



ORIGINAL ARTICLE

Towards epistemic justice doing: Examining the experiences and shifts in knowledge of lived experience researchers over the course of a mental health research training programme

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ABSTRACT: Participation of people with lived experience (LE) in mental health research is vital for improving the quality and relevance of research priorities, outcomes, and knowledge translation. Inclusion of people with LE is also recognized as central for achieving health service reform including commitments to human rights, social, and epistemic justice. Although a lack of research training is cited as a barrier to LE participation, few studies have examined the value of training for, or the specific requirements of, people with LE. This study seeks to address this gap. It reports on a longitudinal, qualitative study examining shifts in experience and knowledge, and unmet needs, of people with LE over the course of a coproduced research training programme. Findings indicate that the programme enabled participants to understand the role, value, and levels of LE participation in research. Participants also stressed the importance of the ‘embodied lived expertise’ of LE researchers who co-delivered the training programme. Nonetheless, participants indicated that they felt unprepared for the challenges of working in systems where LE knowledge is subordinated, and experiences of being silenced and powerless could mirror those previously experienced in mental health services and the community. Participants indicated a need for training that provided them with the epistemic resources to render such experiences intelligible. Findings also indicate that training in participatory research is required for conventional mental health researchers, to support them to navigate power asymmetries and value LE knowledge contributions.

KEY WORDS: capacity building, consumer participation, educational activities, mental health, research ethics.

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INTRODUCTION

Within Australia and internationally, government agencies recommend partnership between conventional mental health researchers (conventional researchers) and people with lived experience (LE) at all stages of the research process (National Institute for Health Research 2015; National Health and Medical Research Council 2018). Partnership with people with LE represents a radical shift in how knowledge is produced within academic and healthcare organizations. Unlike conventional researchers, people with LE purposefully and publicly bring to their research work 'lived expertise' gained through experiences of mental and emotional distress and contact with mental health services (Sandhu 2017). In this paper, we adopt the terms 'person/people with lived experience' and 'lived expertise', which are increasingly preferred over terms such as 'patients', 'clients,' or 'service users' for emphasizing the expertise of the person (Australian Health Ministers' Advisory Council 2013, p.5). Although in common usage, we also avoid the term 'consumer', which, as Baum (2015) argues, can reduce participation to market-based consumer satisfaction as opposed to focusing on the rights of citizens to democratic participation and decision-making in health care. Commitment to partnering with people with LE in research has arisen, in part, from the mental health consumer/survivor/ex-patient (C/S/X) movements, recognition of human rights violations against people with LE (Campbell & Rose 2010; Epstein 2013), and historical acknowledgement of the efficacy of LE leadership and partnerships (Trainor *et al.* 1997), which are associated with improving the relevance of research priorities and outcomes, and raising the quality of research interpretation and knowledge translation (Brett *et al.* 2012).

BACKGROUND

Partnership with people with LE sits on a continuum of participation (Roper *et al.* 2018). Arnstein's (1969) 'ladder of citizen participation' details the levels of participation with lower rungs of the ladder constituting 'nonparticipation', where citizens are excluded; mid-level rungs depicting 'tokenism' where citizens are heard without influence; and top rungs equating to genuine partnership and leadership (p. 217). Despite stated commitments to 'top-rung' participation in research, people with LE still tend to be recruited as subjects rather than active agents in research, or are

consulted in tokenistic ways (Scholz *et al.* 2019). Multiple structural barriers to partnership or LE led research (LE research) have been noted, including stigma and discrimination (Patterson, Trite & Weaver 2014); positioning people with LE as vulnerable and incapable (Happell *et al.* 2019); limited opportunities for career advancement (Beresford 2020); exclusion from research stages (Martineau *et al.* 2020); and inflexible academic time frames, bureaucracy, and metrics (Patterson *et al.* 2014; Scholz *et al.* 2019). The wider research community can also disregard and devalue LE research via claims of LE bias (Beresford 2020; Happell & Roper 2007; Martineau *et al.* 2020), which ignore the proven value and reliability of LE involvement (Hancock *et al.* 2012; Mjosund, *et al.* 2016). LE researchers can be disadvantaged in research compared with conventional researchers, by being less oriented to and confident in research methods, having little exposure and few exemplars of LE led research, and/or doubting their own capacity due to experiences of stigma and discrimination (Happell & Roper 2007; Martineau *et al.* 2020).

The systemic marginalizing of LE knowledge(s) has been described as an 'epistemic injustice' (LeBlanc & Kinsella 2016), which Fricker (2007) defines as the wrong done to people in their capacity as knowers, whereby their testimonies are discredited (testimonial injustice) or they lack collective interpretive resources to render their experience intelligible (hermeneutical injustice). LE activists, researchers, and advocates, therefore, argue that research partnership and leadership of people with LE is not only a matter of improving research quality, but also a matter of epistemic justice doing (Beresford 2020; LeBlanc & Kinsella 2016).

