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Attaining Inclusive Research Priority-Setting: Essential Views from People with Lived Experience and the Public

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Abstract

In health research, involving people with lived experience and members of the public is crucial from both ethical and scientific perspectives. True engagement entails their active participation as full partners in research projects. Despite this, partnership-based involvement is rare in practice, particularly during research priority-setting. A key question remains: what conditions are necessary for agenda-setting to be co-led by researchers and people with lived experience and/or members of the public (or their representative organizations)? Currently, there is minimal ethical guidance addressing this topic, especially from the standpoint of those with lived experience and public members. This study offers initial insights into what these stakeholders perceive as essential foundations and obstacles for shared decision-making in health research priority-setting and in health research more broadly. In 2019, an exploratory qualitative study was conducted involving 22 semi-structured interviews with key informants from the UK and Australia. The analysis highlighted three categories of foundational elements necessary for enabling shared decision-making: relational, environmental, and personal. Collectively, these foundations mitigated many—but not all—of the barriers to equitable power sharing reported by participants. Based on these findings, practical recommendations are provided for researchers, engagement practitioners, research institutions, and funders to foster meaningful engagement in health research. Furthermore, the study examines major international research ethics guidelines on community engagement in light of these findings.

Keywords: Patient and public involvement, Ethics, Inclusion, Priority-setting, Power, Engagement, Health research, Partnership

Introduction

The importance of patient and public engagement in health research has grown substantially in recent years. Research institutions, funding bodies, and international research ethics guidelines increasingly view engagement as an ethically and scientifically essential element of research [1-4]. Genuine engagement requires involving patients, members of the public, or organizations representing them as full partners or collaborators [5]. This means supporting shared decision-making throughout research projects and maximizing community empowerment [6]. Participation is expected not only in data collection, analysis, and dissemination but also in setting research topics and questions and shaping the design of projects [3, 7, 8]. In this paper, the terms "people with lived experience" and "members of the public" are primarily used rather than patient, community, or community member. These terms are chosen because they represent two key perspectives that participants bring to research: (1) the lay/public/citizen perspective and (2) the patient/community/service user perspective.

Including people with lived experience and/or members of the public, particularly those from socially disadvantaged or marginalized groups, is fundamentally a matter of justice [9-11]. Their involvement enhances

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the visibility of their voices in agenda-setting and knowledge production [3], addresses epistemic injustices, and contributes to research questions that more directly focus on improving access to and affordability of health services [9-12]. This makes their participation in priority-setting especially critical.

Despite these ethical and practical considerations, individuals from marginalized groups and their organizations are infrequently included as decision-makers during agenda-setting. They rarely initiate research projects themselves and are seldom invited by researchers to influence agendas or project design. For instance, a recent quantitative study showed that over 60% of community organization respondents had rarely or never co-submitted a grant application when engaged in collaborative research partnerships [13]. Structural barriers in current funding mechanisms further limit pre-grant engagement. Even when these participants are included, unequal power dynamics may lead to tokenistic involvement: presence without influence or voice without impact, particularly among the most marginalized [14].

This raises the question of what conditions are required for priority-setting to be genuinely shared between researchers and people with lived experience and/or members of the public (or organizations representing them). Currently, ethical guidance on this topic is limited, especially guidance informed by the perspectives of those with lived experience and the public. Although substantial literature addresses engagement and participation amid power imbalances across fields such as political philosophy [15-17], development studies [18-23], health policy [24-26], and community-based participatory research [27-31], these works rarely focus specifically on research priority-setting [32]. Moreover, few studies foreground the voices of people with lived experience, members of the public, or engagement practitioners.

This study aimed to access these perspectives to determine what is essential for shared decision-making during agenda-setting in health research projects. Ethical guidance is strengthened when it draws from both theoretical frameworks and the considered judgments of those with direct experience, including researchers, people with lived experience, engagement practitioners, and members of the public. Omitting these voices risks perpetuating epistemic injustice and excludes a vital source of knowledge from ethics discourse.

To explore this, 22 semi-structured interviews were conducted with key informants from the UK and Australia. Both countries were chosen because engagement in health research is well established. Given the UK's longer history of "patient and public involvement" in research policy and funding, UK participants were expected to have distinct experiences and perspectives on power-sharing compared to Australian participants. Thematic analysis identified the foundations necessary for shared decision-making and the barriers preventing it. In this study, foundations refer to conditions essential for power-sharing, while barriers describe factors that impede it.

