



Involving experts-by-experience in knowledge mobilisation

Reflections from research and practice

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Introduction

Over the last 15 years or so, inspired partly by gains from evidence-based medicine and health policy, efforts to ensure that public policy is underpinned by evidence have expanded. This can be seen in the proliferation of a range of What Works Centres (WWCs)¹ or 'knowledge brokering organisations' (KBOs), such as the Wales Centre for Public Policy (WCPP), which aim to bridge the gap between academic research and policy by mobilising evidence for policy and practice (MacKillop & Downe, 2022). There is also a broader range of KBOs² beyond the What Works Network which mobilise evidence for policy and practice.

Traditionally, WWCs and other KBOs have focused on connecting policy makers with academic research and policy experts. More recently, some organisations have begun to explore the role that experts-by-experience, or those with direct, lived-experience related to policy or practice agendas or priorities, can play in mobilising knowledge for policy and practice. This is distinct from the role that people with lived experience more often play as research participants through contributing to the evidence base by sharing their experiences. It is also distinct from 'learned expertise' which people, such as academics and policy makers, gain through study or work. Many people have some degree of both lived and learned expertise and it can be helpful to avoid a binary approach.

However, despite more established approaches to involvement of experts-by-experience in knowledge mobilisation in relation to health policy³, this remains an emergent development in knowledge mobilisation in other policy areas. There are divergent views and practices across KBOs. While around half of WWCs have involved experts-by-experience in their work, this is not featured in the Evaluation Task Force *What Works Network Strategy* (2023).

To strengthen practice in this area, the Wales Centre for Public Policy (WCPP) has led a unique project as part of an ESRC What Works Policy Innovation Fellowship⁴ to explore whether and how experts-by-experience can best be involved in knowledge mobilisation. This project was advised and supported by a working group of WWCs and KBOs⁵.

To answer these questions, we:

- Conducted a rapid review of existing evidence (Crompton et al., 2025);
- Interviewed 25 knowledge brokers with varying levels of seniority and from a range of policy specialisms (Nayak et al., 2025); and
- Completed two reflective research projects in WWCs. This Insight Note brings together key learning from across this research, along with perspectives from WCPP's own practice, for KBOs to learn from.

We found that there are a range of significant risks and challenges – from both scientific and participatory perspectives – associated with involving experts-by-experience in knowledge mobilisation. But, when carefully managed in the right circumstances, experts-by-experience can significantly enhance the impact of knowledge mobilisation efforts whilst also helping to make the process more equitable, diverse and inclusive (EDI), in line with UKRI's ambition to create a research and innovation system 'by everyone, for everyone' (UKRI, 2023).

¹ The UK What Works Network (WWN) is comprised of thirteen evidence centres dedicated to mobilising research to inform policy and practice. They are varied in terms of their goals and methods but share a common mission to enable evidence-informed policy making.

² For example, the [Modern Slavery Policy Evidence Centre \(PEC\)](#) is one such organisation.

³ See, for example this NIHR guide: Swaithe, L. (2024) How to involve the public in knowledge mobilisation: insights from the NIHR. NIHR Evidence. doi: 10.3310/nihrevidence_62360. Available at: <https://evidence.nihr.ac.uk/collection/how-to-involve-the-public-in-knowledge-mobilisation/>

⁴ The Fellow was Dr Rounaq Nayak who was supported by Research Assistants Dr Katie Crompton and Dr Alex Jones.

⁵ As well as the Wales Centre for Public Policy, the Fellowship working group was made up of: the Youth Futures Foundation, the Centre for Homelessness Impact, the Centre for Ageing Better, the Modern Slavery Policy Evidence Centre and the International Public Policy Observatory.

The value of involving experts-by-experience in knowledge mobilisation – why do this?

Experts-by-experience can bring a unique form of expertise to strengthen and enhance knowledge mobilisation and ultimately the uptake and application of evidence among policy makers and practitioners. A range of rationales for this approach were identified through the interviews and existing literature.

Problem identification, framing and scoping



Experts-by-experience can help to ensure that the issues KBOs (and policy makers) focus on align with real-world experiences and priorities. Experts-by-experience can add value in this way at an organisational, programme or project level.

'It helps me think about my research differently. It helps me come up with different questions.'