Research training for people with LE has been a long-term request (see Morrell-Bellai & Boydell 1994) and is increasingly recommended by key organizations (Health Consumers NSW Research4ME 2017; INVOLVE 2012). However, the available literature indicates that training programmes for LE researchers tend to focus on project requirements, such as qualitative interviewing, or specific tasks such as review of grant applications (Saunders *et al.* 2008; Wright *et al.* 2006). Only a few research training programmes for people with LE exist that have been explicitly developed with LE input. In Australia, Hancock *et al.* (2012) collaboratively developed training modules with people with LE, which were delivered over a 10-week period by a conventional researcher. Evaluation indicates that the training programme increased

participants' confidence with research terms but did not increase their confidence to undertake research tasks (Marshall *et al.* 2010). This may relate to a lack of opportunity for research work experience, which is known to increase research confidence (INVOLVE 2012).

This paper, which was co-authored with LE researchers, reports on an evaluation of a 'Lived Experience Research Training' (LERT) programme that was co-developed and co-facilitated by LE researchers and conventional researchers and incorporated theoretical and experiential elements. The evaluation of the LERT programme, which was also co-conducted, aimed to explore shifts in participants' knowledge and experience over the course of the training programme.

METHODS

The training

LE and conventional researchers engaged in a coproduction process to design, deliver, and evaluate the LERT programme. Coproduction aims to create a culture that privileges the expertise of people with LE, who collaborate in all aspects of research including co-planning, co-design, co-delivery, co-evaluation, and co-dissemination (Happell *et al.* 2019; Roper *et al.* 2018). The co-design of the LERT programme was based on principles of critical adult education theory and community development (Coombe 2012; Freire 1970, 1982), which emphasize community dialogue, citizen power, and praxis (Freire 1970). The co-designed LERT programme was not envisioned as a final product, but as the basis for an iterative dialogue between all those involved in the design, delivery, participation, and evaluation of the programme to inform ongoing development.

The programme involved 10 two-hour research training workshops, which were co-delivered by LE and conventional researchers in a face-to-face format within a tertiary education setting. Participants were also asked to do pre-reading or watch a short video prior to each workshop. Each workshop covered specific topics, including an overview of research design and practice; levels of LE involvement in research; qualitative, quantitative, and arts-based methodologies; and examples of LE led research presented by established LE researchers. After the sixth research training workshop, participants were given the opportunity to have input into the content of the programme to ensure it met their learning needs. Further detail of the LERT

programme sessions and topics, including workshop participants' special interest topics, is provided in Table 1. Participants were also linked to paid research opportunities in teams with conventional researchers from across university and health service settings. Conventional researchers were selected who expressed a commitment to LE research and had a track record of researching with people with LE. At least, two participants were linked to each team. The programme was delivered between 2018 and 2019 and was attended by a total of 12 people with LE.

Design

The coproduced research evaluation aimed to explore shifts in the knowledge and experience of participants over the course of the LERT programme, including training workshops and research work experience. A longitudinal, qualitative research methodology was chosen as it allows researchers to examine the experiences of participants and the impact of an innovation over time (Grossoehme & Lipstein 2016).

Data collection and analysis

This study was approved by the relevant University Human Research Ethics Committee. Of the 12 people with LE in the programme, 7 (60%) agreed to participate in the evaluation. Data were collected at 3 time points: 1: Prior to commencing the LERT programme; 2: After the sixth research training workshop; and 3: At the completion of the LERT programme, following participation in research work experience. Participants engaged in two focus groups (time points 1 and 2) and individual interviews (time point 3). Focus groups and interviews were audio-recorded and transcribed verbatim by a research assistant who was not involved in the design and delivery of the programme. Data were de-identified prior to analysis.

Data were analysed by LE and conventional researchers (BB, HK, and JR), using a trajectory analysis (Grossoehme & Lipstein 2016) informed by a 'thinking with theory' approach (Jackson & Mazzei 2012). Trajectory analysis is a structured approach to examining experiences and shifts over time and is useful when the phenomenon of interest is a response to a process (Grossoehme & Lipstein 2016). Thinking with theory favours using multiple theories and epistemologies to inform qualitative inquiry (Jackson & Mazzei 2012), which was pertinent to this study as it brought together LE and conventional researchers with

TABLE 1 Lived experience research training programme sessions and topics, including workshop participants' special interest topics