Finally, this paper critically reflects on lessons learned for sharing power with people with lived experience and members of the public in health research priority-setting. Based on study findings, practical recommendations are provided for researchers, engagement practitioners, research institutions, and funders to support inclusive research priority-setting. Their ethical responsibilities are highlighted, reflecting their capacity to establish essential foundations. Key international research ethics guidelines on community engagement are also examined in relation to the study's findings.

Methods

Study methods and sample

This study employed in-depth interviews as the principal method to capture rich, detailed accounts of participants' experiences and perspectives. A total of 22 semi-structured interviews were conducted with three types of participants:

- Individuals with lived experience who have engaged in health research (16)
- Members of the public involved in health research (2)
- Engagement practitioners working within health research (4)

Engagement practitioners are professionals within research institutions whose role is to assist and guide researchers in involving patients and the public in research initiatives. Their work includes fostering collaborative relationships among researchers, institutions, and the public, as well as developing the ability of patients and public participants to actively contribute to research.

Initial recruitment followed a purposive approach: participants with lived experience and engagement practitioners were identified in the UK and Australia via BP's networks. In Australia, recruitment was further supported through snowball sampling and posts on the Research4Me Facebook group. In the UK, the study was advertised through a university patient and public involvement email list, yielding the remaining participants.

Among the participants, five were men and seventeen were women; twelve resided in the UK and ten in Australia. Lived experience included mental health conditions (2), chronic illness (6), and various disabilities (physical, cognitive, psychosocial) (6), while two participants chose not to disclose their condition(s). Nine participants (eight with lived experience, one public member) had prior experience with research priority-setting—seven from the UK and two from Australia. Participants' engagement varied widely, from brief involvement in single activities such as focus groups to sustained engagement across multiple projects over periods of one to five years, with some having decades of experience. Interviews continued until thematic saturation was reached.

Data collection and analysis

During interviews, participants with lived experience and public members were initially asked to describe the roles they had undertaken in health research. Follow-up questions explored their experiences and perspectives on sharing power within these roles. Since not all participants had co-design or priority-setting experience, questions regarding those processes were only posed when relevant. Roles represented in the study included funding panel member, participant in James Lind Alliance priority-setting, co-applicant, community researcher, steering or advisory group member, and focus group participant. Engagement practitioners were asked to discuss co-design, providing broader insight into power-sharing across research contexts.

Interviews were transcribed verbatim. Thematic analysis followed a five-step process: creation of an initial coding framework, coding, assessment of inter-coder reliability, framework revision, and final coding of all transcripts [33, 34]. BP and NE developed the initial coding framework by co-coding five Australian transcripts and generating a preliminary code list. The remaining Australian interviews were coded by BP, with the code list refined iteratively. BP and JS then applied the framework to a UK transcript, checked intercoder agreement, and revised the framework as needed [34]. JS, a new coder, tested whether the framework could be reliably applied to UK data without prior study involvement. Six transcripts were co-coded, achieving full agreement, with contributions balanced between coders. Fifteen additional subcategories (of 61 total) were incorporated based on UK data. The finalized framework was then used by BP to code all 22 transcripts. Consistent with Campbell *et al*. [33], after achieving high intercoder agreement, a single coder may complete the remaining coding, preferably the one whose codes were most consistently adopted during earlier discussions.

Study limitations

Acknowledging the limitations of this study is essential. First, participants were drawn solely from Australia and the UK. Although engagement in health research is increasingly established in these regions, other countries—including many low- and middle-income nations—also have active public and patient involvement that was not captured here. Future studies should aim to include perspectives from these contexts. To address this gap, the author has initiated two case studies on health research priority-setting in India and the Philippines.

The participant group was uneven in several ways: there were fewer men than women, fewer members of the public compared to people with lived experience, and more participants from urban than rural settings. The overall diversity of the sample is difficult to determine, as detailed demographic information was not collected. In the UK, participants self-selected after receiving study information via a university patient and public involvement listserv, which an engagement practitioner noted lacked broad diversity. Interviewees themselves also highlighted that limited diversity is a wider challenge in health research engagement. Nevertheless, participants reported a variety of lived experiences, including chronic illnesses and cognitive, psychosocial, or physical disabilities. Several participants identified as non-Caucasian, including African, Hungarian, and Indigenous backgrounds. Age diversity varied: Australian participants ranged from young adults in their 20s and 30s to those approaching retirement, while UK participants were generally older, though not all were retired.

