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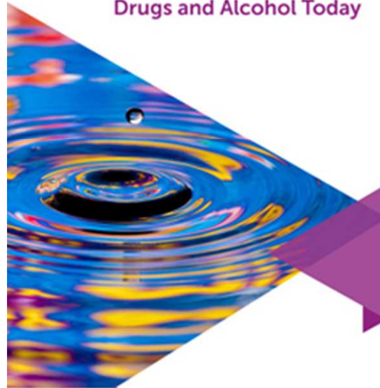

Co-production in substance use research

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Editorial

Co-production in substance use research

Jo Cairns and James Nicholls

Typically, social science research is concerned with generating robust and replicable evidence, using methods that assume researchers maintain critical distance from the subject matter. As such, social enquiry aspires to the principles of dispassionate observation at the heart of the scientific method. By contrast, critical social science has long argued for recognition of the limitations of research objectivity; pointing out that social science research is always situated in social contexts and interpreted through the lens of personal or ideological positions. Similarly, in recent decades health research has moved from a 'top-down' model of knowledge generation to an approach that places an increasing focus on the critical value of public and patient *experience* in developing interventions and treatments.[1] This reflects the understanding that where a treatment is the intended outcome of research, it is critical that those to whom the treatment is targeted be consulted – both for practical and ethical reasons. Not only do patients have the right to be part of research aimed at their wellbeing, but there is the increasing recognition that patient involvement brings insights and experiences that make it more likely interventions will have the intended effect.

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Writers such as Beresford (2003) argue that there is also an epistemological component: that while objectivity and dispassion are one route to truth, when it comes to research involving people 'the greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted' (p.22). In other words, there are spheres of activity in which truth – at the very least, the pragmatic 'truth' of *what works in practice* – is not arrived at through conventional hierarchies of evidence, but through direct engagement with complex, lived experience. Clearly, this holds for many areas of substance-use research: experiential knowledge of substance-related harm provides essential insights into what might be needed to aid treatment and recovery.

Since the 1970s there has been a gradual epistemological shift in health research more generally. We have seen an emerging paradigm from 'top down' to 'bottom up' research involving patients and service users in the context of mental health and social work to improve the quality, efficacy and relevancy of research (Trivedi & Wykes, 2002; Beresford, 2013). One key influence on to this was the emancipatory disability movement of the late 1960s, which went on to play a significant role in redefining disability services and research. The disability rights movement sought to tackle the unrecognized marginalization that can occur when decisions were made on behalf of the intended subjects of interventions, without seeking their perspective on those actions. This, like many critiques of established knowledge hierarchies, was associated with a wider social critique of power, being directed towards 'the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs' (Oliver, 1992, p.110). Research, which (whether intentionally or otherwise) was experienced as exclusionary, disempowering and potentially damaging was,

[1] There is no consistent terminology used to describe people with lived experience. 'Experts by experience' is our preferred terminology which recognises the value of experiential knowledge.

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thus, viewed as a form of social control rather than curative practice. Supporting this position, and making explicit the post-Marxist perspective that underpins some of the more radical approaches, Oliver (1997) not only calls for academic researchers to ask *who* benefits from research, and to 'examine our own research practice', but to do so 'in the context of current oppressive and material relations of research production' (unpaginated).

The call for greater public involvement need not, however, imply a radical critique of medical research as an 'oppressive' practice. It can equally be based in the more modest recognition that research 'beneficiaries', for entirely pragmatic reasons, should have input into research. Indeed, it can arise from a distinctly different political model in which patient involvement is understood as a *consumer* right. For instance, the National Institute for Health Research (NIHR) made it a requirement for public involvement in health research following the introduction of a national advisory group, Consumers in NHS Research (now INVOLVE), which was set up in 1996 (under a Conservative administration) to support greater public involvement in NHS, public health and social care research. What began as a novel attempt to bring patients in from the margins, sits, increasingly, at the heart of medical research principles. The Department of Health's Research Governance Framework (2001, p11), for instance, stipulates that where possible participants (or their representatives) should be involved 'in the design, conduct, analysis and reporting of research'.