(Participant 19)⁶

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

(Participant 7)

Co-creation of more robust and valid conclusions, insights and findings



Some knowledge brokers have found that involving experts-by-experience in the co-creation of conclusions, insights and findings can help to make them more 'robust' (Willis et al., 2024), strengthen their 'quality and relevance' (Redman et al., 2021), and improve trust in the findings (Beames et al., 2021). They can help KBOs to explore how insights from evidence may or may not be applicable in their particular context.

Indeed, if we accept that knowledge mobilisation is not a neutral act and in fact plays a role in problem identification, problem framing, and the adjudication of 'what counts as evidence for policy' (MacKillop et al., 2023), then their involvement in knowledge mobilisation can be seen as a potentially important part of the broader policy making process.

'Experts-by-experience help us see the real-world implications of our work and refine the conclusions we draw from our research.'

(Participant 1)

'Experts-by-experience help translate findings into something that makes sense to the people who need it the most. Without them, research findings might not resonate with the intended audience.'

(Participant 3)

⁶ Throughout this Insight Note, unless otherwise stated, all quotes derive from this Fellowship report based on 25 interviews with KBOs and evidence centres: Nayak, R., Crompton, K. & Hill-Dixon, A. 2024. Involving experts-by-experience in knowledge mobilisation: Analysis of interviews with What Works Centres and evidence centres. Wales Centre for Public Policy. Available at: <https://doi.org/10.54454/25091902>

Outputs, communication and dissemination



Experts-by-experience can contribute to developing more accessible and engaging outputs and communicating and disseminating these.

'We tend to rely on more academic terms, and everything is so complex. Our lived experience researchers really make us simplify things.'

(Participant 14)

'Experts-by-experience help us think beyond traditional academic reports. They suggest using storytelling, visual aids, and different media formats that make findings more engaging and accessible.'

(Participant 7)

'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 when lived experience experts were involved.'

(Participant 2)

Impact on policy and decision-making



Involving experts-by-experience in knowledge mobilisation offers the potential to improve engagement amongst policy makers and practitioners, and ultimately their uptake and use of evidence. Previous research has found that the involvement of experts-by-experience leads to 'more effective transfer of evidence into practice' Fitzpatrick et al. (2023, p. 1739), highlighting the potential for wider and more effective research dissemination and translation (Beames et al., 2021).

'Policy makers alone can't solve grand challenges... bringing in diverse publics and their lived experience enables reasonable conclusions.'

(Participant 18)

As a policy partner of one of the What Works Centres said:

'I think it's the thorough nature of it. Usually, we would say this is a great piece of research, now we need to speak to people with lived experience and policy officials, but it felt like this report included all of that so we were able to just move it forward.'

In addition, some argue that involving the end 'user' of a policy or service in knowledge mobilisation projects is likely to improve that product or service for the 'user' (Willis et al., 2024).

Ethics, empowerment and democracy



If done carefully, the involvement of experts-by-experience in knowledge mobilisation can help to promote greater inclusion, diversity and equity in evidence-informed policy making, thereby enhancing ethical standards (Beames et al., 2021) and helping to address forms of epistemic injustice in which only scientific forms of expertise are treated as legitimate (Fricker, 2007). It is also argued, as part of a democratic rationale, that citizens should have a right to participate in processes ‘that seek to represent them and/or address their interests’ (Fitzpatrick et al, 2023, p.2).

Participation in knowledge mobilisation can also, if managed carefully, offer positive psychological benefits and a sense of empowerment for experts-by-experience:

‘There’s the therapeutic benefit of feeling someone’s listened to you.’

(Participant 21)

‘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.’

(Participant 17)

As this latter quote suggests, the primary aim behind the involvement of experts-by-experience in the work of KBOs is not to ‘support’ participants or improve their lives; KBOs are not ‘front-line’ support organisations and instead aim to improve outcomes for communities via policy and practice. Nevertheless, it is clear that experts-by-experience can gain a huge amount from working with KBOs.



In what circumstances should we or shouldn't we involve lived experience experts?

The involvement of experts-by-experience can be considered a 'practice choice' by KBOs. Rather than necessarily being applied on all projects, knowledge brokers need to carefully consider whether particular circumstances or evidence needs are likely to make a participatory approach ethical, feasible and/or meaningful. This needs to be considered from the outset. It is likely, as highlighted in our rapid review (Crompton et al, 2025, p.18), that the following 'conditions' will need to be met to make this approach advisable:

- There are **particular people or groups** who have lived experience related to the issue or policy area in question;
- There is a **clear purpose** for involving experts-by-experience; it is not just being done 'for the sake of it' or as a 'tick box' exercise (which can be considered tokenistic);
- There is **sufficient flexibility and openness** in the programme, project or process to enable experts-by-experience to inform the shape or outcome; and
- There are **sufficient resources** (financial, staff, time, skills) to enable effective, ethical and authentic participation.