Notably, not all participants had experience with research priority-setting, as many had not been involved in early stages of health research. About half had priority-setting experience, predominantly from the UK, where engagement roles such as participation on funders' grant panels or acting as co-applicants are more common.

Results

Foundations

Analysis identified three essential types of foundations that must be in place to enable meaningful engagement and effective power-sharing in health research: relational, environmental, and personal. There were no substantial differences in foundations reported by participants from Australia versus the UK, though the UK's research funding system was described as generally more supportive of including people with lived experience and members of the public in agenda-setting activities than the Australian system.

Relational foundations

Two key relational foundations were highlighted: building trust and forming connections. The types of connections emphasized include (1) personal connections between researchers and the individuals actively engaged in research, and (2) broader connections linking researchers, their institutions, and the community or public.

Creating personal connections involves demonstrating empathy, being open and transparent, sharing personal experiences, listening attentively, understanding others' perspectives, recognizing strengths and weaknesses, and performing kind acts. These practices are considered fundamental for fostering inclusive participation:

Once you've developed that [relational understanding] between a gatekeeper to a society and someone that's experienced oppression, you give them an olive branch to become included. So that to me is key. (person with lived experience, Australia)

Establishing strong ties with the community or public was highlighted as a key factor for effective power-sharing in agenda-setting:

I do see good researchers do that, you know they, they will spend a couple of years mingling with a community before they ask for something. I think it's really good practice. (person with lived experience, Australia)

Making ourselves as organizations and as researchers accessible and not asking people to step over our thresholds but stepping over our own thresholds to go and really be accessible to others. (engagement practitioner, UK)

These connections are essential for fostering trust and raising awareness about engagement in research, its significance, and how research relates to people's everyday lives. Informal interactions were highlighted as crucial for establishing both personal and community connections. Participants emphasized that spending time on activities that are not strictly research-focused at the beginning is as important as progressing to co-design, particularly when engaging individuals with experiences of marginalization. To cultivate personal connections, creative activities such as crafting or harmonica lessons were described by a UK engagement practitioner as "especially levelling" because "if you can learn to do something with someone where you're both equally unknowledgeable and unpracticed, it creates a bond to start you off." For building connections with communities, initiatives such as community festivals, film nights, and introductory or educational sessions with panels combining researchers and people with lived experience were highlighted. These activities primarily:

Had nothing to do with sitting around the table doing co-design with our researchers, but they also had everything to do with how we build our relationship with our community that leads to people wanting to come and sit at the table with us… we set up an expectation that what we really value is our difference of opinion… we are respectful of all voices and we wanna hear all voices. (engagement practitioner, Australia)

Trust was also recognized as a fundamental foundation for power-sharing. It was described as bidirectional: researchers needed to trust the individuals they engaged, which was framed in terms of people with lived experience and members of the public having "credibility":

You are the consumer, you are the outsider, you have to prove that you're up to this and then if you manage to establish your credibility people will suddenly start listening to you. (person with lived experience, Australia)

For power-sharing to occur, people with lived experience and members of the public needed to trust both the researchers and the institutions they represented. As noted by an Australian engagement practitioner:

When you've got that basis of trust there, you can sit across the table and then go actually I really disagree with that you're saying, what I want you to hear from me is this and you can have far more robust, equal power sharing relationships.

Here, the practitioner is referring to relationships maintained throughout the research process, beginning with priority-setting. Establishing these connections and fostering trust enables participants in health research to feel secure in expressing vulnerabilities and offering constructive criticism to researchers. While participants' vulnerabilities can be the most difficult to elicit, they often provide the most valuable insights for agenda-setting, allowing researchers to pinpoint the issues that most deeply affect people and prioritize them in research.

