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Summary

- As part of the ESRC Policy Innovation Fellowship, this report provides an analysis of 23 interviews with a range of evidence and research centres, focusing on their understanding, views, and practices regarding the involvement of experts-by-experience in knowledge mobilisation.
- The aim of the research was to explore current practices, identify challenges, and highlight good practices, both within and beyond the What Works Network.
- The extent to which interviewees routinely involved experts-by-experience varied significantly, from minimal involvement in one What Works Centre to full integration into every aspect of one knowledge brokering organisation's practice.
- Interviewees highlighted the value of involving experts-by-experience in informing strategic direction, problem identification, effective dissemination, increasing impact, ensuring inclusive practice, and empowering those involved.
- We found that:
 - a) strategic, well-resourced, and inclusive approaches to engaging experts-by-experience can be crucial for enhancing the relevance and impact of knowledge mobilisation activities when certain pre-requisites are met; and
 - b) ensuring ethical and meaningful involvement is essential to maximise benefits and minimise potential harm.
- Key challenges identified by interviewees included resourcing needs and constraints, sustaining momentum, balancing individual and generalisable insights, and ensuring safeguarding and ethical practices, including those related to remuneration.
- Interviewees shared a range of key approaches to effective involvement, such as creating structured engagement frameworks, providing adequate training and support for both experts-by-experience and staff, and implementing safeguarding measures to protect experts-by-experience from potential harm, such as reliving trauma.
- Those who routinely involved experts-by-experience in their work highlighted the importance of dedicating time to build trusting relationships based on open, accessible, and honest communication.
- Interviewees noted that, through iterative dialogue with experts-by-experience from diverse perspectives, policy makers may be able to better make sense of evidence and understand its implications for policy.

Introduction



Since November 2023, the Wales Centre for Public Policy (WCPP) has hosted an ESRC What Works Policy Innovation Fellowship to explore whether and how experts-by-experience can best be involved in knowledge mobilisation. The aim is to improve practice in the What Works Network (WWN) and more broadly across knowledge mobilisation activities.

This report presents an analysis of 25 interviews with What Works Centres (WWCs) and 'peer' evidence and research centres, examining their views, understandings, and practices related to involving experts-by-experience in knowledge mobilisation or related activities, such as policy research. We also explore the impact of this approach, key challenges, strategies for overcoming them, and examples of best practices.

Interviewees highlighted the inherent inequalities within traditional knowledge production systems, which often prioritise academic expertise and exclude marginalised voices. They stressed the importance of challenging dominant narratives and broadening the definition of expertise to include diverse lived experiences. These debates about what constitutes 'evidence' or 'expertise' are central to the operations of the WWCs, offering both opportunities and challenges for their remit and strategy. Effectively integrating these diverse forms of expertise effectively is crucial for advancing equitable knowledge mobilisation practices.

As part of their work, these evidence and research centres participate in the mobilisation of policy-related research and evidence. Although not all explicitly use terms like 'knowledge mobilisation' or 'knowledge brokering', we refer to 'knowledge brokering' throughout as it best represents the practice of these organisations in this research.

Key Terms

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 strengthening the link between them. Although terms such as ‘dissemination’, ‘knowledge exchange’, and ‘knowledge translation’ are also used, knowledge mobilisation specifically requires sustained effort, collaboration, and is much more than simply sharing research findings (Levin, 2013). According to Levin (2013), knowledge mobilisation is a cooperative, social task that cannot be achieved without active partnerships, involving a two-way process between researchers, knowledge brokers, and knowledge users.

What Works Network

At the intersection of evidence-informed policy and practice, the WWN comprises thirteen evidence centres dedicated to mobilising evidence to inform policy and practice. However, despite nearly half of these centres publicly committing to involve experts-by-experience, the approach within the WWN is variable, with room for sharing and developing best practices.

Knowledge brokering organisations

In addition to the formal WWN, there is a broader range of ‘peer’ knowledge brokering organisations that play a crucial role in bridging the gap between research and policy. They differentiate themselves from other organisations in the evidence-policy field, such as think tanks, through three key characteristics: evidence is central to their mission, theory of change, and practices; they engage in knowledge mobilisation practices such as evidence synthesis and roundtables; and they maintain strong links to the government, often through funding arrangements and commissioned evidence outputs. This study included 14 of these organisations.

Experts-by-experience



An approach to mobilising knowledge for policy making is to involve individuals with lived experience of specific policy issues in the process. There is a growing movement towards involving experts-by-experience in research concerning them and their needs (Johnston et al., 2021). Moving beyond considering these individuals solely as research participants, advocates now call for their involvement directly in research processes, as advisors, co-researchers, or full partners in research processes (Hawke et al., 2024).

This shift highlights the expertise of those with lived experience of a particular issue, rather than merely using their lived experience as evidence. The distinction between ‘evidence’ and ‘experience’ is significant: ‘evidence’ refers to data or information gathered from lived experiences, often shared in the form of testimonies or narratives. In contrast, ‘experts’ refers to the insights and understanding gained from navigating the challenges and complexities of particular issues, which can be used to provide expertise and identify research and knowledge gaps. The term ‘experts-by-experience’ refers to those whose lived experience provides broader expertise beyond just evidence collection.

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 mean that experts-by-experience should not necessarily share specific personal experiences but rather draw on their experience to offer expertise.

Co-production



Co-production is an asset-based approach to developing more equal partnerships between people who use or are affected by policies and services and those designing, delivering, evaluating or conducting research related to policies and services. In research or knowledge mobilisation, it involves sharing power, with partners and researchers working together to develop the research agenda, design and implement the research, and interpret, disseminate, and apply the findings (Redman et al., 2021).

The ESRC Policy Innovation Fellowship

This ESRC Policy Innovation Fellowship aims to investigate the role of experts-by-experience in knowledge mobilisation within the WWN and beyond. It began in November 2023 and will complete in April 2025. The fellowship seeks to provide guidance on effective practices for involving experts-by-experience in knowledge brokering, including understanding the contexts that enable meaningful and impactful involvement.

Led by Dr Rounaq Nayak, who is hosted by the WCPP, it is a collaboration with three other WWCs: 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 and Human Rights Policy Evidence Centre and the International Public Policy Observatory. To support the Fellowship, a working group has been formed to facilitate collaboration among participating WWCs and other partners. The working group serves as a central platform for sharing best practices, providing guidance on project implementation, and supporting the dissemination of key findings and tools generated by the Fellowship within the WWN and beyond.

Methodology



The key questions guiding this research were:

1. What, if anything, is the value of involving experts-by-experience in knowledge mobilisation?
2. How far, and in what ways, do knowledge brokering organisations involve experts-by-experience in their work?
3. What are the key challenges faced and how are they overcome?
4. What are the key principles for effective, impactful and ethical practice?

Participants

For Phase 1, eight individuals in leadership positions across six WWCs participated in interviews. For Phase 2, a further 17 individuals, in various positions across 14 knowledge brokering organisations, participated in interviews. The WWCs and external organisations disseminated a participant information sheet within their teams, and recruitment occurred between November 2023 and March 2024 for Phase 1, and between January 2024 and April 2024 for Phase 2. Employees with relevant experience in involving experts-by-experience in knowledge mobilisation and policy research activities were recruited, including both leadership and non-leadership roles.

When the participant information sheet was distributed to WWCs, they were also asked whether they had involved experts-by-experience in any of their projects. One WWC had begun this process and informed their experts-by-experience about the fellowship to gauge interest. Two experts-by-experience volunteered to participate and share their perspectives on their involvement with the Centre.

Details of participants' current roles and length of service are provided in Table 1. It is important to recognise a self-selecting sample bias: WWCs and external knowledge brokering organisations engaged in this type of work were more likely to participate than those that do not routinely adopt this approach.

Phase	Employment type	Number of participants	Length of service (years)
Phase 1 – WWN (Participants 1 – 8)	Community organiser	2	1.5–2
	Head of evidence & data	2	4
	Research officer/fellow	2	1–4
	Director of policy & practice/ communication	2	3 months–10 years
Phase 2 – Outside of WWN (Participants 9 – 25)	Assistant director	2	3–6
	Research officer	1	1.5
	Expert-by-experience	2 ¹	3–4
	Chief executive officer of co- production network	1	3 months
	Partnerships manager	1	5
	Lived experience engagement manager	3	5–6
	Director of policy	2	1.5–5
	Impact manager	1	10
	Public involvement lead	1	2
	Rapid research lead	1	10
	Engagement lead	1	2
	Senior communities and network officer	1	7 months

Table 1: Interview participants' employment information

¹ It was challenging to recruit experts-by-experience from What Works Centres as six centres are at the very early stages of involving experts-by-experience, with most having no prior engagement. Additionally, seven other centres do not consider it within the scope of their work.

Data collection

A semi-structured interview schedule (Appendix 2), comprising four sections, was developed:

1. Section 1 included background questions exploring participants' roles, organisations, duration of service, and involvement in supporting the participation of experts-by-experience, as well as the value attributed to their involvement;
2. Section 2 focused on participants' views on key terms;
3. Section 3 mapped current practices adopted by knowledge brokers and/or policy makers in supporting the participation of experts-by-experience; and
4. Section 4 explored the challenges faced and future opportunities associated with adopting this approach in knowledge mobilisation and policy research.

A total of 25 semi-structured interviews were conducted between November 2023 and June 2024, each lasting between 45 and 60 minutes, recorded and transcribed using Microsoft Teams.

Data analysis

Recorded interviews were automatically transcribed by MS Teams and proofread by one of the authors before being de-identified. Following an inductive thematic coding approach outlined by Braun and Clarke (2006), the transcripts were analysed to identify, examine, and report patterns within the data (Flick, 2014). The preliminary list of codes and the coding framework are provided in Appendix 3.

Ethics approval

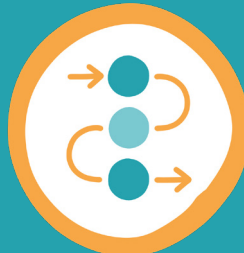
This research received approval from the ethics committee at the institution where the first author was employed at the time of data collection. Written informed consent was obtained from all participants.

Findings

In this section, we present the findings from the interviews in relation to the following key themes:



The value of involving experts-by-experience



Current practices



Challenges faced

The value of involving experts-by-experience



This section explores the various ways in which participants felt that involving experts-by-experience, when supported by effective practices, can bring significant value to knowledge mobilisation efforts. For some organisations, this value was driven by a moral rationale, emphasising the ethical imperative to ensure that those directly affected by policies or interventions are meaningfully included. For others, the value was more instrumental, focusing on the practical benefits that lived experience brings to the effectiveness and relevance of the work. One participant's account illustrates both the moral and instrumental value of involving those with lived experience, showing how ethical engagement can also lead to improved outcomes:

'Involvement of experts-by-experience was something that we wanted to strive to do... not just because it's the right thing to do, but also because it would improve the quality of the work that we do as a centre...'

Participant 11

The responses from participants highlight the recognition among organisations of the contributions experts-by-experience can make across the life cycle of a project, from conceptualisation and design to implementation and dissemination. It also shows the potential benefits of involving experts-by-experience in shaping project scopes, refining methodologies, and validating or strengthening findings and approaches to communication and dissemination.

