SPECIAL ISSUE

'Outside the Original Remit': Co-production in UK mental health research, lessons from the field

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ABSTRACT: *The aim of this discursive paper was to explore the development of co-production and service user involvement in UK university-based mental health research and to offer practical recommendations for practitioners co-producing research with service users and survivors, informed by an overview of the key literature on co-production in mental health and from a critical reflection on applied research through the medium of a case study. The paper is co-written by a mental health nurse academic and a service user/survivor researcher academic. The authors argue that the implications of co-production for mental health research remain underexplored, but that both the practitioner and service user/survivor researcher experience and perspective of co-production in research can provide practical reflections to inform developing research practice. The theories and values of emancipatory research can provide a framework from which both practitioners and service users can work together on a research project, in a way that requires reflection on process and power dynamics. The authors conclude that whilst co-produced investigations can offer unique opportunities for advancing emancipatory and applied research in mental health, practitioner researchers need to be more radical in their consideration of power in the research process.*

KEY WORDS: *co-production, mental health nursing research, patient and public participation, research methodology, service user and survivor research.*

INTRODUCTION

Co-production is a relatively recent concept, and in the UK, it is often associated with policy rhetoric in health and social care practice (Carr 2016a; Needham & Carr 2009). The approach is gaining traction in mental health research and practice in Australia and New Zealand, where service user and survivor research academics are playing a leading role in its definition and implementation in the field (Roper *et al.* 2018). However, implications of co-production for mental health research in the UK remain relatively underexplored, particularly as conceptualizations of service user involvement in research in UK are dominated by the agenda of generic 'patient and public involvement' (PPI) (INVOLVE, 2012). PPI does not necessarily promote fundamental examination of equality and the power and control dynamics in mental health research (Beresford 2005; Rose *et al.* 2018) demanded by transformative co-production and emancipatory research (Carr 2016a,b).

This discursive paper is co-written by a mental health nurse academic and educator and a survivor research academic. It explores some of the implications of co-production and power realignment through a collaborative examination of co-production concepts and theories in mental health research and critical

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reflection on a case study which illustrates some ethical and practical challenges of working co-productively in a study from the practitioner researcher perspective.

The respective authorial perspectives have proved invaluable for exploring the practicalities of undertaking co-productive research and for constructing and presenting the ensuing recommendations for co-produced research practice.

The discussion focuses on issues of power and control, both individual and structural, and how the application of co-productive and emancipatory research principles demands that power and control dynamics between those traditionally situated as 'patient' and 'clinician' must be fundamentally addressed in research practice (Carr 2016b).

CONCEPTUALIZING CO-PRODUCTION FOR MENTAL HEALTH

A brief contextual overview on the origins, concept, and principles of co-production is helpful in understanding how the terminology of co-production has become embedded in mental health policy, practice, and latterly, research discourse, and why it has become complex in its applications. Originating in US general public management theory during 1980s to describe the interdependent relationships between citizens and public institutions in resource administration (Ostrom 1996), the meaning of co-production took a more radical turn towards social justice and citizenship when defined by Edgar Cahn in his book 'No More Throwaway People' (Cahn 2000). Cahn's version of co-production was concerned with societal rather than service transformation to 'fundamentally challenge administration and service delivery, locating power and worth with the citizen, rather than using them to improve the 'system' or service delivery and effectiveness' (Carr 2018).

In relation to his own experiences as a patient, Cahn framed co-production as being 'a fight over being declared useless' (Cahn 2000 p. 5) and called for the positioning of service users from 'subordination and dependency to parity' (Cahn 2008 p. 35). A version of the type of co-production Cahn offered was later adopted and defined for English health and social care reform (HM Government, 2007; Stephens *et al.* 2008) as 'a potentially transformative way of thinking about power, resources, partnerships, risks and outcomes, not an off-the-shelf model of service provision or a single magic solution' (Needham & Carr 2009 p. 1), with co-production in the English mental health system being

conceptualized as 'the transformation of power and control' (Slay & Stephens 2013).