'We did a project over about a month last summer... we just didn't have time to involve experts-by-experience meaningfully.'

(Participant 19)

The ongoing and/or in-depth involvement of experts-by-experience is likely to require significant resource, and it is therefore unlikely that many KBOs would be able to take this approach across all projects.

Instead, organisations should carefully consider which areas of work require and allow for the meaningful and ethical involvement of experts-by-experience.

'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)



Clarity about purpose, role and degree of participation is vital

A key way of ensuring ethical and meaningful participation is to ensure that the purpose and approach to involving experts-by-experience is clear among knowledge brokers, experts-by-experience and, if involved, policy makers or practitioners (Walker et al., 2021).

'First and foremost, involvement has to be meaningful... It is about identifying 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)

In addition, our research suggests that it is important to be clear and transparent about the degree of participation that is possible or desirable in a particular knowledge mobilisation scenario. There are several frameworks that KBOs use to determine this (e.g., the Wheel of Participation (Dooris & Heritage (2013) adapted from Davidson (1998))).

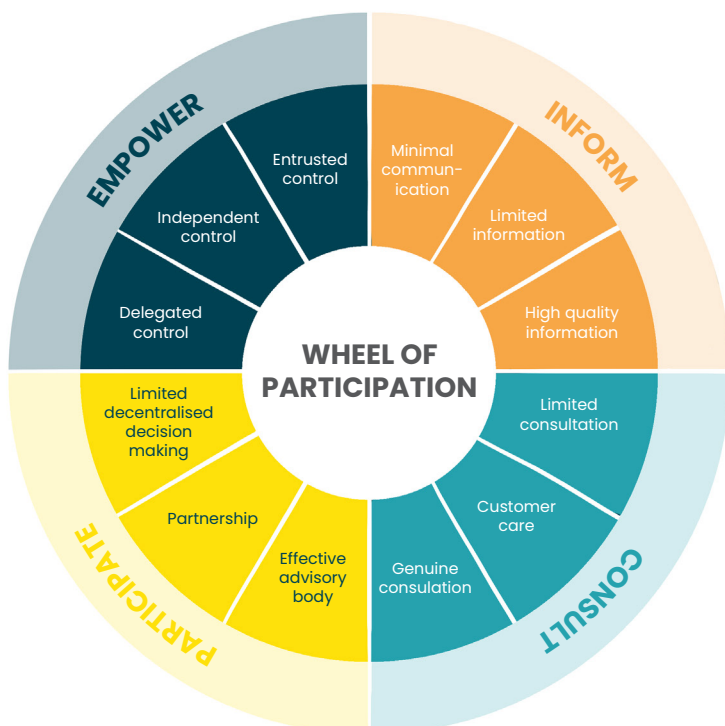


Figure 1: Wheel of Participation (Dooris & Heritage, 2013)

Some KBOs aim to empower experts-by-experience by taking a co-productive approach as this is often viewed as enabling 'transformative' practice.

'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.'

(Participant 24)

However, operating in an empowering or co-productive way is not always possible or feasible.

'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)

Whatever level of participation is being sought, it is essential that KBOs are transparent and clear internally and externally about what degree of participation they can enable in any particular scenario (Redman et al., 2021). This is a key dimension of ethical practice and is essential to effectively managing expectations of both experts-by-experience and evidence users.

'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)

How can experts-by-experience and KBOs work together?

Existing literature and our interviews revealed a wide and diverse range of ways in which KBOs are involving experts-by-experience in their work in terms of breadth, depth, methods and purpose. In principle, they can be involved in any aspect of a KBO's work, although the most appropriate role for them is likely to depend on a range of factors. Below we highlight some of the main ways in which KBOs and experts-by-experience are working together.

Recruitment



KBOs tailor their recruitment approaches to the extent and duration of involvement, with longer-term or more in-depth involvement warranting more structured, transparent and sometimes competitive recruitment processes (Nayak et al., 2025). As can be seen in relation to challenges below, a key element of this involves considering what kind of lived experience expertise, as well other forms of expertise or skill, are required and how to recruit for a diversity of perspectives.

Some interviewees highlighted the importance of 'on boarding' or induction for allowing experts-by-experience to contribute as fully as possible.

