Discursive Paper

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

Abstract

The aim of this discursive paper is to explore the development of co-production and service user involvement in UK university-based mental health research and to offer practice recommendations informed by an overview 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 under-explored, 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.

Keywords

Co-production; Research methodology; Service user and survivor research; Mental health nursing research; Patient and public participation.

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 ([redacted]). 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 conceptualisations 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) demanded by transformative co-production and emancipatory research ([redacted]).

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 a case study illustrating some challenges of working co-productively in a study from the practitioner researcher perspective. The practitioner-led applied research case study is used to highlight some ethical and practical aspects of implementing co-production and power realignment with service users from marginalised groups in research practice.

The respective authorial perspectives have proved invaluable for exploring the practicalities of undertaking co-productive research and for constructing the recommendations for 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 ([redacted]).

The illustrative case study provides an example of how one of the authors experienced ceding power and control as a practitioner researcher working with diverse groups of women with mental and physical health issues in a study about health inequalities. She describes the process of challenge and disruption to the traditionally powerful role of the researcher; the boundaries of conventional focus group data collection methods; and explores the role of the practitioner researcher as supportive, equal collaborator. The critical reflection yields practical lessons on the importance 'letting go' of power and control as a mental health nurse practitioner researcher, and what co-production could mean for ethics and practice in mental health nursing research more widely.

Conceptualising 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 1980's 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' ([redacted]).

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 (Stephens et al, 2008; HM Government, 2007) 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' ([redacted]), 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, [redacted] 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', has been especially influential in responding to people who experience mental distress. 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), and then critique 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 their historical and current practices of control, pathologisation, containment, treatment and detention that have often resulted in dependency or loss of agency for people using their services. The authors concluded:

> '…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' ([redacted])

Therefore, for mental health, the generic core co-production concepts relate 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. The case example from the perspective of a mental health nurse researcher gives a very practical illustration of this dynamic.

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 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 Organisation Declaration of Helsinki of 1964 explicitly frames the power dynamic in biomedical research as being between doctors and human ('patient') research subjects ([redacted]).

This historical legacy has present implications for the way co-production can be conceived and undertaken in research because of a residual power and control dynamic between researcher and researched that 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 1970’s and 1980’s 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). They developed a core epistemological and methodological power base from which disabled, service user and survivor researchers work, and can form a shared value-based, theoretical and methodological framework for co-productive research between service users and practitioners in mental health. 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 illustrates from a practitioner researcher point of view the practical challenges of working within and emancipatory and co-productive research framework that demands critical

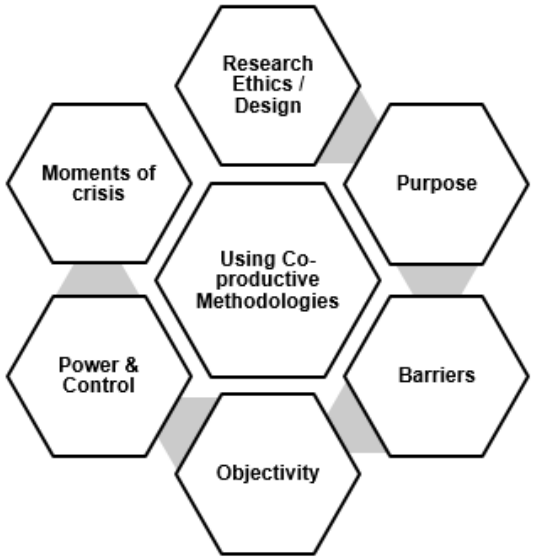
reflection on dynamics of power and control, and promote action to address these.

Case Study: Critical and practical reflections on power and co-production from a practitioner researcher perspective

As discussed, best practice in co-produced research remains contested, with a significant theory-practice gap forming and critical reflection is used here as a tool to consolidate new understandings (Helyer, 2015). This practitioner researcher reflection, shaped by Mesirow's 1997 work on transformative learning, aims to consolidate applied and academic approaches and clarify some of the processes.

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

Figure 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). 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. This critical reflection identifies some of the key issues and potential solutions linked to the theme of power and control redistribution.

Research ethics and design

A shared, iterative approach to research design can cause operational difficulties within pre-determined 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. However 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 to 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 was that did not require any changes on resubmission.

Initially advice was given to concentrate on a more empirical question and select a recognisable 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 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 it is another challenge inherent to coproduction, it is a methodology better placed to respond to ‘wicked problems’ (Churchman and West, 1967).

The project aim was to explore the experience of women with multiple needs, but 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 meant that people who wanted to address this issue found the study by themselves 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. The advisory group were essential in terms of ethics, which was an iterative process rather than a fixed stage. In a conventional study clearance is granted and activity proceeds within it, in a study where researchers share control the expectations can change. In this case it is important to have shared understandings around ethical principles and framework and to work from a strengths-based approach. To work creatively to support engagement at different levels and in phases, by interested parties, rather than working to 'screen' people out of participation.

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 provide 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 are a homogenous group and that they are in hospital settings and unable to consent or usefully contribute to 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 jeopardising their benefit payments. The advice in regards to paying people in receiving benefits frequently changes.

Practitioner researcher practice lessons for implementing an emancipatory research framework for co-production

Challenging objectivity

One reason to work co-productively may be to avoid the theatre of objectivity being used to suggest greater scientific credibility to legitimise work that could unnecessarily harm dignity and wellbeing. 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 jeopardises 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 conceptualised as a shared project. When control and power can flow back and forth, with each party contributing understandings and expertise 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.

What has been learned

At least 70 women so far have directly participated in and shaped this collaborative research project. While 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 expertise 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. This did not happen, but I have come out with a far better understanding of the research topic, a completely altered perspective on the workings of conventional health research approaches for co-production and very practical suggestions to improve the work as well as my research practice.

Conclusions

As the critical reflection in this paper demonstrates, in co-productive research non-service user and survivor academic and practitioner researchers need to recognise 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.

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 concern the ethical conduct of research as a continual, collective and iterative process, as outlined in emancipatory research principles 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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