Chapter 11

Collaborating to Explore the Reproductive Health and Social Care Needs of Women Who Use Drugs: A Doctoral Research Study

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Abstract

Collaborative approaches to research, public involvement, and community engagement (PICE) have become an expectation when undertaking research in public health. An often-forgotten fact is that doctoral studies are essentially research training and career development programmes of work. In addition, little guidance is available to them when conducting research with underserved populations, particularly for those doctoral students, who like me, were at the beginning of their research career. This chapter provides a reflective and reflexive account of the approach to PICE I adopted when researching the sensitive topic of reproductive health and well-being amongst women who use drugs. This chapter explores the challenges of PICE work and also makes suggestions for how best to engage with this sensitive subject and topic area. Throughout the chapter, reflective narratives from Donna Kay bring the work to life and also allow you, the reader, to consider the impact and implications PICE may have for those collaborating with lived experience communities. The chapter

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Public Involvement and Community Engagement in Applied Health and Social Care Research: Critical Perspectives and Innovative Practice, 133–144

doi:10.1108/978-1-83608-678-920251011

concludes with a discussion about the practical considerations and planning needed to undertake PICE in doctoral research studies.

Keywords: Lived experience; community engagement; women; drug use; reproductive health; motherhood

Introduction

This chapter aims to give a detailed account of the approach to PICE and the way in which it shaped my exploration of the reproductive health and social care needs of women who use drugs. Within this chapter, we give a detailed account of the impact PICE had on the lead author's doctoral research, supported by the reflections of a co-author, who at the time was involved in the research as a community activist. This chapter is a sympathetic critical self-appraisal of practice with a focus on the importance of positionality, relationship building, and incorporating the voices of underserved and marginalised populations in research. We provide a context for this chapter by discussing the ways in which women with lived experience of substance use became involved in the research. We use the chapter to illustrate how we utilised the experiences and expertise of these women in a collaborative way to refine and shape the study and co-produce our research. The chapter concludes with reflections on the importance of planning and communication when undertaking community involvement in doctoral research, and if done well, this can be helpful in forging meaningful and lasting relationships between communities and researchers.

PICE in PhD Research

PICE is an important part of contemporary research and is often stipulated as essential in funding bids (McGrane et al., 2023; NIHR, 2024). Evidence of the benefits of PICE in qualitative research has been well documented (Brett et al., 2014; Gilchrist et al., 2022; Gray et al., 2021); however, there are few publications that relate to PICE in doctoral research (Troya et al., 2019). The National Institute for Health and Care Research (NIHR) amongst other national funding bodies (and charities and regulatory bodies, such as Health and Care Professional Council) have led the way in promoting and ensuring PICE work in research and research practice, recommending that it is undertaken 'with' or 'by' members of the public rather than 'to' or 'about' them (NIHR, 2021). This approach advocates for the involvement of underserved groups and the incorporation of their views and perspectives in the design of research projects (NIHR, 2021).

Women who use drugs and other marginalised population groups are sometimes considered 'harder to reach', meaning their voices and experiences are often excluded from research (McGrane et al., 2023). Some researchers report they have difficulty in reaching participants to engage in PICE, and it is largely accepted that this creates difficulties in capturing the insider perspectives

(Islam et al., 2021). Whilst underserved populations may be difficult to engage with because they may be at risk of harm, be disenfranchised, excluded because of their location, or due to digital poverty, they are experts in their own experiences. For this reason, every effort should be made to include and incorporate them in research studies (Ellard-Gray et al., 2015). As discussed in depth by other authors in this collection, some marginalised populations have experienced stigma within the communities they live in, and this may further prevent them from coming forward and participating. They may also be concerned about whether researchers have their best interests and will listen to their perspectives and views (Islam et al., 2021). Previous research has identified that marginalised populations are unlikely to participate in research without referral (Liamputtong, 2019; Padgett, 2017). One potential way to overcome this barrier to engagement is to liaise with gatekeepers (e.g., third sector voluntary organisations who may support them).

