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Co-production in substance use research

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.

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 and Wykes, 2002; Beresford, 2013). One key influence on 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 unrecognised marginalisation that occurred 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, 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 on 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 (2001, p. 11) Research Governance Framework, 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 vs 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 also 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, may be 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 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 helpfully defines 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, organisations 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 medicalised. The “public” may cast the net too wide. “Service users” is commonly applied within the field but limits the definition to individuals in direct whom access services, which does not 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 and health professionals that have worked with those with personal experience.

Principles of equality, co-operation 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 do not. Co-operation is about working “with” rather than “on” people and making sure there is a 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 characterised by exploration, innovation and (inevitably) a degree of trial and error. Relatively little has been published, and relatively few research projects in the field can claim to embody the 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 200 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 flavour 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 characterised 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 years 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 focussed on examining co-production within substance use research; rather, it was about identifying and tapping into community resources for those early on 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 “woolliness” 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 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, would not 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 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.

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.

Note

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.
References


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Researching drinking “with” young people: a palette of methods

Samantha Wilkinson and Catherine Wilkinson

Abstract

Purpose – The purpose of this paper is to outline a study characterised by “pockets” of co-production and argue for the benefits of offering young people a palette of interdisciplinary methods to “opt into”, giving participants the opportunity to discuss their drinking practices and experiences “on their own terms”.

Design/methodology/approach – In total, 40 young people, aged 15-24 years, from the suburban case study locations of Chorlton and Wythenshawe, Manchester, UK, were recruited for multi-stage qualitative research. The participants were presented with a suite of both long-standing and innovative methods that they could “opt into”, including: interviews, peer interviews, diaries, mobile phone interviews, text messaging and participant observation.

Findings – This paper shows that both long-standing and innovative methods have their own individual strengths for researching into young people’s alcohol consumption practices and experiences. Yet, each of the methods utilised in this study also had specific drawbacks for researching substance use. Offering a palette of methods for participants to “opt into” was thus beneficial in: offsetting the weaknesses of other methods; triangulating the study findings; and enabling participants to communicate with the researcher in culturally credible ways.

Originality/value – By offering an honest account about the successes and failures of deploying a range of methods when exploring young people’s drinking practices and experiences, this paper is valuable for researchers in, and beyond, the field of substance use, seeking to broaden their methodological toolkit.

Keywords Alcohol, Qualitative research, Young people, Co-production, Participatory methods, Drinking

Paper type Research paper

Introduction

This paper critically reflects on the experiences of conducting mixed-methods qualitative research with young people (aged 15-24), with the aim of exploring their alcohol consumption practices and experiences. We purposefully emphasise researching “with” to demonstrate that research is a shared process of knowledge creation between all those participating in the research (Leyshon, 2002). It is worth noting from the off-set that this study was not an entirely co-produced one: the aims and objectives were set by the researcher; the analysis occurred in isolation from participants; and the writing up has not involved participants (see Wilkinson and Wilkinson, 2017). What we are stating though, is that the project involved “pockets” of co-production (Franks, 2011, p. 15). For instance, the first author offered a suite of methods for young people to “opt into” (Leyshon, 2002), including interviews, peer interviews, diaries, mobile phone interviews, text messaging and participant observation. Such methods enabled participants with a variety of different skills to participate in the research “on their own terms” (Leyshon et al., 2013, p. 180). We also contend that it is important that such methods are not deployed in a “one-size-fits-all” manner; instances are highlighted where the research design was refined and developed through listening to the experiences of young people in the study. The above methodological approach works with Bennett and Roberts’ (2004) notion of participatory research as a methodological philosophy that reflects the desire of researchers to give more control to participants; it is a philosophy that aims to be interactive, as opposed to extractive.
Research about substance use and its place in the lives of young people has employed flexible approaches. For instance, MacLean (2015) offered both individual and friendship group interviews in a study of young adults’ (18-24) drinking in Australia. Further, Jarvinen and Ravn (2011) offered participants the chance to take part in a focus group, either with a group of friends, or with other drug-experienced clubbers. If they felt uncomfortable in participating, they were invited to participate in an interview either alone or with a friend. Moreover, Seaman and Ikegwuonu (2011) investigated the role of alcohol within the transitions to adulthood of 18-25-year olds living in Glasgow, UK using both interviews and a drink diary. Nonetheless, such studies often rely on a narrow range of long-standing methods; they do not offer a diverse palette of long-standing and innovative methods which reflect the varying skills and abilities of young people. Moreover, such publications on substance use typically present the research process as a seamless act of formulating aims, collecting and analysing data, and presenting findings. This makes it difficult for early career researchers to gain a true insight into the challenges of deploying specific methods. In this paper, we go some way towards filling this void by foregrounding the successes and complexities of using a variety of qualitative methods as a means of researching young people’s drinking practices.