In England, implementing co-production has been problematic for mental health services. Needham and Carr (2009) note the vocal concerns from various stakeholders that where co-production does not redistribute power and control, it becomes theatre that can reinforce regimes of control and containment for people with mental health issues, rather than disrupt them. The idea of an individual's defectiveness, or in Cahn's terms, 'uselessness', is especially relevant to people who experience mental distress and mental health service use. It is not just being in the mental health system that implies that people are unable to function, it is because they are often 'dissident, non-conformist and different in their values' (Beresford 2009) in the critiquing of that system, that leads to fundamental tensions in co-production.

An investigation into the readiness of mainstream mental health services in England for 'transformative co-production' highlighted the historical and current practices of control, pathologization, containment, treatment, and detention that have often resulted in dependency or loss of agency for people using those services led the authors to conclude that:

> '...progress[ing] transformative co-production can...be significantly limited by institutional control. This includes restrictions on service users exercising their agency and power and through the maintenance of professional or service power and agency...traditional [legacy] rules and roles can negatively affect the way practitioners can work equally and collaboratively with service users...However, transformative co-production is about dismantling institutions, changing their cultures and practices and rebalancing power. It means disrupting traditional fixed roles and power relations between professionals and service users and should not be solely determined by the institution or organisation'
>
> (Carr 2016a p. 1–2)

Therefore, for mental health, the generic core co-production concepts necessitate thorough attention to what the UN General Assembly Human Rights Council *Report of the Special Rapporteur* called 'power asymmetries' (UNHCR, 2017). If co-production in mental health is a 'transformation of power and control' between service users or patients and practitioners in traditional positions of power in the mental health system, including nurses, it follows then that the same should apply to co-production in mental health research. This implies service users and patients accepting greater power and control, and clinicians or

clinical researchers giving up power and control they have inherited through its historical and structural distribution throughout the system. Very recently, service users, survivors, and allies in UK, Australia, New Zealand, and elsewhere have constructed evidence-based sets of principles and frameworks for co-production which acknowledge and address this fundamental issue for mental health research and practice (Carr & Patel 2016; INVOLVE, 2018; Roper *et al.* 2018).

EMANCIPATORY RESEARCH: SOME IMPLICATIONS FOR CO-PRODUCTION IN MENTAL HEALTH RESEARCH

Co-productive approaches need to involve service users collaborating with practitioner allies to challenge and resist the restrictions of traditional, interpersonal, and structural power dynamics within research (particularly that conducted within academic institutions). Here, service users are not just research participants or advisors, but autonomous producers of research who can have multiple roles (Beresford 2005). Transformative co-production in mental health research both demands and is dependent on a more fundamental paradigm shift in research, knowledge, and knowing towards valuing and legitimizing experiential and first-hand knowledge within the full spectrum of mental health research (Beresford 2003; Tew *et al.* 2006; Beresford 2010; Beresford & Russo 2015; Faulkner 2016; Rose, 2017).

Discussions on co-production in mental health research should be situated within the general debate on politics, power, and control in research ethics and knowledge production, which includes practitioners and clinicians. Even though the experience of research ethics process can be experienced as lengthy, administrative and mechanistic, and categories of 'vulnerability' often questionable, the origins are a reminder that research control and power relationships between the researcher and researched can be harmful and must be reflected upon throughout the process. The Nuremburg Code, the Declaration of Helsinki, and the Belmont Report (WMA, 2013; Zimmerman 1997) exist because of atrocities carried out in the name of scientific and biomedical research on humans, and World Health Organization Declaration of Helsinki of 1964 explicitly frames the power dynamic in biomedical research as being between doctors and human ('patient') research subjects (Carr 2016b).

This historical legacy has present implications for the way co-production can be conceived and undertaken in research. because a residual power and control dynamic between researcher and researched exists which mirrors that between clinician and patient. In terms of conceiving research ethics from a service user and survivor perspective, it again returns to the issue of power and control because 'the more control you have over research, the more chance it will be empowering and you will find you have benefited. If you don't have any control then the more chance you will find it harmful' (Faulker, 2004 p. 3).

