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The challenges of navigating participatory research: the perspective of a doctoral student who co-ordinates a team of researchers with lived experience of mental health challenges

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ABSTRACT

Participatory research (PR) involves people with lived experiences of the research topic as co-creators of knowledge. I have the dual role of being both a doctoral researcher and the co-ordinator of a research group – the Converge Evaluation and Research Team (CERT) – which consists of researchers with lived experience of mental health challenges. I am using evaluation projects conducted by CERT to offer insightful case studies for my doctoral research, in which I am exploring coproduction in mental health research. I use learning from my doctoral research to explore how CERT can maximise opportunities for coproduction. Using a CERT evaluation of an arts project for adults with severe and enduring mental health challenges as an exemplar, this article considers my reflections on the challenges of PR as a doctoral researcher elucidated by Southby (2017): power and sharing control; adhering to the standards and procedures of an individualistic academy; inexperience and fear of failure; competing priorities; and time and effort. In addition, remuneration is also considered as a crucial challenge in contemporary research.

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Introduction

Participatory research (PR) is a process whereby people with lived experiences of the research topic become co-creators of knowledge, where the different and diverse knowledge and experience of all involved is valued, and where there is engagement in all aspects of the process: research design, data collection, analysis, reporting and dissemination (e.g. Lenette et al. 2019). PR begins from a social, ethical and moral commitment not to treat people as ‘*captive research material*’ (Faulkner and Morris 2003, 18) whose data ‘*becomes the property of the researcher*’ (Pickering and Kara 2017, 300). As Cornish et al. (2023, 2) explain:

PAR [participatory action research – a more political type of PR] does not follow a set research design or particular methodology, but constitutes a strategic rallying point for collaborative, impactful, contextually situated and inclusive efforts to document, interpret and address complex systemic problems.

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Kara (2017) also observes that an intrinsic aim of PR is to defuse power differentials between professional researchers and the community of interest.

Operating at York St John University and Northumbria University Newcastle, Converge provides free educational courses for adults using, or have used, mental health services. Courses, including theatre, music, visual arts, creative writing, and social sciences, are offered free of charge and no qualification or experience is required. Participants are known as 'Converge students', emphasising the educational philosophy. I co-ordinate the Converge Evaluation and Research Team (CERT), a group of (currently) 14 Converge students: CERT Researchers. Any Converge student can join CERT and there is a wide range of experience, from none to PhD level. CERT engages in academic research and evaluations of mental health related projects, adopting a strongly participatory approach, seeking to maximise opportunities for coproduction where *'researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project'* (Hickey 2018, 5).

As a white, British female with lived experience of mental health challenges who identifies as a survivor researcher, I inhabit a dual role as doctoral researcher and CERT co-ordinator. My doctoral research employs CERT projects as case studies to explore coproduction in mental health research. I use learning from my doctoral studies to improve how CERT navigates the complex nature of PR. As such, my personal positioning, CERT activity and my doctoral research are very much intertwined.

Klocker (2012) observes that PR is more demanding than conventional research; that doctoral researchers will *'face many battles'* (151); that it is a *'time intensive activity'* (153); and is a collaboration based on *'dialogue and negotiation'* (155). Baum, MacDougall, and Smith (2006) add that PAR can be unpredictable – Dedotsi and Panić (2020) note that *'The advice "not to do AR" [action research] at the doctoral level was [often] given as a "friendly advice"'* (3). Southby (2017) elucidates five challenges arising from PR for doctoral researchers: power and sharing control; adhering to the standards and procedures of an individualistic academy; inexperience and fear of failure; competing priorities; and time and effort. As they resonate with me, this article describes my experience of navigating these challenges using a CERT evaluation of an arts project in London for adults with severe and enduring mental health challenges as an exemplar of wider relevance. In addition to Southby's challenges, the thorny topic of remuneration is discussed.

Arts project evaluation context

In 2022, funded by a grant awarding Trust, the arts project required CERT to conduct a broad evaluation of the experiences of their members. Here, 'members' refers to those attending the project, and 'member co-researchers' refers to the six members who participated in this evaluation as co-researchers.