New Labour's reforms to the National Health Service sought to increase the role of citizens in healthcare services, particularly through the Local Government and Public Involvement in Health Act (2007) and the Health and Social Care Act (2008), which sought to better democratise health service provision and increase accountability in the expenditure of taxpayer's money. While, in many respects, a key development in the improvement of public involvement, the New Labour approach has not been without its challenges. In particular, critics draw attention to the difference between 'choice versus voice' (Greener, 2008). Vincent-Jones et al. (2009), for instance, argue that New Labour's framing of patient and public involvement shifted in focus from an earlier concern about the lack of citizen voice in healthcare to 'a more exclusive focus on consumer choice' in which the collective voice and citizen involvement is 'relegated to a secondary role' (p.249). It is striking, in all this, that the principle of public and patient involvement is not, despite the fact it is often framed as part of a wider political project, by necessity tied to a particular, or narrow, political analysis.

The rise of public involvement was driven by political and ethical considerations, but aslo by the demand for accountability in publicly-funded research. In this regard, accountability means researchers demonstrating that their work does not solely operate in an ivory tower, divorced from the needs and perspectives of the 'public' who, depending on one's perspective, maybe patients, the taxpayer or both. The emergence of patient and public involvement as key to medical research funding requirements is a testament to how firmly this principle has been established, and it has extended beyond medicine into the fields of social work and mental health particularly.

Despite all this, substance use research has yet to fully embrace service user involvement let alone co-production. To this end, this special issue entitled 'Co-production in substance use research' makes the case for not only greater involvement of service users, or experts by

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experience, in substance use research but also a wider exploration, and reflection on the implications, of co-production in the research process.

Definitions

The terms ‘public involvement’ and ‘co-production’ overlap, but are qualitatively distinct. NIHR INVOLVE defines helpfully public involvement as ‘research being carried out ‘with or ‘by’ members of the public rather than ‘to, ‘about’ or ‘for’ them’. The ‘public’ may include people with lived experience, patients (or potential patients), people who use health and social care services, carers, organizations who represent people who use services, advocates, the general public and so forth. Who is involved will largely depend on the type of research being conducted.

Typically, ‘involvement’ may be conceived as ‘consultation’, but Needham (2008) argues that the distinction between consultation and co-production is an important one. Consultation can reassert traditional roles and divisions in research whereas co-production involves a more radical approach to dialogue, interaction and negotiation. Through seeking, as far as possible, *equal partnership* throughout the entire research process, co-production aims to empower those who may otherwise be disempowered by research, even where they are the intended beneficiaries. Our working definition of co-production in research is:

> *Where possible, working in equal partnership with stakeholders with respect to designing, delivering and communicating research. Approaching research as a collaborative effort which draws on the strengths of everyone involved. Recognizing that the knowledge held by all parties is valuable and carries equal, though different, potential.*

In the case of substance-use research language can be fraught, and it is always imperfect. Terms such as ‘patient’ can be far too narrow, and in many regards far too medicalized. The ‘public’ may cast the net too wide. ‘Service users’ is commonly applied within the field but limits the definition to individuals in direct access with services, which doesn’t even cover most people with dependency, never mind the wider body of people who may be negatively impacted by substance use. Perhaps most helpful is the term ‘expert by experience’, which can be defined as anyone with lived experience of substance use. This experience may be direct or indirect and may include, but not be limited to, people with personal experience of substance use, a relative, friend or those that may have cared for people with personal experience, health professionals that have worked with those with personal experience.

Principles of equality, cooperation and participation are essential for the meaningful involvement of experts by experience. Equality entails mutual respect: valuing everyone’s experience, and, as it were, assuming the person you are talking to knows something you don’t. Co-operation is about working ‘with’ rather than ‘on’ people and making sure there is meaningful collaboration between participants. Participation means everyone being active participants in, rather than passive subjects of, research (Lowes and Hulatt, 2005).

Co-production in substance use research is an emerging field. As such is it characterized by exploration, innovation and (inevitably) a degree of trial and error. Relatively little has been

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published, and relatively few research projects in the field can claim to embody principles of co-production. This is a challenge for researchers, funders and peer reviewers: how can the exploratory, and essentially unpredictable, methods of co-production align with the principles and practices of mainstream research? How should grant applications be designed, when research development may itself be part of a co-production project? How should findings be communicated, when publication in often narrowly focused, and highly academic, journals is a key measure of research success? (We are aware of the irony of asking this question in this context…). How should reviewers judge co-production, whether in funding applications or outputs, when the criteria of success may be far less tangible than conventional research design?

