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RESEARCH ARTICLE

Trauma Informed Participatory Research: Reflections on Co-Producing a Research Proposal

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Abstract

This article discusses the development of a co-produced research proposal. The authors reflect on the process of this work and some of the challenges that were experienced by a team who had a mix of lived, clinical and academic experience of the research topic. We highlight the need to embed trauma informed principles into co-produced research and the ways in which doing so can support the development of co-produced work. As such, the article focuses on how we established safety, choice, collaboration, trustworthiness and empowerment during the process of developing the proposal. Within this we offer our reflection on some of the challenges we experienced and our learning from undertaking this work.

Keywords

Co-Production; Participatory Research; Trauma Informed Research; Inclusion; Epistemic Justice

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Introduction

Participatory and co-produced research is gaining popularity with researchers and funders. To undertake research in this way means all interested parties work in partnership to design, deliver and disseminate projects. People who have been affected by the issues the research is exploring often have a unique understanding as a result of their lived experience. They see things in a different way, which gives the researchers a greater insight into how their research will affect the community. In this way they can help ensure that research questions get to the heart of the matter and that the results are relevant to the very people the research affects. However, achieving the goals of co-production within health and social care research has some way to go. As Lambert and Carr (2018, p. 1276) point out, 'It is challenging to resist the systems and influential peers that mandate that "good" mental health research must reflect clinical methodology and medical models, and that any diversification from these approaches inevitably jeopardizes objectivity, therefore impairing research quality and reliability'.

By placing people with lived experience at the centre of the research, the aim is to shift the narratives from those that are imposed upon a marginalised group to those where people are enabled and supported to be heard on their own terms and in their own ways. While the benefits and value of working in a participatory manner have been amply explored within the literature, what is missing is a consideration of some of the challenges that can arise when developing a co-produced research proposal. In particular, there is little published on drawing on the principles of a trauma informed approach to support such participatory work. Others have also commented on the lack of a 'frame of reference' for increasing 'collaboration, inclusion, and emancipation […] in the processes and practice of PR' (Aldridge, 2017, p. 27). This article addresses this gap by providing a reflective account of the experiences of a group of researchers who co-produced a research proposal.

The Research Context

The reflections in this article are situated in the context of a research proposal developed during 2020. The proposal was a response to a tender calling for research exploring autism and personality disorder. The initial idea to respond to the tender came from a member of the team who had personal experience of the topic. Thus, the development of the research proposal was grounded in these experiences, and the final research team that came together was composed of people with lived, and/or clinical and/or academic experience of relevance to the topic (discussed further below). The ethics of the research was of primary concern to us and we worked carefully together to identify and discuss the ethical considerations of the research we were proposing. Despite very positive feedback on our proposal, we were unsuccessful with this bid; however, we intend to apply for another funding opportunity, and we will use what we have learned (presented here) to support further development of the work. After we had finished developing the proposal, we spent time reflecting together on the experience and sharing some of the issues that were raised for us. Whilst each of us understood the principles and values that underlie participatory and trauma informed working, enacting these in practice (and within a very limited timeframe) proved challenging.

As a team, we recognised the likelihood of there being a high prevalence of trauma in the people with whom we wished to engage for the research. We understood how trauma affects people and had a strong commitment to ensuring that our research did not have a negative impact or re-traumatise the people who chose to engage with the work. As such, we embedded the principles of trauma-informed practice within the research design and process and intended to critically reflect on the work and the ethical implications throughout the research process (should we be successful with our bid). It was also important for us to consider how we embedded these principles into our work together as we developed the research proposal.

This article provides a reflection on how we sought to do this and some of the lessons we learned during the process and through the conversations we had afterwards. The principles of trauma informed work are safety, choice, collaboration, trustworthiness and empowerment. In the following sections we explore each of these principles and share reflections from different members of the research team on how we sought to embed them in our work. Making use of this framework enabled us to think carefully about the ethics involved in working together (although formal ethical approval was not required in order to develop the research proposal) and also to think about the ethical aspects of the work we were proposing to undertake.

Whilst we have dealt with each of the principles separately within this article, it is also important to acknowledge that they intersect and that seeking to work within a trauma informed framework means acknowledging the interplay between these key principles (for example, it would be very difficult to ensure safety without employing the other principles). We also discuss the challenges that we faced and make recommendations on how these challenges might be addressed by others who are developing research in a similar way. The article is a collaborative team reflection, and it should be emphasised that much of the insight and reflection came directly from the members of the team, who also brought their own lived experiences to the work.