The value of involving experts-by-experience

Informing strategic direction



One form of value highlighted by some participants was how experts-by-experience can help inform and shape the strategic direction of an organisation, when involved across a number of different projects or at an organisational level.

‘Working with experts-by-experience across projects allows us to develop our strategic pillars and objectives.’

Participant 7

‘A lot of it relies on the quite constant engagement and integration of experts-by-experience in everything that we do. This includes designing our team’s strategy...’

Participant 14

For one organisation, this level of involvement extended beyond mere consultation and included participation in governance bodies, decision-making forums, and strategic direction-setting activities. Other organisations expressed plans to involve experts-by-experience in shaping their organisation’s strategic direction. One employee with lived experience shared their organisation’s journey of integrating experts-by-experience into their work:

‘As an organisation, we started with lived experience in the research process itself, and now we’re looking to move that out into other areas of the organisation focus... We definitely went on a journey as an organisation. We put that [the involvement of experts-by-experience] in our strategy as a really central part of our work.’

Participant 11

This suggests that experts-by-experience can help shape the strategic direction of knowledge brokering organisations, such as helping to identify key issues to focus on. Furthermore, the involvement of experts-by-experience can be an integral part of an organisation’s methodological strategic direction. Either way, involvement at this level demonstrates the value that some knowledge brokering organisations place on this approach.

The value of involving experts-by-experience

Problem framing and definition



Interviewees highlighted how involving experts-by-experience can help knowledge mobilisation organisations identify and understand key social issues at the problem identification and framing stage of projects. Participants noted that working with experts ensured that research questions were relevant and meaningful, offering up-to-date, valuable context and insights that went beyond academic or policy-driven perspectives:

'Working with experts-by-experience helps us to see if a research question makes sense, whether it is something that we should investigate further...we gain value from listening to a different perspective... it is more than learning from an academic or policy driven research question... we get to understand what it means to be experiencing the policy issue at that moment. We gain a lot of value from the context and to doublecheck our findings...'

Participant 4

Another participant also highlighted the role of experts-by-experience in helping their organisation think early on about what to produce and its intended use:

'From a knowledge mobilisation point of view, their involvement is key from the very beginning around what do we want to produce, when do we need to produce it and how is it going to be used...having the right people around the table to make decisions is important when thinking about knowledge mobilisation, bringing them on board from the very beginning... many times we don't think about our final outputs or dissemination until after we've completed a study and we've analysed our data... dissemination should be one of the first things that we decide because it's all about use...'

Participant 14

Involving experts-by-experience allows organisations to understand issues in a more contextualised and holistic way. As one participant noted, being able to connect various pieces of work with real-life experiences helped the centres produce 'better work' and make more informed decisions that had a lasting impact beyond individual projects:

'...my ability to connect the dots between disparate pieces of work that we are doing in the context of someone's life that I've heard about and learned from, enables us to do better work and make better decisions that extend far beyond the life course of the project itself.'

Participant 1

'The perspective of experts-by-experience really helps to know that you're doing the right kind of work... I think it's the only way really of knowing that you're... answering the questions that are that need to be asked... it added a richness to it, it added the sort of reality to it, aliveness to it.'

Participant 20

The value of involving experts-by-experience in relation to problem or question framing was also reiterated by an expert-by-experience:

'...What I found a lot of the time was when we were setting the questions together or when they were deciding how they were going to do things by involving us [experts-by-experience], ...they understood things differently...because I think people are so used to their way of working and so used to existing systems, it can be difficult sometimes to think about other perspectives... they don't see things with curiosity anymore, than perhaps someone who's living and experiencing them.'

Participant 21

The value of involving experts-by-experience

Shaping communication and dissemination



The involvement of experts-by-experience added value to knowledge mobilisation processes for several of the organisations we interviewed by helping to communicate and disseminate findings effectively. For example, experts were involved in considering the most helpful ways to interpret findings from evidence synthesis in relation to the policy issue:

'... sometimes we jump to an evidence review or a literature review, as the way of getting insights into the questions that we have... However, there are many different approaches that we can use to reach the same conclusions... The voice of experts-by-experience can help us even if we are commissioning by speaking to people to understand what the real problem is, and how best to interpret the findings from the evidence synthesis...'

Participant 1

One participant explained how experts-by-experience can also offer novel ideas for communicating findings, which may be more accessible to those the findings are aimed at reaching:

'...We tend to rely on more academic terms and everything is so complex. Our lived experience researchers really make us simplify things, and think about a wide range of communication styles, leaving some of that academic jargon to one side. There's an element there around communicating with a wider audience and then different communication channels. We've worked with really young lived experience researchers in getting us to think about the use of media and videos and things that might be more appropriate to those audiences.'

Participant 14

Experts-by-experience involvement in thinking about how best to disseminate findings can also include co-planning events, again focusing on how best to reach the target audience:

'We have a lot of needs in the centre for short-term, including one-off, involvement exercises. Sometimes we need discussion groups to help us agree about a particular event that we are delivering, and we want to figure out how we need to do it...'

Participant 3

The value of involving experts-by-experience

Securing buy-in, evidence use and impact



Several organisations believed that, in certain policy areas or with specific policy makers, having policy research shaped and supported by experts-by-experience could add credibility to their work. They felt that the involvement of experts-by-experience could help gain buy-in from policy makers by demonstrating that the 'content' was informed by experts-by-experience:

'...when we host events and when we do an evaluation of the event, we often find that the content is more appreciated by our audience, which is mainly people working within the sector and in local government, when they are told that lived experience experts were involved...'

Participant 2

'Policy makers alone can't solve grand challenges...when you bring people together from different perspectives... then diverse publics can really weigh up the challenges, discuss those together, bringing into the mix all of their lived experience, because it's a deliberative process, bringing into the mix the information that they've heard from experts by profession, to arrive at really reasonable conclusions... I think some of the grand challenges that we experience as society cannot be solved by any single person, and they require these diverse perspectives.'

Participant 18

This quote from Participant 18 highlights the value of involving experts-by-experience, as well as 'experts by profession', in a process of iterative dialogue, in which policy makers can make sense of evidence and understand its implications for policy through conversation with these diverse perspectives.

Furthermore, participants described the increased buy-in from external partners and members of the public when there is a sense that a process, whether an intervention or a policy, has been produced by people experiencing similar situations to themselves:

'When publics in general see that people like themselves have been involved in the design of a process and that lived experience has been part of that, they are much more likely to have buy-in to the process than if they think that it has just been designed by... people in ivory towers...'

Participant 18

Organisations believed that, in certain policy areas or with specific policy makers, having policy research shaped and supported by experts-by-experience could add credibility to their work. They felt that the involvement of experts-by-experience could help gain buy-in from policy makers by demonstrating that the research was robust and grounded in lived experiences:

'...particularly when it is national policy, and we are talking about working with national policy makers, the work that we do has to be accompanied by very robust evidence and should be credible enough to convince policy makers...that is why it is about finding a person [or a group of experts] that believes in the process and sponsor it and see it through...'

Participant 1

By involving experts-by-experience in projects, knowledge brokering organisations are effectively enabling greater influence for experts-by-experience in the policy making process:

'...as part of the policy influence work... we're trying to encourage policy actors themselves to better include lived experience in their policy making. So, one way that we do that is providing them with research and policy outputs that have been informed by experts-by-experience.'

Participant 10

The value of involving experts-by-experience

Inclusive and equitable practice



Organisations underscored the multidimensional impact of involving experts-by-experience, highlighting its potential benefits not only in improving project outcomes but also in promoting equality, diversity, and inclusion within organisations, as well as fostering more democratic and equitable policy making processes. They emphasised the broader societal implications of involving experts-by-experience beyond the immediate project context:

'Involving experts-by-experience could strengthen our work...it is aligned with trying to promote equality, diversity, and inclusion within our organisation...making policy-making more democratic. Often departments [within the organisation] are thinking about understanding various perspectives and ways of co-design of events through an expert-by-experience's voice...'

Participant 3

'If our organisational mission and objective is to connect policy makers and decision-makers with...expertise...we should take an inclusive approach to understanding what we mean by evidence and expertise...'

Participant 7

Interviewees highlighted the inherent inequalities in traditional knowledge production systems, which often prioritise academic expertise while excluding marginalised voices as equal partners. They stressed the importance of challenging dominant narratives and expanding the definition of expertise to include diverse lived experiences. Participants underscored the role of experts-by-experience in democratising knowledge production and promoting inclusivity within policy development processes. Moreover, they advocated for recognising the unique value that experts-by-experience perspectives bring to evidence-informed decision-making, challenging epistemic hierarchies, and fostering more equitable forms of knowledge production.

Some participants felt that by involving experts-by-experience in policy work, the power imbalance between policy makers and communities could be reduced. Recognising the value of involving experts-by-experience, they suggested that power sharing could occur, helping to address structural inequalities:

'The value of bringing in lived experience is that we are designing...a society in which we are valuing how they are experiencing the world. If we include that experience in an effective way, we are sharing out the hierarchical power across our communities to influence that and make it better for all of us. I think there's great value in involving experts-by-experience because we start breaking down some of that hierarchical power that can make our society unequal for certain people and building on those structural inequalities and actually look at deconstructing that through sharing power and saying we value your life experience and your views to making this community better.'

Participant 24

'...social justice issues and inequality result from imbalance of power and structures that are designed in a way so as to exclude and continue to exclude the people who are marginalised and disadvantaged within that structure and it's really vital, if you're trying to solve any of those structural issues, to be shifting that power and to be breaking those structures open to be able to meaningfully involve and benefit from the insights and expertise of people who are affected by those issues... leads directly to the conclusion that experts-by-experience need to be in the driving seat as much as possible.'

Participant 23

This latter quote suggests that involving experts-by-experience may be particularly appropriate for projects that aim to address inequalities and promote diversity and inclusion.

The value of involving experts-by-experience

Diverse perspectives



Organisations with experience of involving experts-by-experience across projects identified the unique perspectives provided by these experts-by-experiences as essential for enriching project outcomes and enhancing their impact. They emphasised the value of incorporating diverse lived experiences into project design, implementation, and dissemination processes. These organisations highlighted the role of experts-by-experience in offering critical insights, enhancing understanding, and ensuring the relevance and effectiveness of interventions. Moreover, they stressed the importance of incorporating storytelling and narrative-based approaches alongside traditional data-driven methodologies, fostering deeper empathy and understanding among project partners by involving experts-by-experience throughout the project lifecycle:

'It helps me think about my research differently. It helps me come up with different questions. It helps us think about the best way to find out information and the best way to use, to do our research design and it helps us think about our findings, what have we found out, what do they mean and how do we disseminate them to people? So, for the whole research cycle, experts-by-experience will bring different perspectives and just help us sort of think outside the box.'

Participant 19

'I think we would kind of in research, call it thick description... that's what the experts-by-experience really help with. They make that research alive.'

Participant 20

'Thick description' refers to the detailed account of experiences in which the researcher, or in this case, the expert-by-experience, makes explicit the patterns of cultural and social relationships and places them in context (Holloway, 1997). Interviewees suggested that the involvement of experts-by-experience can make the work more real, which can help organisations empathise and potentially work more effectively:

'I've worked for many years in domestic violence and I worked with groups of survivors... we had fantastic insight into their experiences... you know, the barriers that they'd face to access services and what they would have needed.'

