What are important ways of sharing power in health research priority-setting? Perspectives from people with lived experience and members of the public

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Abstract: Community engagement (patient and public involvement) is gaining prominence in health research worldwide. But there remains limited ethical guidance on how to share power with communities in health research priority-setting, particularly that which has been informed by the perspectives of those being engaged. This article provides initial evidence about what they think are important ways to share power when setting health research projects' topics and questions. Twenty-two people with lived experience, engagement practitioners, and members of the public who have been engaged in health research in the UK and Australia were interviewed. Thematic analysis identified fifteen key ways to share power, many of which are *relational*. This study further demonstrates that tensions exist between certain ways of sharing power in health research priority-setting. More research is needed to determine how to navigate those tensions.

Key words: ethics, inclusion, power, priority-setting, engagement, partnership, health research, patient and public involvement

Introduction

Community engagement (patient and public involvement) is gaining prominence in health research worldwide (Reynolds & Sariola, 2018). But people with lived experience, members of the public, and communities, especially those considered disadvantaged and marginalised, rarely have a say in the agendas (research topics and questions) of the research projects that aim to help them (Tremblay, 2015;

ANONYMOUS 1). That is problematic for ethical and instrumental reasons discussed more comprehensively below.

To help address the issue, ethical guidance is urgently need on how to share power with communities in health research priority-setting. This study contributes by providing initial evidence on what those who are engaged think are important ways to share power when setting health research projects' agendas. Their views can provide important insights beyond those of researchers, ethicists, and other stakeholders. In this paper, health research priority-setting refers to defining the research topic and study questions for individual health research projects or programs, rather than defining a set of global, national or institutional research topics that require priority funding and implementation.

Value of sharing power in health research priority-setting

Sharing power with communities, especially those considered disadvantaged or marginalised, in health research priority-setting is considered valuable and ethically important for several reasons. It is a vital means of facilitating self-determination and addressing epistemic injustice by ensuring that the voices of those already marginalized by social institutions and norms are included in research projects' topics and questions (ANONYMOUS 2). Where voices from marginalised communities aren't heard, health research projects won't necessarily prioritise the key problems they face in accessing and affording health care and services. Without their input, projects are much less likely to generate evidence that will improve health care and systems for them and, thereby help reduce health disparities (ANONYMOUS 2). It is, therefore, very important to carefully design health research priority-setting processes to share power with communities.

Power sharing has been identified as an ethical goal (amongst others) of engagement in health research. So far, no consensus exists on whether the ethical goals of engagement in health research should span the intrinsic, instrumental, and transformative. However, transformative goals like empowerment and compensating for or resolving existing differences in power, privilege, and positionality have been ascribed to engagement in health research (Sariola & Reynolds, 2018; Ahmed & Palmero, 2010).

Evidence on the impact of sharing power in health research shows that it generates several benefits. This evidence focuses on power sharing during health research projects, not priority-setting specifically. It shows that participatory methods like community-based participatory research (CBPR) and participatory action research (PAR) generate an enhanced understanding of community needs and priorities, lead to the design of relevant research interventions, lead to greater research uptake and policy impact, foment empowerment, and break down hierarchies of knowledge within the research sector[1] (Wallerstein and Duran 2010; Bensimon et al. 2004; Mackenzie et al. 2012; Apgar et al., 2016; Hammad et al., 2019). Mackenzie et al. (2012) found that “research interventions were specific and targeted at knowledge and information priorities that had been set by stakeholders themselves.” Hammad et al. (2019) found that CBPR helps to transform those engaged from beneficiaries into partners. Positive transformative effects included developing research skills, self-confidence in their ability to research and engage, and new modes of thinking and working.

Negative outcomes of research approaches that share power have also been identified such as generating social discord. Such approaches often challenge existing power structures and this can lead to backlash, especially for marginalized groups (Khanlou & Peter, 2005). They are also time and resource intensive and can create burdens on community members. Wallerstein and Duran (2006) report that tribal committee members “expressed concern about the burden of extra time commitment and drain away from their other responsibilities, especially as they began to participate as interviewers in the data collection, along with the University research team.” There is always a risk with PAR, and other forms of engaged research, that the expectation of impact is not realised. Clark and Jasaw (2014: 519) call this ‘the danger of participatory little-action research’ and affirm that it can contribute to the disillusionment of academic and community research partners. It is important to bear these potential negative outcomes of power sharing in health research in mind and seek to mitigate/avoid them.

Existing work on power sharing

A significant amount of existing literature explores the concepts of engagement and participation in contexts of power disparities, spanning disciplines like political philosophy, development studies, health policy and community-based participatory research (see Abelson, Giacomini, Lehoux, & Gauvin, 2007; Arnstein, 1969; Benhabib, 1996; Cargo & Mercer, 2008; Cornwall, 2011; Crocker, 2008;

Gaventa, 2004; Gaventa & Cornwall, 2006; Goulet, 2006; Hickey & Mohan, 2004; Kitchin, 2000; Mitton, Smith, Peacock, Evoy, & Abelson, 2009, 2011; Muhammad, Wallerstein & Sussman, 2015; Peuravaara, 2015; Young, 1996, 2000; Wallerstein & Duran, 2006). Four main elements of power sharing in decision-making are described in that wider literature: who initiates, for what purpose, who participates, and how they participate (ANONYMOUS 1). Sharing leadership is thus a key aspect of power sharing. Gaventa (2006) affirms that participation as freedom is not only the right to participate effectively in a given space but also the right to define and shape that space. It is important to consider who instigates decision-making: does it come from the grassroots (the people, local leaders), the national centre, and/or foreign personnel (Cohen and Uphoff, 2011)?