Critical co-production exponent Pestoff has argued that co-production is more than service users and citizens being 'invited in' to make existing public services (or research) more efficient and effective, but requires creating separate platforms and power bases where service users and patients can collectively interact and from which they can work (as is the case with survivor research [Rose *et al.* 2018]) (Pestoff 2013). Using an approach such as Pestoff describes, during the 1970s and 1980s disability and survivor movements in England, collectively critiqued the claims of research to neutrality and objectivity that they experienced as political and about reinforcing structural inequality and developed emancipatory research to challenge researcher claims to apoliticism and to gain control over the means of production of the knowledge about them (Beresford 2003; Oliver 1992). In the UK, the disability and survivor movements developed a core epistemological and methodological power base from which disabled, service user and survivor researchers could work and form a shared value-based, theoretical and methodological framework for co-productive research between service users and practitioners. Stone and Priestley (1996) set out six key principles of the emancipatory research paradigm that explicitly name and addresses power and control in the research process and upon which co-productive research practice in mental health can potentially be built:

1. 'the adoption of a social model of disablement as the epistemological basis for research production
2. the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation
3. the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers
4. the evolution of control over research production to ensure full accountability to disabled people and their organizations

5. giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences
6. the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people' (Stone & Priestley 1996 p. 708–709)

Within the emancipatory research paradigm, knowledge production is not an end in itself, but is used for empowerment and change. For mental health research, this means more equal social relations of research production, the empowerment of service users, and the making of broader social and political change. The following critical reflection of a case study illustrates, from a practitioner researcher point of view, the practical challenges of working within an emancipatory and co-productive research framework that demands critical reflection on dynamics of power and control.

CASE STUDY: CRITICAL AND PRACTICAL REFLECTIONS ON POWER AND CO-PRODUCTION FROM A PRACTITIONER RESEARCHER PERSPECTIVE

By way of background, I was discouraged from research when in practice by seeing studies that seemed to be the research equivalent of a data 'smash and grab' where participants were treated with disregard by researchers following their research operational criteria to the point that it made their behaviour unintentionally callous. I was concerned to see this. However, I was also fortunate to see more inclusive practice and understood that there were ways to be a researcher that aligned with my professional and personal values. Before I began the research upon which this case study is based, I attempted to practice in a person-centred and recovery-orientated way. However, I underestimated the personal and professional impact of researching in this way and came to realize that in fact my focus was initially on undertaking research that would be acceptable to my academic peers, to professional journals and doctoral assessors. The type of research I wanted to undertake necessitated a different set of standards and priorities.

From a practitioner research perspective, the first issue you meet in co-production in relation to power is the 'myth of the disinterested researcher'. It is challenging to resist systems and influential peers that mandate that 'good' mental health research must reflect clinical methodology or medical models, and that any diversion from these approaches inevitably jeopardizes objectivity, therefore impairing research quality and reliability. I believe that research has validity when there is a clear articulation of rationale and a transparent account of your positionality. This in turn, empowers the reader to judge the study's reliability for themselves. My nursing and teaching are influenced by thinkers like Freire (2007), so research practice that shares power and promotes social justice seems logical to me. My positional and ethical stance informs all my work and my research is an extension of it, not a separate issue.

As discussed, best practice in co-produced research remains contested, with a significant theory practice, with a significant theory-practice gap forming. Critical reflection is used here as a tool to consolidate new understandings (Helyer 2015).

The research project itself, 'An Exploration of the Experience of Women with Physical and Mental Health Needs', is not the focus of this reflection, rather it is the critical consideration of the experience of using co-produced methodologies which generated an awareness and an active response to the complex issues encountered (Taylor 2017).

The data itself were elicited using reflective development tool designed by Helyer and Kay (2015) to intentionally re-conceptualize practice, and thematic analysis was used in conjunction with critical discussion to generate the themes noted below in Figure 1.