Environmental

Three key environmental foundations were considered essential for power-sharing in priority-setting: researcher support, funding mechanisms and policies, and norms. Each of these elements needs to be embedded in the research environment to enable meaningful engagement. Researcher support involves creating resources and spaces that allow people with lived experience and members of the public to participate fully, ensuring that "people who are less confident, that are coming from a marginalized position, can step powerfully into that [research decision making] space." Five specific forms of support were highlighted:

- Providing training for participants and researchers
- Addressing diverse needs and accommodations
- Establishing safe spaces for sharing vulnerabilities and giving critical feedback
- Implementing pairing or mentoring systems
- Ensuring participants feel valued

Training should be tailored to the needs of those engaged in health research. Sixteen interviewees, including four engagement practitioners, stressed its importance. Training topics include grant writing and funding processes, ethics procedures, research methods and terminology, and the roles of patients and the public in research. For agenda-setting activities, a participant with lived experience from Australia emphasized that training on grant writing and funding procedures is particularly crucial:

Skills around okay well what does grant writing look like… a lot of that stuff is really kind of like university bureaucratic behind the scenes stuff and that's really like where the power kind of relations really are… I also was interested in those processes but that's kind of not available to you as a community researcher sometimes I think.

Access to training on grant writing and funding processes is frequently limited for people with lived experience and members of the public, preventing their participation in these stages of research projects. Training for researchers was also highlighted, focusing on familiarizing them with patient and public engagement and guiding them to carry it out in a genuinely inclusive manner. To initiate this training, a UK engagement practitioner explained that s/he might:

have a panel of which the researchers can, who come, can post their questions and we'll also have some sort of pre-decided questions so that patients can talk a bit about their experience and then we've got some group work. And it's, as much as anything, I think it's trying to show researchers that a lot of researchers who don't see patients day to day are quite frightened of them, they're really anxious about talking to patients and I think it's showing them that they aren't there unnecessarily to criticize, patients really, genuinely, they really want to help and they will do that in a constructive way.

Researchers are expected to accommodate diverse needs, which people with lived experience described as making reasonable adjustments to ensure engagement activities are accessible and achievable, and as providing support "in an unequal manner to provide equity." Two overlapping approaches were highlighted: presenting information in ways that participants can understand and addressing disabilities—whether physical (mobility, vision, hearing), psychosocial, or cognitive. The first approach includes, but is not limited to, adapting materials for different literacy levels and language abilities, avoiding technical jargon, and providing interpreters for meetings. The second involves measures such as ensuring physical accessibility, using easy-to-read large print, offering sign language interpreters, and allowing flexibility in how tasks are completed by those engaged.

Researchers should also foster safe engagement spaces, ensure participants feel valued, and implement pairing or mentoring systems where feasible. A safe space was described as one where participants feel comfortable being critical and sharing experiences and vulnerabilities without feeling "stupid." Making participants feel valued was illustrated by a UK person with lived experience through practices such as providing a welcoming venue with refreshments, remembering names and personal details, being friendly, and making statements like "we really value [you] and feel you can make a valuable contribution." Pairing systems could connect a person with little or no engagement experience with someone who has substantial experience, or link a participant with lived experience or a member of the public to a researcher.

Funders are encouraged to provide support for pre-grant engagement, enabling people with lived experience and members of the public to contribute to the development of grant applications and the setting of research project agendas:

In England, there's local organization so they, they operate across an area called research design service, RDS, and they can give researchers access to some pots of money that can help them do the patient and public involvement work before the main funding comes, if it comes. As I say in Scotland that doesn't exist I've been told. (person with lived experience, UK)

Engagement should also be included as a funding criterion, a practice already adopted by some funders. A UK interviewee with lived experience noted that the UK National Institute of Health Research applies such criteria, stating:

If you don't show evidence that you've actively involved people with a condition, then you've got no chance whatsoever getting funded [by the National Institute of Health Research].

These forms of support and funding are critical because they allow people with lived experience and members of the public to engage at the earliest stages of health research (pre-grant award) and to feel secure in sharing both their personal experiences and critiques of proposed research plans.

Beyond the provision of researcher support and funding, it is essential to cultivate a research environment where norms surrounding public engagement actively reinforce power-sharing. In contexts where diverse experiences and types of evidence are respected, community knowledge is more likely to be recognized and incorporated into both agenda-setting and the design of health research projects.