Empowerment and capacity development are also key aspects of power sharing. They entail building individuals' and communities' knowledge, confidence, relationships, identities, and capacities (Hickey & Mohan, 2004; Kitchin, 2000). These affective and cognitive changes can generate behaviour changes that challenge power dynamics (Oden, Hernandez, & Hidalgo, 2010). Where engagement is undertaken for purely instrumental rather than for transformative purposes, it is much less likely to empower individuals and communities.

Iris Marion Young (2000) notes that power sharing involves not only who is invited to be present for a decision-making process but also how they are involved: do they have an equal opportunity to share their ideas during the process? Diverse perspectives—namely, all segments of the community potentially affected by the decision being made—should be represented (Young, 2000; Ahmed & Palermo, 2010). They should be able to raise their voices and be listened to during the decision-making process (Cornwall, 2011). Power dynamics should be mitigated in order to ensure that tokenism does not occur, i.e. certain individuals are present but not heard (Gibson, Martin, & Singer, 2005).

The contribution of this study

Despite the recognised value and impact of sharing power with communities in health research, there remains limited ethical guidance on how to achieve it when setting research agendas. The existing body of work on engagement and participation in contexts of power disparities largely does not consider engagement in the context of *research priority-setting* (ANONYMOUS 2). Within it, there is also limited literature from the perspective of people with lived experience and members of the public, and community members. In this paper, the terms 'people with lived experience' and 'members of the public' are primarily used in order to reflect two key perspectives that people who are engaged bring to research studies: 1) the lay/public/citizen perspective and 2) the patient/community/service user perspective.[2]

This study aims to identify ways of sharing power in health research priority-setting that are important to those being engaged. It is part of a broader program of ethics research seeking to characterise the sites of power that exist during priority-setting for health research projects and to develop ethical guidance on how to share power at those sites. Sites of power refer to features of priority-setting or decision-making processes that affect who sets up the processes, who participates in them, and whose voices are reflected in their outputs.

As part of that broader research program, conceptual work was first undertaken, consisting of analysing publications on participation in contexts of power disparities from six bodies of literature to deconstruct the concept of engagement into its components and their associated sites of power and to interpret how they could be understood in the research priority-setting context. This included some literature on participation from the perspective of people with lived experience. Initial guidance on how to share power at those sites during health research priority-setting was proposed.

Next, empirical work was undertaken to gather information from practice on what is necessary to share power with communities in health research priority-setting. 29 in-depth, semi-structured interviews and one focus group were undertaken with health researchers, ethicists, and community-based organization staff. Thematic analysis identified additional components of engagement and additional sites of power and described strategies that are employed in research practice for sharing power at those sites. The conceptual and empirical work is described (ANONYMOUS 1, 2, 4) and has been integrated (ANONYMOUS 5).

However, a key limitation of the conceptual and empirical work is that people with lived experience and members of the public were not interviewed and thus their voices were not strongly reflected in its findings. This is problematic because the most robust ethical guidance is informed by both theory and practice—in this case, the perspectives of those with key insights and experience of engagement in health research. This means not only researchers but also people with lived experience, engagement practitioners, and members of the public. If the latter voices aren't captured, they are largely absent from ethics discourse and a key source of information is excluded or missing. If based solely on the perspectives of "expert" ethicists and researchers, the ethical guidance developed as part of the broader research program will reinforce hierarchies of knowledge in health research that devalue or ignore the knowledge of people with lived experience and members of the public. Talking with them about power sharing in health research addresses epistemic injustice and helps democratise knowledge within the ethics field.

This study describes ways of sharing power in health research priority-setting that are identified as important by those who have been engaged. 22 people with lived experience, engagement practitioners, and members of the public who had been involved in health research were interviewed. Interviewees had lived experience of several chronic illnesses as well as several forms of disability (cognitive, psychosocial, physical). They had been involved in a range of types of health research: biomedical, clinical, public health, health services, mental health, and disability research. Participants were from Australia and the UK because engagement in health research is prominent in both countries, though it is more established in the UK. It was thought that participants from these countries would thus have ideas and experiences related to power-sharing in health research and that UK interviewees might potentially have different ideas and experiences relative to Australian interviewees that would be important to describe. Thematic analysis of interview data identified fifteen sites of power and ways to share power at them. Many of these sites were relational: sharing, listening, facilitation, equal treatment. Interviewees' insights are described and compared to the previous conceptual and empirical work. Variations amongst and tensions between their views are discussed.

It is acknowledged that, while the sites of power and ways of sharing power identified in this study are relevant to health research generally, the latter may need to be specified for different types of health research. A diversity of types of health research exist, ranging from basic science, clinical, genomic, and traditional epidemiology to more applied types like public health, health systems, and social epidemiology. It is beyond the paper's scope to consider whether and how the ways of sharing power identified here could be further specified for priority-setting in different types of health research, but the value of exploring such questions in the future is recognized.

Methods

In-depth interviews were chosen as the primary method to explore the topic because they allow for the rich details of key informants' experiences and perspectives to be gathered. 22 semi-structured interviews were conducted by DJ [changed for blinded review] with key informants in three main categories:

- People with lived experience who are or have been involved in health research (16)
- Members of public who are or have been involved in health research (2)

- Engagement practitioners who work in health research (4)

Sampling was initially purposive; potential participants with lived experience who had been involved in health research and engagement practitioners were identified in the UK and Australia through DJ's existing networks. In Australia, snowball sampling and posting information about the study on the Research4Me[3] Facebook group were then used to identify additional interviewees. In the UK, information about the study was sent out on a university's patient and public involvement email listserv and this generated the remainder of interviewees.

In total, five men and seventeen women were interviewed. Twelve interviewees live in the UK and ten in Australia. Interviewees had lived experience of several chronic illnesses as well as several forms of disability (cognitive, psychosocial, physical). Interviews continued until data saturation was achieved.