> The community I represent in research and support have experienced stigma and shame and they are often not only forgotten, but also silenced. Giving women space to voice their experiences and what is important to them is important for making future changes in practice. We think research is important and to be given a voice, to be listened to and to be heard is important if these experiences are to be incorporated into research and practice. For me as an activist, I want to see changes made in the future in relation to changes for mothers, fathers, working class families and children. As an activist and a mother, I want to reduce the harms and trauma of families as they engage with services and for services to learn (through research) that others do not have to go through the same experiences. (Donna Kay, Community Activist)

One of the key lessons I have learned as a doctoral researcher relates to the importance of nurturing, developing, and maintaining a range of fieldwork relationships with organisations, communities, and individuals that serve and support the community you are researching. This requires serious introspection, skill and ability, however, if done with authenticity, it can lead to a range of fieldwork and research related outcomes. Good quality PICE work offers up the potential to positively affect the quality of research and strengthen the methodological rigour of the results (Brett et al., 2014; Gray et al., 2021; Gilchrist et al., 2022; McGrane et al., 2023; Troya et al., 2019). Incorporating PICE into research has been identified as having a positive impact which enhances the quality and appropriateness of research, an important aspect for early career researchers (Brett et al., 2014). PICE also gives cultural relevance and a broader understanding for the researcher undertaking the study, which is in turn translated into the findings, making them potentially more relevant and more likely to impact and inform policy and practice (Brett et al., 2014; Gray et al., 2021; McGrane et al., 2023). Credibility of findings with stakeholders is important when attempting to influence policy and practice, and PICE allows researchers and its public contributors to identify gaps and plan future collaborative research projects (Brett et al., 2014). This was further demonstrated by Troya et al., whereby her PICE group had informed her PhD research on self-harm in older adults (Troya et al., 2019). The incorporation and prioritisation of PICE are clear, however, this requires researchers to engage in quality PICE, moving beyond what some have referred to as 'tokenistic' PICE (Gray et al., 2021; Gilchrist et al., 2022; Islam et al., 2021). In research 'tokenism' is best understood as a process were research PICE work becomes perfunctory or symbolic to the subject area of community. Researchers can overcome tokenistic PICE by establishing a pre-defined model and involving PICE from inception to dissemination (Gilchrist et al., 2022).

Co-producing Sensitive Research with Women

Reproductive health and the social care-related needs of women who use substances are a sensitive subject area (McGovern et al., 2024). In recent years, there has been a focus on researching the lived experience of people who use drugs in the North East of England (Adams et al., 2022; Alderson et al., 2021; McGovern et al., 2021, 2023; Spencer et al., 2023), however, few studies have focussed only on women's experiences. A 2023 report focussed on 'Dismantling Disadvantage' for women with multiple unmet needs in the North East, including deprivation and poverty, the 'toxic trio of vulnerabilities' (mental health, drug use, and domestic abuse) and child removal, however, the report did not consider women's reproductive health and sexual well-being (Agenda Alliance & Changing Lives, 2023, p. 42). My PhD research, which was conceptualised in 2020, sought to begin to address the gap in knowledge about the reproductive health and social care of women who use drugs in the North East and practitioners who support them.

PICE was central to the design and development of this qualitative study, and I endeavoured to incorporate the expertise of women with lived experience early in the project. At the beginning of my PhD, I actively attended and participated in community and research events relating to women's health. The purpose of this was to increase my visibility within the community and highlight the importance of the research I was undertaking. Being known by others and attending to the more (commonly referred to) mundane aspects of networking, attending events, having and re-having conversations, and turning up are important to early career researchers. After attending many organisational and community events and discussing and presenting my research to a range of audiences, I was introduced to one person who has experience of activism and advocacy for women who have lived experience of substance use. Upon meeting to discuss the research aims and objectives, she helped me to begin to identify community members from her own personal and professional networks who shared our passion and enthusiasm for understanding and improving women's experiences of services. Through discussion, negotiation, and a shared understanding, she then decided to vouch for me within her networks and recommended I approach three other women to consult on the research study.

An Expert Advisory Group (EAG) was formally established in January 2022, with four women from the North East of England who had lived or lived experience of substance use. Aside from all women having experience of substance use, the four women involved in the EAG had many other lived experiences which they drew upon to support and inform the development of this research. These lived experiences included: mental ill health; domestic violence and abuse; sexual abuse; adverse childhood experiences; child removal and involvement with the criminal justice system. All four women involved in the EAG were known to each other through peer support networks and community organisations they accessed in the North East.