Participant 24

This highlights how the perspectives of experts-by-experience can add value to many aspects of a project, from selecting appropriate research questions and research design to contributing to decisions on how this knowledge should be mobilised. There was an awareness that the work carried out by knowledge brokering organisations impacts (albeit indirectly) the public, and therefore including the perspectives of those affected by a policy issue is crucial:

'... although we work on different projects across most WWCs, the one constant that unites us is that we work on projects that have direct impact on local communities which in turn has a direct impact on individuals who are [lived experience] experts in particular policy issues... By not engaging with these experts, often we are not thinking about the policy issue through a lived experience expert's perspective...'

Participant 1

The value of involving experts-by-experience

Empowerment for experts-by-experience



During Phase 2, two experts-by-experience, who worked for knowledge brokering organisations, were interviewed. These interviews provided insight into the value of involvement from the perspective of the experts themselves. Both participants highlighted how sharing their expertise was an empowering experience, helping them develop feelings of self-worth. This empowerment was fostered by the sense that what they had to say was of interest to others and that they were being listened to. Furthermore, there was a sense of camaraderie and togetherness within the experts-by-experience network. One expert-by-experience discussed their observations of facilitating the involvement of new group members:

'...you could really get a sense of how they [experts-by-experience] can make a difference to each other, how their experiences that they were going through could actually, they could see some positivity that could come from it and it really gave them self-worth and strength and then a positive support network of people that understood what they were going through on a day-to-day basis.'

Participant 24

'There's the therapeutic benefits of feeling someone's listened to you and has heard you. You feel that someone's taking an interest... that's part of why I got started doing involvement stuff and wanted to go into research... I meet these people and I'd be like, yeah, I'd like to go back to uni and I'd like to do some research and stuff.'

Participant 21

This viewpoint was reiterated by a participant who worked closely with an advisory group of experts-by-experience, highlighting how a positive outcome could emerge from a negative experience through involvement in the work as an expert:

'We're not a support group, we're a research advisory group, but I know that people... get so much out of doing this kind of work as well, particularly when they've had really difficult circumstances. I think someone had said to us that it feels like the only good thing that could have come out of it is to be able to try and contribute to something or make a change for the future so that people don't experience the same things as they did.'

Participant 17

It is important to note that benefits for participants are not inevitable but the result of good participation practices. There is a real risk of harm, which must be avoided. Additionally, while WWCs aim to tackle inequality, they are not front-line delivery organisations and are not funded to deliver positive outcomes for 'service users'. However, positive outcomes can be a welcome by-product of involvement. For more details on safeguarding approaches to mitigate these risks, please refer to the discussion in the 'Ethical and pragmatic considerations' section.

Current practices



This section provides an overview of current practices related to supporting the participation of experts-by-experience within WWCs and broader knowledge brokering organisations. Interviews revealed a wide range of approaches to involvement, with varying degrees of routine application across organisations. Key areas of practice explored included the identification of participation opportunities, efforts towards co-production and quality assurance, as well as initiatives focused on piloting the development of an internal guidance. Organisations highlighted that engaging with experts-by-experience can assist them in scoping and understanding problems, interpreting evidence review findings, and governing through boards.

While participatory evidence synthesis – where experts-by-experience synthesise existing evidence to contribute their perspectives and contextual insights – was common, alternative approaches were also used. These included priority-setting partnerships to determine what questions experts deem important and how they should be addressed, working groups and workshops to design the entire knowledge mobilisation process, and deliberative democracy approaches. The insights provided by experts-by-experience offered valuable perspectives in understanding the underlying issues and interpreting research outcomes effectively.

Current practices**Decision making****Whether to involve**

One of the questions interviewees were asked was: 'How do you and your team decide when to, and when not to, involve people with lived experience expertise?' Among the responses, some organisations explained that there would rarely be an occasion where experts were not involved, while others highlighted that it very much depends on the type of project:

'It might be doing a very short project, so we don't have time to do it meaningfully. So we did a project over about a month last summer, maybe two months, for the X Government, in which they wanted us to do an evidence review about a new piece of legislation that they were bringing in and we just didn't have time to involve experts-by-experience meaningfully.'

Participant 19

A couple of organisations emphasised the importance of adopting a strategic approach to involving experts-by-experience by carefully selecting projects and activities where their expertise could have the most significant impact. They suggested prioritising projects based on the potential to benefit from experts-by-experience input and focusing on key areas where their perspectives could contribute to meaningful outcomes, avoiding tokenistic involvement:

'I think we should select the projects carefully [where we involve experts-by-experience]... it could be a major part of probably one or two projects [in a year]. It could then inform the remainder of the projects.'

Participant 6

Several organisations highlighted the importance of ensuring that key principles and skills were in place to enable effective participation practices:

'... In terms of ensuring quality, having some principles is quite important... Principles around when to and when not to involve stakeholders, including experts-by-experience, and understanding why and on what basis we should work with them are first taken into consideration prior to involving [experts-by-experience].'

Participant 5

Time scales of projects played a significant role in the decision-making process. Interviewees highlighted that involvement should only occur when there is enough time to do it properly. For projects with a particularly fast turnaround, which is common in knowledge brokering organisations, it may not be appropriate due to the time it takes to adopt this approach meaningfully:

'The time scales involved [in policy engagement] are unbelievably rapid and it's not part of my role to have a relationship with a network where I could draw on an expert by experience... and I think that is a fundamental sticking point here that policy cycles often do not allow for time to build relationships and make those connections with experts-by-experience. Time is needed to develop that level of trust as to why they [experts-by-experience] should be engaging. This work is really hard to do and if you're going to do it well, it's exceptionally time consuming.'

Participant 15

Organisations whose primary focus is evidence synthesis and knowledge mobilisation considered involving experts-by-experience in only a minority of their projects due to the resources required for such involvement:

'... this kind of work requires a lot of staff time... If we planned to do this on every project, it would not be possible [as many projects have a tight turn-around time]... So logistically and ethically... it would not be possible.'

Participant 6

Depth and breadth of involvement



The level of integration of this approach within organisations varied, ranging from involvement in all aspects of the organisation's work to participatory evidence reviews or one-off consultations. For one WWC, the interviewee explained that this approach has not yet been adopted, although there was interest in how it might be introduced. For other organisations, the involvement of experts-by-experience is still in its early stages, with plans to integrate it more frequently. There were also organisations that have adopted this approach throughout every aspect of their organisation and view it as a vital part of their work.

'It's essentially a relational approach to knowledge mobilisation and involves a whole kind of shared dialogue between people who use care and support, people who provide it, people who manage it, i.e., the whole cross-section of people across social care... [it] really is about bringing people together to talk about issues and opportunities...'

Participant 9

Wheel of participation



Organisations utilised models such as the Wheel of Participation (Davidson, 1998) to determine the depth and extent of involvement of experts-by-experience. This model indicates various levels of involvement, ranging from design and consultation to monitoring, feedback, and communication (see Fig. 1).

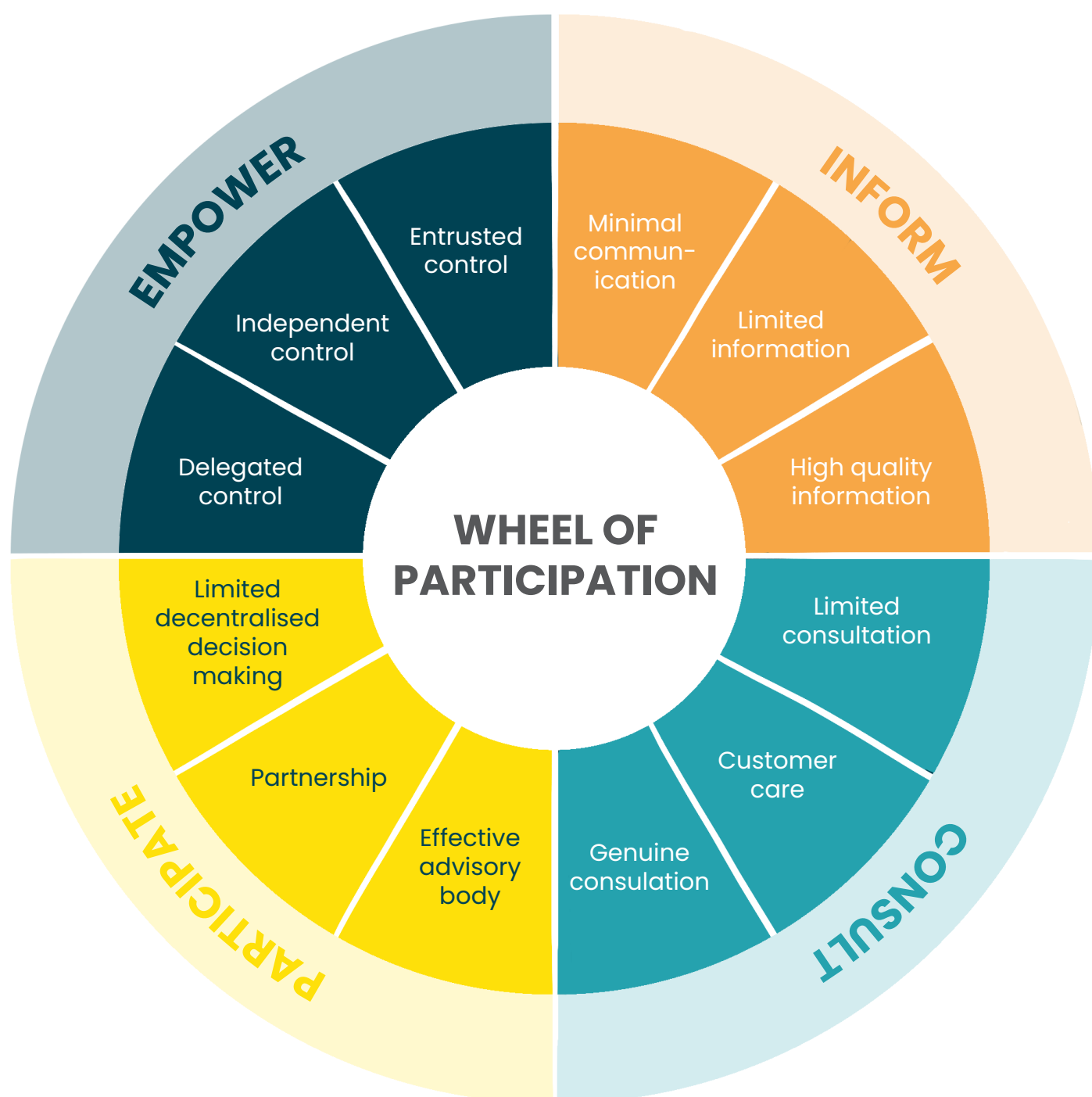


Figure 1: Wheel of Participation (Dooris & Heritage, 2013)

Organisations involved individuals at different stages of projects based on their expertise, interest, and capacity for engagement:

'The participation wheel indicates various levels...we involved experts-by-experience in lots of different ways – some we involved right from the design stage, while in other projects we only involved them in monitoring and providing feedback...'