During interview, people with lived experience and members of the public were first asked what roles they had been engaged to perform in health research. Subsequent interview questions asked about their perspectives and experiences sharing power in the context of that or those specific role(s). This was because not all participants had experience in research priority-setting or in co-design of research projects, which entails being engaged during agenda-setting. Where interviewees had a priority-setting role, interview questions were asked in the context of that role only. Collectively, interviewees had the following roles in health research: member of funding panel, member of priority-setting process for the James Lind Alliance, co-applicant, community researcher, member of steering or advisory group, and/or member of focus group. Engagement practitioners were asked about their experiences and perspectives on co-design. Thus, the study data speak to power-sharing not only in health research priority-setting but also more broadly.

Interviews were transcribed verbatim and thematic analysis was undertaken by two coders in the following five phases: initial coding framework creation, coding, inter-coder reliability and agreement assessment, coding framework modification, and final coding of entire dataset (Campbell, Quincy, Osserman, & Pedersen, 2013; Hruschka et al., 2004). The initial coding framework was developed by DJ and NE co-coding five transcripts from Australian interviewees independently and jointly coming up with a list of codes. The remaining Australian interviews were then coded by DJ and that initial list of codes was revised. Using the initial coding framework, DJ and JS next undertook an iterative process of coding a UK interviewee transcript, assessing inter-coder reliability and agreement, and modifying the coding framework (Hruschka et al., 2004). A second co-coder (JS) was brought in to see if the coding framework could be reliably applied by someone with no prior involvement in the study and to test that the coding framework was applicable to the UK interviewee data. Six transcripts were co-coded and 100% intercoder agreement was achieved, with agreement going the way of both parties fairly evenly in most cases.[4] Fifteen new sub-categories (of 61 sub-categories total) were added to the coding framework based on the UK data. Once the coding framework was finalized, the lead coder applied it to re-code all 22 transcripts. According to Campbell et al. (2013), once high inter-coder agreement is reached, a single person can perform the remaining coding, provided it is the person whose coding generally carried the day during the negotiation process.

Ethical approval for the study was obtained from the [removed for blinded review] Human Ethics Advisory Group.

Results

Sharing power

Fifteen sites of power in health research priority-setting and ways to share power at them were described by interviewees (Table 1).

<u>Sharing</u>: The term “having a say” was critiqued as creating “a them and us, power imbalance.” Instead, “it’s about sharing stories”. The language of sharing was used by one-third of interviewees from both the UK and Australia.

Sharing vulnerabilities was identified as especially key for health research agenda setting. According to an interviewee,

> “people don’t want to share their pain, they don’t want to share their vulnerability, they wanna conceal it. But pain often brings about purpose. So the thing that pains you is the antithesis that you need to pursue.”

S/he stressed that it is important those engaged feel comfortable sharing their vulnerabilities because those things that pain people the most are what need to be pursued in research projects.

Listening: Interviewees noted that there is a clear difference between listening and being heard. One interviewee stated that both are “very powerful”, while another interview affirmed that listening was at a “smaller level” than being heard.

Several key aspects of listening to share power were described. First, listening entails dialogue and documentation:

> “You [researchers] run the risk of getting yourself into trouble later on if you don’t sort of ask them [those engaged] to qualify something you don’t agree with or, or sort of question them sometimes. And that doesn’t need to be aggressive or, or unpleasant but I think it’s, otherwise it’s misleading really to just sort of listen and go yep, yep, yep.”

Listening avoids dismissing people’s comments without considering and responding to them. It avoids talking over people, interrupting them, and reinterpreting what they’ve said:

> “I mean really listening to people rather than listening and then interpreting it in whatever way that you decide to interpret it. So actually listen to the words and listen to the sentences rather than just you know going off on your own tangent with what the person has said.”

Being heard: Being heard was described in two contexts by interviewees: 1) where people with lived experience and members of the public were not decision-makers and 2) where they shared decision-making. Many interviewees assumed researchers decide what information gets used in health research priority-setting and design and were ok with researchers not using all of what they had shared:

> "At the end of the day I mean you know it's the patients, the clients haven't actually got the power have they? In fact, it will be down to the researcher, cause the researcher might think well actually I don't want it done like A and B, even though you think that it should be done like A and B, so I think the patients just have to sort of like go along with it a bit. But then I think they do because obviously we're not as educated as you in those kind of things, you know, I don't, I wouldn't expect any researcher to take a hundred percent of what I've said on board."

Going entirely with the suggestion of a person with lived experience or a member of the public was even described as "an extreme example".

While many interviewees assumed that researchers had decision-making power, they also identified conditions for its acceptable use. They felt that, where researchers were the decision-makers and they were consultants, researchers should:

1. Be transparent about what information they have used, providing evidence of what changes have been made due to people with lived experience and members of the public's input and feeding it back to those who were engaged.
2. Be transparent about what information they haven't used.

3. Provide a justification for what they have used versus what they haven't used.

According to an engagement practitioner,

> "it's misleading really to just sort of listen and go… that's all great and then afterwards go well we're not gonna use any of what they said without saying that to the patient's face. I think that's really, it's misleading, it's disrespectful and it, you know it undermines the whole idea of co-production."

Example satisfactory justifications took account of the relevance of the information provided and the people providing the information. An interviewee affirmed,

> "you know there's no problem with saying actually we didn't use it because we didn't feel it was relevant."

Another interviewee said that when the topic is something where s/he has more knowledge than the others with lived experience, her ideas and perspectives should be weighted more than theirs. When researchers know the strengths and weaknesses of those engaged,

> "then we can work out when to give me weight and when to just kind of, I'll have a say, but you know mine's not gonna be the one that makes huge decisions about where we go with that, it's gonna be can we just remember this or you know it might be a small part to play. And I'm okay with that."