Participatory research with young people

Since the 1990s, research with children and young people has witnessed significant changes in methods and epistemologies that have challenged long-standing research methods (Weller, 2006b), and have endeavoured to dismantle conceptions of children as mindless and deviant (see Pain, 2003). The literature has witnessed a surge in children-centred and, less so, young people-centred research methods. Such methods endeavour to remedy power inequities by supporting young people to choose their own methods of communication (Weller, 2006). This is in line with the emphasis within social sciences upon young people’s agency (e.g. Holloway and Valentine, 2000). Alongside this movement, participatory research has gained increasing popularity (Wright et al., 2006) and can be seen as an effective, and more inclusive, way of engaging hard-to-research populations in the research process.

Whereas children and young people were previously considered passive, or at best marginal, in research encounters, participatory research positions them as co-creators of knowledge. Often methods are employed to draw on skills possessed by the age group. For instance, older children may be involved in methods such as completing diaries and story-writing, whilst younger children may be invited to participate in drawing activities. Accommodating different skill sets is important as young people are a highly differentiated group, and approaches that are appropriate for children may be unsuitable or unacceptable for teenagers, and vice versa.

As Pinter and Zandian (2015) point out, creative participatory methods can provide heightened opportunities for enjoyment, education and a sense of empowerment. Importantly, however, though potentially enjoyable, adopting creative participatory methods does not guarantee that young people have genuine opportunities to develop and perform agency throughout a research project (Waller and Bitou, 2011). To explain, the success of the implementation of these methods is, in part, related to the positionality of the adult researcher. There are arguments that researchers should adopt the “least adult” role (see Randall, 2012), and debunk children’s impressions of the powerful and “potentially dangerous” researcher (see Phelan and Kinsella, 2013, p. 85).

However, Ansell (2001) cautions that equal research relationships are impossible. The joint production/co-construction of research is complex as young people often do not possess the same level of data collection and analysis skills as researchers, who may have spent several years at university honing their skills. Enabling young people to develop the knowledge, skills and responsibility to co-construct research signals the “conscious exchange of power” (McCartan et al., 2012, p. 10) between adult researchers and young people. Participatory research, then, increases young people’s capacity to identify and solve problems affecting them. However, this is not without critique, and some authors have condemned such “teaching” as implying that participants would benefit from “superior” knowledge (see Ansell, 2001, p. 103). Others instead argue that participatory research is a process of
mutual learning (Ho, 2013); whilst young people may be trained as peer researchers, developing skills in interviewing and facilitating focus groups (see e.g. Cahill, 2007), researchers become co-learners in their everyday lifeworlds (Minkler et al., 2002).

Methodology

The research was conducted in the suburban case study locations of Chorlton and Wythenshawe, Manchester, UK. Suburban locations were selected due to a pre-occupation in the substance use literature with cities, typified by a large body of work on the night-time economy (Holloway et al., 2008). Chorlton and Wythenshawe were chosen, in particular, due to the differences in ethnic diversity, socio-economic status, educational attainments and drinking micro-geographies between the areas; this makes for a useful comparative analysis. The first author recruited 40 young people, aged 15-24, for multi-stage qualitative research over the course of 12 months (September 2013-September 2014). The first author aimed for a relatively equal distribution of participants between both suburban case study locations, resulting in 19 young people talking part from Wythenshawe, and 21 young people taking part from Chorlton. Further, slightly more young women ended up taking part in the study (eight young men, and 11 young women in Wythenshawe, and eight young men and 13 young women from Chorlton).

In order to recruit participants, the first author contacted gatekeepers at local universities, secondary schools, sixth forms, colleges, community organisations, libraries, leisure centres and youth clubs, in, and in close proximity to, the case study locations. She also distributed flyers and business cards to houses and businesses in both case study locations; posted on online discussion forums concerning Chorlton and Wythenshawe; used Twitter recruit; and posted on Facebook groups about the two areas. Further, the first author arranged to be interviewed by the morning host of a local community radio station, Wythenshawe FM 97.2, in order to broaden her recruitment strategies. As this paper now turns to explore, the research was conducted utilising a "palette of interdisciplinary methods" (Mason, 2006, p. 13).

Towards a “palette” of methods

The palette of methods (Mason, 2006) that the first author presented for the participants to “opt into” consisted of: interviews, peer interviews, diaries, mobile phone interviews, text messaging and participant observation. Each of these methods was neither dependent on a minimum sample size, nor an equal sample size across the case study locations (Leyshon et al., 2013). Participants opted into the methods they perceived to be the most enjoyable and felt the most comfortable with – they were by no means obliged to participate in all of the methods, although they were more than welcome to do so. This was a research strategy successfully deployed by Leyshon (2002) in his research with young people in the countryside. As Holland et al. (2008, p. 19, emphasis in original) argue, “by enabling young people to choose how they wish to communicate with us we recognise them as social actors and begin to move our practice away from adult-centric procedures”. As Gallacher and Gallagher (2008) demonstrated, we are committed to an attitude of “methodological immaturity”, which privileges an open-ended process over a predefined technique. This is reflected in the first author’s commitment to modifying methods in light of the preferences and characteristics of different young people (Ansell et al., 2012). We now demonstrate this by discussing individual and friendship group interviews. It is worth highlighting though, that there are difficulties in adopting a truly open-ended approach, given the structure and nature of many university ethics committees (Skelton, 2008).

