larger community the opportunity to interrogate and respond to the potential uses of phylogenetic analysis in HIV prevention.	Known as the Community Insights in Phylogenetic HIV Research (CIPHR) Project.

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
Cloke et al., (2023)	Empirical study	To report on a study of a facilitated interactive group learning approach, through Collaborative Implementation Groups (CIGs), established to enhance capacity for equity-sensitive evaluation of healthcare services to inform local decision-making: (1) What was the experience of participants in the CIGs? (2) How was knowledge mobilisation achieved? (3) What are the key elements that enhance the process of co-producing equity-sensitive evaluations?	A thematic analysis of qualitative data obtained from focus group (FG) discussions and semi-structured interviews explored participants' experiences. All FGs included representation from participants across different projects in the programme. Interviews were conducted with a member from each team participating in the first cohort after their final workshop.	Knowledge mobilisation was made possible through establishing and brokering relationships between knowledge stakeholders and actors. This took place through the dissemination and synthesis of knowledge via online databases, communication strategies, and evidence synthesis services. Interactive learning and co-production were facilitated through participatory research projects and action learning sets.	Project conducted by the University of Liverpool.

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
Fitzpatrick et al., (2023)	Commentary	To examine the utility of a published systematic framework designed to improve clarity about co-creation as a concept and approach. The framework is explored based on the first two processes that correspond to the authors' own work to date: co-ideation and co-design.	An instrumental case study grounded in the authors' own experience of designing and coordinating the Co-Creating Safe Spaces project. By capturing salient information on 'how', 'what', and 'why' questions, including those of an interpretative or critical nature, this case study allows researchers to generate an in-depth, multifaceted understanding of broad, complex questions in their real-life contexts, with findings that may be transferable to other contexts.	The <i>Co-creating Safe Spaces</i> project was a community-based participatory research initiative that provided deep insights into the benefits of different safe space models, as well as potential challenges and facilitators of effective practice. The evaluation framework was used to assess key outcomes related to reach, effectiveness, adoption, implementation, and maintenance.	An evaluation following the "Co-Creating Safe Spaces" initiative.
Flynn, (2023)	Thesis	To propose a relational approach to enhance knowledge mobilisation and community engagement for research in Inuit Nunangat.	Using a case study, this work evaluates a collaborative research partnership with the Nunatsiavut Government, using participatory scenario planning for community-engaged policy making.	Knowledge co-production with community and Indigenous research partners within Inuit Nunangat focused on Inuit research priorities, knowledge, and experience to improve the usability of research products.	3-year research project conducted by a PhD student from the University of Leeds.

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
Freebairn et al., (2022)	Protocol	This protocol describes the methods that will be used to engage local communities using systems science methods to mobilise knowledge and action to strengthen youth mental health services.	Using participatory action research principles, the research team engages with local communities to ensure user-led participatory systems modelling processes and enhance knowledge mobilisation within research sites. Aboriginal and Torres Strait Islander community voices are included. A site selection process ensures the community is committed and has the capacity to engage in research activities. Stakeholder engagement begins at the site selection stage, aiming to build trust between researchers and key stakeholders. The research team establishes a variety of engagement resources and provides opportunities tailored to each site's local context, needs, and targeted audiences during the process.	This protocol describes the inclusive community engagement and knowledge mobilisation process for the 'Right Care, First Time, Where You Live' research programme. A flexible theoretical framework for applying systems approaches to knowledge mobilisation will enable the implementation of a participatory action research approach. This protocol commits to a rigorous and genuine stakeholder engagement process that can be applied in mental health research implementation.	Project conducted by the University of Sydney.