Some interviewees, in contrast, discussed contexts of shared decision-making. There again was not always an expectation that all or any of their ideas and views got used:

> "I don't expect anybody to do what I think, you know, I'll have my say and I'm quite happy in a group situation that they go a different way if that's what they think."

Deciding which ideas were used or which research topics were priorities could be determined by voting, ranking, or discussing until consensus is reached. Consensus was described as a decision "everybody can live with, everybody is comfortable with".

Equal treatment: Equal treatment was discussed in relation to speaking time, having views and ideas listened to (giving them equal consideration), and decision-making by interviewees:

> "It's like, we're all gonna make a decision and your vote and your say is equal to some, the person who works in a senior position."

Each level of equal treatment built on the previous level, culminating with equal decision-making: the strongest form.

Most interviewees discussed equal treatment of people with lived experience and members of the public relative to researchers. Some interviewees noted there should also be equal treatment of those engaged. Researchers should not play favourites.

An opposing view was raised that perhaps people with lived experience and members of the public should be treated *unequally* and given greater voice than researchers:

> “I do remember the facilitator being slightly annoyed. Her role wasn’t to ensure that patient voices were heard, right, her role you know in terms of the outcome, the final priorities that were decided was that everybody’s voice was heard, do you know what I mean, that, that you’ve got viewpoints from a wide range of people, both medics and non-medics.”

Stage of participation: Interviewees proposed that people with lived experience and members of the public should be part of priority-setting and resource allocation by public and philanthropic funders. They should also be involved from the start of research projects, which ideally means during priority-setting and/or prior to funding being awarded:

> “This is my amazing idea is you could just have you know if the grant was already there and it wasn’t tied to any particular thing if you could get in a group of community researchers and they set the topic and the research questions, like really build it up that way rather than kind of coming onboard to something that’s already has a certain set of parameters.”

> “They did the PPI [patient and public involvement] bit almost first of all just to find out what the crucial topics were amongst the patients and public, then they went back and said right which of these can we make into a really good research topic. But that’s like turning things almost, not quite on their head… But I guess that would be the ideal.”

An interviewee noted that involving people with lived experience and/or members of the public so early could generate tension when they and researchers identify different research priorities. Where this happens, s/he suggested the way forward is for researchers to justify to those engaged why they could not take certain health research priorities forward, pass those priorities on to other researchers who can study them, and then give feedback that the priorities have been referred on and what has happened with them.

<u>Level of participation</u>: Decision-making was identified as the ideal level of participation by several interviewees but another suggested people with lived experience and/or members of the public should not be decision-makers:

> "Because I think that the researchers are the ones who've done all the work, they're the ones who have the skills, they're the ones who know what the outcome is that they want."

The importance of *cycles* of engagement over different roles and research projects was discussed by interviewees as a way of increasing one's level of participation over time. People with lived experience and/or members of the public should be involved in small ways to start and then build up to decision-making and co-design if that's what they want to be involved in.

<u>Control</u>: Control was discussed in two ways: 1) being able to make decisions about the nature of one's engagement and 2) having self-determination. The former was more individualistic and the latter was more collectivist. The former was discussed

more often by interviewees and meant those engaged determined their stage(s) of participation, level of participation, and role in a health research project:

> "She asked us to be participants, but I said instead we should be community researchers and she agreed…Nothing for us without us. I take that to mean nothing but we control the whole thing from every angle, we aren't just guinea pigs."

Self-determination meant that a health research project was community-led:

> "Letting us do things our way because we know ourselves and we know our culture, we know our connection to ourselves and our community."

Control was thus linked to leadership.

Compensation: Compensating those engaged was identified as an important way of showing them that they are valued. Payment for time was described by interviewees in both Australia and the UK, where the INVOLVE standards are followed as guidelines. The INVOLVE standards call for payments to members of the public in recognition of time, skills and expertise. The rate offered will vary by situation. One-off consultations, for instance, are likely to have lower payments than ongoing involvement through project groups and undertaking research. The INVOLVE daily committee fee of £150 includes payment for preparation and attendance at a meeting (Mental Health Research Network and INVOLVE, 2013).

Yet INVOLVE rates are "nowhere near a full-time wage" according to an engagement practitioner. In contrast, some interviewees from Australia described being *employed* by research institutions as community researchers and put on contracts. Often, these contracts were casual rather than fixed term, which meant they were less secure and short-term employment that does not come with benefits (e.g. sick leave, superannuation). Ideally, an interviewee said s/he would prefer to be on a fixed term contract.

Diversity: Interviewees emphasised the importance of engaging the breadth of society or community being researched, rather than primarily engaging retired, white men. Engagement should be across socio-economic status, literacy level, spoken language, education level, age, and gender. Capturing a “wide cross-section of everyone” means engaging different perspectives—people with lived experience, carers, and people who work in health care and social support industries—and people of colour, minorities, different sexualities, and people living with disability.

It was also thought especially essential to engage those who are less-well off and harder to access:

> “To get true consumer engagement we need to engage those people who are not that easy to engage and that, that’s really important. I mean we need to engage my friend [name] who is on dialysis, who’s sick, who’s you know lives in poverty who you know, his voice is just as relevant and just as important as my voice is, actually probably more important.”

Table 1: Sharing power in health research

Site of power	*Way of sharing power*

Sharing	Those engaged share relevant personal stories, experiences, vulnerabilities, and views with researchers and are comfortable doing so.
Listening	Researchers engage in dialogue (ask questions and for clarifications) about what those engaged have said *and* document what they have said.
Being heard	The views of those engaged are taken on board and the information provided is acted upon; A joint product is created with inputs from researchers and those engaged: “your views have been acknowledged and woven into the equation. And you’ve had some influence in determining some of the priorities, or how the priorities were voiced.”
Facilitation	Facilitators and chairs of discussions and meetings ensure everyone (researchers and those engaged) has an equal opportunity to speak and draw out quieter voices.