Individual and friendship group interviews

In total, 35 young people opted in to the interview method. Individual interviews enabled the first author to gain insight into the participants’ perceptions, which are subjective in nature (e.g. of their motivations for drinking, how they feel when they drink, where they like to drink) (Kaar, 2007). Whilst the individual interview has its benefits, there are also drawbacks. Some young people did not feel comfortable participating in a one-to-one interview with an adult researcher, and asked to be interviewed with their friends. To address this, the first author
implemented a friendship group style of interviewing. The first author had not intended to use this method; this illustrates the agency of participants to shape the research design, and the need for researchers to be flexible.

There are advantages of conducting interviews in friendship groups for substance use research. Friendship group interviews create a non-threatening and comfortable atmosphere for participants to share drinking experiences (Renold, 2005). Moreover, friendship group interviews provide access to interaction between participants (Miller et al., 2010) – this helped tease out the importance of friendship and care to young people’s drinking practices (see name see Wilkinson (2017a)). Overall, friendship group interviews allowed the researcher to collect data that otherwise may not be accessible (Miller et al., 2010). Although occasionally suppressed by more dominant friends, less confident participants may not have participated in the research otherwise. When researching young people’s alcohol consumption practices, the presence of adults may restrict young people from speaking about their experiences and thoughts surrounding drinking (Katainen and Rolando, 2015). Recognising the “otherness” (see Jones, 2008) of participants younger than herself, the first author also employed peer interviews.

**Peer interviews**

In total, 13 young people opted into the “peer interview” method. Peer interviews acknowledge that young people’s experiences of spaces and places differ from those of adults (Schäfer and Yarwood, 2008). Young people are suitable for conducting peer interviews because they speak the same language as other young people (Kilpatrick et al., 2007). Further, they often have first-hand insights into matters affecting peers, as they are often affected by these issues themselves (McCartan et al., 2012). As Alderson (2008, p. 278) rhetorically questions, if young people’s “social relations and culture are worthy of study in their own right, then who is better qualified to research some aspects of their lives than [young people] themselves”?

Despite contentions that peer interviews can offer a “genuine perspective” into young people’s lives (Schäfer and Yarwood, 2008, p. 4), we found that peer interviews provided a space for some young people to playfully fabricate their drinking stories. Take the following exchange:

Rik: Can you tell me what you get up to on a night out?

Oscar: Get a taxi to town [said in an ironic tone].

Rik: And get wankered in the Union [laughs].

Oscar: And meet some ladies.

Rik: Meet some ladies and take them back to my house.

Oscar: [laughs].

Rik: And you know where to go from there don’t ya.

Oscar: [laughs].

Rik: No, I’m only joking, only joking. (Rik and Oscar, 15, Wythenshawe, peer interview).

Oscar and Rik, aged 15, quoted above, playfully fabricated accounts of their drunkenness through hyperbolic descriptions, in order to perform and produce particular kinds of “cool” masculinities through their alcohol consumption. The notion that this story is an embellished one can be gleaned through: the ironic tone in which the young people spoke; the laughing which permeated this section of the peer interview; and Rik’s frank admission at the end, in which he states “no, I’m only joking, only joking”. As von Benzon (2015) says, silencing playful contributions can risk losing valuable data, and ignoring one form of young people’s voices. We argue that the young people’s fantasies are interesting in illuminating their ingrained assumptions about alcohol consumption. For instance, Rik and Oscar appear to assume that alcohol is associated with enabling men to meet women, and to have sexual relationships.

A drawback of standalone interviews (whether individual, friendship group or peer-led) is that participants often do not feel as if they have much time to think through their answers – an immediate response is expected (Literat, 2013). Recognising this, the first author also offered young people the choice of participating in drawing elicitation interviews.


**Drawing elicitation interviews**

Seventeen young people in the study opted into the drawing elicitation interview method. Each drawing elicitation interview lasted approximately 45 minutes, and took place in spaces participants felt safe and comfortable in, including: schools, homes and cafes. Through the drawing elicitation interview, “the visual representation becomes a process of “working through”, rather than spontaneously responding” (Literat, 2013, p. 210). After providing the young people with a blank sheet of A3 paper and a pack of colouring felt tip pens and some pencils, the first author asked the participants to draw free-hand sketch-maps of their drinking spaces and places. Discussing their maps enabled participants to look back on their products reflexively, along with giving them an additional medium through which to express their thoughts (Lehman-Frisch et al., 2012). Inviting participants to interpret their own maps further facilitated a sense of empowerment, as the researcher became a respectful listener of the young participants who were in charge of the discussion (Literat, 2013).