Personal

The personal attributes and skills of both researchers and participants—people with lived experience and members of the public—were identified as critical prerequisites for meaningful power-sharing in health research. Lead researchers who genuinely value engagement were consistently viewed as indispensable for promoting shared decision-making across all stages of research, including during priority-setting:

I have heard from people who have done a lot of PPI [patient and public involvement], when they get, feel like the chief or the principal investigator is fully onboard with it and treats them as like you know an equal and bothers to keep in touch with them, that is absolutely vital. (engagement practitioner, UK)

In addition to valuing engagement and co-design, researchers are ideally expected to demonstrate humility, a willingness to share personal experiences to build relationships, and openness to listening to perspectives that differ from their own. Key skills for researchers include effective communication, the ability to facilitate engagement and co-design, negotiation, and conflict resolution.

For people with lived experience and members of the public participating in health research, essential qualities and skills include:

- Representing the diversity of experiences within a service or community
- Being well-informed and connected within their community, with a thorough understanding of local issues
- Acting as a voice for others and sharing collective stories rather than focusing solely on personal experiences
- Having a genuine motivation to improve outcomes for others and strengthen the health system
- Possessing the confidence to speak up and assert their views
- Being articulate and credible
- Demonstrating analytical capabilities
- Showing strong teamwork and interpersonal skills
- Having negotiation and conflict resolution abilities

Choosing participants with lived experience and members of the public who have the confidence to engage directly with senior researchers and challenge their ideas was considered particularly important in situations where researchers had limited engagement or co-design experience, or where their approach to involvement was largely tokenistic. As noted by an Australian engagement practitioner,

it felt like this first experience of co-design was a test case that was kind of winning them over to a new way of working. So for this particular co-design, especially I needed really skilled people sitting at the table coming *from a lived experience perspective because it's cracking open the door and opening the way.*

Possessing an understanding of research and maintaining credibility were also considered important qualities in this context. Nonetheless, the interviewee noted that prioritizing confident and articulate individuals for participation could unintentionally silence other voices. Consequently, engagement programs within research institutions should focus on developing the skills and confidence of a diverse range of community members or public participants, "so that people that are less confident, that are coming from a more marginalized position can step up into that space."

Barriers

Interviewees highlighted seventeen barriers to effective power-sharing in health research, spanning personal, relational, and environmental dimensions **(Table 1)**. Some barriers were tied to participants' own qualities, behaviors, or perceptions, including limited knowledge, low awareness of research engagement, the formation of cliques, internalized feelings of powerlessness, and intimidation. Other obstacles reflected researcher-related factors, such as inexperience with engagement, lack of commitment to inclusive practices, favoritism, and undervaluing community knowledge. Additional barriers arose from the way engagement was structured, including challenges with funding, insufficient diversity, bureaucratic hurdles, logistical difficulties, technological limitations, time pressures, language issues, and inadequate or missing compensation.

Table 1. Challenges to Equitable Collaboration in Health Research. Source: Analysis of Interview Data by the Author

Challenge	Details
Personal Barriers	
Reluctance to Engage in Health Research	Researchers: "Many researchers see it as a heavy load, feeling pressured to do more. They find it time-intensive and some, especially those in fundamental scientific work, doubt its worth." (engagement practitioner, UK) Patients/Public: "People in communities often don't view research as something that matters to their daily lives." (engagement practitioner, Australia)
Disregarding the Expertise of Those with Lived Experience and the Public	"As the sole patient representative among thirteen others, I sensed resistance from a high-level healthcare figure who clearly didn't value my presence. I'm seasoned enough to handle it, but it's clear some professionals, with years of training, struggle to accept a patient's input due to perceived differences in expertise." (person with lived experience, UK)
Self-Perceived Inferiority Among Those with Lived Experience and the Public: Not Feeling Equal to Researchers	"Honestly, I always felt like I wasn't a legitimate researcher. There's this nagging sense that university researchers are the 'real' ones, tied to internalized biases about ability and status. Even with supportive teams urging me to shape the research, it's tough to shake that feeling of being just a helper." (person with lived experience, Australia) "They're the specialists. We don't know enough about medical processes to challenge their decisions." (person with lived experience, UK)
Intimidation from Educational and Socioeconomic Gaps	"Some less-educated individuals might feel scared to participate, yet they're exactly the ones who should be involved." (member of the public, UK) "Most people I know with mental health issues wouldn't join in—they'd feel overwhelmed or out of place, worrying about looking underdressed or out of their depth in a polished setting." (person with lived experience, UK)
Unawareness of Opportunities to Participate in Health Research	"Too few people in the general public even realize they can take part in research." (member of the public, UK)
Limited Research Knowledge or Engagement Experience	Researchers: "Their idea of co-design is superficial; they talk about wanting involvement but don't grasp how to do it or that it requires sharing control." (engagement practitioner, Australia) Patients/Public: "I was turned away at first because I was new to patient and public involvement, and the panel—professors and clinicians—felt I lacked enough experience to join." (person with lived experience, UK)