Equal treatment	Researchers and those engaged have equal time to speak, have an equal say in decision-making, and are shown equal respect.
Control	Those engaged have control over their stage of participation, level of participation, and tasks performed during health research projects; Have self-determination.
Level of participation	Refers to how deeply those engaged participate during health research projects. *Decision-making* means being responsible for making key choices in research agenda setting. Two levels exist: where community members have equal decision-making power and where community members have decision-making power but it is not equal to that of researchers. *Consulting* means giving input into what research priorities should be set but having no assurance that it will be used by those who decide. *Informing* means being told what research is

	happening but not having any influence over the study agenda or design.
Stage	Engage as part of research priority-setting and resource allocation by funders. Engage from the start of research projects (developing a grant application and setting research projects' topics) AND involve either through all stages of research or keep in the loop about stages didn't want to be part of.
Role	Have a clearly defined role: know what's expected of you, what tasks you're to perform, who to go to if you run into challenges.
Compensation	Employ those engaged as members of the research team or pay them for time worked; Preferable to covering expenses.
Diversity	Engage the breadth of the community or patient group, including those who are less well-off and hard to access.

Mass	Have sufficient numbers of people with lived experience or members of the public on the research team or on a panel/committee: "Because if I raise something that against the, the stream of the conversation and it's really hard for me to raise it, but then there's another person with lived experience that goes actually yeah I agree with what, what she's saying with that because of this, or so that, that helps to validate and offset that power dynamic… So it's, it's offsetting that power dynamic by allowing more than one lived experience force in the room so that there's support between."
Space	Conduct engagement in *local* spaces rather than the university, a hospital or locations at a distance from those being engaged.
Ground Rules	Have terms of reference or agendas.
Feedback	Keep in touch and brief those who were engaged as to how things are

	going, e.g. whether a grant is awarded for a research proposal.

Equal treatment was described by over half of UK interviewees but not by any Australian interviewees. All other ways of sharing power were described by interviewees from both the UK and Australia. However, the importance of *facilitation* was discussed by more UK interviewees than Australian interviewees. The importance of *control* was discussed by more Australian interviewees than UK interviewees.

Accepting unequal power dynamics

Some interviewees from the UK and Australia felt that sharing power equally with people with lived experience or members of the public is not necessary in health research. One interviewee affirmed not only that power cannot be shared equally between researchers and those engaged but also that doing so should not even be a goal:

> “I don’t think you can ever make it equitable. I think the most that you can do is let the patient advocate know that they’re valued, and that what they’ve had to say has been valuable and can be incorporated into the work that you’re doing. It, you know, that they certainly are not at the same level as the researcher, nor do they expect to be… I don’t think that as a researcher that you should worry too much about trying to make the patient feel equal because I don’t think that that’s a word that would enter into their lexicon… I don’t think any patient goes into a research milieu expecting to

> have power. I think that we need to change that word and turn it into value, that they, they go there expecting to be valued and expecting that perhaps some of their lived experience may be helpful in helping to frame the work that you're doing."

Rather than sharing power, what's important during engagement is making people feel valued and included by letting them share their stories and listening to them. Researchers should be the decision-makers.

Another interviewee's comments indicated acceptance of unequal power relations, where researchers take the lead, rather than endorsing co-design (shared decision-making) or people with lived experience or members of the public taking the lead:

> "I mean I think we all accepted on the patient's side that they [the researchers] had the power because they were leading this thing. They were controlling the purse strings and the agenda largely, but we were happy that our role was to put in our views, our two pounds. And I don't think anybody wanted to be, from our side as it were, wanted to be in a power situation. I think we had influence but then so did everybody else…We couldn't have led it even if we wanted to."

Discussion

Sharing power between communities and researchers in setting health research projects' topics and questions is vital. Yet communities, especially those considered disadvantaged or marginalised, are rarely included in health research priority-setting. Ethical guidance on how to share power with them during priority-setting is urgently needed to help address this issue.

The study reported here comprises a first effort to document the views of those being engaged in health research on power sharing. It provides initial evidence about what people with lived experience and members of the public think is necessary to share power in health research priority-setting. Gathering their perspectives and using them to inform ethical guidance on engagement in health research is essential because they offer key insights that will otherwise be excluded or missing, which is a form of epistemic injustice. Their perspectives on ways to share power were collected as part of a broader research program. They are compared below to those identified by the program’s prior conceptual and empirical work, which captured concepts of power sharing in the wider literature on participation and from the perspectives of researchers and ethicists.

Interviewees identified fifteen sites of power and strategies to share power at them. Some of these sites of power were not captured by the broader research program’s prior conceptual and empirical work: *listening*, *equal treatment*, *compensation*, and *control*. However, control and listening do overlap, to some extent, with two previously identified sites of power—leadership and deliberation respectively. Leadership refers to who takes the lead on key aspects of research priority-setting: planning, implementing, ensuring outputs are fed back and used (ANONYMOUS 1, 2). One aspect of control identified in this study was self-determination or community-leadership. Deliberation means deliberative decision-making processes are used to select research topics and questions. Listening encompassed deliberating about the comments made by those engaged (ANONYMOUS 1, 2).

In the prior empirical work with researchers and in the wider literature on participation, having voice, raising voice, and synthesis refer to being able to speak and be heard (ANONYMOUS 1, 2; Cornwall, 2011). In this study, the language of ‘sharing stories and views’ was used instead and the term ‘having voice’ was thought to reinforce unequal power dynamics. Listening was thought to be distinct from being heard. In effect, interviewees identified three sites of power: sharing, listening, being heard. The former two were not identified in the prior work.