Workshop Session	Workshop Training Topic
1	Introduction and Overview: Welcome and overview of the LERT programme Research Design and Lived Experience Participation: Qualitative and quantitative research design; research cycles and processes; history and value of lived experience participation in research; levels of lived experience participation
2	Philosophy and Ethics in Research: Exploring ontology, epistemology, and research ethics Choosing a Method: Advantages /disadvantages of qualitative and quantitative research methods; method choice; key qualitative and quantitative approaches; data management; analytical approaches
3	Qualitative Research Methodologies: Overview of descriptive, interpretive, and critical qualitative research methodologies Research Example: A lived experience led qualitative study using a phenomenological method
4	Qualitative Research Methods: Collecting data via interviews, focus groups, and arts-based methods Research Example: Co-design and coproduction approaches to research, including data collection, analysis, and arts-based research translation
5	Qualitative Field Work: Case study and ethnography; observations/data collection in real world scenarios and ethical issues Research Example: Practices of ethnographic research; ethical issues; data collection and analysis
6	Quantitative research methods: Randomized control trials, quasi-experimental studies, case-control, cohort, and cross-sectional studies, and statistical analysis Research Example: Example projects of lived experience participation in quantitative research
7	Workshop Participant Special Interest Topic: A lived experience led approach to measuring experiences of recovery
8	Workshop Participant Special Interest Topic: Review of key session topics, including lived experience participation in research, research methods, and ethical dilemmas
9	Workshop Participant Special Interest Topic: Panel discussion with lived experience and conventional researchers. Discussion driven by participant questions
10	Workshop Participant Special Interest Topic: Exploring opportunities for lived experience participation in research. Presentations by lived experience and conventional researchers

multiple theoretical, epistemic, and disciplinary perspectives, including: knowledge from the C/S/X movement; LE epistemologies; 'mad' studies scholarship (Chamberlin 1978, LeFrancois et al. 2013; Tomes

2006); Foucault's (1972) post-modern critique of power discourses; and feminist theory (Collins & Bilge 2016; Crenshaw 1991).

First, each researcher read the data individually, noting participant experiences and knowledge acquisition at each time point. Then, the team came together to examine the data line-by-line. Participant experiences and knowledge acquisition were discussed at each time point, prior to looking across the full data to examine and note shifts in experiences and knowledge over time (Grossoehme & Lipstein 2016). 'Data absences', which can signify variation over time, were also noted (Grossoehme & Lipstein 2016, p.4). For example, if participants expressed concern about a lack of research knowledge at time point one, but not at time point two, this could indicate that this concern had dissipated.

In the second stage of analysis, the identified data shifts across the three time points were analysed using a thinking with theory approach (Jackson & Mazzei 2012). This involved LE and conventional researchers engaging in a dialogue about the data shifts at each time point from multiple perspectives. A dialogical approach, which has been described in detail by Wells *et al.* (2020), was used to avoid settling on a monological analysis and appropriating or dominating LE perspectives in the research process. The dialogue supported articulation of embodied and situated LE perspectives, as well as collective knowledge of the C/S/X movement and/or theoretical knowledge. Preliminary analytical descriptions of the data shifts, that captured the team dialogue, were developed into themes. Through an iterative process of team discussion, these were then refined until three key themes about participants' knowledge and experience across the three time points were formulated into a synthesized account.

RESULTS

The three themes in participants' knowledge and experience of LE research across the three time points were as follows. At time point 1, prior to commencing the LERT programme, participants expressed a sense of *Uncertainty and being the isolated subject*, where they mostly expressed uncertainty about the different levels of LE participation that were possible and felt isolated in their LE perspective. At time point 2, following the sixth research training workshop, participants indicated a growing sense of *Agency and taking the Expert Position* as they came to see the levels of participation possible in research and the value of LE contribution. Finally, at time point 3, after undertaking research work experience, participants

expressed a sense of *Resistance to being the Contributing Subject*. Although they valued the opportunity to work as a LE researcher, they questioned the status quo in research that limited available opportunities for LE participation.

Uncertainty and being the Isolated Subject

Prior to commencing the LERT programme, all participants had some understanding of qualitative and quantitative research and the influence of research on policy and practice. Three participants had little to no research experience, two had experience consulting on research projects, and two had engaged in consultation and co-design of research projects.

Participants with little to no research experience tended to assume that people with LE were the subjects of research, recruited to ‘obtain their opinions’. Among this subgroup, the idea of extending LE involvement was taken to mean increasing the diversity of ‘subject’ samples. As one participant explained, ‘the sample needs to be diverse... [otherwise] it’s not really fully inclusive’. Participants with previous research experience rejected the subject position and some described higher levels of LE involvement in research, yet they primarily struggled to articulate higher levels of LE participation:

So, I was involved in consultation... Is co-design with a consumer and someone else designing something? No? Am I totally off track because I don’t know! (FG1)

All participants viewed research as the domain of conventional researchers, predominantly situated in universities and health services. As one participant articulated, researchers are ‘the people running the research’, and universities are where ‘research is happening’. Many participants considered their individual LE knowledge as disconnected from the broader knowledge of the C/S/X movement, and LE input into research as disclosure of their personal experience to enhance conventional researchers’ understanding. As a participant explained about what people with LE bring to research:

I think by bringing our own experiences, maybe things that other people haven’t had the experience of having mental illness mightn’t think of, or maybe different insights of ways of looking at things. (FG1)

However, participants held doubts about the utility of LE in research spaces if people with LE lacked conventional research knowledge. As one participant commented, people with LE were, ‘not at the level to converse with these people [conventional researchers]’.