In previous evaluations, CERT employed a questionnaire created in collaboration with the project's management alongside face-to-face interviews conducted by CERT Researchers. CERT analysed the data internally and I compiled the report. However, in 2022, inspired by my doctoral research, we sought to adopt a participatory approach. As highlighted by Cornish et al. (2023) it is important to involve co-researchers from the beginning, establishing a shared understanding and truly collaborative research plan. This ensures that the questions asked reflect the concerns and needs of those being 'researched'.

Prior to visiting, we asked the manager to recruit members to participate in our evaluation. On our first visit, we invited the six members who volunteered to become co-researchers. We explained our plan for four visits across which we would complete the evaluation. Three CERT Researchers were present for each visit.

To begin, we shared CERT's previous methodology – questionnaires and interviews – and different methods including art, photography and creative writing. Following discussion, the member co-researchers decided to use art as the main methodology. Their plan was that members would be invited to draw or write responses to two questions on postcards: 'why is art important to you?' and 'what difference does [the arts project] make to your day?' There is a long tradition of employing art as a research method (e.g. Leavy 2019). This is because, as Leavy explains, arts-based research '*harnesses and melds the creative impulses and intents between artistic and scientific practices*' (4) – thus, using art may achieve unique, valuable insights in our evaluation unobtainable with conventional methods.

When we shared this plan with the project's managers, they feared low engagement in our creative approach. They were keen that, in addition to postcards, we should use a questionnaire. Since we did not have timely access to them, and because we felt the request was reasonable, we agreed to use a questionnaire without consulting our member co-researchers. Personally, I was uncomfortable with this decision; nevertheless, the arts project was our customer, so I felt pressured to deliver the style of evaluation they wanted. To offer control over the questionnaire to member co-researchers, on our second visit we brought previous questionnaires for them to discuss, choose from and add to. This process led to many interesting insights. For example, one previous question asked whether members felt that since coming to the arts project, they use mental health services less (in past years the answer was generally yes). The member co-researchers rejected this question because while they felt their mental health had improved since attending the project, they believed that what mental health services offer them does not accurately reflect what they feel they actually need – a nuanced insight we would not have gained without this process.

On our third visit, the goal was to facilitate the member co-researchers to analyse 18 completed questionnaires. Due to time, we could not cover the whole questionnaire, therefore I pre-selected five questions for discussion. During this session, five member co-researchers were highly engaged: their responses to the questionnaire data offered many insights into their experiences of the project, well beyond what CERT might have achieved without this approach.

Our aim for the final session was to facilitate a collaborative thematic analysis of 21 postcards among six member co-researchers. It was important to me that the identification of themes was led by the member co-researchers. They determined five key themes, (which interestingly were similar to those identified in previous evaluations). Member co-researchers expressed feeling their involvement had contributed something important – that they were giving something valuable back to support the project. Clearly proud, they asked to display the work created during the analysis on the wall for other members to see.

Compiling the report is a crucial process in term of who influences its content and should carefully consider data ownership. In this project, engaging the member co-researchers in writing the final report was difficult: they were far away; many did not have necessary equipment (e.g. a computer) or writing experience; tight timeframe; and a limited travel budget. These hindered opportunities for meaningful collaboration; disappointingly, member co-researchers played no part in writing the report. To recognise their valuable

contribution, we offered the opportunity to be named as co-authors, but none took this up – perhaps indicating a lack of interest in written dissemination in contrast to the visual art component of which they were so proud. The lack of funds meant that, sadly, we were unable to return to the studio to talk to the member co-researchers about their experiences, which would have been insightful for my doctoral research.

Specific challenges

Power and sharing control

Many scholars have grappled with power and sharing control in a PR context. Cook et al. (2019) observe that *'PAR places a relational process at the centre of the research practice'* (379). However, while Cornish et al. (2023) describe PAR as an emancipatory form of scholarship, power is not usually clear cut (Mitchell-Williams et al. 2004). Indeed, Baum, MacDougall, and Smith (2006) note that many of the dilemmas surrounding PAR revolve around contested power dynamics. According to Hawkins (2015), PAR is not an easy undertaking – it is both messy and complex, and they advise that issues relating to power need to be constantly and continually considered throughout the course of the project. Similarly, Gombert et al. (2015) explain that while *'Power relations and hierarchies determine social interactions, institutions and organisations [. . .] Action research can be seen as an attempt to change these structures with the goal of improving the well-being of the participant'* (591). Vitaly, Gombert et al. go on to note that *'every action research project holds a set of often unforeseen or unknowable ethical dilemmas and challenges which only become apparent when in the field'* (594). Thus, the emergence of these dilemmas and how they are addressed is a crucial consideration for researchers using PR approaches.