Many of the other sites of power identified in this study were described in the prior empirical work interviewing researchers and in the wider literature on participation: diversity, mass, stage, level, facilitation, ground rules, space, and accountability (feedback) (ANONYMOUS 1, 2, 3). However, two previously identified sites were largely not discussed by interviewees: purpose and framing. Purpose refers to what goal(s) are set for the priority-setting process. Framing encompasses what issues can be brought into the priority-setting space and what issues are not allowed as well as what information is presented or shared with participants at the start of the priority-setting process (ANONYMOUS 1, 2, 3).

Interviewees also offered insights about ways to share power in health research priority-setting that were not captured in the prior work. What involving people with lived experience and members of the public from the outset of research looks like was described, with several interviewees recommending participation prior to grant applications being submitted. They thus expressed support for being involved not only in priority-setting for research projects but also in broader research priority-setting exercises by funders. The importance of sharing vulnerabilities to identify research directions was highlighted. In relation to being heard, many interviewees affirmed not expecting *all* their ideas and views be used. Interviewees provided information on how to be heard when research priorities are externally and internally synthesised. Internal synthesis means that the output of decision-making is a ratified collective conclusion. It is an explicit product of deliberation that is endorsed by all participants. External synthesis means that the output of decision-making is an inferred product constructed by experts following deliberation (O'Doherty, Gauvin, Grogan, Friedman, 2012). The latter gives experts the power to interpret the content of deliberations amongst those being engaged or amongst themselves and those engaged. External synthesis is acceptable to those being engaged when researchers are transparent about which of their inputs were used or not used and why. When research priorities are internally synthesised, interviewees felt the inputs of researchers and inputs of people with lived experience and members of the public should be treated equally. The voices of those engaged should not be privileged and neither should researchers' voices.

Interviewees (all from the UK) described having equal voice, equal consideration and equal decision-making as ways to share power. However, where voices have historically been excluded, privileging them is perhaps the just course of action, which is a perspective a facilitator seems to have shared. The question of whether or when the voices of people with lived experience and members of the public should be privileged versus treated equally in health research priority-setting could be further explored with Australian interviewees and interviewees from other countries.

Other clear variations existed in interviewees' perspectives. Some interviewees talked about sharing power as leading priority-setting and being part of decision-making. In contrast, others assumed researchers decided what inputs were used from people with lived experience and members of the public and were okay with not being decision-makers. The latter interviewees' comments could be interpreted to mean that external synthesis of health research projects' topics and questions is consistent with or sufficient to share power as long as certain conditions are met. It is also possible that interviewees' assumptions that researchers are the decision-makers reflects engagement experiences closer to consultation than shared decision-making and perhaps some degree of internalised powerlessness, which was voiced by several interviewees. Or perhaps they anticipate the burden of participation as decision-makers to be too great without adequate compensation and training. The question of whether and when external or internal synthesis is preferable and/or results in adequate power sharing in health research priority-setting for people with lived experience and members of the public requires more exploration.

Some interviewees further expressed the view that people with lived experience and members of the public should *not* be leading research projects or be involved as decision-makers. Relations between researchers and those engaged can't be made equal and shouldn't be. Those engaged don't expect to have power, they want to be valued. Future research might explore the question of whether people with lived experience and members of the public want to share power in health research priority-setting and/or be valued and what the two concepts mean in relation to one another. Identified sites of valuing overlapped with two sites of power: sharing and listening. This may suggest that sharing power at these sites alone is not sufficient to share power equally; listening was described as sharing power at a “smaller level” than being heard. This raises another question for investigation: what’s needed to share power *equally* and is this what people with lived experience and members of the public want? Or is sharing some power sufficient for them?

Study data thus demonstrates there is potential for tension to arise between certain ways of sharing power. Having control means that people with lived experience and members of the public decide when and how they are engaged in health research. But they may or may not want to be engaged from the outset of studies or as decision-makers, which were identified as key ways of sharing power by some interviewees and in the literature (Crocker 2006, 2008; Goulet, 2005). The burden of participation in PAR and CBPR on community members has been documented (Wallerstein & Duran, 2006) and may be a factor in the priority-setting context as well, deterring deeper levels of participation. As noted above, not all interviewees thought it was necessary or appropriate to be involved as decision-makers. Thus, giving those engaged control over their level of participation may not result in deeper levels of participation. Perhaps ensuring those engaged have control should be privileged over engaging them early and as decision-makers. That may not be problematic from a sharing power perspective but there are other benefits of co-design that would be lost such as maximising the social knowledge used to set research priorities (Oswald, Gaventa, Leach, 2016). Additionally, where interviewees discussed sharing power as having a defined role, they assumed that researchers defined their role, which again seems inconsistent with people with lived experience and members of the public having control.

Several differences were reflected in the sites of power identified by UK interviewees relative to Australian interviewees. UK interviewees' greater discussion of facilitation could reflect that their roles in health research often involved meetings of committees, advisory groups, focus groups and panels. Why they identified equal treatment and Australian interviewees did not and why more Australian interviewees discussed control are less clear.

It is also critical to acknowledge the main limitations of this study. First, interviewees were recruited from Australia and the UK only. While engagement in health research is increasingly common in both these countries, there are other countries where engagement is frequently occurring in health research, including in low and middle-income countries.

The interviewee sample had fewer men than women, members of the public than people with lived experience, and individuals living in urban than rural areas. The diversity of interviewees is also somewhat unclear, as the study did not collect demographic data about interviewees. UK interviewees self-selected themselves to participate after information about the study was sent out on a university's patient and public involvement listserv. That listserv in itself was not thought to be exceptionally diverse by the engagement practitioner who runs it. Lack of diversity was identified as a problem for engagement in health research as a whole by interviewees. Nonetheless, interviewees had lived experience of a range of disabilities (cognitive, psychosocial, physical) and chronic illnesses. Several mentioned being of non-Caucasian ethnicities such as African and Indigenous. In terms of age, Australian interviewees spanned younger ages (20s and 30s) to retirement age. UK interviewees were generally older but not all were retired.