Participants also generally agreed that, without research training, it could be, ‘quite daunting for some people, who think, “they [conventional researchers] don’t want my opinion, mine’s not as valid as theirs”’.

Nonetheless, participants with research experience expressed resistance towards conventional researcher dominance and the tokenistic involvement of people with LE. As one participant explained, ‘it just becomes a ticking the box exercise’.

Agency and taking the expert position

At time point 2, participants could articulate understanding of higher levels of LE involvement in research, recognize the value of lived expertise, and situate their emerging knowledge as part of the collective endeavour for change for people with LE. One participant reflected on how they had tacitly absorbed the idea that having LE precluded them from engaging in research as anything other than a subject, and how the LERT programme had shifted this perspective:

I think it affected a lot of my belief in myself, whether it was the illness or whether I could do it or not. [LERT] opened my eyes to a way that yeah, I can be involved in research and contribute to change, especially in the mental health system. That was like, wow, very exciting and yeah, motivating. (FG2)

Participants began to question the authority base of conventional researchers, including the notion of conventional researcher objectivity:

This idea of objectivity is nonsense, because a researcher is not a cardboard box. Everybody is kind of involved – and that’s not bad. You should reflect on that and be explicit about it, so you can examine the relationship between yourself and your research. (FG2)

Participants also critiqued notions of LE bias in research. This was demonstrated in a conversation between three focus group participants:

Participant 1: I would say one of those assumptions is this suspicion around this vested interest. When you say a consumer has a vested interest, and therefore they’re not appropriate to do the research, of course we have a vested interest! We have a vested interest in this going well, and this actually helping people and having a positive outcome!

Participant 2: And you’ve got people who are more motivated and determined.

Participant 1: Yes, so I think.

Participant 3: A vested interest is always perceived pejoratively.

Participant 1: Sure, yes. But I don't necessarily think it's bad, because I know from myself –

Participant 2: We have more insight and knowledge, and –

Participant 1: - and we wouldn't be doing all this work, and we wouldn't be doing all this volunteering, if we didn't have a vested interest in the outcomes of this work.

Participant 3: It should be seen as a positive, not as a negative. (FG2)

Furthermore, participants questioned the relevance and utility of research driven by conventional researchers when it did not have LE input:

Maybe with consumers you might see what's more important for the people, for what areas to research, what would be helpful. [Not] 'oh that's interesting'. How is that going to make a difference to people's lives? You can't look at it on the outside and say this is what we're going to do. (FG2)

More broadly, participants questioned widely accepted academic research traditions, noting the need for further scrutiny to determine their alignment with LE perspectives:

You actually have to change how you do the scholarship. It's not just about whacking consumers into existing paradigms and existing ways of researching. It doesn't mean throw the baby out with the bathwater. Some traditions that we have from more traditional research, they're there for a reason and they may have developed over time and be well justified. But I think we really need to consider, when we bring consumers into leadership roles in research that we may have to do things differently. (FG2)

Participants commented that the LERT programme supported them to consider LE involvement in research not only as an individual contribution of personal experience, but also as part of the collective endeavour of people with LE for action and change. As a participant explained:

It became apparent to me that consumer research, it's part of a broader shift, a broader paradigm shift, where people are increasingly recognising the need for a collaborative mental health system. (FG2)

As participants recognized that LE expertise extended beyond research knowledge, they placed less emphasis on training in research methods:

There's expertise to be gained by studying things, but there's also expertise to be gained through lived experience... The information [in the LERT] has been a

really good springboard for me to start thinking and not feeling like it's a no-go zone. (FG2)

Participants began to consider how LE gave them a particular vantage point in research. As one participant explained, LE perspectives could be 'counter-narrative', challenging the status quo in mental health research, and moving beyond 'recycling of terrible ideas,' which could be 'discriminating and stigmatising'.

Participants explained that it was not only the content of the LERT programme that bought the value of LE experience to their awareness, it was also the model of co-facilitation and presentations by established LE researchers. As one person recalled, the LE co-facilitator 'probably brought it to that level of equality straight away'. One participant commented that the visible valuing of LE expertise by conventional researchers 'stunned me. That anyone was interested in that at all'. Another participant referred to the established LE researchers as, 'embodied lived experience expertise', and stated that this had been an important 'vehicle for agency'.

Resistance to being the contributing subject

At time point 3, participants expressed mixed feelings about the work experience element of the training. Participants described being satisfied with providing input into research, with one participant stating that it was 'priceless to be able to put some of my experiences to good use'. Another participant explained their delight in being able to contribute new ideas, 'there were some surprising things that we were able to reveal to them [conventional researchers]'. However, participants reported that they had very little influence over the projects they worked on. It was clear to participants that conventional researchers maintained ownership and control of the research projects, and that their role was to contribute only as requested. As a participant explained, 'I think the person in charge of the project was very knowledgeable, [but] our job was just to look at the questions he was asking'. Having moved from positioning themselves as subjects of research, to considering themselves agents in research, participants described being now re-positioned by conventional researchers as 'contributing subjects' to research.