'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)

As with recruitment more generally, this varies depending on the breadth and depth of involvement in question.

Scoping and problem framing



Experts-by-experience can contribute to scoping, priority identification and problem framing, helping KBOs explore which issues and questions they should focus on.

'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.'

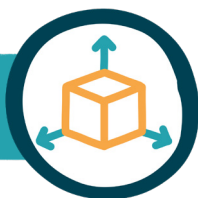
(Participant 4)

One practice-based example of this is WCPP's programme of work on **Poverty Stigma**. This came about because experts-by-experience highlighted this as a key dimension of poverty which warrants attention. In particular, experts-by-experience highlighted the mental health burden of being in poverty and the role of poverty stigma in linking poor mental health and poverty.

Some KBOs have used particular methodologies to involve experts-by-experience in scoping and problem definition. For example, our rapid review revealed the particular methodology of Priority-setting Partnerships, made up of the full range of experts and partners, who can be involved in priority-setting following a structured process (Crompton, 2025). This seems to have been used primarily in health (Freebairn et al., 2022; Sinclair et al., 2023).

As well as helping to define problems, challenges and priorities, KBOs also reported that experts-by-experience can help them think through what impact they want to achieve and what they need to deliver to achieve those goals.

Breadth and depth



Some KBOs seek to integrate and involve experts-by-experience throughout their work at all levels, including at a governance level.

'A lot of it relies on the quite constant engagement and integration of experts-by-experience in everything that we do... It's a core set of five people who are part of everything that we do.'

(Participant 14)

On the other hand, sometimes experts-by-experience are involved in knowledge mobilisation for short-term, one-off or ad hoc activities, such as participation in an event or to contribute to a blog (Nayak et al., 2025). One of the challenges with one-off engagements is that they do not in themselves allow for the development of trusted relationships which are key to effective involvement and the avoidance of tokenism (Walker et al., 2021; Machin et al., 2023). One way that some KBOs have sought to overcome this tension is by developing ongoing panels or networks of experts-by-experience with whom they aim to develop trusting and reciprocal relationships based on mutual understanding. KBOs can then invite panel members to contribute to individual projects on a one-off basis whilst benefiting from an ongoing relationship via the panel or network.

'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)

Panels or networks are likely to work particularly well when they focus on a particular issue or demographic and sometimes KBOs can tap into existing panels or networks run by specialist and often community-based organisations.

Research, evidence synthesis and knowledge mobilisation



Experts-by-experience can also contribute to research, evidence-synthesis and knowledge mobilisation itself. At the more in-depth and empowering/co-productive end of the spectrum, experts-by-experience are sometimes involved as peer researchers or co-analysts throughout a project.

'We have specific studies where lived experience researchers are part of the research team... 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)

Some KBOs routinely involve experts-by-experience in the evidence synthesis process. For example, the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) advocate for this approach and have produced a guide detailing how to go about this (EPPI-Centre, 2007). On the other hand, experts-by-experience sometimes play more of an advisory role, for example by commenting on search terms, or by sense-checking and validating findings.

'We gain a lot of value from the context and to double-check our findings... [experts-by-experience help us] understand what it means to be experiencing the policy issue at that moment.'

(Participant 4)

This can help to contextualise the findings and recommendations of KBOs by grounding them in the lived realities of those affected by the issues being considered. As explored in the Value section above, experts-by-experience can also play a role in helping to develop outputs, and in communicating and disseminating knowledge to inform policy and practice.

Risks and challenges

There are also a range of risks and challenges involved, both for experts-by-experience, and for KBOs. As outlined above, our research found that experts-by-experience should only be involved in particular circumstances and in line with key practice principles.

Contrasting theories of change



An underlying fundamental challenge which KBOs and experts-by-experience are likely to encounter when working with each other is the often-differing theories of change that the work of each group may rest on. This source of conflict in co-production can be seen in terms of differing values, knowledge and preferences; uneven distribution of resources, status and power; and divergent expectations about outcomes (Gallagher and Scolobig, 2020).

KBOs, by their very nature, tend to operate on the basis of a technocratic theory of change which posits that policy decisions should be grounded, at least in part, in expertise and empirical evidence. KBOs work closely with and within existing systems of government and institutional power, rather than attempting to radically change those systems. This approach assumes that rational, evidence-informed policies are likely to improve societal outcomes.