Participant 7

Most organisations whose work focuses predominantly on one policy issue actively identify opportunities for experts-by-experience involvement across various projects and activities. This includes initiatives to engage them in communications activities and campaign development to address policy issues:

'... people who can and are willing to share their experience of XYZ are usually involved across various projects and supporting activities such as communications and campaign development... We often look for ways through which these experts can share their experiences and help us to shape and refine the messages and the topics of focus as the campaign evolves.'

Participant 1

Principles of meaningful involvement



Organisations that involved experts-by-experience emphasised that their decision-making processes were guided by principles that stressed the importance of providing meaningful opportunities for influence and contribution. This included identifying projects where individuals could shape the work, ensuring boundaries were set, and ensuring feasibility within time constraints:

‘First and foremost, involvement has to be meaningful... It is about identifying meaningful opportunities where experts-by-experience have the opportunity to influence and shape the work that we are doing and contribute to it in some way.’

Participant 1

‘We knew from the start that meaningful involvement of experts-by-experience was something that we wanted to strive to do as a strategic objective as a centre, not just because it’s the right thing to do, but also because it would improve the quality of the work that we do as a centre...’

Participant 11

One implication of this is that where meaningful involvement is not possible, it should not be attempted. It was also identified that decision-making around involvement needed to be guided by the alignment of goals and interests between individuals and organisations. Interviewees suggested that this alignment can help ensure that mutual benefits are realised:

‘If in fact that their goals and interests weren’t aligned with our approach... we would look elsewhere because we wouldn’t want to have somebody in a network expecting to get work and not getting it simply because their interests weren’t aligned with our priorities and our projects.’

Participant 2

Part of working effectively with experts-by-experience involved getting to know people and understanding the situations/tasks they were likely best suited to:

‘We have got some people within our network who we feel are most suited to doing individual projects where it’s just them speaking about their own experience... as opposed to people who we feel we can trust to be in group situations where people have varied vulnerabilities.’

Participant 3

Organisations with longer-term experience involving experts-by-experience underscored the importance of establishing transparent and substantive guidelines to facilitate their meaningful participation within teams. This highlights the pivotal role of clearly defined frameworks in promoting shared power and decision-making processes while discouraging superficial involvement practices. Central to this theme is the organisational commitment to fostering genuine engagement with experts-by-experience through the delineation of principles guiding their inclusion across diverse projects and decision-making contexts:

‘... it is important to have a clearly defined framework to ensure substantive and meaningful shared power and decision-making processes...’

Participant 1

Several participants also shared that the counterpoint to ‘meaningful’ participation is ‘tokenistic’ participation, where involvement is carried out merely as a marker rather than to genuinely inform thinking, practice, outputs, or impact.

‘You can’t really have people taking part in things almost as decoration. You know, as a co-chair of this ministerial advisory group, but they’re not really acting as a co-chair in the true sense. There’s a risk that people are there because it ticks a box... but they don’t come out necessarily feeling that they’ve contributed and the meeting hasn’t changed because of their involvement or the research hasn’t changed because of their involvement.’

Participant 19

Current practices

Recruitment and engagement



Organisations that involved experts-by-experience adopted a variety of approaches to reaching out to and recruiting experts. It was common for organisations to reach out to existing networks of experts-by-experience, and several worked closely with one or two pre-existing networks on a regular basis. Alternatively, some organisations dedicated time to building their own network of individuals with lived experience, who worked across relevant projects.

Several organisations prioritised consistency in their outreach efforts by assigning the same staff members to engage with partner organisations, ensuring continuity and reliability in communication:

'A lot of consistency within our organisation comes from having the same two members of staff make the approaches. They now have a process of approaching these experts, and the experts also know these staff members...'

Participant 2

Below, we explore three key approaches shared: personalised approaches and relationship-building, community partnerships and frontline engagements, and working with networks.

Personalised approaches and relationship building



Organisations emphasised the importance of personalised approaches and relationship-building in reaching out to experts-by-experience and inviting them to engage with project teams. Rather than relying solely on formal recruitment processes, in some centres, staff members with lived experience relevant to the organisation's mission played a significant role in approaching experts-by-experience and inviting them to participate on a one-off basis:

'People were being approached by a member of staff with lived experience and asked to do things on a one-off basis... some of those people kept in touch with the centre and did further work...'

Participant 2

One organisation gave an example of how they have used a non-traditional approach to recruitment, which they feel is more appropriate for those with lived experience:

'...We took a slightly less traditional route with the recruitment process for example, asking for CVs can be a bit challenging [for the experts-by-experience], especially if there are lots of gaps in there... To address that, we created our own recruitment process, whereby we [co-created] our own application [with experts-by-experience] where we didn't request a CV, but we still got the information we needed.'

Participant 10

Some knowledge brokering organisations, particularly those more experienced in working with experts-by-experience, emphasised the importance of building relationships at the beginning of a project, involving numerous meetings and discussions about hopes, expectations, and best practices.

'It really requires relationships to be built, so it really requires either someone to be interested and to be possibly trained if they're facilitating some kind of group. So, it requires that kind of expertise and time and enthusiasm to respond to each one individually to offer them support where it's possible.'

Participant 20

As with initial engagement and recruitment, organisations with experience in involving experts-by-experience highlighted the importance of ongoing relationship-building. These relationships should be based on mutual respect, active listening, empathic responding, and consideration of the experts' needs when resourcing a project:

'I think there needs to be that real sense of mutual respect. And a real willingness to listen and then make sure you put the appropriate resources in place, acknowledging that is a really important part of it, genuinely building relationships with people and starting to understand them and genuinely trying to integrate the expertise they offer with other forms of expertise, that might be around a table or feeding into a project.'

Participant 16

There was an acknowledgment that experts-by-experience offer different forms of expertise compared to academics or professionals they may work with, and integrating these forms of expertise collectively can add value to a project.

An emphasis was placed on ensuring sufficient time to build initial relationships, as well as allocating time to think about how to facilitate communication with experts. Ensuring engagement is meaningful, relevant, and of interest to those involved was considered crucial. Finally, time should be spent considering how to provide feedback to experts at the end of a project:

'You need, as well as all the time to have built the relationships, the time to have developed what it is you want to talk about. And really think about approaches that are meaningful and ethical? Is it interesting? Is it fun? How are we asking these questions? What are we doing when we're coming together? How are we making it work? And then, say you do a research advisory group meeting, how do you feedback, how are you giving that to them in a timely way? How do you do show them what difference they've made meaningfully? So, there's like kind of extra work afterwards as well.'

Participant 17

Community partnerships and frontline engagement



Organisations underscored the significance of community partnerships and ‘frontline’ engagement as effective approaches to reach out to experts-by-experience and involve them in their activities. By forming partnerships with frontline services and community groups, organisations gained access to diverse networks and populations, facilitating the identification and recruitment of experts-by-experience. Leveraging these organisations’ established relationships with their communities allowed the centres to access a broader range of lived experience perspectives, which might otherwise have been inaccessible through other recruitment methods. Effective work with experts-by-experience relied on relationships, but when WWCs needed to engage on a one-off basis, they could build upon the relationships that other organisations (e.g., community or gateway organisations) had with experts-by-experience:

‘There are certain spaces that would go to if we needed a lot of participants... forging partnerships with services that are frontline is really crucial, especially if you’re just doing a one-off piece of work.’

Participant 2

Working with networks



Some organisations highlighted the importance of establishing and maintaining networks to support the participation of experts-by-experience and facilitate ongoing engagement and collaboration. These networks can serve as platforms for continuous engagement, collaboration, and knowledge sharing among experts-by-experience and organisational partners:

‘We have a standard group who is the group that also advises into our strategy. So, it’s a core set of five people who are part of everything that we do. Since most of the time those five people will not be able to represent all of the medical conditions or areas where we might work in, we start tapping into existing groups of experts-by-experience, some of whom self-identify as patient representative groups. Others self-identify as a community representative group... in a nutshell, it is a network of groups of individuals, outside of academia, who are interested in informing research based on their lived experience.’

Participant 14

A few organisations also emphasised the creation of such experts-by-experience networks as mechanisms to maintain connections with individuals who have contributed to past projects, thereby facilitating ongoing, longer-term engagement and knowledge sharing:

‘We rely on our experts-by-experience network. Our involvement manager leads on this. It is a network of individuals who have been involved with us through other projects or in other capacities within the Centre...we have established this network to keep in contact with people that we have worked with on specific projects...’

Participant 1

On occasion, organisations worked closely with pre-existing networks or advisory panels. For instance, one organisation worked extensively with a panel of people with dementia and their carers, who collaborate, advise, and inform various aspects of work in this area:

'...with members of the panel, reviewing, providing a kind of peer review of the policy outputs before they're published, or perhaps discussing a particular topic in a bit more detail and drawing that out in terms of what we emphasise in the policy briefs [is common practice]'.

Participant 10

The panel was contracted to work with the organisation on a fortnightly basis to ensure consistent contact at regular intervals. Organisations that relied on such networks believed they fostered sustained relationships beyond specific project timelines, enabling the leveraging of accrued experience for ongoing projects:

'Due to these networks, we have a few experts-by-experience on our board. These are a group of individuals with various lived experiences from around the country, different backgrounds, challenges, perspectives and walks of life... Working with them across projects allows us to develop our strategic pillars and objectives.'

Participant 7

Current practices

Methods of involvement



While the varied approaches to involving experts-by-experience outline overarching strategies for engagement, the methods of involvement focus on specific techniques and frameworks used to integrate experts-by-experience into projects. These methods, including co-production, advisory roles, peer research, and event/workshop participation, provide a more detailed understanding of how experts-by-experience contribute to decision-making processes, project design, and implementation.

Co-design and co-production



Frequently used terms when explaining the approaches to involving experts-by-experience were co-design and co-production:

‘One thing that social care and social work has talked about for a very long time is coproduction and involving people with lived experience in our work... there’s such a rich tradition of co-production and we have some pretty neat ways of doing things.’

Participant 11

It is important to note that the term ‘co-production’ can have a wide range of meanings depending on the context. For some organisations, co-production may involve experts-by-experience as partners throughout the entire research or policy process, while for others, it could refer to a more limited form of collaboration or consultation at specific stages. This diversity in interpretation reflects the varied practices and levels of involvement across different organisations.

Organisations that involve experts-by-experience emphasised the importance of principles such as co-design and co-production in shaping their approach to involvement. This collaborative process entails engaging experts-by-experience in developing strategies, methodologies, and approaches to involvement, ensuring that their lived experiences and insights are embedded into the organisation’s practices:

‘We have specific studies where lived experience researchers are part of the research team. So, that’s where I think the element of co-production also comes to light around [experts-by-experience] acting as researchers themselves.’

Participant 14

Members of experts-by-experience networks engage in a wide range of activities, from co-designing projects to disseminating findings:

'... a lot of the dissemination that we do is in the form of infographics, animation using social media, different kind of accessible summaries and things like that. So, really getting them to kind of lead on our dissemination strategy as well.'

Participant 14

One organisation worked closely with network members to make funding decisions for new projects:

'We run open funding calls, people submit applications... We've included people with lived experience in the funding decisions, say forming part of the peer review panels that make decisions about what projects we fund.'