When speaking about their research work experience, participants spoke in ways that appeared to be hedging, that is they alluded to tokenistic involvement, but avoided direct criticism of conventional researchers:

He [conventional researcher] was for the most part on the same page as people with lived experience, which

said to me that he really did value contributions from me and people like me in a more than tokenistic way. But I'm hoping that the specific skills that I learnt in the program will be more helpful to things in the future. (Interview 1)

Another participant also demonstrated this pattern of hedging:

When you first see it [survey], you think that the person that made it has no idea of [the topic]. But that's just how it's set out. So, there's like ratings, and that's just – yeah. So, that was the research I was involved with. That was cool. I would like to have more – a lot more involvement, maybe with other research teams. Yeah. Maybe something a little bit more intense. (Interview 2)

This participant's 'yeah' is telling. Their objection peters out and their words are softened without further critique, as though they tacitly accepted that the conventional researcher held power and did not wish to provide more disruptive critiques. Although participants did not appear to assign intent or blame to the conventional researchers, they indicated that the conventional researchers privileged more 'tame' LE views, that is their LE was valued as long as it was not disruptive to the research process.

Participants discussed how the coproduced LERT programme had shifted their perspectives on what was possible in research:

Why doesn't everybody fucking do this [coproduction research]? It [LERT program] really encouraged me to keep going in the direction I'm going, because it shows that there are people and systems out there, both with and without lived experience who recognise the value of lived expertise. And want to put that to work for improving human rights for folks. (Interview 1)

However, underwhelming work experiences in research teams left some participants questioning whether research was for them. One participant said it left them wondering if, 'maybe I should just leave this whole field and get a regular job'. However, participants viewed their individual experience as representative of, and part of, the broader struggle for recognition of LE expertise, which as one participant put it is, 'under-recognised, under-appreciated and under-funded'.

Participants had several ideas for how the research training workshops could better prepare them for research work. One participant recommended that the LERT programme should make more explicit the links between the C/S/X movement and LE research:

It would have been cool to bring us all up to speed on where consumer research is at, no matter how dire the situation is, the state of this type of research and what agencies are involved, or what kind of funding is out there and what's available. (Interview 4)

Another participant stated that it would have been helpful to 'include a map of the consumer/survivor/ex-patient movement. And what that looks like across research practice'.

Importantly, participants recommended that the LERT provides more structured and sustained support to people with LE *and* conventional researchers, so that they could engage in more collaborative work. As one participant stated, conventional researchers need to be made 'aware of what is consumer research, and how is it valuable'. Participants also recommended that training programmes such as LERT be supported by universities to ensure sustainability. As one person stated, 'the training program was really, really good and it's fantastic that they're having it... [but if] it doesn't sustain you lose the potential of the program'.

DISCUSSION

The findings indicate that participation in a coproduced and co-delivered LERT led to key shifts in participants' knowledge and experience related to LE research. A lack of research training has been raised as a barrier to LE partnership and leadership in research (Patterson *et al.* 2014). The current study findings confirm this, indicating that, prior to training, people with LE mostly express limited knowledge of higher levels of LE involvement, and therefore, viewed research as the preserve of conventional researchers. Participants in this study tacitly positioned LE involvement as that of subjects of research, or, 'givers of stories', for use by conventional researchers, who were 'running the research'. This aligns with the lower 'nonparticipation' and 'tokenism' rungs of Arnstein's (1969) ladder, (p.217). Despite efforts to increase LE engagement (National Health and Medical Research Council 2018), as Scholz *et al.* (2019) have argued, in current academic practice people with LE are more likely to be recruited as subjects or consulted in tokenistic ways than engaged with as research partners. However, what was mostly unknown to participants prior to LERT was the higher levels of LE research leadership and partnership that were possible, as well as the collective knowledge(s) of the C/S/X movement and 'mad'

scholarship (LeBlanc & Kinsella 2016; Russo & Beresford 2015).

Participants' tacit assumptions are likely related to the widespread and systemic subjugation and invisibility of LE knowledge(s). Wylie (2011) has noted previously that, within universities, researchers select out what is powerful and not necessarily what is knowledgeable, thereby subjugating the knowledge(s) of those who are socially marginalized (p.160). LeBlanc and Kinsella (2016) have argued that 'sanism' is one mechanism by which LE knowledge(s) become marginalized and invisible, constituting an interpretive (hermeneutical) injustice (LeBlanc & Kinsella 2016). Sanism (Perlin 1992) refers to the systemic oppression of people with LE due to discriminatory notions about 'madness' (akin to racism, sexism, or homophobia). In the case of the LERT participants, limited access to knowledge about LE research partnership and leadership, as well as the C/S/X movement more broadly, left them with limited role exemplars leading to them being mostly positioned as disempowered, uncertain, and isolated research subjects.