Finally, not all of interviewees' insights were directly about priority-setting because they had not had roles during the early phases of health research. At least half the interviewees had some priority-setting experience. More of these were from the UK, where engagement roles on funders' grant panels are common.

Best Practices

This study has identified fifteen sites of power and ways of sharing power at them during priority-setting that are important to those being engaged in health research. *Relational* sites of power such as sharing, listening, being heard, facilitation, equal treatment, and control were emphasised by interviewees. These findings supplement previous work to identify what is necessary to share power between researchers and communities in health research priority-setting at the project level.

While only an initial study, the results suggest that the fifteen sites of power and ways of sharing power at them may be necessary (though not sufficient) to share power in health research priority-setting. (Additional sites of power were identified by the broader research program.) It thus may be important for researchers and their partners to make an effort to implement the ways of sharing power described by this study when setting health research priorities. Researchers and community partners might undertake individual and collective reflective practice when designing and performing priority-setting to consider the sites of power identified in this study and how power can be or whether power is being shared at each of them. Where health research priority-setting processes implement power sharing strategies at those sites, they not only bring the voices of people with lived experience and members of the public into the design of priority-setting processes *but also* do so in ways that are important to those being engaged. Implementing the strategies can further promote the delivery of projects with research topics and questions that more accurately reflect the healthcare and system needs of people with lived experience and members of the public. As shown by CPBR, sharing power with communities can enhance the relevance of research priority-setting to better align with their needs (Mackenzie et al., 2012).

Since interviewees came from Australia and the UK, these recommendations may be especially pertinent when engaging people with lived experience and members of the public in health research priority-setting in *high-income countries*.

Research Agenda

Although the identified ways of sharing power can usefully inform research practice, this study highlights that tensions may arise when trying to uphold them. In particular, tensions were identified to occur between sharing power in relation to control and level of participation. How to resolve that tension requires further consideration. It could involve exploring people's reasons for not wanting to be engaged early or as decision-makers to see if the issue is about having the power to choose or is, instead, related to barriers to participation that can be addressed. Co-design is very time-consuming, often during work hours, and not necessarily paid like a full-time job. Future research could also investigate whether other relationships exist between the various ways of sharing power, i.e. do they facilitate or are they in tension with each other?

Based on other findings of this study, additional questions to explore in future research include:

- whether or when the voices of people with lived experience and members of the public should be privileged versus treated equally in health research priority-setting,
- whether and when external or internal synthesis is preferable in health research priority-setting for people with lived experience and members of the public,
- whether people with lived experience and members of the public want to share power in health research priority-setting and/or be valued and what the two concepts mean in relation to one another, and

- what is needed to share power *equally* in health research priority-setting and whether this what people with lived experience and members of the public want.

Given this study's limitations, future research should explore the views of people with lived experience and members of the public from LMICs on what is important to share power in health research priority-setting in order to capture their views as well. The author has started to do so as part of two case studies of health research priority-setting being conducted in India and the Philippines.

Future research could also explore whether and how the ways of sharing power in health research priority-setting should be specified for different types of health research, the burdens and negative impacts of power sharing with communities in health research priority-setting, and how to mitigate/avoid them. Although this study identified sites of power and ways of sharing power in priority-setting at the project level, another matter to consider further is: to what extend do they apply to and/or could be adapted for health research priority-setting at other levels, e.g. institutional, funder, national, and global.

Educational Implications

The growing prominence of community engagement (patient and public involvement) in health research means research ethics training for the field should include the topic of engagement. As part of this training, how to share power with people with lived experience and members of the public in the research process, including during priority-setting, should be covered. The sites of power and ways of sharing power at them that are described in this article can inform the content of such training. They can be used to help teach health researchers and their partners how they can design and undertake priority-setting processes to ensure people with lived experience and members of the public are represented and heard.

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Endnotes

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[1] Sharing power shifts the culture within researchers as they get to know community members and reduces biases in thinking that they know everything and community members know nothing (ANONYMOUS 3).

[2] They use the service being researched, have the condition being researched, or are from the community being researched.

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[3] Research4Me is an extended network of people and organisations in Australia that share a common passion for involving people in health and medical research: https://research4.me/

[4] Where a coder identified codes that the other had not, agreement to include or exclude the code went DJ's way 53-61% of the time and JS's way 39-48% of the time for four transcripts. Agreement to include or exclude the code went JS's way 52% of the time and DJ's way 48% of the time for two transcripts.

References

Abelson, J., Giacomini, M., Lehoux, P., & Gauvin, F.-P. (2007). Bringing "the public" into health technology assessment and coverage policy decisions: From principles to practice. *Health Policy, 82*, 37-50.

Ahmed, S.M., & Palermo, A.S. 2010. Community engagement in research: Frameworks for education and peer review. *American Journal of Public Health, 100(8)*, 1380–1387.

ANONYMOUS 1

ANONYMOUS 2

ANONYMOUS 3

ANONYMOUS 4

ANONYMOUS 5

Apgar, J.M., Mustonen, T. Lovera, S. & Lovera, M. 2016. Moving beyond co-construction of knowledge to enable self-determination. *IDS Bulletin, 47(6),* 55–72.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, *35*, 216-224.

Benhabib, S. (1996). Towards a deliberative model of democratic legitimacy. In S. Benhabib (Ed.), *Democracy and difference: Contesting the boundaries of the political* (pp. 67-94). Princeton, NJ: Princeton University Press.

Bensimon, E.M., Polkinghorne, D.E., Bauman, G.L., & Vallejo, E. 2004. Doing research that makes a difference. *Journal of Higher Education, 75(1)*, 104–26.