Reference	Type of literature	Scope / Purpose of article	Methods	Knowledge mobilisation	Additional Information
Grindell et al., (2022)	Review	To understand why researchers choose to adopt co-production, co-design, and co-creation approaches, how they achieve knowledge mobilisation in the management of health conditions, and the extent to which knowledge mobilisation is accomplished.	Studies that explicitly used the terms co-production, co-design, or co-creation to mobilise knowledge in the management of health conditions were included. The databases Web of Science, EMBASE via OvidSP, MEDLINE via OvidSP, and CINHAL via EBSCO were searched. Quality assessment was carried out using the Joanna Briggs Institute qualitative quality assessment checklist. Pluye and Hong's seven steps for mixed studies reviews were followed. Data were synthesised using thematic synthesis.	Those using 'co-' approaches believed that knowledge mobilisation could be achieved through various mechanisms, but there was no evidence that these mechanisms led to improved health. The framework of key aspects and mechanisms of 'co-' approaches developed may help researchers meet the principles of these approaches. However, there is a need for robust evaluation to determine whether 'co-' approaches produce improved health outcomes.	Conducted by the Health and Care Research Unit, University of Sheffield.

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Grindell et al., (2022)	Empirical study	Improving knowledge mobilisation in healthcare. To investigate the impact of creative co-design on the knowledge mobilisation process. To understand how it affects the application of research knowledge in routine clinical practice.	Semi-structured interviews were carried out with 20 participants from 14 projects. Data were analysed using the Framework approach. A workshop involving the first 10 participants was held prior to the final interviews and analysis.	The findings indicate that creative co-design successfully facilitates knowledge mobilisation in healthcare. This is represented by three interconnected themes: creative and visual; design-led; and creating the right conditions. These themes highlight how the approach supports engagement and creates a safe space for knowledge sharing and synthesis in a non-hierarchical environment.	Conducted by the University of Sheffield.

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Hawke et al., (2024)	Commentary	After reviewing the literature on the science of lived experience (mental health or substance use) engagement, we held two knowledge mobilisation events to translate the findings to relevant partners and gather their feedback to guide our future research.	Project planning and funding acquisition occurred with a PWLE advisory group, with two PWLE as co-applicants for funding. One PWLE co-facilitated the events. A patient engagement in research coordinator with personal lived experience contributed to the development and facilitation of a knowledge mobilisation event. A family engagement in research coordinator, with expertise in research engagement and family partner experience, further contributed to event development and facilitation. The results were brought back to the PWLE advisory group for discussion and brainstorming about next steps. One person in a PWLE role was a co-author of the report, alongside team members with multiple perspectives, including research and lived experience roles.	Two knowledge mobilisation events were held to translate findings to relevant partners and collect their feedback to guide future research. This brought together the perspectives of people with lived experience, family members, research staff, research trainees, and scientists, as well as attendees holding multiple roles. Scoping review findings were presented, followed by discussions to solicit feedback and encourage the sharing of perspectives.	Conducted by the Centre for Addiction and Mental Health.
Hughes et al., (2024)	Commentary	To outline principles and strategies for patient involvement in research, including setting research priorities, identifying and designing interventions, selecting outcomes, and disseminating and translating research.	Throughout this report, a wide variety of methods for involving patients in all stages of research are discussed, with examples provided.	One section of this report describes the involvement of the public in disseminating and translating research.	Collaboration between the University of Sydney and The Children's Hospital, Sydney, Australia.

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Hugh-Jones et al., (2024)	Empirical study	This study contributes to public sector capacity to work in trauma-informed ways with adolescents by co-designing and evaluating the implementation of a youth-informed organisational resource. The study provides insights into what adolescents and public sector organisations in the UK want from a TIA resource for development and implementation.	This is an Accelerated Experience-based Co-design (AEBCD) study followed by a pre-post evaluation. Public sector organisations or services and adolescents connected with them collaboratively reflected on lived experience data assembled through creative arts practice, alongside data from epidemiological national datasets. These presented knowledge about the impact of adverse childhood experiences on adolescents' mental health (stage 1). Collaboratively, priorities (touchpoints) for organisational responses were identified (stage 2), and a low-burden resource was co-designed (stage 3) and offered for implementation (stage 4) and evaluation (stage 5) in diverse settings.	The study provides insights into what adolescents and public sector organisations in the UK want from a TIA resource, the experience of services/ organisations in implementing this, and recommendations for resource development and implementation. Learning was shared across study participants in a workshop at the end of the study. Knowledge products included a website detailing the created resource, a youth-created film documenting the study process, the elements of the co-designed resource, and experiences of implementation, along with recommendations.	Study conducted by three collaborating universities.