Participant 10

In this way, knowledge brokering organisations can draw on lived experience insights, as well as their broader institutional knowledge and evidence bases, to inform key decisions, such as those related to funding external projects. In some knowledge brokering organisations interviewed, the involvement of experts-by-experience is woven into most or all of what the organisation does, extending to the employment of experts-by-experience as staff members:

'A lot of it relies on the quite constant engagement and integration of experts-by-experience in everything that we do. This includes designing our team's strategy, designing each of our studies, and engaging with them when we are generating preliminary drafts for dissemination. Some of the experienced experts-by-experience are also part of the team as researchers themselves, so offering training and research methods, bringing them on board as part of the team, inputting into analysis and dissemination... so we've got a few academic publications with lived experience researchers as co-authors...'

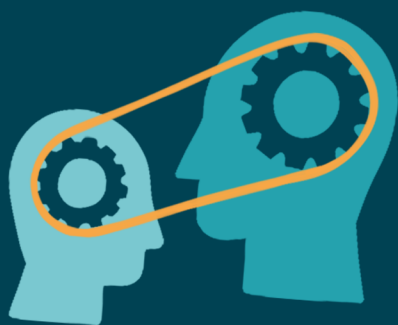
Participant 14

Organisations discussed the importance of facilitating this co-productive approach effectively by employing a range of creative methods:

'...make sure that you facilitate in a way that allows the voices to come forward... using creative and different ways of facilitating groups... make sure they don't just sit around a table and tell us what they think, but are allowed to be creative and interactive while accommodating for different people who have different ways of thinking and sharing their experiences'

Participant 24

The following case study demonstrates an example of how experts-by-experience were involved in the co-design and co-production of a project aimed at mobilising knowledge about child criminal exploitation:



Case Study 1: Knowledge mobilisation with young people

'One of my colleagues did some research on child criminal exploitation, particularly about county lines gangs. And there was a local authority in Wales that was working with some news workers as well as working with some young people. What came out of the research was that young people were saying we really need some better education tools. You'll watch these staged videos made-up little scenes and they just think they're rubbish or they just get kind of lectured by teachers or police. They say what they'd value was hearing directly from people who had lived experience.'

So, we set out to do this. And we got some interest from this project, from the local authority. Amongst a group of young people, there was a group of girls and a group of lads, and they were quite interested... [together] we came up with ideas about what they would want to say in a video. They mapped out what that would look like... the local authority paid for the venue and refreshments and we paid... money to professional film makers to come in to work with the youth. The professional film makers helped steer them in the right direction... this allowed them to design the video in one session, in the second session, they filmed the video and then they came in for a third one to premiere it.'



One-off involvement and event/ workshop participation



At the other end of the spectrum from co-production, some organisations discussed involving experts-by-experience on a one-off basis, often through participation in events, workshops, or specific activities. This form of involvement allowed experts-by-experience to contribute their insights, share their stories, and provide input on specific topics or issues relevant to the organisation's work. By facilitating one-off involvement opportunities, these centres enabled experts-by-experience to make meaningful contributions (i.e., aligned with their expectations from being involved) without requiring long-term commitments:

'I have been supporting people to get involved in a one-off basis... to contribute to a report, to illustrate an example of a phenomenon that we are reporting about in that report...'

Participant 2

'We have a lot of needs in the centre for short-term, including one-off, involvement exercises. Sometimes we need discussion groups to help us agree about a particular event that we are delivering, and we want to figure out how we need to do it...'

Participant 3

Guidance, resources and toolkits



Organisations utilised a variety of guidance, resources, and toolkits to ensure the meaningful and supportive involvement of experts-by-experience. Some were developed internally by organisations, while other external documents were used by teams when planning the involvement of experts-by-experience in projects. These included guidance from UK Research and Innovation (UKRI) and the National Institute for Health and Care Research (NIHR), as well as resources from the Co-production Collective. Internal resources and templates included standards to consider during recruitment, remuneration policies, safeguarding policies, introductory emails, consent forms, expressions of interest forms, and impact measurement tools, all designed to create a positive environment for involvement.

One organisation stated that their internal resources were available on their website for use by external organisations. In contrast, another organisation explained that, rather than using specific policies for experts-by-experience, they relied on their standard project checklists for involvement. For organisations that had established a wide range of resources, there was a strong message that these resources were constantly revisited and revised, with each resource going through a very iterative development process:

'... Those policies have developed organically as we've identified a need for them... We've come up with guidance around... involving experts-by-experience in meetings, both closed meetings and big events, to come up with a set of rules that we use at the beginning of all events where we think people with lived experience may be present...'

Participant 12

One organisation, which involved experts-by-experience in many aspects of their work, highlighted how policies and toolkits were co-produced with staff and experts-by-experience (where possible) to assist staff in understanding the steps required for meaningful engagement. These resources also provided guidance on how to involve experts-by-experience across relevant projects:

'We involve them [experts-by-experience] in all areas... So, just to give some examples with the working group... So a piece of work that we've been working on there is developing a 'survivor 'payments' toolkit which is a really important area... so that there is some supporting guidance out there for professionals when working with survivors. [The purpose of the toolkit is to help organisations] know how to remunerate them fairly, identify challenges that they could face and how to address them...'

Participant 10.

'We have guidance on how one can express written or recorded expression of interest to join the network... we have information that we send out and ask people to tell us a little bit about themselves, their expertise or experience and what sort of project they are interested in getting involved in.'

Participant 2

Challenges faced



This section highlights the challenges associated with involving experts-by-experience in activities within the WWN, as identified by WWCs and peer organisations.

Challenges faced

Resource constraints



Organisations with experience of involving experts-by-experience emphasised the need for adequate resourcing, including both financial investment and time allocation, to facilitate meaningful engagement with experts-by-experience. They acknowledged the inherent tensions between the desire for efficiency and the necessity for thorough engagement processes, emphasising the importance of prioritising quality over speed.

Participants commented on a range of resource and practical considerations when working with experts-by-experience. These included considerations related to accessibility to different venues, travel and dietary needs, and more complex issues around how to support and enable experts-by-experience to be involved in projects:

'...like who might need travel or different dietary things, or need to bring a support worker, and for carers in particular because they get excluded from a lot of stuff because there are, especially unpaid carers. If you want to take part in something, then that person still needs to be cared for.'

Participant 21

'I think there are the sort of the very practical resources that you need and then things like providing spaces and venues and catering, you know those sorts of things that can seem a bit trivial can be massively, I think, enabling. They can be massively unlocking because it's not always straightforward for people to access spaces or venues.'

Participant 16

The following case study demonstrates some of the challenges a project team might face in terms of resource constraints when involving experts-by-experience. It highlights how the resources needed for such engagement can differ from those required for non-participatory projects, and how some resources – although sometimes discreet or less easily recognisable – play a significant role in ensuring the successful engagement of experts-by-experience.



Case study 2: Resource constraints

'It's so challenging, like someone might not turn up [to working group meetings] for a while and you'll be following up with them and then you'll find out that actually they don't have any data left [on their phone] and we can help with that. But sometimes asking for it is really challenging, even though we've known them for years now... and we've sent it before. That kind of shame, that barrier is always there and it's really complicated. Or they don't have the technology or they're not using it as much as they're not as confident. So I think all of those things are kind of barriers and resources that people don't always think about, especially when they're just used to popping on teams and not everybody is. And not everyone has the same access that you would imagine.'

Then meeting a person, you really need to think about how people are getting there, how you're covering transport and covering it so that they don't have to spend it first. Even just in the few years that we've been working with these parents groups, you can see the cost of living crisis biting so hard. For example, where I am, university systems are not geared up to this in any way, shape or form. They're a cashless organisation. So, to be able to reimburse the bus ticket, I've got to take out my own money and then claim my own expenses.'

Participant 17



Organisational capacity, training and expertise



Organisations stressed the importance of building capacity and skills within staff teams to ensure a positive experience for experts-by-experience. Additionally, they highlighted the necessity of clear communication, consent protocols, and contextual understanding to optimise the engagement process and facilitate organisational learning:

'...it is really important to have enough capacity within your staff team to be able to give people a good experience...making sure that consent protocols are followed correctly, and people understand exactly how the input will be used.'

Participant 2

Another participant highlighted the importance of embedding relevant expertise within the team to provide support and guidance to less experienced colleagues:

'...having a manager at the centre who is an expert in this process and someone who can offer advice and guidance to project teams that are involving experts-by-experience is important. That for us is an essential way of ensuring quality control.'

Participant 1

The complexity and standard of training required to effectively utilise this approach were recognised by interviewees. There was an understanding that it takes time to develop the knowledge and skills needed to engage meaningfully with experts-by-experience in knowledge mobilisation activities:

'I think there's a lack of training available for knowledge mobilisers or academics in this space. It is not something that you can complete a short training course on and then go in and do this well, it is something which has to be really learned.'

Participant 15

Organisations also highlighted the additional time required for co-production initiatives, particularly when collaborating with external partners such as local authorities, national governments, and experts-by-experience:

'...it needs proper resourcing... Things have to go slower... In pretty much all of the projects that we are delivering with local authorities and often times, alongside national government, the ability to do genuine co-production requires all collaborating partners to buy into this approach and this can be a long-term journey.'

Participant 1

Financial constraints



The financial constraints highlighted by interviewees pointed to two distinct challenges. The first was that there was often insufficient funding to allow organisations the time needed to meaningfully involve experts-by-experience in projects:

'...unbelievable financial pressures on those organisations right now. I mean, everywhere being squeezed so to be able to meaningfully involve them [experts-by-experience], you should be funding them within the projects. And often there aren't always opportunities for that when budgets are squeezed. So I think it's a really tricky landscape'

Participant 17

Secondly, interviewees emphasised the challenges of securing funding for projects that involve experts-by-experience:

'I think there's significant problems with the way funders view some of this [involvement of experts-by-experience] as well. We've had some very interesting grant application feedback in relation to involvement [of experts-by-experience]... feedback ranged from 'wasted resources' to 'involvement of a few experts-by-experience not being representative of the wider population, impacting scalability of interventions...'

Participant 17

One participant explained the necessity of merging funding from different sources to effectively involve experts-by-experience in projects:

'I've definitely done things where I have leveraged funding from different schemes and creatively interpreted what those schemes are for. And it nearly always pays off because the story you have of whatever the research is and the other work that you've supported, does align to the schemes. But I suppose I've done it on a bit of a wing and a prayer and taking a punt that this, I think this thing [involvement of experts-by-experience] is worthwhile and will align. And then it does.'

Participant 16

Challenges faced***Ethical and pragmatic considerations***

All participating organisations emphasised the importance of ensuring that experts-by-experience engagement was conducted ethically and meaningfully, actively avoiding tokenistic and extractive practices. They acknowledged the challenges involved in balancing ethical imperatives with practical constraints, such as time limitations and resource availability. The organisations stressed the need to critically assess their organisational capacity to involve experts-by-experience in a responsible and effective manner, weighing the potential benefits against the inherent risks and challenges. Furthermore, they highlighted the importance of creating supportive environments that prioritised the wellbeing and empowerment of experts-by-experience. The complex interplay between ethical principles, practical constraints, and the imperative to ensure meaningful involvement of experts-by-experience was a consistent theme:

‘...there are ethical and pragmatic reasons why we might choose not to adopt this approach. Sometimes we feel that an individual is just not understanding the point of the project. However, it is important for the organisers of the centre to reflect on how the group [of experts-by-experience] is functioning rather than thinking of it as the individuals not participating in the group... it is important to think about the experts-by-experiences’ wellbeing and to think about ways in which we can enable their empowerment.’