In contrast, many experts-by-experience involved in social change efforts are often imbued in a grassroots model of social change which tend to emphasise the power of collective action from the bottom up, to directly create change in communities and/or to campaign and pressure governments to change policies from the outside. One of the interviewees highlighted this challenge when working with experts-by-experience:

'...you're quite often working against traditional bureaucratic practices or organisational structures... 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... this is not going to be a linear project...'

(Participant 15)

Both theories of change have their strengths and challenges. In reality, the situation is not as polarised as this suggests with many experts-by-experience and KBOs seeing the value in both theories of change and operating across them to greater or lesser extents. The involvement of experts-by-experience in knowledge mobilisation can be seen as an attempt to forge a hybrid theory of change which takes action at multiple levels, from within and outside of existing systems, and by drawing on multiple forms of knowledge. But as we explore below, this is not without its challenges.



Risks to experts-by-experience



There are a range of risks facing experts-by-experience when participating in knowledge mobilisation, all of which need to be considered and addressed by KBOs, often in collaboration with experts-by-experience.

The risk of being 'let down'

One of the reasons why involvement in knowledge mobilisation may appeal to experts-by-experience is because of the potential for policy/practice impact that this approach can offer via closer engagement with governments compared to involvement in traditional academic research (which often lacks a direct route to impact). There may be a temptation among KBOs to (over-) emphasise this potential for impact as part of their engagement and recruitment efforts. While there may be greater potential for impact, this can never be guaranteed as many factors driving decision-making are outside of the control of KBOs. As such, interviewees emphasised the importance of managing expectations of change among participants:

'You need to be honest from the start about what's possible and what's not. People get invested, and if you can't follow through or the policy world doesn't respond, that can feel like a betrayal.'

(Participant 18)

Expectation management of this kind can help to avoid disappointment, ensure full transparency from the outset, and support experts-by-experience to make informed decisions about their involvement (Hugh-Jones, et al., 2024; Walker et al., 2021). Another approach can be to ensure a defined route to impact from the outset of projects (and to make this clear), whilst allowing for unforeseen routes to impact to emerge or be taken advantage of through the course of projects.

The risk of emotional harm or re-traumatisation

One of the risks that experts-by-experience face when becoming involved in knowledge mobilisation related to (often difficult) policy/practice issues, is the potential emotional harm that can result from (re-)sharing personal lived experiences which can lead to re-traumatisation. At its worst, where this benefits a KBO organisation, this can potentially be extractive or exploitative.

'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...'

(Participant 4)

As outlined by Nayak et al. (2025), there are multiple ways of ensuring that harms to experts-by-experience are avoided. This should be considered as part of a broader organisational ethical and safeguarding framework, and as part of project design and planning. Key elements are likely to include:

- Training for staff in safeguarding and trauma-informed practice;
- Robust informed-consent processes;
- Safeguarding and ethics policies (ideally overseen by an ethics board or similar);
- Avoiding asking experts-by-experience to 'relive' difficult conversations unless absolutely necessary, and only with consent;
- Experienced facilitation which can create safe and supportive spaces; and
- The provision of psychological support services if needed e.g. free counselling.

'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)

One potential ethical advantage of involving experts-by-experience as co-producers or advisors within knowledge mobilisation processes, rather than as research participants, is that it is less likely that there is a need to ask them to share their personal experiences directly.

The risk of extraction or tokenism

Another connected risk facing experts-by-experience when participating in knowledge mobilisation is the possibility that this could be or feel extractive or tokenistic. Interviewees described tokenistic practice as 'decoration' or as a 'tick box' exercise and as the opposite of 'meaningful' practice.

'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)

Some interviewees believe that more meaningful involvement is best achieved by power sharing and working co-productively:

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

(Participant 1)

Another way to help mitigate against extraction is by ensuring that experts-by-experience are remunerated for their contributions as part of a reciprocal relationship, albeit this will not be enough on its own.

'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)

Key challenges related to remuneration include: limited budgets, creating perverse incentives, potential implications for people's tax and benefits situation, and institutional barriers related to administering small ad hoc payments. There are a range of resources available to support organisations to develop remuneration policies, such as the Social Change Agency's Payment for Involvement Playbook (2023).

In addition, some KBOs choose to remunerate experts-by-experience with in-kind support, instead of or as well as cash or voucher payments. Such support can include training, mentoring or time-credits. Whatever approach KBOs take, it is important to be transparent and consistent from the outset, and ideally take into account participants' preferences.

Overall, KBOs should think through how to work with experts-by-experience in a way which will be a positive and rewarding experience for them, as well as being beneficial to the KBO. Ensuring regular feedback opportunities and loops is a key way of ascertaining how far this is the case and what can be done to improve practice.