FIG. 1: *Thematic analysis.*

Emancipatory research principles informed this project and the ethical responsibilities inherent in its aims indicated a need for a co-produced design from the outset (Stone & Priestley 1996). More specifically, I wanted firstly to employ a properly resourced collaborative advisory panel of women who were experts by experience to partner in scoping the topic, determining the research questions and focusing the investigation. The group would help me to design interview schedules, look at documents, etc. to ensure that the research was accessible and encouraged participation. They were also to act as an advisory group in the case of any ethical concerns.

However, it became apparent that traditional research frameworks were ill-fitted to the real-world requirements of transforming power and control needed for co-productive practice. A common barrier to co-researching with people mental health issues is the low expectations by professionals. Many wrongly assume that all women with mental health issues would be in hospital and unable to consent or usefully contribute to research or collaborate with a practitioner researcher. I was further stymied by an initial lack of resources to work in this way. When I did secure funding to pay my co-researchers, the process was complicated and disadvantaged some women who wanted to contribute but who could not do so without jeopardizing their welfare benefits.

Research ethics and design

A shared, iterative approach to research design can cause operational difficulties within predetermined biomedical research frameworks. For example, ethical approval is needed for a process to manage safety rather than for a set research itinerary. Until an advisory group meets, questions cannot be generated or research documentation completed. It is challenging to get funding for what can appear to be a speculative project where the outcomes are undetermined.

These systemic issues can prevent work being undertaken and best practice would be to reshape the ethics process so it is fit to review co-produced projects. Issues like this may be surmounted by approximating the expected scope of the research and submitting it with the proviso that an advisory group will rework the submission once details are decided. If both parties agree to this the advisory group can gain provisional ethical clearance to undertake their work and afterwards, a final iteration can be resubmitted back to the ethics committee. This two stage process

takes time and needs to be understood by all parties. Interestingly, this process, which resulted in comprehensive discussion at the start of the project, produced detailed documentation that did not require any changes on resubmission.

Initially, advice was given to concentrate on a more empirical question and select a recognizable target population like 'women with cancer and depression' or 'schizophrenia and diabetes'. However, there is little evidence to suggest that any specific combination of physical and mental health issues would be any more relevant to explore than any other for the women concerned. As soon as the process of co-production started, women spoke about the impact of wider social, economic, and political issues as well as individual health-based ones. This complexity echoes reality in a way that predetermined questions cannot and whilst complexity is another challenge inherent to co-production, developing a methodology to address complexity can be better placed to investigate to 'wicked problems' (Churchman West 1967). As a result, the research scope was extended and the study conducted with the recognition that processes and methodologies need to be flexible.

The project aim was to explore the experience of women with multiple needs. The logical approach was to ask them and be guided in this process by them. However, getting ethical clearance to approach people who self-identified as willing to contribute on this topic was problematic. Traditionally, services have acted as gatekeepers to research participants who may be vulnerable. In this case though, contact with service user groups and the use of social media contacts meant not only that the research process was formally devised by women with complex needs but also that by being 'in their world', people who wanted to address this issue found the study by themselves informally and requested to participate. This change from research recruitment to managing participation can require thoughtfulness on the part of the research team on how to support people who may experience vulnerability. It involves working creatively to support engagement at different levels and in phases, by interested parties, rather than working to 'screen' people out of participation.

Research process

The process of the research itself challenged me throughout. I visited the women's groups to discuss the research and ask whether they were interested in

collaborating, leaving information about the context and purpose of the research, and potential co-productive research processes. Once a consensus was established about what we wanted to know, I acted as a consultant to the participants to suggest ways that we could collect that information.

This communal and collaborative approach challenged conventional expectations of the focus group data collection process. It is unusual for a focus group to be larger than eight participants, a number regarded as optimum for the data collection method. However, one of the women's groups decided they would all come, and some would just watch, bringing the total number to 17. I arrived early to find my focus group already seated in anticipation with a ring of excited spectators. I was aware that I was in their space and intruding on their time; I was also very aware that I had asked people to help and they had responded with genuine enthusiasm. I managed the situation by explaining again and asking for their help in resolving my concern of being overwhelmed by numbers and a system of turn-taking whilst talking was quickly devised, and I printed more consent forms.