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Human Trafficking Foundation, (2023)	Report	To review the work carried out by LEAP from July 2022 to July 2023.	LEAP highlights, in the review, the projects they have been working on, the organisations they have collaborated with, and other activities they have been involved in, such as consulting on research projects.	A section of the review highlights how LEAP has worked to influence policy. Examples of knowledge mobilisation include: LEAP both submitted written evidence to the Home Affairs Select Committee inquiry into human trafficking and provided oral evidence to the Committee; LEAP also sent an open letter to the Prime Minister, highlighting their concerns about the impact of the Illegal Migration Act on survivors of modern slavery.	LEAP (Lived Experience Advisory Panel).
Jones et al., (2024)	Commentary	To share how the Centre for Ageing and Dementia Research co-designs research within a national programme of work to improve the lives of older adults and those affected by dementia. Through examples of this work, the authors identify the barriers and enablers to participatory approaches and lessons to inform future involvement activities.	This study reflects on implementing the UK National Standards for Public Involvement into practice. Of international relevance, the observations span the research process from prioritisation and design to implementation and knowledge exchange.	Knowledge exchange events are arranged with experts-by-experience as an integral part of the dementia research programme.	Part of the DEEP (Dementia Engagement and Empowerment Project)

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Langley et al., (2017)	Conference paper	To explore the contribution of knowledge mobilisation theory within health on and through the practice of design, specifically co-design workshops.	Through the practice of Lab4Living and User-centred Healthcare Design, the author gained experience in doing design in healthcare using co-design approaches for participatory research, service improvement, and service redesign.	The paper aims to unpack the details of knowledge mobilisation, design, and creative practices relationships through case-study exemplars.	Affiliated with Lab4Living (a design-led interdisciplinary group) and User-centred Healthcare Design (www.uchd.org.uk).
Langley et al., (2018)	Commentary	Within a co-design model, this paper offers a specific approach to sharing, mobilising, and activating knowledge, which they have termed 'collective making.'	In a co-design process led by designers, a portfolio of techniques called generative methods is employed. These cover a wide range of activities through which co-design participants are 'led' to capture experiences, knowledge (explicit, tacit, embodied), habits, behaviours, and ideas. The distinguishing feature of these designer-facilitated activities is that they involve some form of 'making'. The making helps co-design participants explore, reflect, and consider experiences, share, articulate, and express them, and compare their experiences with those of others.	The article suggests that collective making has three domains of influence: on the participants, on the knowledge discovered and shared, and on the mobilisation or activation of this knowledge.	Produced by Lab4Living (a design-led interdisciplinary group).
Lazarus, (2018)	Book chapter	This chapter is from the book <i>Power and Identity in the Struggle for Social Justice</i> and highlights the authors' experience of conducting participatory action research in South Africa during the 1980s and 1990s.	While working for the Education Policy Unit, the author collaborated with students in schools to identify actions to be pursued in the education struggle occurring in those schools. A participatory approach was used that involved students in the research process. The participatory process in this project included the collective development of research and action aims.	Actions were collectively identified for implementation in schools. The students developed public factsheets to share the findings with other students in the schools.	Author employed by the Education Policy Unit (South Africa).

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Loizidou et al., (2023)	Empirical study	In this study, selected stakeholders from four Mediterranean coastal areas, highly vulnerable to the impacts of Sea Level Rise (SLR), were engaged through a structured participatory process for developing solution-oriented, case-specific, and site-specific Policy Tools to address SLR.	The DeCyDe-4 participatory method and tools were implemented. This adaptable, site- and case-specific decision support method leads to informed, science-based, and justifiable decisions on issues relating to sustainability and resilience. DeCyDe-4-SLR was implemented in four phases: 1) Baseline Study, where stakeholders were mapped, basic perceptions recorded through semi-structured interviews, and relevant information recorded through factsheets; 2) development of tools for successful implementation of DeCyDe-4-SLR; 3) implementation of participatory stakeholder workshops; 4) outputs were synthesised for the development of Policy Tools.	The Policy Tools developed in this study used information from previous phases of the method to define an action plan responding to the most pressing needs identified at each site.	Produced by Isotech Ltd Environmental Research and Consultancy, Nicosia, Cyprus.
MacGregor et al., (2022)	Empirical study	To explore the use of arts-informed approaches across three projects for co-production in education.	A multi-case design and cross-case synthesis were conducted across three studies that used arts-informed approaches. A common focus across the cases was evidence use in the K-12 education sector, though each engaged with this focus by involving different types of evidence and sets of education stakeholders.	The project focused on how arts-informed approaches to co-production create opportunities for knowledge mobilisation.	Produced by Queen's University, Canada.