Participant 3

‘I initiated a process internally to try and set down on paper a position on when and how and why we might bring experts-by-experience into our work... To avoid a situation in which we were asked to do it in a tokenistic or an extractive or an exploitative way...’

Participant 5

Effective and accessible communication with experts-by-experience was identified as a central ethical challenge in engaging with them. Regardless of whether English was their first, second, or at times, third language, the need to help experts-by-experience fully understand their role in knowledge mobilisation and research processes was highlighted:

‘...being able to provide information in plain English, checking that people have understood it rather than just signed a document, is quite important. It is important to make the time to do that [ensure experts-by-experience have understood]...’

Participant 2

Ethical approaches, safeguarding, and capacity building



Organisations underscored the importance of adopting ethical approaches and implementing robust safeguarding mechanisms to mitigate the risks of experts-by-experience reliving trauma during knowledge mobilisation activities. This often involved providing staff with organisational training focused on building capacity in areas such as ethical storytelling, facilitation skills, and effective safeguarding protocols. The aim was to ensure that staff within the WWCs could respond appropriately if safeguarding concerns arose, while also maintaining their own wellbeing when faced with potentially traumatic situations.

For example, one organisation provided training to ensure safeguarding practices were upheld, using ethical approaches to storytelling. This included emphasising the importance of establishing boundaries that respect an individual's autonomy in sharing their experiences. The training also covered how to handle situations in which experts-by-experience felt particularly upset or traumatised. As one participant noted:

'We've had organisational training on ensuring safeguarding and about ethical approaches to storytelling... laying the groundwork... that the boundaries are within that individual's gift to draw... learning some of those facilitation skills, about what to do when an expert felt particularly upset, traumatised, angry...'

Participant 1

Additionally, formal safeguarding mechanisms, such as ethical approval from governing bodies and the presence of internal support structures, were seen as necessary to ensure the safety and wellbeing of experts-by-experience engaged in projects. Participants also highlighted the need for clear protocols to be in place, ensuring that staff were adequately prepared to address safeguarding concerns when they arose. Creating safe spaces was another critical element of the safeguarding strategy. Organisations carefully planned for potential triggers when sensitive topics were discussed, particularly when experts-by-experience included vulnerable groups such as young people:

'Thinking about how we create a safe space is important, as these conversations can be upsetting, triggering... considerations around safeguarding, creating safe spaces for conversation, especially with experts, including young people, who have particular vulnerabilities.'

Participant 4

Collaborating with experts-by-experience to develop safeguarding policies was another practice shared by some organisations. This approach ensured that the needs and perspectives of experts-by-experience were directly integrated into the safeguarding process, making it more participatory and transparent. One interviewee explained:

'... when somebody... within an experts-by-experience forum is having a conversation about what safeguarding is and why we do it, but also about an approach that is working alongside them, often safeguarding is seen as something that happens to people... we always have a conversation about how safeguarding would support them and make it clear when we might need to take action. There have been occasions where safeguarding action was required, but it was clearly communicated to the person why it was being done and how it would support them.'

Participant 24

Once involved, organisations adopted strategies to provide ongoing support to experts-by-experience, including the creation of breakout rooms or 'safe spaces' where individuals could step away if they felt overwhelmed. Additionally, organisations ensured that a wellbeing contact was available to provide further support if needed. This kind of capacity-building for WWC staff, alongside organisational policies, helped to create a supportive environment not only for experts-by-experience but also for staff who were facilitating their involvement:

'...we will always have a breakout room, which is like a quiet room, a quiet space... and people use the well-being person for all sorts of reasons. And I found that it's really nice, actually, how normalised it can become to just use the wellbeing person and to just have a chat with that person.'

Participant 18

Furthermore, organisations prioritised safeguarding, particularly when involving young people or other vulnerable groups. Safeguarding was seen as crucial in creating an environment where participants felt safe, comfortable, and empowered to contribute:

'... safeguarding is the utmost priority, irrespective of what we are asking of our experts when they are young people... it is important for them to feel safe and happy and comfortable to participate... it is something that requires a lot of work as if you don't [focus on safeguarding], that is when you have variability in quality.'

Participant 7

Remuneration challenges



Organisations highlighted the importance of fair compensation for experts-by-experience based on their contributions and expertise, ensuring that remuneration rates were equitable and accurately reflected the value of their involvement. Remuneration was not solely based on lived experience expertise but extended to other skills and perspectives that experts-by-experience brought to the table. This holistic approach recognises the whole person and acknowledges the diverse talents they contribute, beyond their lived experiences. Additionally, the principle of fair compensation extended to reimbursing individuals for their time and expertise, particularly when engaging with topics that might be emotionally taxing or require significant commitment:

‘We have a policy where we pay our experts-by-experience... But the crucial thing is that we try to involve people not only based on their experiences, but also based on the other types of skills that they might have... So it is about seeing the whole person.’

Participant 3

‘I just think it is obviously essential that you reimburse people for their time... You have to think how you do it in a way that doesn’t have unintended consequences... You don’t affect people’s benefit payments, for example...’

Participant 5

Organisations emphasised the importance of ethical remuneration practices to ensure that financial compensation did not create perverse incentives or unintended consequences for experts-by-experience, particularly for those who might be experiencing financial difficulties or rely on government benefits. This included discussions about setting appropriate boundaries around payment arrangements, to avoid situations where individuals could feel pressured to share traumatic experiences for financial gain. Ethical considerations also extended to informed consent processes, where individuals were fully informed about potential impacts on their benefits and given the autonomy to decide whether or not to accept payment:

‘We’ve really grappled with this as an organisation... what we’ve pushed for is to move towards a much more informed consent approach... making clear to the people that there could be a problem if they were in receipt of benefits... making it clear that the onus is on them to make the decision if they want payment in cash or other forms.’

Participant 2

'The challenge comes... because we're not an academic body. We can't pay people without tax implications. So, we're trying to work out at the moment, how do we involve those groups, but not under value their involvement by not paying them. I've got a very strong view that if you involve somebody because they're using social care or they're an unpaid carer, then you know ethically you should be rewarding them for that involvement. Now we're grappling with the question of how do we pay people? How do we involve them and pay them for their involvement? Because it really isn't ethical to do it any other way....'

Participant 9

At times, organisations faced challenges in remunerating experts-by-experience due to budget constraints. In such cases, expenses were often covered, but interviewees expressed the view that experts should be compensated for their time:

'So, we reimburse them for their time as in for their travel expenses and we bought them lunch, but we didn't pay them for their participation in terms of hours. I personally think we should, especially with young people, and with the cost-of-living crisis, I think that would have given them the opportunity to participate more but we didn't have the budget for it.'

Participant 20

Another reason remuneration can be difficult is that it may jeopardise individuals' eligibility for social security benefits (e.g., Universal Credit). In these cases, project teams must explore alternative ways to remunerate experts-by-experience:

'The other issues [around remuneration] have been around, often experts-by-experience have issues around accessing Universal Credits and [social] benefits and payment isn't always the best route to provide remunerations...we have often explored different routes to provide that payment, whether it's via a voucher, so that allows them to have flexibility to have a payment without it being acknowledged as a monetary payment or looking at time credits which allows them to have access to some remuneration for their time without impacting on their benefits.'

Participant 24

This challenge regarding how to remunerate without affecting an individual's earnings or benefits is a complex issue. For example, regarding vouchers, recent guidelines specify that what individuals must report and pay to HMRC depends on whether the vouchers are exchangeable for cash (Gov.uk, 2024). The guidance also provides a list of exempt vouchers, which do not need to be reported. These typically cover work-related travel and accommodation vouchers.

As highlighted, a key aspect of the challenge surrounding remuneration is the desire among organisations to fairly compensate experts-by-experience for their time, while balancing this with financial constraints and the potential risk to some participants' eligibility for ongoing social security support.

Challenges faced

Motivating participants vs managing expectations



Concerns were expressed about sustaining momentum and interest in experts-by-experience involvement over time. Organisations noted that while initial engagement efforts might be successful, maintaining enthusiasm and commitment from experts-by-experience could prove challenging, particularly if individuals no longer wished to remain closely involved in the process. These challenges manifested as unanswered emails, experts-by-experience arriving late to meetings, not attending at all, and generally high drop-out rates:

'I've worked in an organisation where I would frequently get like less than half of the people who say they're going to show up would show up in the room.'

Participant 18

'Sometimes you've done a lot of work to onboard someone, to train them, and then for different reasons they can no longer commit. So, there is a [high] turnover, of course, of members.'

Participant 14

Additionally, sustaining momentum may require ongoing efforts to demonstrate the value and impact of experts-by-experience contributions, which can be labour-intensive:

'Getting people to... want to do it again and again... can sometimes be quite challenging, particularly if those individuals don't want to be particularly close to the process.'

Participant 1

Organisations emphasised the need for clear communication, context-setting, and support mechanisms to help mitigate the potential loss of momentum and ensure that experts-by-experience have a positive and enriching experience. They stressed the importance of providing adequate information, explaining the project's context, and clarifying expectations regarding participation. Several of the external knowledge brokering organisations with experience in involving experts-by-experience in their work strongly advocated for being open, honest, and transparent in communication, particularly regarding what change or impact could realistically be expected from a project:

'Our first meeting with our student panel was actually just figuring out what good practise would mean for them... The first thing I did was explain to them what they could and couldn't change. I think that was really important so that they didn't think that they would be able to come in and be really disappointed when they couldn't affect a greater change. And being really clear about what the project was going to do, what the limits of it are.'

Participant 20

'... building trust and transparency, those are some of the key things, having really clear communication about what the parameters are and what is available to be influenced, being really clear about the expectations at the start and being able to understand the limitations of the piece so that people aren't coming in thinking this is going to change their life.'

Participant 23

These participants suggested that an element of 'expectation management' was necessary, avoiding over-promising in communications with experts-by-experience. This balance must be maintained with the imperative to encourage people to both become and remain involved.

Indeed, interviewees highlighted the importance of ensuring experts-by-experience were made aware of the potential complexities involved in knowledge mobilisation and government-funded projects. Realistic conversations about the potential impact of the work were essential, particularly in emphasising how challenging it can be to influence and change policy, and ensuring that expectations for experts-by-experience were well-managed:

'...Having trusting relationships, but also being quite frank about what each partner is bringing and why they are involved. To be really doing this work well, it is understanding that you're trying to navigate your way through a really potentially messy, complicated policy problem or policy issue, and you're quite often working against traditional bureaucratic practises or organisational structures, and so I think to do it well, you just have to become very, very agile and flexible and always relaying that to your expert-by-experience around this is not going to be a linear project together, it will inevitably have a few bumps on the way and I think, if you are able to maintain that excellent communication both ways throughout, then it should generate an effective project at the end.'

Participant 15

Challenges faced

Balancing individual experiences, diversity and generalisability



Some interviewees discussed the challenge of balancing individual experiences with the need to generalise and make decisions that affect a broader population in research and policy making contexts. While individuals' experiences provided valuable insights, translating these experiences into generalisable principles across policy research and knowledge mobilisation projects is complex, if not impossible. There was often a perceived tension between honouring the diversity of individual experiences and distilling key insights that could inform policy decisions effectively.