Overqualification in Scientific Knowledge or Engagement Experience	Patients/Public: “Some researchers prefer working with fresh patients who haven’t been involved before, as those of us with experience start spotting strengths and flaws in projects, which they might not want.” (person with lived experience, UK)
Health Limitations	“Travel is tough for patients. Our conditions restrict us—some lack the energy, are too ill, or, like with dialysis, feel awful despite being alive.” (person with lived experience, Australia)
Interpersonal Barriers	
Favoritism Toward Certain Participants	“I’d say something, and it was ignored, but when a service user rephrased it, researchers praised it as brilliant. They’d fuss over one person—offering drinks, asking about holidays—while completely overlooking others, making you feel undervalued and sidelined, but it’s hard to call out without seeming petty.” (person with lived experience, UK)
Formation of Exclusive Groups Among Participants	“The toughest situations are when participants are close friends who always work together. It’s nearly impossible to break into their circle or contribute, as a few dominate the discussion.” (person with lived experience, UK)
Systemic Barriers	
Technological Limitations	“Urban folks can attend meetings, but rural people face hurdles. Many lack Wi-Fi, iPads, or smartphones—just old landlines, which limits their ability to join research efforts.” (person with lived experience, Australia)
Lack of Diversity	“Most patient and public involvement contributors I work with are retired, older, white, and middle-class. Reaching younger voices or diverse socioeconomic and ethnic groups is tough, and we need to do better.” (engagement practitioner, UK) “Historically, UK lay representatives were mostly white, retired men. White women have gained ground, but funding panels still lack enough representation from ethnic minorities like Chinese, Pakistani, or Muslim communities.” (person with lived experience, UK)
Bureaucratic Obstacles	Complex Application Processes and Strict Criteria for Involvement: “It feels like gatekeeping—you’re welcome to join our committee, but only if you meet a long list of requirements.” (engagement practitioner, UK) Criteria include: being a healthcare user, computer proficiency, high literacy, interest in the topic, committee experience or communication skills, and increasingly, having connections to charities, hospitals, or clinicians. (person with lived experience, UK)
Logistical Challenges	Travel Barriers: “Many might want to participate locally, like at a nearby doctor’s office or school for an afternoon, but even affordable transport takes effort and commitment.” (member of the public, UK)
Time Constraints	“True co-design and consensus-building demand a lot of time.” (engagement practitioner, UK) “Timing is a major issue—most roles are unpaid and scheduled during standard work hours.” (person with lived experience, UK)
Language Barriers	Using Complex Jargon and English-Only Engagement: “Academics and clinicians need to avoid technical terms that laypeople can’t follow.” (person with lived experience, UK)
Insufficient or No Compensation	“In the UK, payment is tricky. Participants get paid, but it’s far from a living wage—just a basic rate, like £150 per day, per Involve guidelines.” (engagement practitioner, UK) “For a London trip, they gave us £30 for travel—barely enough for a peak-time train ticket—plus a small shopping voucher.” (member of the public, UK)
Funding Issues	Pre-Grant Engagement Not Funded: “Budgets rarely allow for community researchers to lead projects early on, as grants are tied to specific topics with fixed boundaries.” (person with lived experience, Australia) Lack of Strong Engagement Requirements: “Funders aren’t always strict about requiring patient involvement at multiple stages, so researchers might only add it late, making minor tweaks after quick feedback.” (member of the public, UK)

	Engagement Budget Cuts: “Patient and public involvement is often the first thing cut from funded project budgets.” (engagement practitioner, UK)