Campbell, J. L., Quincy, C., Osserman, J., & Pedersen, O. K. (2013). Coding in-depth semistructured interview: Problems of unitization and intercoder reliability and agreement. *Sociological Methods & Research*, *42*, 294-320.

Cargo, M., & Mercer, S. L. (2008). The value and challenges of participatory research: Strengthening its practice. *Annual Review of Public Health*, *29*, 325-350.

Clark, G., & Jasaw, G.S. 2014. Evaluating team project-work using triangulation: Lessons from communities in northern Ghana. *Journal of Geography in Higher Education, 38(4)*, 511–24.

Cohen, J., & Uphoff, N. (2011). Participation's place in rural development: Seeking clarity through specificity. In A. Cornwall (Ed.), *The participation reader* (pp. 34-56). New York, NY: Zed Books.

Cornwall, A. (2011). Whose voices? Whose choices? Reflections on gender and participatory development. In A. Cornwall (Ed.), *The participation reader* (pp. 203-223). New York, NY: Zed Books.

Crocker, D. A. (2008). *Ethics of global development: Agency, capability, and deliberative democracy*. Cambridge, UK: Cambridge University Press.

Crocker, D.A. (2006). Forward. In D. Goulet (Ed.), *Development ethics at work: Explorations-1960-2002* (pp. xxvii). New York, NY: Routledge.

Gaventa, J. (2006). Finding the spaces for change: A power analysis. *IDS Bulletin, 37(6)*, 23-33.

Gaventa, J. (2004). Towards participatory governance: Assessing transformative possibilities. In S. Hickey & G. Mohan (Eds.), *Participation from tyranny to transformation* (pp. 25-58). London, England: Zed Books.

Gaventa, J., & Cornwall, A. (2006). Challenging the boundaries of the possible: Participation, knowledge and power. *IDS Bulletin, 37,* 122–8.

Gibson, J.L., Martin, D.K., &Singer, P.A. 2005. Priority-setting in hospitals: fairness, inclusiveness, and the problem of institutional power differences. *Social Science & Medicine, 61(11)*, 2355-2362.

Goulet, D. (2006). *Development ethics at work: Explorations-1960-2002*. New York, NY: Routledge.

Goulet, D. (2006). *Development ethics at work: Explorations-1960-2002*. New York, NY: Routledge.

Goulet, D. (2005). *Development ethics: A guide to theory and practice*. New York, NY: Apex Press.

Hammad, S., Alunni, A., & Alkhas, T. 2019. Reflections on the potential (and limits) of action research as ethos, methodology and practice: A case study of a women's empowerment programme in the Middle East. *Action Research, 17(2),* 162–185.

Hickey, S., & Mohan G. (2004). Towards participation as transformation: Critical themes and challenges. In: S. Hickey and G. Mohan (Eds.), *Participation from tyranny to transformation* (pp. 2-24). London: Zed Books.

Hruschka, D. L., Schwartz, D., St John, D. C., Picone-Decard, E., Jenkins, R. A., & Carey, J. W. (2004). Reliability in coding open ended data: Lessons learned from HIV behavioral research. *Field Methods*, *16*, 307-331.

Mental Health Research Network and INVOLVE. (2013). Budgeting for Involvement: Practical Advice on Budgeting for Actively Involving the Public in Research Studies. Eastleigh: Mental Health Research Network, London and INVOLVE.

Mitton, C., Smith, N., Peacock, S., Evoy, B., & Abelson, J. (2009). Public participation in health care priority setting: A scoping review. *Health Policy*, *91*, 219-228.

Muhammad, M., Wallerstein, N., Sussman, A.L., et al. (2015). Reflections on the researcher identity and power: The impact of positionality on community based participatory research (CBPR) processes and outcomes. *Critical Sociology, 14*, 1045–63.

Khanlou, N., & Peter, E. 2005. Participatory action research: considerations for ethical review. *Social Science & Medicine, 60*, 2333–40.

Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability & Society, 15(1)*, 25-47.

Tan, P. L., Hoverman, S., Baldwin, C., & Mackenzie, J. 2012. The value and limitations of participatory action research methodology. *Journal of Hydrology, 474*, 11–21.

Oden, K., Hernandez, B., & Hidalgo, M.A. 2010. Payoffs of participatory action research: Racial and ethnic minorities with disabilities reflect on their research experiences. *Community Development, 41(1)*, 21-31.

O'Doherty, K., Gauvin, F.-P., Grogan, C., & Friedman, W. (2012). Implementing a public deliberative forum. *Hastings Center Report*, *42*, 20-23.

Oswald, K., Gaventa, J., & Leach, M. (2016). Introduction: Interrogating engaged excellence in research. *IDS Bulletin*, *47(6)*, 1–18.

Peuravaara, K. (2015). Reflections on collaborative research: To what extent and on whose terms? *Scandinavian Journal of Disability Research*, 17(3), 272-283.

Reynolds, L., & Sariola, S. (2018). The ethics and politics of community engagement in global health research. *Critical Public Health, 28(3)*, 257-268.

Tremblay, C. (2015). Global Trends in Community University Research Partnerships. In B. Hall, R. Tandon, C. Tremblay (Eds.), *Strengthening community university research partnerships: Global perspectives* (pp. 31-40). Victoria. British Columbia: University of Victoria and PRIA.

Wallerstein, N., & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice*, *7*, 312-323.

Young, I. M. (2000). *Inclusion and democracy*. Oxford, UK: Oxford University Press.

Young, I.M. (1996). Communication and the other: Beyond deliberative democracy. In S. Benhabib, ed., Democracy and difference: Contesting the boundaries of the political (pp. 120-136). Princeton, NJ: Princeton University Press.