For those whose expertise lies primarily in quantitative data collection and statistical analysis, shifting to an approach focused on individual experiences posed challenges. From this perspective, some interviewees expressed that individual lived experiences, unless structured in a way that reflects broader societal patterns, may be viewed as anecdotal or illustrative rather than robust evidence. This tension underscores the difficulty in balancing individual insights with the need to generate generalisable findings that can inform policy decisions:

'...applying project experiences to the wider population... is a lot more complicated... it is a difficult balance to strike.'

Participant 3

'We have such a breadth of experience... it is really hard to make that research and the facilitation of the participation accessible to both groups without pitching it wrong.'

Participant 4

In this context, a further challenge arose in ensuring diversity within a group of experts-by-experience. Relying on the same group of experts and struggling to reach a more diverse socioeconomic group was highlighted:

'Who we target as well, there's a big debate... around a kind of diversity inclusion in terms of the involvement of experts-by-experience – we tend to always involve, write to, the same people. How do we reach other populations so that we're presenting kind of a wide range of views?'

Participant 14

This challenge in ensuring a diverse range of perspectives stemmed from difficulties at the recruitment stage of a project, with particular challenges in reaching marginalised or disempowered groups who are likely to face greater barriers to participation:

'Taking the words of this small group of individuals as meaning that's the design for all service users can be inaccurate... actually what they had is an example of a very small pool of experiences and definite gaps around class, race, sexuality, that were not being seen because there were multiple structural barriers... When you advertise for people who have lived experience, there are certain people that have the [relative] privileges of coming forward in a way that others don't.'

Participant 24

'When we recruit our participants, it's really important to make sure that you don't just get the people who shout the loudest... it takes an awful lot of resources to recruit them and then not just the recruitment but the onboarding process, which is absolutely essential, especially if you're working with people who are traditionally disempowered.'

Participant 18

Challenges faced

Learning and iterative improvement



Organisations highlighted the importance of continuous learning and iterative improvement in the process of involving experts-by-experience. They emphasised the need for organisations to remain open to feedback, adapt their approaches based on lessons learned, and continuously improve their practices to ensure that experts-by-experience involvement remains effective and meaningful over time:

'I think there's definitely a place for involving experts-by-experience, and I think we will increasingly struggle to justify not including them... However, as a Centre, we must be mindful about continuously learning how to engage with the experts most effectively.'

Participant 5

'It is surely a more inclusive approach and is another way of making policy making more democratic... Getting continuous feedback from employees as well as the experts is important to be able to learn how to improve as an organisation and as a team...'

Participant 6

Organisations also explained the importance of learning from other teams and members within teams, sharing and reflecting on their practices, and adapting them where appropriate to ensure best practices are followed:

'I think it's a dynamic kind of process and we're always learning from other teams, other organisations in terms of what they're doing. So, there's a lot of kind of sharing of that learning as well that helps.'

Participant 14

'So, obviously within the team, we have a lot of expertise. We work with participation all the time and we share the learnings within our team all the time. So, we have quality assurance on all of our projects. We do lots and lots of sharing of the learning that we do in formalised and informal ways throughout the team. We have a really open approach to any sort of questions that we have.'

Participant 18

Key principles and pathways



Based on the findings and insights from interviews with various WWCs and external knowledge brokering organisations, we have identified the following key principles and pathways to enhance the involvement of experts-by-experience in knowledge mobilisation and policy research. These principles aim to address existing challenges and leverage opportunities for more effective and impactful engagement. They will be revisited throughout the Fellowship based on evidence gathered.

Ensure ethical practice

Ethical practice in involving experts-by-experience requires careful consideration of safeguarding, autonomy, experience, and support. Organisations must ensure that experts-by-experience are engaged meaningfully, avoiding tokenistic practices. Safeguarding measures must be implemented to prevent re-traumatisation, particularly when discussing sensitive or potentially distressing topics. This can include providing staff with training in trauma-informed practices and ensuring a safe environment where experts-by-experience feel comfortable participating.

In addition to safeguarding, ethical considerations also extend to fair remuneration. Whenever possible, experts-by-experience should be compensated for their time unless they are already receiving payment through other means (e.g. employment). Organisations must be transparent about the implications of compensation, especially for those who rely on social security benefits. Providing clear information about how payment might affect their benefits enables experts-by-experience to make informed decisions about whether they wish to participate.

Ethical practice also requires organisations to assess their capacity to engage experts-by-experience responsibly. This includes ensuring there are adequate resources and support systems to facilitate their participation and wellbeing throughout the process. Additionally, it may be helpful for organisations to develop or refer to established ethical guidelines (e.g., to ensure staff are equipped to engage with experts-by-experience in a responsible and effective manner).

Ensure a positive experience for experts-by-experience

To ensure that experts-by-experience have a positive and enriching experience, clear communication, context-setting, and support mechanisms are essential. Providing experts-by-experience with enough information, autonomy, and options to make an informed decision about whether the benefits of participation outweigh any potential 'costs' can help facilitate a positive overall experience. There should be sufficient time allocated to build relationships with experts-by-experience, based on open and honest conversations. These discussions help manage expectations (e.g. regarding likely impact) and enable organisations to meet individual needs and preferences where possible.

Resource allocation

Adequate resourcing is essential for the meaningful, ethical, and impactful involvement of experts-by-experience. This requires not only securing the necessary financial resources to be able to remunerate appropriately but also allocating sufficient time and staff capacity to effectively manage and facilitate the engagement process. Practical resources, such as accessible venues, engagement platforms, and safe spaces, along with consideration for travel needs, are also vital to ensure effective participation. Organisations should consider allocating dedicated budgets to support these activities, ensuring that they are considered an integral part of project planning and execution processes. Proper resourcing can help address the challenges associated with the additional time and effort required for effective experts-by-experience engagement and relationship-building. If sufficient or appropriate resources are unavailable, participation should be reconsidered or avoided to ensure meaningful involvement.

Take a considered approach to decision making

Adopting a strategic approach when selecting projects that will most benefit from the input of experts-by-experience is key. This can be achieved effectively through pre-agreed frameworks and decision-making tools. Prioritising projects with high potential impact and clear relevance to lived experiences maximises the effectiveness of their contributions. By focusing on projects where their insights are most needed, organisations can ensure that experts-by-experience are making the greatest possible impact on policy and practice.

Effective communication

When involving experts-by-experience, communication must be accessible, transparent, and honest. Future initiatives should prioritise effective communication throughout the duration of a project. Open, transparent communication can help maintain enthusiasm and commitment over time, ensuring experts-by-experience remain engaged. Regular updates on the impact of their contributions, as well as fostering a sense of community, are key in building long-term motivation and engagement. Establishing and maintaining a supportive network for experts can also help sustain momentum and reinforce their ongoing commitment to the work.

Capacity building, learning and reflection

Investing in organisational capacity building is crucial for supporting the engagement of experts-by-experience. This includes providing training for staff to collaborate effectively with experts-by-experience, developing clear communication protocols, and establishing supportive environments that facilitate meaningful participation. Continuous learning and adaptability are essential for improving the involvement of experts-by-experience. Iterative improvement ensures that engagement practices remain relevant and effective. Regular feedback between knowledge brokers and experts-by-experience helps identify areas for improvement, driving more effective engagement strategies. Building this organisational capacity can help address challenges related to varying levels of staff knowledge and experience in involving experts-by-experience, ensuring all participants can contribute meaningfully.

Promoting inclusivity and diversity

It is vital that the process of involving experts-by-experience promotes equality, diversity, and inclusion within organisations and policy making processes. Actively seeking out diverse voices and creating inclusive platforms that allow a broad range of perspectives to be heard and valued is essential. Promoting inclusivity can address challenges related to the representativeness of the engaged experts and ensures that a wider range of experiences is considered. Organisations must be mindful of barriers to participation, such as accessibility needs, language barriers, and caring responsibilities, which may limit some experts' involvement.

Encouraging experts-by-experience to shape their own input

Incorporating personalised approaches alongside traditional data-driven methodologies can enrich the experience for experts-by-experience. Experts bring valuable perspectives that humanise and contextualise data without the need to quantify it, making policy discussions more relatable and impactful. The involvement of experts-by-experience should not solely focus on illustrating quantitative findings. Narrative approaches are especially valuable in conveying the real-life implications of policy decisions and enhancing partner engagement.

Pathways to professionalisation

Where possible, knowledge brokers could consider pathways to professionalisation for experts-by-experience. Organisations can play a critical role in supporting this development through opportunities to build professional skills, mentorship, and facilitating access to formal training and qualifications.

Experts-by-experience who work as peer researchers, for example, may aspire to continue their careers in research. To support this pathway, research teams can offer targeted skill-building opportunities, such as training in research methodologies, data analysis, and academic writing. Additionally, providing mentoring relationships between experts-by-experience and established professionals can help bridge the gap between experiential knowledge and professional roles, offering guidance and career development support.

These pathways are vital for helping experts-by-experience leverage their unique insights while developing the broader skill sets necessary to transition into professional roles if they choose. By supporting their professional growth, organisations ensure that they not only benefit from the expertise of those with lived experience but also contribute to expanding career opportunities for these individuals within their field.

Organisational commitment

A strong organisational commitment to integrating experts-by-experience is necessary for effective engagement. This commitment involves embedding the principles of engagement into the organisational culture and ensuring that all staff members understand and value this approach. An organisational commitment helps to address challenges related to varying levels of buy-in and support across different levels of the organisation.

Relationship building

Building positive relationships with experts-by-experience is paramount for meaningful engagement. Sufficient time must be dedicated to building trust and mutual respect before the project begins, with a commitment to honest, open communication maintained throughout the life of a project. It is important to consider the needs of each individual and ensure that the project is resourced to meet these needs appropriately. Finally, feedback should be provided consistently throughout the project and at its conclusion to inform participants of the impact of their engagement.

Conclusion



The involvement of experts-by-experience in the activities carried out by WWCs and wider knowledge brokering organisations presents significant opportunities, as well as notable challenges. This report has highlighted the valuable role that experts-by-experience can play in enriching knowledge mobilisation by offering unique insights that can enhance the relevance and impact of project outcomes, and be valued by policy makers and other evidence users. The insights gained from interviews with staff across various organisations underscore the importance of strategic, well-resourced, and inclusive approaches to effectively engage experts-by-experience.

The level of integration of this approach across organisations varied, from full involvement in all aspects of work and at a strategic level in some organisations, to occasional one-off consultations in others. Most organisations operate somewhere in between these extremes. Areas of practice explored in this report include identifying appropriate opportunities for participation, recruitment and engagement efforts, and particular methods of involvement, such as co-production, the use of guidance and toolkits, and quality assurance. Interviews revealed a range of approaches to involvement, including working groups, priority-setting partnerships, and participatory evidence reviews.

Key challenges identified include the need for adequate resourcing, effective communication, balancing individual and generalisable insights, ensuring diversity among those involved, managing tensions between policy timelines and the need for flexible/long-term approaches to working with experts-by-experience, and ensuring safeguarding and ethical practices. Addressing these challenges effectively requires organisational efforts to build capacity, promote inclusivity, and foster continuous feedback and iterative improvement. Additionally, designing and managing this work in a way that maximises the potential benefits while minimising the potential risks, such as safeguarding concerns, is key.