Felner (2020) cautions that the inherent power held by academic institutions poses a major barrier to achieving equity in PAR, arguing that scholars should interrogate how PAR can *'address, rather than reify, power inequities between academics and marginalized communities'* (553). Continuing, Felner highlights the importance of examining *'how the power and privilege held by academics shape and constrain opportunities for community partners to authentically engage in co-research'* (553). Thus, in order for PR to be empowering for participants, the power to make decisions and control the research process must be shared with participants by researchers (Southby 2017).

Questions relating to who has the opportunity to be heard are common in PR (e.g. Cornish et al. 2023; Wheeler, Shaw, and Howard 2020), and the way in which this is handled has a significant impact on research quality, offering insights for my doctoral research. Here, our sessions were held at the studio, a familiar and, presumably, safe environment for members. However, we needed to consider when to hold sessions: early morning might exclude members with a long journey, or those whose medication or mental health makes getting up hard (all likely in this project): importantly, Schneider (2012) noted that marginalised people, including those with mental illness, may need extra support to fully participate.

Prior to our first visit to the arts project, we asked a manager to recruit members to join us as co-researchers. Here, the manager, as the only means of connecting us with members, held significant gatekeeping power: such gatekeepers have the potential to impact research protocols in ways which impair data collection and sometimes ethical practice (Agbebiyi 2013). Our considerations were: who did they tell? How was our

evaluation explained? If they left people out, was this intentional or accidental? If intentional, was their motivation reasonable (e.g. only asking those they felt could manage) or were they seeking to silence any potentially critical voices?

Often, my personal power lies in my function as a gatekeeper for CERT Researchers' engagement in projects – again, influencing who is heard. On occasion, I have made unilateral decisions about involvement – encouraging some rather than others to participate. Usually this is based on my assumptions about who might be interested, who has the time, or my belief that they possess relevant skills. However, sometimes because of group dynamics and ease of interpersonal interactions.

Another key power-related consideration relates to data ownership: who has the right to use it. Pickering and Kara (2017) note that data should not become the property of the researcher. Furthermore, Schneider (2012) questions *'whether the professional researcher should be able to use the data for his or her own purposes, for example, in articles or presentations for which the community members do not participate in the analysis and writing'* (160). This point is relevant to me as it has implications relating to securing consent to use data for anything other than the evaluation, including my doctoral thesis.

In relation to the arts project, there were three key moments when I exercised power in a non-PR way. Firstly, I wanted a CERT co-researcher with strong facilitation skills – thus, I directly asked an experienced researcher rather than offering the opportunity to CERT more broadly, a decision with implications for democracy within CERT. Secondly, my decision to use a questionnaire when the member co-researchers chose not to. This was due to my inexperience as a researcher (discussed later) and my keenness to produce the style of evaluation report our paying customer wanted. Thirdly, because there were considerably more questionnaire data than could be covered in an afternoon, I unilaterally selected five questions I felt would be interesting to discuss. This selection should have been made by member co-researchers; however, this was not possible because of time and limited access to them. This decision about content will have directly influenced the knowledge generated during the session.

Adhering to the standards and procedures of an individualistic academy

Southby (2017) writes that PR blurs *'the boundaries between the roles of "researcher" and "participant"'* explaining that this means that *'deliberately or not – [they are] subverting the accepted (and possibly expected) path of a research-degree student'* (134). This concern is shared by Klocker (2012), who observes the literature examining PAR from the perspective of doctoral student is sparse and often despondent. Dedotsi and Panić (2020) cite the risk *'of "failing" to complete my PhD within the expected time frame and risking my dissertation completion with a report of "failed" action ... [producing] something "which does not meet the expected or accepted norms"'* (3). Klocker remarked that *'Postgraduate students contemplating PAR are warned that they will face many challenges beyond those experienced by "ordinary" doctoral students – including a battle for acceptance within their scholarly institutions'* (149). Considering these warnings, I was fortunate that my university was open to PR approaches, and I did not experience problems with the University ethics committee.