The women involved in the EAG had no previous experience of PICE work or research involvement, however, they felt the topic of reproductive health and well-being was important for the communities they represented. Previous research has reported that public involvement in research is more likely if it contains an 'action agenda for reform' which address issues such as empowerment, inequality, oppression, domination, suppression, and alienation which may encourage them to design questions, collect data, analyse information, or reap the rewards of the research (Creswell, 2013). Given their understanding and own lived experiences, the EAG felt this research offered an opportunity to empower other women.

Whilst the process of involvement was interesting and new to the women, it was also important to us that our EAG did not become fatigued by their involvement in our research, and we were flexible in opportunities to contribute to aspects they felt comfortable with and had the time to do so. A group messaging app (WhatsApp) was used to organise meetings on online video conferencing (Zoom). Both platforms were identified by the EAG as the best methods to support our communication throughout our work on the study. We also met in person for coffee mornings to discuss the research in community organisations the women identified as safe spaces. The gendered nature of safety has been explored theoretically and empirically in research (Lewis et al., 2015), and for us, it was about coming together to explore sensitive concerns without fear of judgement. We had discussions regarding the sensitivity of the topics covered in this research, and that it may be triggering for women involved in the EAG. Research with participants in sensitive subject areas and the involvement of people with lived experience can lead to trauma and also compassion fatigue, particularly when they engage with fieldwork elements of research (Steenekamp & Barker, 2024). Therefore, at the open and close of all meetings, I made members aware they could contact me directly if they had any concerns; additionally, I could facilitate onward signposting to access further specialised support. As recommended in published PICE guidance (NIHR, 2021), all of the women involved in PICE in this research were offered remuneration for their time and contribution to the study (NIHR, 2021).

Reciprocal Learning Opportunities in PICE

When incorporating members of the public with lived experience in research, it is important to listen to their views and perspectives and consider suggestions they make to the study. In the early stages of this research, the EAG was key to ensuring the research (including the language used) was accessible and free from stigma (a prerequisite for this collaborative work). Positive group identity was also of importance to them, and our consultation with the EAG led to a very simple, but also very important change (in terms of ownership) to the study being renamed as the ‘Women’s Sexual Wellbeing’ study. We had in-depth discussions about the term reproductive health, and they felt using the initial research title was ‘too academic’ and specifically, they felt the term reproductive health was ‘too clinical’ and would not appeal to potential participants. The individual and group identities of individuals in marginalised communities are important (McGovern et al., 2024), and the EAG also felt that having the study titled ‘Women’s Sexual Wellbeing’ was a way to empower women and increase the likelihood of participation. This also allowed us to illustrate partnership involvement and demonstrated to our PICE group that their perspectives and contributions were ‘heard’ and valued.

> What is important to me as an activist is the way the women have been treated during the whole project. They have been respected and listened to. It’s really helped to build some confidence and there is that cliché saying that “talking in safe spaces, takes the shame away from them”. (Donna Kay, Community Activist)

The EAG supported and challenged the research design and development processes including aspects of the topic guide and the relevance and importance of the questions in relation to the research. The EAG were also key to making fundamental suggestions for improvement throughout, including adding a retrospective question to explore how women’s views may have changed on relationships and family planning due to drug use. They were also interested in incorporating a question relating to children’s social services (based off their own lived experiences). We came together to discuss this between the team and after critical reflection, we decided to see if this topic would come up naturally during interview as opposed to probing the subject with participants. As our research developed, we found that working collaboratively on the development of the topic guide, built rapport between the team and demonstrated that their suggestions were important to the research and also improved the quality of the data collected (Hoddinott et al., 2018). It also highlights the reciprocal learning opportunities PICE afforded to both the researcher and the women with lived experience. As we reflected on at various stages of this chapter, doctoral study is a research training programme that is concerned with both the generation of knowledge and development and training of early career researchers.