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Machin et al., (2023)	Commentary	To introduce requirements for co-production applying the 4Pi Framework, reflecting on specific characteristics of co-production in rapid research. Strengths and challenges for the involvement of Lived Experience Researchers in rapid research are discussed, with recommendations provided to achieve meaningful involvement.	The 4Pi framework, developed by people with lived experience and co-produced by the National Survivor User Network (NSUN) is used in this article to discuss the requirements for co-production. 4Pi stands for Principles, Purpose, Presence, Process, and Impact.	The article highlights how dissemination, as part of the Impact (the final strand), can be overlooked as an integral part of the research process and lost as academic teams move onto their next project. When dissemination is seen as an activity that occurs after project completion, LERs may be unintentionally excluded, exaggerating the emotional labour of co-production. However, such exclusion is a missed opportunity: LERs bring additional networks and skills, which may provide benefits for ensuring the study's results reach a wider audience beyond that typically reached by traditional academics.	The 4Pi Framework was produced by the National Survivor User Network (NSUN).

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McCloskey et al., (2021)	Empirical study	To identify key themes related to gaps in care and root causes of inequities in care post-delivery after being pregnant, particularly for Black, Indigenous, and other women of colour.	The initiative <i>Bridging the Chasm between Pregnancy and Health across the Life Course</i> was launched, bringing together patients, advocates, providers, researchers, policy makers, and systems innovators to create a National Agenda for Research and Action. A 2-day conference blended storytelling, evidence analysis, and consensus-building to identify key themes related to gaps in care and the root causes of inequities. Stakeholders joined six working groups to reach consensus on strategic priorities based on equity, innovation, effectiveness, and feasibility.	Each working group held five conference calls over five months and advanced the Agenda through a consensus process to create: 1) a problem statement, 2) a synthesis of findings based on an analysis of peer-reviewed and grey literature and key informant interviews, 3) a ranked list of strategic priorities to constitute the Agenda for Action and Research to Bridge the Chasm.	Conducted by the Bridging the Chasm Collaborative.
McEwan et al., (2022)	Empirical study	To evaluate a unique, transdisciplinary participatory research and knowledge exchange methodology developed in the Drought Risk and You (DRY) project and offer it as a transferable framework for others engaging stakeholders and systemic connections with environmental risk.	An evaluative multi-method research methodology was applied to this process, using surveys, in-meeting reflective evaluations, and summative semi-structured narrative interviews. This paper reflects on participant experiences of the 'open' scientific modelling development, 'storying' approaches, and their iterative interaction.	The project proposes a transferable research framework that promotes participatory, place-based, narrative-science knowledge exchange for building local capital to manage systemic environmental risk.	Conducted by the Centre for Water, Communities and Resilience, University of the West of England.

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McKendrick et al., (2021)	Review	To appraise how those with lived experience of poverty are involved in the co-production of policy and service development. The Commission was particularly interested in practices relevant to the Scottish context, and how these align with best practices presented in academic literature when involving experts by experience in co-production.	This rapid review included examples of participation that could be regarded as genuine and effective co-production. A sequence of iterative and refined searches for relevant sources was undertaken using Google Scholar and titles and abstracts were screened against eligibility criteria.	The report itself mobilises knowledge about the co-production of policy and service delivery in Scotland. It includes work to improve service design and delivery, better understand key issues, engage communities, articulate policy priorities, and evaluate services.	The Poverty and Inequality Commission tasked the Scottish Poverty & Inequality Research Unit (SPIRU) of Glasgow Caledonian University to conduct this rapid review.
McQuaid et al., (2021)	Commentary	To explore how research-led applied arts can advance participatory methodologies to bridge the gap between participatory research engaging girls meaningfully within the research process and knowledge exchange processes that connect policy making with their lived experiences.	Using a creative mixed methodology, situating visual, material, and creative outputs alongside each other, perspectives were gathered from a range of stakeholders, while simultaneously building the capacity of 54 girls from a government school to engage in knowledge production through creative expression.	In the second phase, fortnightly workshops were facilitated to work with girls on using this evidence to develop a series of three creative, research-led performance-intervention events.	Partnership between the University of Leeds, Makerere University, Jinja Municipal Council and one government primary school in Walukuba/Masese.