Another challenge to researcher control came when I asked a question in another group which the participants did not know how to answer. To my surprise, someone produced their mobile phone and called an absent group member who had the information needed to answer the question. Five minutes later that woman arrived at the group, ready to help. Again, I had not expected to need a management protocol for an incident of this kind, but I had a set of baseline collaborative principles we were working to. I had asked for help to understand an issue, and it had been creatively and unstintingly supplied by a member of the group. I paused the group to ensure that the new participant understood the situation, and with group member agreement, she signed a consent form and contributed her specialist knowledge. I am aware that some of my academic peers will feel that data gathered in this way are 'corrupted' because the systematic collection process had been disrupted. However, I feel that if you ask people to collaborate in a structured information gathering exercise and they endeavour to own that process, you cannot then recoil and assert control when they collaborate on their own terms. There is a lot written about so-called 'hard-to-reach' populations, but perhaps it is researchers who sometimes create the distance.

In half of the focus groups, multiple languages were spoken. I asked the group members how they wanted me to manage interpreters joining us. They came up with their own solution, advising that they would interpret as a group as we proceeded, so that a collective understanding could be established. I was concerned that individual difference would be edited out in the process, but we discussed this and planned how to address this should it occur.

As the focus groups understood more about research processes, it stopped being a question of me extracting data from them and then deciding its relevance. There was a shift to deep discussion with focus group members around gathering the data and making sense of it 'in action', as a shared process. We gradually moved as a group from the position of having little understanding of what research could achieve, (illustrated by a comment where one woman explaining to another stated 'if you tell her what the matter is – she will tell the government and it will be fixed'), to a point where the focus group members checked their data and explored and commented on the results across the different groups. They collaborated in disseminating the findings to be scrutinized by other women in a range of communities; from women's events to health conferences, and they have continued to speak up about research and use their knowledge as health activists for their communities. From my perspective, I had the data that would answer my question, but when I checked with the group of self-selected representatives from the focus groups, they wanted to know whether the experiences we were discussing were particular to their locality or whether they were more widespread. They shaped what became an online survey disseminated via social media asking questions to explore whether other women had similar experiences and were emphatic about the importance of a wider group of women participating in the research.

Outcomes

At least 70 women so far have directly participated in and shaped this collaborative research project. Whilst my learning is described here, the women who co-produced the research said that they learned about and from each other, about research processes and participating in a study. Representatives from the focus groups and the advisory group have member checked the data and collaborated on both the findings as well as the process. All the women who joined in the process from the advisory panel to the focus groups, member checkers, the women visiting the women's community centre who commented on the findings on

the notice boards, and those who participated online showed a clear expertize on a wide range of experiences of physical and mental health issues were eager to work together and had read the preliminary paperwork, and prepared their contributions. They raised many key issues that the literature review had not identified. Most importantly, they determined and confirmed that this topic was of interest to them and an issue of practical concern.

After we had talked about the expectations of the research and the processes, I expected the expert by experience co-producers to think like I did as a practitioner researcher. However, they had many pertinent questions about the suitability of the established research process and were extremely direct in dismissing research conventions that the felt had no relevance to co-production. Initially, I thought that co-production would give my research a form of legitimacy and credibility, and expected to come out with my planned output complete. But because of the demands and outcomes of co-productive processes employed, this did not happen, but I have come out with a far better understanding of the research topic. As a result I gained a completely altered perspective on the workings of conventional health research approaches for co-production and some very practical suggestions to improve the study as well as my research practice.

CONCLUSION AND RECOMMENDATIONS

As the critical reflection in this paper demonstrates, in co-productive research, nonservice user and survivor academic and practitioner researchers need to recognize that power and control are inherent in the research process and that it is all our responsibilities to manage it ethically. Working co-productively can be easier for practitioner researchers already using similar approaches in other areas of practice. The ensuing recommendations for co-produced research practice, partially presented using themes from the emancipatory research framework, have been co-constructed based on our respective perspectives as mental health nurse academic and service user/survivor researcher academic in response to the collaborative examination of co-production concepts and theories in mental health research and critical reflection on the case study.