In this project, I was very conscious of the extent to which my roles as CERT coordinator and doctoral researcher were blurred, sharing aims about achieving the best possible participation in the circumstances. However, there was a possible danger of the

research becoming so participatory that it becomes unacceptable to include as a case study for my doctoral research in the eyes of my examiners, raising challenges relating to the previous discussion about data ownership.

An occasional problem I experience is the standard of work produced by CERT Researchers: for paid work, reports must be high quality. Sometimes, it has been necessary to raise the standard of a CERT Researcher's work when there was no time to involve them in the revisions. For me, this is challenging: the need to develop someone else's writing calls for tact and acute sensitivity. CERT offers opportunities for CERT Researchers to develop their skills through developing internal projects, for example, an ongoing project exploring experiences of mental health waiting rooms. Here, we enjoy the luxury of time, creating opportunities for CERT Researchers to develop skills in less pressured circumstances.

Inexperience and fear of failure

Southby (2017) observes that for doctoral students, PR can be risky, testing their skills and competencies through the pressure of producing a substantial piece of original research. Dedotsi and Panić (2020) discuss the risk to students using of PR of failing to finish their PhD within the expected time frame and potentially failing their dissertation due to it not meeting accepted norms. Reflecting on this evaluation, I acknowledge that my inexperience at times led me to work in ways not always in the spirit of PR. Additionally, as alluded to before, I worried whether my work would be informative as a PR case study and at the same time acceptable to my doctoral examiners.

My lack of confidence as a researcher in the postcards methodology chosen by member co-researchers led to me comply with management's request to use a questionnaire without consulting them. This decision, forced by time and access considerations, is counter to how PR should function. This relates to both my inexperience/lack of confidence in defending PR approaches to unfamiliar parties and my desire to keep the paying customer happy. It is interesting that, contrary to management's fears about low engagement, more members created postcards than completed the questionnaire.

Competing priorities

Southby (2017) observed that then needs/requirements of the research student, community partners, and university supervisors/examiners are not necessarily aligned, a concern is shared by Felner (2020). This range of stakeholders opens up a series of challenges relating to differing priorities and role negotiation. In the arts project, there were many competing priorities: managers required a high-quality evaluation which they could use to demonstrate the project's achievements; member co-researchers wanted to share their experiences and be involved in improving what is offered to them and their peers; CERT was interested in broader social justice alongside a genuine interest in the arts project; and my PhD examiners will be concerned with the academic rigour of my research. In addition to sharing CERT's motivations, achieving an informative case study to explore in my doctoral research was a key priority for me. My role as co-ordinator is to ensure all these competing priorities are managed.

One problem I experience as CERT co-ordinator is that securing engagement from CERT Researchers can sometimes be challenging. Different priorities/situations mean that

sometimes teams are smaller than hoped, or researchers disengage mid-project. CERT Researchers' availability varies because of fluctuating mental or physical health; work, study, or caring commitments. Often CERT Researchers have different preferences: some are happy just to talk about a project in our regular meetings; some enjoy creating questionnaires; others enjoy thematic analysis and report-writing. Balancing these preferences is delicate, but for me it is important CERT Researchers can engage with projects on their terms. The challenges of meeting CERT Researchers' individual needs and interests offers insights for my doctoral research.

Time and effort

Southby (2017) observed that PR *'requires a greater investment of time and resources than non-participatory research – time and effort to develop relationships, maintain contact and sustain involvement'* (138). Concurring, Husted and Tofteng (2021) identified time as a key barrier in PAR. Working in a PR way definitely made organising the arts project evaluation more complex, considerably increasing the burden of work for myself, CERT Researchers, and member co-researchers compared to our previous non-PR evaluations.

Most problematic was the accessibility of member co-researchers. Distance meant we could not easily pop in with questions – chiefly why I unilaterally made the decision to use questionnaires and pre-selected the questionnaire questions for analysis. Reflecting on these decisions, I wondered whether we ought to have made more effort to find a way of communicating online.