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Powell et al., (2013)	Protocol	This population health study in Port Lincoln, South Australia, offered the opportunity to develop and apply the co-Knowledge Transaction Framework to the entire research process. This is a new framework designed to facilitate knowledge formation collaboratively between researchers and communities throughout the research-to-intervention implementation process.	This study employs a five-step framework (the co-KT Framework) formulated from engaged scholarship and action research principles. By following these steps, a knowledge base will be co-created with the study population that is useful to the research aims.	The co-KT Framework is a method for embedding the principles of knowledge transaction into all stages of a community-based research process. Specifically, Step 2 refines the research issue and knowledge base by integrating context-specific details and conducting knowledge exchange events. Step 3 involves interpreting and analysing the knowledge base and integrating evidence to inform intervention development.	Funded by the National Health and Medical Research Council.

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Phipps et al., (2021)	Empirical study	To shift the focus of intersectoral actors towards the contextual factors contributing to health inequities through Equity-focused Intersectoral Practice (EquiP), a novel methodology that merges participatory research principles with the strategic positioning of grounded expertise (lived experience).	RentSafe EquiP was co-created as participatory action research and implemented from 2016 to 2019 by a research team that included academic researchers and community researchers with grounded expertise in housing inadequacy, who also brought experiences of Indigeneity, single parenting, trauma and resilience, and peer advocacy leadership. The team's work was complemented by a research advisory committee, involved in all phases of research design and implementation.	<ul style="list-style-type: none"> • Draft research report shared with all participants for feedback • Final research report presented at a meeting of a high-level intersectoral table (~70 attendees), • RentSafe-Owen Sound Roundtable held following the formal briefing (50 attendees) • Research participants and others decided to continue convening as RentSafe in Owen Sound 	Collaboration between the Centre for Environmental Health Equity and Queen's University.
Redman et al., (2021)	Commentary	To summarise the articles in the BMJ collection <i>Co-producing Knowledge</i> and suggest several considerations for co-production	The article summarises four distinct considerations for co-production: a) it is highly context-dependent; b) it requires trust, genuine power sharing, and respect for the different expertise brought by stakeholders; c) there are practical requirements; and d) it requires a different approach to research funding.	The article highlights how co-production has been used to build skills and systems that increase the use of research by policy agencies.	On behalf of the Co-production of Knowledge Collection Steering Committee.

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Reid et al., (2023)	Empirical Study	To investigate how peer collaborators perceived and described their involvement in <i>Raising the Curtain</i> , a community-based participatory research project, focusing on their social participation and ability to convey social messages about dementia.	In the community-based participatory research (CBPR) project <i>Raising the Curtain on the Lived Experiences of Dementia</i> , eleven individuals living with dementia participated as 'peer collaborators' in weekly co-creative workshops over two years. Data gathered from the workshops, including transcripts (8) and one-on-one evaluation interviews (103), were used for analysis.	Raising the Curtain: a project that mobilises knowledge on living with dementia.	Collaboration between the Vancouver Foundation and the Social Sciences and Humanities Research Council of Canada.
Santaella et al., (2023)	Conference paper	To present the inclusion of Lived Experience Experts in designing the National Hemophilia Foundation's National Research Blueprint for individuals living with inherited bleeding disorders.	Seven multi-disciplinary working groups (WGs) were created. The WGs were tasked with addressing critical questions in the creation, sustainability, and eventual expansion of the Lived Experience Experts-focused research network. Basic demographic information for members of the WG was collected. Of the 62 members, 30 were Lived Experience Experts.	The working groups include those responsible for knowledge mobilisation activities including 'Policy, Research and Development and "Community Engagement'.	Presented by the National Hemophilia Foundation.
Sinclair et al., (2023)	Empirical study	To identify the top 10 priorities for building the evidence base for research, policy, and clinical practice for autistic adults with alcohol or other substance use disorders (AUD/SUD).	A priority-setting partnership was used, comprising an international steering committee and stakeholders from various backgrounds, including people with lived experience of autism and/or addiction. First, an online survey was used to identify key questions about substance use, alcohol use, or behavioural addictions in autistic people (SABA-A). These initial questions were reviewed and amended by stakeholders, and then classified and refined to form the final list of top priorities via an online consensus process.	Identification of the top ten priorities for health policy.	Funded by a grant from the Society for the Study of Addiction (SSA) and hosted by the University of Southampton.