However, the power and authority of conventional researchers, and the concurrent erasure of LE knowledge(s) experienced by the participants, was incomplete. Some participants were able to articulate higher levels of research and expressed ambivalence or resistance to the authority of conventional researchers and their inclusion of people with LE as a 'tick box exercise'. This supports LeBlanc and Kinsella's (2016) argument that, despite reduced hermeneutical resources, people with LE are able to articulate dissent even in the face of institutional power.

The findings of this study indicate that research training considerably improves the research knowledge of people with LE and can provide them with the hermeneutical resources to make sense of research practices and power relations. After engaging in the LERT research training programme, participants were able to articulate levels of LE levels of participation in research commensurate with the upper 'partnership' and 'leadership' rungs of Arnstein's (1969, p.217) ladder. Over the course of the training programme, participants were also able to deconstruct their tacit assumptions about people with LE as isolated subjects and to consider the particular vantage point of lived expertise. Participants began to challenge the legitimacy of conventional researcher dominance, including unpacking notions of objectivity and bias as 'nonsense' that can be used to subjugate LE researcher perspectives (Beresford 2020; Happell & Roper 2007).

Furthermore, participants were able to discursively reposition themselves as authoritative insiders who knew what would be 'important for the people'. This echoes notions of 'vivencia' (Glassman and Erdem 2014) and 'concientization' (Freire 1970), which describes comprehensive knowing and critical consciousness raising among people with LE about socio-political patterns and processes of injustice.

Leadership of people with LE in the LERT programme appeared to be a vital element in creating these shifts. Participants emphasized the particular value of LE co-facilitators as embodying the possibility of leadership and partnership in research, while the presence of a conventional researcher was described as demonstrating a 'level of equality' and respect between LE and conventional researchers. This finding supports the work of educational philosopher Palmer (1998) who argues for the importance of embodied knowing and 'connectedness' in education. As Palmer contends, teachers not only teach concepts, but they also teach who they are and their embodied connectedness, to the knowledge being taught (1998, p.11), or in the words of a participant, 'embodied lived expertise'.

Despite the positive findings of this study, they also indicate that LE leadership is not sufficient. Facilitators of LE research training need to make visible the challenges for LE researchers of engaging in participatory research endeavours, as well as the current status quo in mental health research, and the links between these struggles and the broader struggles of the C/S/X movement. As participants' accounts indicated, they were under-prepared for experiences with conventional researchers where their contribution was reduced to that of a contributing subject. LE researchers in our team also proposed that the hedging pattern observed across participant interviews was likely related to power asymmetries between conventional and LE researchers, and the desire among LE researchers to secure the future employment. This echoes the work of MacKinnon *et al.* (2021) and other authors (e.g. Guta *et al.* 2014), who suggest that the precarity of lived experience researcher roles, which are usually casual and reliant on the ongoing patronage of conventional researchers, while appearing inclusive can in fact reinscribe experiences of powerlessness, silencing and discrimination that mirror those experienced by people with LE in mental health services, labour markets, and the broader community.

As participants suggested, the need for training extends beyond those with LE and conventional researchers need to be made aware of 'consumer

research, and how is it valuable'. Conventional researchers require training that centres on the principles and practices of research partnership with people with LE, to improve their own capacity to collaborate and avoid re-inscribing epistemic harms. Indeed, conventional researchers may be unaware of the potential harms of assuming power and failing to invite critique even when they have a stated commitment to LE involvement (Happell *et al.* 2019). Additionally, conventional researchers may hold unexamined and unarticulated intentions that are at odds with the intentions of LE researchers. While many people with LE get involved in research for the purposes of making social and political change, conventional researchers may not always hold the same commitments, and may instead be accessing LE perspectives for 'add-on' information (Beresford 2020, p. 2).

The evaluation of a LERT programme suggests that such programmes are of great benefit but should include structured supports for LE researchers. This might include combined training for teams of LE and conventional researchers that attend explicitly to issues of power, as well as dedicated spaces for LE researchers to unpack the potential challenges of working in systems where LE knowledge is subordinated. Additionally, since systemic issues are beyond what a single training programme can fix, there is also a need for broader recognition and training about the epistemic injustice and harms towards people with LE, alongside more material supports for LE led research. Future research might investigate processes within universities that could devolve power and enable meaningful LE contribution and leadership.

Limitations

The value of qualitative methods is in exploring experiences and meanings that cannot necessarily be predicted in advance (Yardley 2015). Despite careful coproduction processes and selection of qualitative methodologies, this study has some limitations. While the research team comprised LE researchers, it is still the case that the study design positioned LE participants as research subjects who at times may have had only minimal power within the overall research process.

CONCLUSION

This study supports the importance of coproduced research training programmes to enhance the

hermeneutical resources of people with LE who wish to engage in research. Training should be co-facilitated by LE and conventional researchers to convey the valuing of LE involvement, as well making the embodied lived expertise of LE researchers visible. Importantly, training also needs to make visible the challenges and struggles of people with LE in research spaces, as well as a broader understanding of the C/S/X movement. Finally, given the current status quo in research, training is required for conventional researchers on the epistemic harms of power asymmetries and the inadvertent silencing and devaluing of LE knowledge(s) - and mechanisms by which this occurs - in order to promote genuine collaboration and systemic change.