Study purpose

Working in a person-centred and recovery-orientated way as a mental health nurse and educator is an expectation; however, it is still unusual for research to be explicitly framed in this way. There are tacit assumptions around what research is for and what it should look like and a pressure to perform research that is acceptable to academic peers, professional journals, and doctoral assessors. Co-production can necessitate a different set of standards and priorities, and it is key to be clear about the purpose of the research in the initial stages as it is easy to find projects becoming diluted.

Barriers to co-production

Research processes are unlikely to be prepared to support co-production research studies so expect resistance. Ethics committees may be unversed in considering best practice in this area – providing a rationale for this approach is important and best practice guidance such as the 4Pi National Involvement Standards (NSUN, 2015) which was developed and produced by a collaborative group of mental health service users and survivors provides helpful guidance.

A common barrier to co-researching with people mental health issues is the low expectations by professionals. Many wrongly assume that people with lived experience of mental distress and/or service user are a homogenous group or that they are in hospital settings and unable to consent to or get involved with research. This may come from a lack of nuance when considering vulnerability in terms of research participants or a lack of knowledge about the experience of mental health issues. Vulnerability can be situational and is a state which can fluctuate for everyone and one way to address the inherent power imbalance in research is to engage with co-production – work by Bashir (2017) offers a useful consideration of this issue.

In addition to finding the resources to work co-productively, the process of paying co-researchers can also prove complicated and it may disadvantage people wishing to contribute, but current UK welfare rules mean that those in receipt of welfare benefits are unable to receive payment, and sometimes even expenses, without jeopardizing their benefit payments. The advice in regard to paying people in receiving benefits frequently changes.

Challenging objectivity

One reason to work co-productively may be to avoid the theatre of objectivity being used to suggest greater scientific credibility to legitimize work that could

unnecessarily harm dignity and well-being. It is challenging to resist systems and influential peers that mandate that 'good' mental health research must reflect clinical methodology or medical models, and that any diversion from these approaches inevitably jeopardizes objectivity, therefore impairing research quality and reliability. However, different types of research are required to answer different questions, and research has validity when there is a clear articulation of rationale and a transparent account of positionality. This in turn, empowers the reader to judge the study's reliability for themselves.

Power and control

People working co-productively have described the difficulty of giving up power, but working collaboratively can allow the research to be conceptualized as a shared project. When control and power can flow back and forth, with each party contributing understandings and expertize in a reciprocal research relationship richer data can be produced.

Moments of crisis

A mentor can be useful, as at times the researcher will find themselves in uncharted territory seeing familiar aspects of the research process from a new perspective. The researcher will need to decide which aspects of the research are vital to maintaining its academic integrity, and what can be approached flexibly to support engagement. Understanding how other researchers have made these decisions is helpful, as is seeing co-researchers as a resource to draw on instead of an obstacle.

Researchers from both practitioner and service user/survivor backgrounds need to know the rules of research to know which ones are 'bendable' and which are 'unbreakable'. One fundamental set of unbreakable rules concerns the ethical conduct of research as a continual, collective, and iterative process, as outlined in emancipatory research principles (Stone & Priestley 1996) and service user and survivor research ethical concepts of control and harm (Faulkner 2004). Rather than research ethics being an initial procedural 'hurdle', for co-production, ongoing dialogue and mutual reflection on power and control are required. Mental health research is rarely a clean and controlled process, and is shaped by historical context, structural power distribution, and present legacy power dynamics between 'patient' and 'clinician'. This can potentially be addressed in co-productive research projects between mental health nursing practitioner researchers and service user and survivor researchers, by working to a framework of emancipatory research principles and agreeing on shared set of applied ethical values, which can enable all parties to engage in continual reflection about power and control in the collaborative research endeavour.

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