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Tremblay and Jayme, (2015)	Empirical study	To describe the process and outcomes of a participatory video project that uses videos as a communication tool to enhance dialogue with policy makers in three municipalities about recycling.	During a week-long workshop, leaders from participating cooperatives were trained in video technology, storyboard development, and postproduction media. Through a participatory action research initiative, four short documentaries were co-produced over two years, and a collaborative research design was developed to use the videos as a communication tool for enhancing dialogue with policy makers in three municipalities.	This was a knowledge mobilisation project to mobilise knowledge about recycling programmes to policy makers.	Conducted by two Canadian universities.
Thom et al., (2022)	Empirical study	To describe a kaupapa Māori co-production project called He Ture Kia Tika/Let the Law be Right, highlighting how kaumātua (Māori indigenous elders), academics, and practitioners merged their voices with people with lived experiences of mental health, addiction, and incarceration to create justice policy and solutions.	The study focuses on the theory and application of co-production, directed by kaupapa Māori methodology. It describes the work of a co-design group that actively guides the project from inception to completion. Processes involved in the collection of co-created pūrākau (storytelling) with 40 whānau (family) participants are detailed, alongside the continued collaboration to ensure law and policy recommendations centred on lived experiences.	The study focuses on informing evidence-based policy through co-production with those with lived experience.	Supported by the Michael and Suzanne Borrin Foundation.

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Walker et al., (2021)	Empirical study	To describe and reflect on the methods and impact of involving young people with lived experience in a complex evidence synthesis.	Involvement was led by an experienced patient and public involvement in research lead. Young people with long-term physical conditions and mental health issues were invited to join a study-specific Children and Young People's Advisory Group (CYPAG). The CYPAG met face-to-face on four occasions during the project, with individuals continuing to contribute to dissemination following report submission.	The Young People's Advisory Group synthesised evidence and continued to contribute to dissemination following report submission.	Conducted by the NIHR Biomedical Research Centre
Willis et al., (2024)	Empirical study	To report on a Citizens' Panel, a representative group of people working with specialists, to create co-designed policy recommendations for reducing carbon emissions from homes.	The method and approach for the Citizens' Panel were designed by the researchers, working with the CCC and facilitation experts Shared Future. It was overseen by an independent advisory panel and evaluated by a separate team of academic researchers. The design of the process was informed by a review undertaken by the research team into the use of deliberative processes in policy making (reference removed for anonymity).	In the case of this Panel, the outputs provided evidence to inform the work of the Climate Change Committee. Upon the publication of the Panel's report, the CCC wrote to the government minister responsible for home energy use to highlight the Panel's findings.	Collaboration between Shared Future and Lancaster University.
Wydall et al., (2023)	Empirical study	To examine the use of co-production in creating the film 'Do You See Me?' to amplify the voices of a 'hard-to-reach' group: older lesbian, gay, and bisexual (LGB) victim-survivors of domestic abuse (DA)	Qualitative methods were used as part of the co-production, including two practitioner focus groups and 14 narrative interviews with lesbian, gay, bisexual, transgender, queer or questioning persons or the community (LGBTQIA+), victim-survivors.	'Do You See Me?' is a six-minute film, the product of a collaboration involving multiple stakeholders, as part of an awareness-raising resource about the lived experiences of older lesbian, gay, and bisexual (LGB) victim-survivors.	Produced by Aberystwyth University, funded by the National Lottery Community Fund and commissioned by Dewis Choice.

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