During the participant recruitment process, the women in the EAG shared the study across their networks, encouraging participation in the study. They also demonstrated the importance of this research and validated that other women’s views and perspectives were important to capture, to give the research the best opportunity to influence change. The importance of being creative and allowing the women to share the study on their social networks was fundamentally important to the success of the study: this was a clear endorsement of the study and one which was most effective for recruitment. The support of the EAG expedited recruitment, meaning most of the data collection for women was complete within the first four weeks of the fieldwork element of the study.

The EAG was not involved in the coding of data or anonymised transcripts. Other research studies have collaboratively undertaken the task of coding anonymised transcripts; however, given the sensitivity of the topic and that women had supported recruitment across their networks, we felt this may make women identifiable, but also, this may be triggering to members of the EAG. In other chapters in this collection (Adams and Ramsey), you can read about concerns with trauma-informed practice and research, whilst also considering the implications of involving participants in the process or learning and coding in relation to sensitive subjects and data areas. The women involved in our study did collaborate on sense-making of the codes and findings in an online workshop. During the initial workshop, we reviewed and discussed codes and emerging themes. We used these emerging themes to co-design an upcoming presentation, recognising this conference dissemination as another opportunity to review our interpretation of the findings. The final themes workshop took place in July 2023, and during this meeting, we discussed the relevance of the findings to ensure they included a cultural and broader understanding of the reproductive health and social care of women who use drugs (Brett et al., 2014).

Collaborative Dissemination

Throughout this study, it was important for us to involve women in every aspect of the research, and this included the dissemination of the findings. We discussed and planned how the results could be translated to improve policy and practice and how they could best be disseminated to maximise impact. This included considering the ways in which the findings were communicated with lived experience communities and members of the public to ‘bridge the translational barrier’ between academic writing and wider public literature (Melvin et al., 2020, p. 232). The EAG has undertaken a variety of collaborative dissemination opportunities, which have allowed us to share our PICE work and study findings with a wider audience. Collaborative and co-produced dissemination included: blog posts; podcasts, people with lived experience conference, and International Women’s Day (IWD) conference. Events and opportunities like those mentioned above can be fashioned and utilised to raise the profile of marginalised communities and raise the awareness of the needs of these communities to practice partners and policymakers.

On IWD 2023 we organised and co-facilitated a research event which focussed on embracing equity by celebrating resilience and showcasing the lived experiences of women in the North East of England. This event featured research and community involvement from academic institutions, voluntary third sector and community organisations. The overall aim of the IWD 2023 research event was to give an overview of current research exploring women’s health inequalities, how this was experienced, and the current unmet need within the region. Handing over power to research participants and allowing them to shape research design, implementation and then dissemination event can be both tricky and rewarding for them. With trust, good communication and support the EAG took ownership over the conference and focussed on making the conference as accessible as possible, to attract a diverse range of people with an interest in women's health and well-being. This included researchers, stakeholders, policy and practice and people with lived experience. In order to make the conference inclusive for as many to attend as they could, the EAG recommended the timings be considerate of those with caring responsibilities (during school time), that the location was accessible via public transport, that all information about the event be in plain English and free of stigmatising language. We co-facilitated our presentation, which included two members of the EAG reading poetry they had written about our research.

> It's a privilege to be able to work in an area I am interested in and passionate. The whole process has been an empowering, enriching experience. I have learned and enjoyed it all. The opportunities that have come from it. The opportunity from the first initial piece of works, brought other opportunities to work with other researchers. It has built a special relationship with 'Recovering Justice' and has been a big part of the 'Women's Project'. The people I have met (Professor Ruth McGovern and Dr Hayley Alderson), having the Spotify Podcast, going to York University to present our work, International Women's Day 2023. Being involved in other research projects and feeding back on research from a lived experience perspective. I am really looking forward to being involved in future research projects that are on the horizon. (Donna Kay, Community Activist)

Those who attended the IWD event reported it to be a positive experience, which had in excess of 80 attendees who listened, contributed, and supported a range of research projects. From a PICE perspective, the event was an invaluable knowledge exchange event and opportunity to evidence how co-production can be achieved through careful planning and engagement with people with lived experience. For all of the EAG involved in this research, they found the event to be an affirmative way to represent their community in research and reported it to be a valuable experience, which they were proud to be a part of.