RELEVANCE FOR CLINICAL PRACTICE

Nurses are well-placed to act as allies for LE leadership (Happell & Scholz 2018), including by using their positions and influence to support LE led research and training within health services and education settings. Nurses can act as facilitators of resources and space for LE research and training, as well as supporting broader recognition about the epistemic injustice and harms towards people with LE in research, and the need to explicitly address power asymmetries that negatively impact LE leadership and participation.

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REFERENCES

- Arnstein, S.R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35 (4), 216–224.
- Australian Health Ministers' Advisory Council (2013). *A National framework for recovery-oriented mental health services: Policy and theory*. Canberra: Commonwealth of Australia. [Cited on 10 June 2021]. Available from: URL: <https://www.health.gov.au/sites/default/files/documents/2021/04/a-national-framework-for-recovery-oriented-mental-health-services-policy-and-theory.pdf>
- Beresford, P. (2020). PPI Or User Involvement: Taking stock from a service user perspective in the twenty first century. *Research Involvement and Engagement*, 6 (36), <https://doi.org/10.1186/s40900-020-00211-8>

- Brett, J.o., Staniszevska, S., Mockford, C. *et al.* (2012). Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations*, 17, 637–650.
- Baum, F. (2015). *The New Public Health*, 4th edn. Melbourne, Australia: Oxford University Press ANZ.
- Campbell, P. & Rose, D. (2010). Action for change in the UK: Thirty years of the user/survivor movement. In: D. Pilgrim, A. Rogers & B. Pescosolido (Eds). *The SAGE handbook of mental health and illness* (pp. 452–471). Los Angeles, CA: Sage.
- Chamberlin, J. (1978). *On our own: Patient-controlled alternatives to the mental health system*. New York, NY: Hawthorn Books.
- Collins, P. & Bilge, S. (2016). *Intersectionality*. Malden, MA: Polity Press.
- Coombe, C. (2012). Participatory approaches to evaluating community organizing and coalition building. In M. Minckler (Ed) *Community Organizing and Community Building for Health and Welfare*. Rutgers University Press, pp. 346–364.
- Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, 43(6), 1241–99.
- Epstein, M. (2013). *The Consumer Movement in Australia: A Memoir of An Old Campaigner. Our Consumer Place*. Victoria, Australia: Recourse Centre for Mental health Consumers.
- Foucault, M. (1972). *The Archaeology of Knowledge*. London: Tavistok Publications Limited.
- Freire, P. (1982). Creating alternative research methods: Learning to do it by doing it. In: B. Hall, A. Gilette & R. Tandon (Eds). *Creating knowledge: A monopoly?* (pp. 29–40). New Delhi, India: Society for Participatory Research in Asia.
- Freire, P. (1970). *Pedagogy of the Oppressed*. New York: Herder & Herder.
- Fricker, M. (2007). *Epistemic Injustice: Power and the Ethics of knowing*. Oxford University Press.
- Glassman, M. & Erdem, G. (2014). Participatory action research and its meanings: Vivencia, praxis, conscientization. *Adult Education Quarterly*, 64 (3), 206–221.
- Grossoehme, D. & Lipstein, E. (2016). Analysing longitudinal qualitative data: The application of trajectory and recurrent cross-sectional approaches. *BMC Research Notes*, 9 (136), 1–5.
- Guta, A., Strike, C., Flicker, S.J., Murray, S., Upshur, R. & Myers, T. (2014). Governing through community-based research: Lessons from the Canadian HIV research sector. *Social Science & Medicine*, 123, 250–261.
- Hancock, N., Bundy, A., Tamsett, S. & McMahon, M. (2012). Participation of mental health consumers in research: Training addressed and reliability assessed. *Australian Occupational Therapy Journal*, 59, 218–224.
- Happell, B., Gordon, S., Bocking, J. *et al.* (2019). “Chipping away”: Non-consumer researcher perspectives on barriers to collaborating with consumers in mental health research. *Journal of Mental Health*, 28 (1), 49–55.
- Happell, B. & Roper, C. (2007). Consumer participation in mental health research: Articulating a model to guide practice. *The Royal Australian and New Zealand College of Psychiatrists*, 15 (3), 237–241.
- Happell, B. & Scholz, B. (2018). Doing what we can, but knowing our place: Being an ally to promote consumer leadership in mental health. *International Journal of Mental Health Nursing*, 27 (1), 440–447.
- Health Consumers NSW & Research4Me (2017). *Involving health consumers in health and medical research: Enablers and challenges from a consumer perspective*. Health Consumers NSW and Research4Me.
- INVOLVE (2012). *Briefing notes for researchers: Public involvement in NHS, public health and social care research*. Eastleigh: INVOLVE. Available from: URL: <https://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEBriefingNotesApr2012.pdf>
- Jackson, A. & Mazzei, L. (2012). *Thinking with Theory in Qualitative Research: Viewing Data Across Multiple Perspectives*. New York: Routledge.
- LeBlanc, S. & Kinsella, E. (2016). Toward epistemic justice: A critically reflexive examination of ‘sanism’ and implications for knowledge generation. *Studies in Social Justice*, 10 (1), 59–78.
- LeFrancois, B., Menzies, R. & Reaume, G. (2013). *Mad Matters: A Critical Reader in Canadian Mad Studies*. Toronto: Canadian Scholars Press Inc.
- MacKinnon, K.R., Guta, A., Voronka, J. *et al.* (2021). The political economy of peer research: Mapping the possibilities and precarities of paying people for lived experience. *British Journal of Social Work*, 51 (3), 888–906. <https://doi.org/10.1093/bjsw/bcaa241>
- Marshall, S.L., Deane, F. & Hancock, N. (2010). Increasing research familiarity among members of a clubhouse for people with mental illness. *Australian Journal of Rehabilitation Counselling*, 16 (2), 119–125.
- Martineau, J., Minyaoui, A. & Boivin, A. (2020). Partnering with patients in healthcare research: A scoping review of ethical issues, challenges, and recommendations for practice. *BMC Medical Ethics*, 21 (34). <https://doi.org/10.1186/s12910-020-0460-0>
- Mjosund, N., Erikson, M., Espnes, G. *et al.* (2016). Service user involvement enhanced the research quality in a study using interpretive phenomenological analysis: The power of multiple perspectives. *Journal of Advanced Nursing*, 73, 265–278.
- Morrell-Bellai, T. & Boydell, K. (1994). The experience of mental health consumers as researchers. *Canadian Journal of Community Mental Health*, 13 (1), 97–108.
- National Institute for Health Research. (2015). Going the extra mile: Improving the nation’s health and wellbeing through public involvement in research. Available from: URL: <https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf>