Implications for knowledge brokering organisations



When considering the specific activities involved in knowledge mobilisation, this report has outlined several ways in which experts-by-experience can add value through meaningful involvement. Experts-by-experience can help knowledge brokers identify and understand key social issues at the problem identification and framing stages of projects. Involving experts-by-experience allows knowledge brokering organisations to gain a more contextualised and holistic understanding of issues, for example, by clarifying what the real problems are and how best to interpret the findings from the evidence synthesis. Their involvement can also assist knowledge brokers in gaining buy-in from policy makers by demonstrating that the knowledge mobilisation process is robust and grounded in lived experiences. Furthermore, experts-by-experience can offer novel ideas on how best to communicate findings.

A key difference between knowledge mobilisation and traditional research is the demand-led, impact-focused nature of knowledge mobilisation. There may be differences in experts-by-experience's willingness to be involved. For example, it may be that experts-by-experience are more inclined to participate in knowledge mobilisation, believing their involvement will have a more direct influence on policy, compared to traditional research. While this can be an advantage in recruitment, managing expectations is crucial.

Future directions



Future directions should include efforts by knowledge brokering organisations to ensure that where they do involve experts-by-experience, they do so in a meaningful way. This includes maintaining effective communication through openness and honesty, providing regular updates throughout a project, building organisational capacity to support their engagement, and promoting strong organisational commitment to their involvement. By addressing these areas, knowledge brokering organisations can ensure that the engagement of experts-by-experience is not only meaningful and impactful but also respectful and supportive of the individuals involved.

Promoting inclusivity and diversity, alongside appropriate resource allocation, will help create an environment where the contributions of experts-by-experience are valued and effectively integrated into knowledge mobilisation. The integration of experts-by-experience into WWCs' activities is a complex, yet vital endeavour, according to most interviewees. It can enrich the knowledge mobilisation process, making it more relevant and reflective of real-world experiences. Going forward, a thoughtful approach to participation will be essential in overcoming existing challenges and fully realising the potential benefits of involving those with lived experiences in policy research and knowledge mobilisation. Through continuous commitment to these principles, WWCs can support more inclusive and effective policy making and practice.

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Appendix 1: Full Methodology



The key questions guiding this research were:

1. What, if anything, is the value of involving experts-by-experience in knowledge mobilisation?
2. How far, and in what ways, do knowledge brokering organisations involve experts-by-experience in their work?
3. What are the key challenges faced and how are they overcome?
4. What are the key principles for effective, impactful and ethical practice?

Sample characteristics and participation

For Phase 1, eight individuals ($n=8$) in leadership positions across six WWCs participated in interviews. For Phase 2, an additional 17 individuals ($n=17$), in various roles across 14 knowledge brokering organisations, took part in the interviews. Four of the participating WWCs were members of the working group, including the WCPP. During the first working group meeting in December 2023, the aims and objectives of the interviews were introduced, and invitations were extended to all participating centres. Additionally, outreach was conducted with the remaining nine WWCs and a further 17 external knowledge brokering organisations, resulting in a total of six centres and 14 external organisations expressing interest in participating. Once consent was obtained, the WWCs and external organisations disseminated a participant information sheet within their teams, with recruitment taking place between November 2023 and March 2024 for Phase 1, and between January 2024 and April 2024 for Phase 2.

Recruitment

The recruitment philosophy for this study was guided by the approach proposed by Urban and van Eeden-Moorefield (2018) and Creswell and Clark (2017), emphasising the selection of individuals best qualified to address the research questions. Given the diversity of roles within WWCs and external knowledge brokering organisations, a sampling strategy suggested by Wilson et al. (2015, p.2131) was adopted. Employees with relevant experience in involving experts-by-experience in knowledge mobilisation and policy research activities were recruited, including individuals in both leadership and non-leadership roles.

Recruitment was conducted using voluntary response sampling, ensuring the participation of individuals willing to share sensitive information (Murairwa, 2015). Details of participants' current roles and length of service are outlined in Table 1. It is important to note the self-selecting sample bias: WWCs and external knowledge brokering organisations that engage in this type of work were likely more inclined to participate than those that do not regularly adopt this approach.

Phase	Employment type	Number of participants	Length of service (years)
Phase 1 – WWN	Community organiser	2	1.5–2
	Head of evidence & data	2	4
	Research officer/fellow	2	1–4
	Director of policy & practice/communication	2	3 months–10 years
Phase 2 – Outside of WWN	Assistant director	2	3–6
	Research officer	1	1.5
	Expert-by-experience	2 ¹	3–4
	Chief executive officer of co-production network	1	3 months
	Partnerships manager	1	5
	Lived experience engagement manager	3	5–6
	Director of policy	2	1.5–5
	Impact manager	1	10
	Public involvement lead	1	2
	Rapid research lead	1	10
	Engagement lead	1	2
	Senior communities and network officer	1	7 months

Table 1: Interview participants' employment information

Data collection

A semi-structured interview schedule comprising of four sections was developed:

1. Section 1: Background questions explored participants' roles, organisations, duration of service, and involvement in supporting the participation of experts-by-experience, along with the value attributed to their involvement;
2. Section 2: Participants' views on key terms were explored;
3. Section 3: Mapping current practices adopted by knowledge brokers and/or policy makers in supporting the participation of experts-by-experience was addressed; and
4. Section 4: The challenges faced and future opportunities associated with adopting this approach in knowledge mobilisation and policy research were discussed.

A total of 25 semi-structured interviews were conducted between November 2023 and June 2024, lasting 45 to 60 minutes each, and recorded and transcribed using Microsoft Teams.

Data analysis

The recorded interviews were automatically transcribed by MS Teams and subsequently proofread by one of the authors before being de-identified. The de-identified transcripts were then imported into QSR NVivo (Version 12) for analysis. Using an inductive thematic coding approach outlined by Braun and Clarke (2006), the transcripts were examined to identify, analyse, and report patterns within the data (Flick, 2014). This method facilitated the grouping of themes for easier comparison. The first and second authors, with experience in co-production and qualitative research, developed a preliminary list of codes, which was then reviewed by the third author, who has expertise in knowledge mobilisation and participatory approaches. Any disagreements were resolved through discussion until consensus was reached. The preliminary list of codes and the coding framework are provided in Appendix 3.

Ethics approval

This research received approval from the ethics committee at the institution where the first author was employed at the time of data collection. Written informed consent was obtained from all participants.

Appendix 2: Interview Schedule



The overarching aim of this project is to explore whether, how, and in what ways experts-by-experience can inform the policy research and policy making process. In Phases 1 and 2, we conducted interviews with WWCs and organisations outside the WWN to investigate the value and role of experts-by-experience in policy research and knowledge mobilisation, while identifying effective strategies for this work. Building on this foundation, we are now collaborating with the Centre for Ageing Better (CfAB) and three other WWCs to deepen our learning through three participatory action research (PAR) opportunities. The aim is to share and apply relevant methods for involving lived experience experts. The purpose of this interview is to explore current views and practices within your organisation regarding the involvement of lived experience experts in policy research, as well as to gather ideas for strengthening understanding and practice. The goal of this PAR opportunity is to actively improve and evolve the centre's approach to involving lived experience experts.

Background information

1. Please could you tell me a bit about your role and organisation?
2. How long have you worked in your current role?

Current practice and understanding

3. How far or in what ways does your current role involve supporting the participation of experts-by-experience?
 - Practice and views on involving experts-by-experience.
4. How would you define the following terms:
 - Experts-by-experience/Lived-experience-expertise (Prompt: Would this involve only marginalised groups & individuals?):

For the purposes of this interview, 'experts-by-experience' is defined as **'people who have developed lived experience expertise by actively seeking to combine their own individual experiential knowledge of a policy issue with the experiential knowledge of other people on whom that policy issue has had a shared impact.'** Typically, this refers to individuals who have lived experience of a particular policy challenge and have also engaged with research, policy, or institutions to share that experience in order to inform policy or practice in some way. (Prompt: The definition within the internal document describes lived experience experts (LEE) as individuals who have personal experience of the issues CfAB seeks to address.)

5. How far do you or your organisation aim to 'mainstream' involving experts-by-experience in the work that you do? – why / why not?
 - How far would you say this approach is 'mainstreamed' in your practice?) Is there other language or key terms that you use in relation to this?
6. How far do you involve experts-by-experience in your team's work? (why / why not?)
7. How far is there agreement within your team on the role of experts-by-experience in your work? If so, how? If not, why not?
8. How, if at all, does your team involve experts-by-experience in your work? (e.g. through co-production, advisory roles, peer research, event/workshop participation, paid/permanent roles etc.)
9. What resources are required to involve EbE? What resources do you use?
 - Are there other resources that you would like to develop or have access to support this work more effectively?
10. How do you and your team decide when to, and when not to involve people with lived experience expertise? Do you have any internal or external guidance that you use to help with this?
11. How do you and your team decide *who* to involve as experts-by-experience? How do you engage/reach them? (Prompts: do you 'quality assure' those you work with in any way? Do you seek to achieve diversity, inclusion and representation and if so how?)
12. How do you ensure a consistent and quality approach? Are there internal or external guides or experts that you draw on?
 - When considering 'quality' or 'good practice' in involving EbEs, how would you define or describe this? What are the key features of 'quality work' in this area?
 - How far and in what ways does the involvement of experts-by-experience strengthen or change your work? Please can you provide examples. What would you consider 'meaningful involvement'?
13. How far is there leadership buy-in to this work, what are the barriers to this and how can they be overcome? How far can and in what ways can a commitment to this approach transcend leadership changes?

Opportunities and challenges

14. What is the value of involving experts-by-experience in policy research / knowledge mobilisation?
 - How far do internal and external stakeholders, such as policy makers, value this approach in your work?
15. What are the challenges to involving experts-by-experience effectively? How do you overcome these?

16. What, if any, methodological concerns do you have with regards to the input of experts-by-experience in your area of work? How far does this matter to you and your team or wider stakeholders? (Prompt: Do policy makers or other stakeholders ever question the validity of the input you get from experts-by-experience? If so, how do you deal with this?)

17. In terms of ethical challenges, how do you seek to overcome the following?

- Tokenism
- Remuneration barriers – are you aware of the CfAB's payment policy for LEE?
- Safeguarding risks

18. Do you have any final reflections or comments to share?

- Thank you for your participation in this interview. Next steps will be to...

Appendix 3: Coding framework

Theme	Macro code	Micro code
Value of involving experts-by-experience	Informing strategic direction	
	Problem framing and definition	
	Shaping communication and dissemination	
	Securing buy-in, evidence use and impact	
	Inclusive and equitable practice	
	Diverse perspectives	
	Empowerment of experts-by-experience	
Current practices	Decision-making	
	Recruitment and engagement	Personalised approaches and relationship building
		Community partnerships and frontline engagement
		Working with networks
	Methods of involvement	Co-design and co-production
		Participation
		One-off involvement and event/workshop participation
Challenges faced	Resource constraints	Organisational capacity, training and expertise
		Policy cycles and timelines
		Financial constraints
	Ethical and pragmatic considerations	Safeguarding considerations
		Remuneration challenges
	Motivating participants versus managing expectations	
	Balancing individual experiences, diversity, and generalisability	
	Learning and iterative improvement	

Report authors



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