Critical Reflections From PICE in PhD Research

As a researcher, whether doctoral, early career, or established, it is important to reflect on the privilege that is afforded to researchers by PICE insights and contributions. Previous guidance on PICE in research has evidenced that the incorporation of the voices of lived experiences can add value to the methods and findings of this research (Hoddinott et al., 2018). In the context of the 'Women's Sexual Wellbeing' study, the EAG's involvement added depth, richness, and rigour to the findings, but this did not come without significant time investment and communication between the EAG and I.

Taking stock of your own practice as a PICE researcher is important and reflecting on your own positionality and values is key for your practice and future learning. We believe the incorporation of the EAG enhanced and improved the study; however, it is important to acknowledge there has been challenges associated with PICE. Although PICE in research has become expected, there is little guidance for how to undertake PICE in PhD research. Incorporating the voices of lived experience individuals in research design and development brings about the responsibility of managing expectations both of the research parameters and of the PICE involvement, which many PhD students may have little experience of. Having a pre-defined plan for PICE involvement may help mitigate some of these challenges, but good quality research requires flexibility from the researcher, to ensure PICE members are not overwhelmed or burdened by participation (Steenkamp & Barker, 2024).

Conclusion

PhD students are often new to the field as researchers, and some may have little or no experience in engaging with the populations they are researching. They may also have no gauge to understand what is expected of them in relation to doctoral study and for this reason, they 'may require expert advice and support on how best to work with vulnerable populations sensitively' (Troya et al., 2019, p. 627). The first author's professional experience of working with vulnerable communities in the context of substance use was useful, but even here, there were barriers that had to be overcome to engage with women on the subject of social care and reproductive health. PICE requires time, planning, and resources in order to build meaningful engagement and rapport. This investment can help build collaborative partnerships with members of the public and those with lived experience. Incorporating the voices of lived experience in PhD research adds value and richness, and overcoming the challenges associated with PICE is achievable and worthwhile. Understanding your subject areas and the experiences of your research population is key to research design and implementation, but also understanding what is important to the communities you serve as a researcher. Taking time and building rapport to connect and understand the priorities, beliefs, and qualities of these communities is also important.

As demonstrated from this PhD research, incorporating PICE requires practical considerations, and it is fundamental that researchers consider these in advance of commencing research (McGrane et al., 2023). PICE work should be celebrated, but it is important to recognise that it can be both rewarding and burdensome for both researchers and, more importantly, for members of the public (Gray et al., 2021). Further reflection should also be given to the needs and capacity of PICE members; the extent of involvement and resources required, which should be undertaken prior to approaching or working collaboratively with lived experience communities (Troya et al., 2019). Discussions about the roles and responsibilities of participation are essential to avoid overburdening PICE members, alongside consideration of their well-being and safety (Gray et al., 2021; Islam et al., 2021). Reimbursement for PICE members should be ring-fenced in funding (if available), and communication about all aspects of involvement, research design, analysis, development of findings, and outcomes should be prioritised in order to ensure PICE members feel included and valued at all times (NIHR, 2024).

Women who have been involved in the EAG have been invited to co-author a publication related to this research and also to co-produce further research supporting their interests in this sector. This is intended to encourage them to exercise their lived experiences and reinforce the importance and value of their voices in future research. One of the most important concerns for newer and more established researchers in relation to PICE is to make sure that their involvement is meaningful and that they maintain good working relationships with the groups they do PICE work with. Essentially speaking, leaving the door open for the person who follows you in social care research is fundamental to the process of building capacity and the creation of new research communities.

> Communication and trust is key to community involvement in research. Speaking to people who are open minded, and non-judgemental has been the pinnacle of it. On one occasion there was a research project were one of the researchers upset a mother and issue was immediately resolved over the telephone. Mothers who I represent have often battled with self-esteem issues because of past experiences, with drugs, self-worth, services and unable to use their voice at specific times. Being able to come to the research team and say I was upset about it. The researchers were able to reflect and consider the concerns and take on board with humbleness and humility – that was an amazing piece of work for us. It helped with confidence because as an advocate I was able to approach them and challenge the perceived power dynamics. (Donna Kay, Community Activist)

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