We begin with an overview of how the team was brought together, before reflecting on the key principles of a trauma informed approach and how these supported the way that we worked together.

The Research Team

In the UK it is a requirement for Higher Education Institutions to involve people with lived experience in social work education. One of the academic members of the team had previously been the lead for this within her department and had therefore developed a range of strong relationships with individuals and organisations. The idea for the research came from a research team member who had been involved in social work education and therefore had an established relationship with this academic (whom she approached with the idea). Through conversation (over the phone and by email), the rest of the team were identified and approached. This meant that, although most of the team knew the academic who had been initially approached, we did not all know each other.

All of us who were involved because of our lived experience had previously been involved in working with social work students. Such work included participation in the design, delivery and evaluation of social work programs. This involvement was supported in a number of ways, including through the provision of training (Lonbay et al. 2020). This meant that we were all used to speaking about aspects of our own experience, although in a very different context. We did not allocate specific roles to each team member, instead agreeing that each of us would contribute towards all aspects of the project in order to ensure that everyone's voice was heard and as a way of avoiding 'othering from within the team' (Michael 2021). The following sections outline how we drew upon the principles of a trauma informed approach to work together and develop the proposal.

Safety

Establishing both physical and emotional safety whilst conducting research in an area that had a tangible personal impact on our lives was essential. As a team, we knew first hand that receiving a diagnostic label could, in itself, be traumatic (Jowett, Karatzias & Albert 2019; Rumball, Happé and Grey 2020). During the research process, we realised that there was a lack of explicit work on staying safe (though of course such work is happening all the time covertly).

For our team, this issue was particularly apparent when we were working to review the current literature. Throughout the project, we had many group conversations about the power imbalance in relation to the roles of researcher and 'participant', and how triggering the language could be. We discussed our dislike of using words like 'patient' or 'participant' to describe people who should be people first and research volunteers second. The language used in academic literature is often medicalised, particularly in regards to autism and personality disorders, and focuses on participants as 'other' (Botha, Hanlon & Williams 2021; Bottema-Beutal et al. 2021). The use of ableist language in research can be particularly dehumanising for marginalised researchers, standing as a constant reminder of our difference. As a group, we felt that current academic literature and service provision was still dominated by the medical field with its core stance of re-scripting and reshaping the voices of service users within the biomedical/illness paradigm.

Russo and Beresford (2015) speak of 'seeking a place for mad people's knowledge in academia'. Our goal was not to reconstruct the experiences of service users, but to represent their voices in a genuine and enlightening way, validating the knowledge of an overlooked and marginalised group. Only in hearing and bringing to light these voices can progress be made in co-production of research in academia, and in narratives, ideologies and service provision. This echoes some of the fundamental principles of knowledge democracy and the central role of the lived experiences of the marginalised (Hall & Tandon 2020). However, in order to engage with the research topic, we were forced to engage with research that was constructed within the paradigm of the medical model. This was a challenge for those of us who had poor experiences with that model. The research remit was clear: autism and personality disorder. However, if you have been labelled with any mental health 'problem', the last thing you want to do is be oppressive to others from whom you seek to learn by continuing to define them by their label. As much as we wanted to focus our work on bringing to life the experiences of people, not labels, we had no choice but to engage with the very thing we were wanting to challenge and that was in itself emotionally difficult. This highlighted for us that, to achieve a sense of safety when working in this way, we needed to acknowledge the impact of engaging with the academic literature. We needed, as a group, to openly explore this and talk about it together in order to create a space of safety where each of us could share any concerns. There was also the wider need for all of us to reflect on the ways in which we write and the language that we use. The knowledge we produce and disseminate is not benign. We need to stop using pathologising language.

Choice and Collaboration

Ensuring that we worked well together and had an equal say in making choices was another important aspect of the work. Again, though, there were challenges in achieving this. Developing a research proposal as a group inevitably presented many decisions that needed to be made. Broadly, these can be divided into two types of decisions: those that related to the group and the way we worked together (for example, the ways in which we collaborated) and decisions about the research project itself.