Together, the three types of foundations helped to mitigate many, though not all, of the barriers to power-sharing in health research identified by interviewees. Developing connections helped to overcome obstacles such as devaluing community knowledge, limited buy-in and awareness of engagement in research, and insufficient diversity among participants. Researcher support contributed to addressing gaps in knowledge and engagement buy-in, making participants feel less intimidated by researchers, enhancing diversity among those involved, and reducing feelings of internalized powerlessness. For example, one interviewee emphasized that creating a safe and supportive environment is crucial for ensuring the voices of individuals who have had:

intense personal experiences of all their power stripped away…I think there is a feeling of powerlessness that those experiences leaves that you bring with you when you come and sit at the table. And so if we genuinely wanna hear those voices I think we have to go the extra mile to make it a safe space and encouraging space for them to feel that their voices have value and they can be heard. (engagement practitioner, Australia)

Unaddressed barriers

Some barriers to power-sharing in health research were not resolved by the foundations identified in this study, including:

- Excessive scientific or medical knowledge, or extensive prior engagement experience
- Illness
- Funding limitations
- Bureaucratic hurdles
- Logistical challenges
- Technology constraints
- Inadequate or absent compensation
- Favoritism among participants
- Formation of cliques

Certain barriers were noted only by UK participants: bureaucracy, lack of diversity, and having overly advanced clinical or scientific knowledge or engagement experience **(Table 1)**. Two UK interviewees reported being excluded from engagement roles due to their backgrounds—a clinical qualification and a PhD. The participant with a PhD reflected that she was fortunate her degree was in plant science rather than a health-related field, saying: “I quite often have to persuade them that I am actually some use because some people think I’m actually a scientist and that’s not what they’re looking for.” Another participant observed that researchers sometimes prefer participants with no prior engagement or knowledge of the research area—“just Joe or Josephine public”—though occasionally a mix of backgrounds is welcomed. Australian interviewees mentioned class and educational disparities as barriers, but did not link them to intimidation, whereas several UK participants did.

Discussion

Developing meaningful ethical guidance for authentic engagement requires an understanding of the challenges experienced by both researchers and their patient, public, and community partners. This study identifies foundational elements for effective engagement in health research from the perspectives of people with lived experience and members of the public, highlighting power-sharing from a non-academic viewpoint.

Although the findings apply broadly to shared decision-making in health research, they provide particular insights for priority-setting. Ethical guidance is especially critical in this context because research agenda-setting is often dominated by academic researchers and funders. Meaningful engagement starts with shared decision-making at the priority-setting stage. Relational foundations—such as forming connections and creating safe spaces—allow participants to share vulnerabilities, offering insights crucial for defining research topics and questions. Environmental foundations, including training on funding processes and pre-grant funding support, enable participation in grant writing and early involvement in projects before research priorities are finalized. Additionally, fostering a research culture that values the perspectives of people with lived experience and members of the public is vital. Personal foundations, such as lead researchers who genuinely prioritize engagement, help ensure early, meaningful involvement.

This study highlights the importance of forming connections, researcher support, and research culture in enabling power-sharing during health research priority-setting. Prior research examining perspectives of researchers, ethicists, and community staff has similarly identified trust, personal qualities and skills of both researchers and participants, funding, and supportive cultural norms as key facilitators for shared decision-making [11]. Literature on participatory development and research emphasizes building connections, trust, cultural humility in researchers, and supports such as training and pairing participants with academic researchers to achieve inclusion [19, 27, 29, 35-37]. However, the specific qualities and skills of people with lived experience and members of the public required for power-sharing are less frequently documented. Furthermore, norms that value diverse forms of knowledge equally are essential, particularly in science and technology contexts [38]. Existing hierarchies and reliance on technical evidence can undermine the credibility of contributions from people with lived experience and the public, making it less likely their perspectives are fully considered compared with those of health professionals [37-40].

This study further highlights that truly inclusive health research priority-setting relies on preparatory work carried out by researchers, engagement practitioners, research institutions, and funders—activities that occur independently of specific funding or research projects. In light of the findings, the ethical responsibilities of these groups to enable authentic engagement can be conceptualized. It is proposed that each adopt particular policies and practices, with specific obligations assigned according to their roles, as each group is uniquely positioned to establish certain foundational elements. (These suggested obligations do not cover the full spectrum of ethical duties these actors have regarding engagement in health research.)