This special issue highlights recent examples of co-produced substance use research. In doing so, it reflects not only on the opportunities this approach presents, but also the practical and ethical challenges that it raises. This special issue emerged from a series of UK-wide workshops, facilitated by Alcohol Research UK, that brought together researchers, funders, service providers, charities and people with lived experience of alcohol harms to explore the challenges and opportunities of better public involvement in substance use research: a programme of activities that culminated in a national conference, which attracted over two hundred attendees and showcased a diverse range of projects. Conference participants were invited to submit papers to this issue. The six papers included here give a flavor of the range of approaches being taken by research teams in the UK today; they set out some of the processes involved in co-productive research, and some of the unique challenges posed by these approaches when applied to substance use.

Wilkinson and colleagues explore insights from research 'co-created' with 15-24 year-olds in Manchester. While all participants played a role, the authors acknowledge that their project only took co-production so far: that it was characterized by 'pockets of co-production', in the wider context of more conventional project leadership in regard to establishing aims and objectives, data analysis, and write-up. Likewise, Clark and Laing find that co-production has practical limitations, arguing that 'it is not always appropriate to involve *all* young people in *all* aspects of research at *all* times'. Working with young people aged 13-18 to evaluate an alcohol misuse change programme, the authors aimed to create a project that was youth-led and fundamentally participatory. However, while full co-production was not the result, their methods helped develop an ethos of discovery, rather than deficit (in which young people are viewed as a 'problem', 'risk' or 'in need' of an intervention) which proved especially helpful when working with this group.

Mai-Brady and colleagues present a randomized controlled trial carried out in collaboration with young people. They illustrate the role that co-production can play in research designs not conventionally associated with co-production. For them, the experience meant being more flexible in response to young people's personal circumstances, particularly when those young people are 'less frequently heard', and especially when dealing with the known problems in recruiting young people with experience of substance use to research projects.

Edwards and colleagues discuss a pilot study not specifically focused on examining co-production within substance use research; rather, it was about identifying and tapping into

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community resources for those early in their recovery journeys. Perhaps understandably, when faced with a novel approach of this kind, NHS professionals struggled with the project dynamics and reported a lack of clarity, feeling frustrated with the 'wooliness' of the co-production approach. As the authors observe, in this instance co-production was 'less of a method and more of a way of breaking down barriers': which starkly highlights the kind of conceptual challenges, and questions of definition and purpose, that need to be addressed if we intend to move towards a culture of greater co-production in this field.

Clayson and colleagues reflect on the *Recovery Voice in Action* project, conducted over a three-year period. Again, they address the 'rub', as they describe it: the practical, conceptual and methodological problem of 'managing the conflicting demands of empirical research with effective co-production methodologies'.

Of course, this is not a zero-sum game. Exploring co-production does not, by itself, imply that more conventional methods should be abandoned. Indeed, as we suggest in the recent report *Public Involvement in Alcohol Research*, public involvement is about *triangulating* knowledge – not replacing one body of knowledge, or source of expertise, with another (Alcohol Research UK, 2017). To use the (imperfect) analogy of aircraft design: passengers may have little to contribute in regard to the precise engineering used in the design of fuselage components, but they will probably have the best insights as to what those components should *do*. Clayson and colleagues, as with many others in this volume, grapple with this problem; however, in approaching it through the lens of power – in asking not only how conventional methods produce outputs, but how they materialize power – they conclude that sustained application of co-production principles should, in their view, lead to change across the board.

The final paper in the issue, by Livingston and Perkins, reflects on their involvement in participatory action research and with 'privileged access interviewers'. Again, they not only consider the challenges around research design, funding and development, but also the political implications of the move towards fully active peer participation in research. As they point out, this kind of engagement is – at face value – simply 'the right thing to do': who, in seeking to use research to develop better interventions, *wouldn't* want to work as closely as possible with those to whom those interventions are directed? However, they also correctly note that such a move, if profoundly adopted, poses a threat to an array of interests: both the positions of research authority on which careers can depend, but also the systems of legitimation and control which, intentionally or not, shore up the structures of university funding.

Again, we should not simply assume that those pre-existing structures and roles are at fault – or that they 'must fall', to echo other recent social justice movements. Rather, careful reflection is needed to work out how the radical perspectives on knowledge, expertise and research practice set out in the projects described here should sit alongside, and inevitably sometimes against, the approaches to knowledge generation that are more familiar to people in the drug and alcohol field.

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This collection is a contribution to that process. It does not claim to present conclusive answers, nor does it establish first principles. Rather it presents a series of reflections on experiments in co-production, each of which invites us to reflect on our own assumptions, and our own positions, in the shared project of using research to better address the problems that substance use can pose.

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