We first started working together during 2020 while the UK was in lockdown due to the COVID-19 pandemic, which meant that we had to get to know each other using video chat rather than meeting in person. On a practical level, we corresponded via email ahead of each meeting to agree the times, and whilst TEAMS was the university's platform for video chat, we used Zoom to meet as this was expressed as a preference by some members of the group. Zoom meetings were set up by one of the academic team members. Agendas were agreed by email ahead of time (by the same group member), which meant that everyone had an opportunity to add items and shape what was discussed in the meetings. Google Drive was also used to support development of the proposal. All documents that were being used were placed in a shared folder, which every team member was able to access. This meant that we could all view and edit documents and share literature that we found. This also meant that every team member actively contributed to writing the proposal. This again was agreed during meetings where we discussed who would write which sections of the proposal.

Our time was often limited, meaning that we had to work hard to ensure that there was enough space to talk and reflect with each other in the meetings. This was particularly difficult to achieve within the timeframe towards which we were working. We all felt that we worked well together, developing a strong and cohesive sense of identity as a research team. This didn't just 'happen' for us; we worked to develop this trust and a sense of shared power through frequent discussion and getting to know each other, taking time to process what was discussed during meetings, and group reflection. For example, we had open conversations with each other about our personal and professional experiences and our own relationship with the research topic. We spent time reflecting on the process, although in hindsight we should have built in more time to do this during the development of the proposal.

Our reflections helped us to realise that we did not always get things right, and we spent a lot of time working out what we could do to deal with these issues. One example relates to the discussion of the literature above. We had agreed within meetings the different parts of the proposal that we would each contribute to writing. It was only through conversation afterwards that the full impact of engaging with this literature became clear. It would have been helpful to have discussed this earlier in the process as this would have enabled us to better support each other during the writing process.

Another challenge we faced was the differing level of knowledge and experience related to research. It was therefore important to spend time discussing and explaining different approaches so that each member of the group could make choices about the research design. In future, it would be beneficial to build in extra time to do more in-depth work on this so that all members of the group would have a good understanding of research methods and be able to make informed choices about how to develop the design of the proposed research.

For those undertaking co-produced research in the future, we urge you first and foremost to create space where each member of the team can be open and honest with each other and feel comfortable to ask for support. Make sure that you build in extra time to talk and share things with each other, including 'debrief' time at the end of each meeting and at the end of the process for reflection. Take time to pay attention and have conversations about how people work, what they prefer and why they need to access the academic world (including training around research methodology, should this be required). Make sure these are provided. Also, take breaks when they are needed and provide down time (with a point of contact should this be needed) between meetings.

There are further questions that need to be unpicked, including whether additional support should be offered to people involved in the research process. With co-produced and participatory research, a clear pathway is needed to support those involved. This should be tailored for the individual: we need to ask at the start what support might be needed. This support, if required, should continue after the research ends, because the impact of reliving past trauma can last for a long time. If researchers get this wrong, it can cause more emotional and psychological harm. Such support is beneficial for all members of the research team. Researching difficult topics can raise emotions for everyone who is involved. This should be acknowledged and addressed, not ignored. As Holmes (2010, p. 147) stated, 'emotions are core to reflexive processes', and there is widening recognition of this across a range of disciplines (Wilcock & Quaid 2018).

Trustworthiness

As a group, we felt that developing trust in each other and establishing clarity over our roles was crucial. Some of the team expressed concerns initially about their ability to carry out the work as they felt they may not have the 'necessary' skills and knowledge to contribute in a meaningful way. Early conversations therefore included discussion of what the roles in the group were and what each person brought to the team. We discussed, as a group, how each of us brought unique and important skills and knowledge to the team,

and that alongside that each of us also had gaps in certain areas. These conversations helped us to build trust in each other.

The mixed experience within the group meant that some of our earlier conversations were about our confidence and ability to engage in academic work. It is easy to fall into the trap of assuming that the 'academics' can supply the information and knowledge needed for those with lived experience to contribute to research, but the reality is that none of us can hold all of the pieces of the puzzle. The academic members of the team had a stronger understanding of research and the process of developing a funding bid, but what they did not have was the unique understanding of the research area that other members of the team brought. The academics might be at ease with the scholastic dance, but those with lived experience understood implicitly the essence of the subject under investigation. Both ways of knowing had an equal seat at the table. Listening and learning from each member of the team challenged accepted ways of working. Academics are used to picking up and producing proposals and other work within very short timeframes. What is missed through this approach, however, is the time and space to talk, listen and reflect, but what emerges when we do so is powerful.