Funders, research institutions, and engagement practitioners should foster an environment in which engagement—particularly during priority-setting—is recognized and valued. Governments could support this through national campaigns raising awareness of engagement roles in health research, while funders might develop research design services that help integrate engagement during proposal development. Funders can further signal the importance of engagement in priority-setting by involving people with lived experience and members of the public in shaping their own priorities and serving on grant selection panels. Existing models include the James Lind Alliance, Diabetes UK, the UK National Institute of Health Research, and the US Patient-Centered Outcomes Research Institute [41-44]. Research institutions could embed meaningful engagement as a formal component of promotion and performance evaluation processes.

Funders and research institutions should also incorporate engagement into their funding policies, grant-making principles, and selection criteria, prioritizing shared decision-making that begins at agenda-setting over late-stage consulting. Preference could be given to research teams that include people with lived experience and members of the public. Funders should consider offering engagement grants to strengthen community connections and build the capacity of communities to participate in research. Patient-Centered Outcomes Research Institute Engagement grants exemplify this approach [45]. Research institutions could establish engagement units to reinforce local community relationships and support researchers in developing the skills and appreciation needed for meaningful engagement, particularly during priority-setting. Engagement practitioners play a key role in facilitating these efforts.

Researchers should proactively lay the groundwork for meaningful engagement by building relationships with the communities they work with and cultivating essential skills and attributes, such as openness and effective communication. They should foster personal connections with community members and enable their involvement in research projects from the agenda-setting stage onward by offering training, accommodating diverse needs, creating safe spaces, and ensuring participants feel valued. Engagement practitioners, institutional departments, and managers should support researchers in implementing these practices effectively.

The findings from this study, alongside the proposed ethical responsibilities, can be compared with leading international guidelines on community engagement in research, including the UNAIDS Good Participatory Practice Guidelines for HIV prevention trials, NIAID’s Recommendations for Community Involvement in HIV/AIDS Clinical Trial Research, and the CIOMS International Ethical Guidelines for Health-Related Research Involving Humans [1, 46, 47]. Among these, the CIOMS guidelines largely overlook the need to establish foundational elements for engagement or designate who should be accountable for doing so. The UNAIDS and NIAID guidance partially address this by recommending researcher support as an environmental foundation and highlighting certain personal qualities, such as valuing engagement and effective communication [46, 47]. Researcher support in these documents includes training, pairing systems, and accommodating diverse needs; however, creating safe spaces or ensuring participants feel valued is not explicitly mentioned [46]. The NIAID guidelines even suggest providing training on funding processes and priority-setting [46]. Nevertheless, none of these documents consider building relational foundations or other pre-project environmental foundations, nor do they assign responsibility for creating them to research institutions or funders, focusing only on researchers and community representatives (e.g., advisory board staff).

It is also noteworthy that the foundations identified in this study do not address all barriers described by interviewees, particularly structural ones. Challenges such as bureaucracy, logistical constraints, and insufficient compensation could potentially be mitigated through targeted policies at the government, institutional, or funder level. Co-developing these policies with people with lived experience and members of the public could help streamline engagement applications, encourage local involvement, provide adequate compensation, and ensure ongoing training for research staff in facilitating engagement. Future research should explore what foundations are needed to overcome structural barriers and determine which actors are best positioned to establish them.

Additionally, some barriers—such as bureaucracy, lack of diversity, and having extensive clinical or scientific expertise or engagement experience—were reported only by UK interviewees. This likely reflects the more formalized, bureaucratic structure of patient and public involvement in the UK, as well as its longer-established practices. Gathering insights from participants in other countries, especially in low- and middle-income contexts, is essential to inform comprehensive ethical guidance. Such studies may also reveal additional barriers or foundations, potentially expanding the categories identified in this research.

Conclusions

This study offers preliminary evidence regarding the foundations considered crucial by people with lived experience and members of the public for sharing decision-making in health research priority-setting and research more broadly. Capturing these perspectives is vital, as it provides insights that might otherwise be overlooked—a form of epistemic injustice.

Interviewees emphasized the importance of relational and environmental foundations, in addition to personal-level foundations. Researchers, supported by engagement practitioners/managers, research institutions, and research funders, are strategically positioned to cultivate these foundations. Therefore, policies and practices should explicitly focus on establishing them to facilitate meaningful engagement of people with lived experience and members of the public in health research priority-setting.

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