- National Health and Medical Research Council (NHMRC). (2018). Guidelines for Guidelines: Consumer involvement. [Cited Xx Xxx Xxxx]. Available from: URL: <https://www.nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement>
- Palmer, P. (1998). *The Courage to Teach: Exploring the Inner Landscape of a Teacher's Life*. San Francisco: Jossey-Bass.
- Patterson, S., Trite, J. & Weaver, T. (2014). Activity and views of service users involved in mental health research: UK survey. *The British Journal of Psychiatry*, 205, 68–75.
- Perlin, M.L. (1992). On “sanism”. *Southern Methodist University Law Review*, 46, 373–407.
- Roper, C., Grey, F. & Cadogan, E. (2018). Co-production: Putting principles into practice in mental health contexts. Creative Commons Attribution 3.0. Available from: URL: https://discovery.college/wp-content/uploads/2019/Coproduction_final-compressed.pdf
- Russo, J. & Beresford, P. (2015). Between exclusion and colonisation: Seeking a place for mad people's knowledge in academia. *Disability and Society*, 30 (1), 153–157.
- Sandhu, B. (2017). The value of lived experience in social change: The need for leadership in the social sector. Creative Commons Attribution. NonCommercialChareAlike 4.0 International license.
- Saunders, C., Girgis, A., Butow, P., Crossing, S. & Penman, A. (2008). From inclusion to independence: Training consumers to review research. *Health Research Policy and Systems*, 6 (3). <https://doi.org/10.1186/1478-4505-6-3>
- Scholz, B., Gordon, S., Bocking, J. *et al.* (2019). ‘There's just no flexibility’: How space and time impact mental health consumer research. *International Journal of Mental Health Nursing*, 28, 899–908.
- Tomes, N. (2006). The patient as a policy factor. A historical case study of the consumer/survivor movement in mental health. *Regulation and Policy*, 25 (3), 720–729.
- Trainor, J., Shepherd, M., Boydell, K., Leff, A. & Crawford, E. (1997). Beyond the service paradigm: The impact of consumer/survivor initiatives. *Psychiatric Rehabilitation Journal*, 21 (2), 132–140.
- Wells, R., Barker, S., Boydell, K., Buus, N., Rhodes, P. & River, J. (2020). Dialogical inquiry: Multivocality and the interpretation of text. *Qualitative Research*, 7, 1–17. <https://doi.org/10.1177/1468794120934409>
- Wright, D., Corner, J., Hopkinson, J. & Foster, C. (2006). Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda. *Health Expectations*, 9, 3–12.
- Wylie, A. (2011). “What knowers know well: Women, work and the academy. In: H. Grasswick (Ed). *Feminist epistemology and philosophy of science: Power in knowledge* (pp. 157–179). Dordrecht: Springer.
- Yardley, L. (2015). In: J. Smith (Ed). *Demonstrating validity in qualitative research, in qualitative psychology: A practical guide to research methods* (pp. 235–251). London: Sage.