Empowerment

We wanted to make sure that we worked together in a way that was validating and inclusive of every member of the team. However, in the medical and research fields there were basic issues where we felt discomfort. Those of us who are seen as 'mentally disordered' can be marginalised in both areas; we are 'other'. Practitioners in the healthcare field may see us as unable to think clearly or rationally, or to have legitimate views. Many service users' experiences are that the 'sick role' is still alive (and kicking) within mental health care (Lebow 1982; Mitchel 2013). In academia, access is affected by structural forces that often affect those with mental health issues disproportionately. Yes, the movement for 'Experts by Experience' has been around for some time, but we are still the 'other'; still very much on the margins, and not fully included and involved (Michael 2021). Within any profession there is language and culture that excludes those outside of the group. Our reptilian brains tell us to find our group, our community; we need to belong to survive and so the professionals align with their community and the Experts by Experience with theirs. The exclusive language and jargon of academia and the healthcare field keeps the 'patient' firmly in their group, and prevents the development of meaningful relationships. And there's nothing like prohibitive paywalls restricting access to vast amounts of professional literature to ensure one group has less power than the other.

If some of us have multiple identities, as researcher/service user/practitioner, then we are often placed in an uncomfortable position and are likely to shift between the two groups depending on context. The position of being the enquirer as well as the subject is tricky. It can bring positives to the group process, allowing us to 'walk in two worlds', but it also opens us up to potential claims of bias. Independence is seen as valuable ('don't work *on* a group if you are *in* that group'), making a distinction between the 'researcher' and the 'researched'. The movement of co-production seeks to address such dilemmas, but it is still about groups working *with* each other and not acknowledging that some will be members of two groups or more. Seeing the world in such binary terms has 'caused untold horror and helped to create a rigid epistemology we now assume we cannot evolve' (Aluli-Meyer 2006, p. 267). Until we can see and declare ourselves as the messy complex humans that we all are, we will continue to switch between groups determined by our survival needs at any given time, perpetuating the illusion that any activity can be without bias.

Conclusion

The process of developing a research proposal together proved to be both challenging and rewarding in a number of ways. In this article, we outlined some of the challenges that we experienced and offered some

suggestions for how to overcome these. Most importantly, we feel that fostering a strong sense of belonging in the team and taking the time to reflect and share thoughts and feelings that arose through the process were essential. This includes acknowledging that the language and content of research literature can be triggering and difficult for people to engage with (particularly within certain fields). Openly exploring this, as a group, was therefore important. Participatory research can offer spaces for these conversations to take place and an ongoing platform within which to challenge and change the narrative (from decision making about what to research through to dissemination of research findings).

If we are to promote and continue to work in collaborative ways, then we must ensure that we have the time to do so properly and in a way that allows important ideas and feelings to be explored. There is a push for co-production, but this doesn't consider the impact on people or the complexity of the processes involved. As Fanjoy and Bragg (2019, p. 5) state, 'despite the ideals of democratic participation and shared knowledge production, research projects take place within a real-world context of limited resources, short timelines and unequal power relations, all of which come to play a role in how knowledge is produced, shared and experienced'. This resonates with our experience and we agree with the authors' conclusion that, rather than 'glossing over the complexity', we must openly acknowledge this and discuss the 'differing priorities and positions' that exist within the teams undertaking co-produced research (Fanjoy & Bragg 2019, p. 15). Finding the space to reflect on and share learning from this work is important. Paying attention to the emotional side of being involved in the research process is also important. We need to work together to identify and find ways to challenge unhelpful and marginalising processes and actions. If we do not do this, then we risk doing more harm than good when we get it wrong; not only to ourselves, but also to others.

We all learned a lot from this process, including from the time we spent reflecting on and talking about it afterwards. Those of us who had lived experience of the research area also learned a lot from thinking about our own experiences in relation to the impact they had on our mental health. We enjoyed the mental challenge and the stimulation we received through sharing our own ideas and concepts with the group. In turn, it made the whole experience more positive and constructive. We all felt fully included, not as nameless 'participants', or 'patients', but as equals. This had a very positive impact on our self-confidence and we felt valued and treated as people in our own right, instead of as nameless entities. With this in mind, we hope we can lead by example instead of following the crowd. Genuine participation should incorporate safety, choice, collaboration, trustworthiness and empowerment into its ethos.

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