Risks to KBOs and their staff



Balancing individual experiences, diversity and generalisability

When involving experts-by-experience, KBOs face a challenge of balancing and respecting individual experiences and insights, while needing to develop evidence and recommendations which are relevant at a population level.

'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'

(Participant 24)

This quote reflects enduring debates in the social sciences about the benefits and limitations of quantitative versus qualitative research and between interpretivist and positivist epistemological paradigms (Guba and Lincoln, 1994). Arguably these debates are more relevant in relation to lived experience evidence, rather than the involvement of experts-by-experience in knowledge mobilisation. Nevertheless, many KBOs acknowledge the challenge of seeking to involve and recruit a diverse and broad range of experts-by-experience in their work.

'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)

'When we recruit our participants, it's really important to make sure that you don't just get the people who shout the loudest...'

(Participant 18)

There are no 'quick fixes' for overcoming this challenge and fully representative participation simply can't be achieved through involvement at this scale. But our research highlights the importance of being thoughtful and purposeful about what kinds of experiences and skills are needed, as well as the barriers that may get in the way for certain groups and how these can be overcome. For example, typically under-represented groups can be approached directly and barriers to participation (such as childcare, transport, language or accessibility) can be addressed.

Navigating differences

One of the key features of KBOs is that they 'bridge' the worlds of policy and practice on the one hand, and of research and expertise on the other. KBOs do this by understanding the motivations, languages and cultures of both worlds, and by effectively 'speaking' with and 'translating' for both audiences as an intermediary (Malin et al., 2020). When involving experts-by-experience in knowledge mobilisation, KBOs effectively need to operate with and between three key stakeholder groups which often creates a much more complex set of relational dynamics to manage and navigate. The rapid review highlighted this in terms of power imbalances, managing different perspectives and language barriers. These dynamics can be difficult to manage in a way which meets everyone's needs and maintains trusting relationships (Crompton et al., 2025, p.34). This issue was also highlighted in interviews with KBOs.

'They [policy makers] understood things differently... because I think people are so used to their way of working... they don't see things with curiosity anymore than perhaps someone who's living and experiencing them.'

(Participant 21)

'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.'

(Participant 2)

Risks to KBO staff

Facilitating or leading participatory processes with experts-by-experience can also pose risks to the staff of KBOs.

Staff can be affected emotionally by hearing traumatic stories or managing safeguarding responsibilities:

'We realised quite quickly that if we're going to do this properly, we need to think about the support for our staff too. It's not easy work. You're dealing with people's lives, their trauma, their stories. That stays with you.'

(Participant 14)

Given the emotional labour that can be required, several interview participants highlighted the importance of providing staff with sufficient support and training:

'Some of our team members have needed training in trauma-informed approaches. It's one thing to be a researcher, it's another thing entirely to be a safe space for someone else's experience.'

(Participant 20)

To aid this work and to help avoid risks to staff, interviewees also suggested that KBOs may wish to consider the relevant skills, experience and competencies which are needed as part of recruitment processes.

Conclusion

Overall, our research found that an increasing number of KBOs are involving experts-by-experience in their work because of the value that they can add to the knowledge mobilisation process and, ultimately, because of the enhanced impact that this can result in. For some, the driver is more intrinsic and based on a desire to embed equality, diversity and inclusion in their practice and to take a more democratically engaged approach.

However, despite these potential benefits, it also presents what can be significant risks to experts-by-experience and KBOs. As such, this approach should only be undertaken when particular conditions are met. KBOs can take steps to foster those conditions if they wish to. In addition, the following practice principles should be considered by KBOs when working with experts-by-experience:

- Ensure **ethical practice** in terms of safeguarding, autonomy, experience, remuneration, support and consent;
- Ensure **clarity and transparency** about purpose, role and degree of participation;
- Develop a **reciprocal and trusting** relationship with experts-by-experience to ensure they have a positive experience;
- Allocate **sufficient resource and time** and consider this approach from the outset;
- Ensure there is a **pathway to impact** from the outset; and
- Consider **equality, diversity and inclusion** in terms of who is able to participate, why and how.

KBOs and organisations that fund them will need to continue to ask themselves what role they want experts-by-experience to play in knowledge mobilisation and evidence-informed policy making. If it is to fulfil its potential, greater investment in this work will be needed, including resourcing the sharing of good practice across KBOs.

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