I was conscious of the nature and burden of work placed on member co-researchers and CERT Researchers, especially those unpaid for their time. An additional burden for me was offering extra support to member co-researchers and CERT Researchers who have health, dyslexia, neurodivergence or other needs. Lastly, many member co-researchers travelled a long way to the studio, coming in especially for our sessions, sometimes at their own expense. This created pressure on us to use people's time well.

Remuneration

Payment for participation is an extremely common conundrum for contemporary research – legally, practically, ethically and emotionally (e.g. Co-production Collective 2021). This directly influences who can financially afford to participate, as with insufficient remuneration participants on a low income might be unable to afford the time. Crucially, Gilfoyle (2024) identifies that doctoral students typically do not have the funding to support paying participants for their time – this was my situation. A further problem in the UK is that those claiming unemployment benefits (as people with mental health challenges frequently are) are restricted in both the number of hours they can work and how much they can earn. A participant in Felner (2020)'s research captures a common scenario:

I've done the math. You don't get that much money from this project unless you go to every session; it's basically 20 bucks a week for 15 weeks. That's only a couple hundred dollars. Now you get a PhD, and you're going to earn lots of money off this project. We don't really get anything but a little bit of money. (552)

Felner (2020) described ruminating on this interaction for months, leading them to question whether PAR *'was in fact an exploitive approach masquerading as socially just'* (552).

Various guidance is available, offering a recommendations to researchers about payment (e.g. NIHR (2022); INVOLVE 2018). However, Sangill et al. (2019) observe that *'User-researchers often work unpaid or with a nominal rate of payment, which does not match their use of time and effort'* (799). Ideally, everyone, CERT Researchers and external parties, would be paid equally for time contributed, however, this is dictated by project resources and parity is seldom the case.

In considering a project, CERT budgets for paying CERT Researchers at the University's research assistant rate, but frequently not for external participants (here, member co-researchers). The reason for this is that, often, charity-funded projects simply do not have sufficient resources to enable equal pay: here, not paying participants is a compromise to make possible what is often important evaluation work. My doctoral research is unfunded and therefore I have no budget for paying participants. Too often researchers rely on participants wanting to 'give something back' as motivation for involvement – leading me to reflect on Felner (2020)'s observation about exploitation. Sometimes a token payment is possible. For example, in the arts project we provided lunch and gave the co-researchers £10 vouchers for every half-day contributed; this is well below the minimum wage, but we felt it was better than nothing. There is a danger, however, that small payments may be experienced as insulting and thus be worse than giving nothing.

Since CERT project payments are irregular in frequency and amount, often CERT Researchers choose not to be paid for fear of jeopardising their benefits entitlement. Attempting to address this, CERT offers vouchers, but because of university finance regulations, and concerns that technically it still counts as payment, usually the value of the vouchers is for less than the full amount which would otherwise have been paid. I find this inequality uncomfortable, especially as I am fully remunerated for my time. The unfortunate reality is that typically within a project, some CERT Researchers will be paid while others, and frequently external participants, will not.

Conclusion

Reflecting on the challenges I face as co-ordinator of CERT and as a doctoral researcher using CERT activity as case studies, I am aware that I perform a very significant role in navigating the challenges presented by PR. Some of these factors affect my role as CERT co-ordinator (e.g. choosing which projects CERT takes on, who takes part and how), while others relate to my role as a doctoral student (e.g. considering how the participation itself was conducted). Balancing factors such as budgets, labour demands, ability and interests can be tricky, but it is important to me that CERT Researchers and external participants can engage with projects on their terms. I recognise in my own experiences in the challenges arising from PR for doctoral researchers identified by Southby (2017): power and sharing control; adhering to the standards and procedures of an individualistic academy; inexperience and fear of failure; competing priorities; time and effort, and additionally, remuneration. In my experience, the additional challenges of working in a PR way are worth the additional effort, leading to insights which could not otherwise be realised. As the co-ordinator of CERT and doctoral researcher, I must be mindful of how the decisions

made when navigating PR – both my own and those of others – may influence a project and must be honest and transparent in communicating this.

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