Through its combination of visual and oral methods, the drawing elicitation interview enabled an understanding of the complexity of young people’s relationships with drinking spaces (Lehman-Frisch et al., 2012). While the first author anticipated that the maps would offer a static snapshot of drinking spaces, she was surprised that young people’s mobilities came through in their drawings. Many young people drew arrows to signal their movements in, through, and beyond, drinking spaces. This method had its weaknesses as, despite the first author’s reassurances, some young people lacked confidence in their drawing abilities (Rose, 2012). It was therefore important to offer alternative methods that do not rely on drawing, or oral communication.

**Diaries**

Diaries are a method through which young people can express themselves, perhaps with less embarrassment, or fewer feelings of being judged, than in interview scenarios. This can be captured through Kelly’s (17, Wythenshawe, drawing elicitation interview) comment: “ah I’ll have to write about it, I can’t, I’m not saying that, I’ll write about it”. In total, 11 young people in the study completed the diary method, five young men and six young women. The first author asked the young people to complete unstructured solicited written diaries, regarding their alcohol consumption experiences, over a minimum of three weeks. Leyshon (2002) contends that utilising a written diary method with young people is challenging, as they perceive it to be time-consuming and it may feel like a form of homework. However, some young people in the study were enthusiastic about keeping a written diary; some participants claimed to have “never had a diary before” (Jemima, 15, Wythenshawe, interview). Far from a tedious homework-like task, for some young people, keeping a diary was novel and exciting.

Diaries yield considerable benefits for substance use research. First, as the diary method was not undertaken face-to-face, it made it easier for young people to be more candid about their drinking practices and experiences than in face-to-face methods (Milligan, 2005). Second, by enabling participants to document their own drinking practices, in their own space and time, a more empowering research relationship emerged between young people and the researcher. The first author found that one of the drawbacks of using diaries is that several young people opted to participate in this method, yet never returned their diaries. An additional downfall with using diaries for research is that they depend on the participant’s writing skills (Buchwald et al., 2009). Relatedly, the first author was often disappointed by the limited detail some of the completed diaries contained. In addition to oral, written and artistic mediums, it is important to offer alternative methods, which enable young people who are technologically skilled to communicate their thoughts on alcohol, drinking and drunkeness. This is now illustrated through a discussion of mobile phone interviews and text messaging (see Wilkinson, 2016).

**Mobile phone interviews**

The first author had planned to ask young people to send her photographs and videos on their nights out, via their mobile phones. Despite gaining ethical approval to do so, this approach was not suitable "in practice" because of the costs involved with sending photograph and video messages. Whilst many young people held a mobile phone contract, which often allows unlimited
text messages to be sent, often this does not include photograph or video messages, which, in the UK, are typically charged at 30-40 pence per message. The first author developed and refined the research design through listening to the experiences of a young person in her study; Heather (15, Wythenshawe, interview) stated: “there’s a party on Friday. I’ll video some of it through the night on my mobile, like video bits and I’ll come in and show you”. Mobile phone interviews involved asking young people to use their phones to take photographs and videos on their nights out. The first author then met the young people individually, a few days after the event, and asked them to navigate through relevant photographs and videos on their phones. The visual data then served as prompts to elicit discussion in an informal interview.

Some of the benefits of mobile phone interviews for substance use research are as follows: asking participants to take photographs and videos enabled “ethnography by proxy” (Bloustein and Baker, 2003, p. 72), for spaces that may be difficult for a researcher to gain access to, such as homes of participants’ friends and relatives. Further, the mobile phone offered participants an opportunity to “show”, rather than solely “tell”, aspects of their drinking identities that may have otherwise remained hidden (as Croghan et al., 2008 note of photo-elicitation methods). In line with this, the interview element of this method acted as a means of triangulating what young people said they did, with what the photographs and videos showed they did. Further, mobile phones changed the materiality of interviewing participants; the young people were, to some extent, “in charge”, whilst the researcher largely watched the scenes unfold.

Text messaging

Ten young people in the study opted into the text messaging method (eight of which were young women and two young men). Text messages were used as data in two predominant ways. First, conversations the first author had with the young people, via text messages, regarding nights in/out that they had invited her to, were a valuable form of data. The first author asked the young people about their plans regarding: where they were going; what they would wear; what they would drink; whom they were meeting, and so forth. Second, the first author asked participants to update her, via text messages, of their experiences and practices during their nights in/out involving alcohol, when she was not present.

Researchers have typically undervalued text messages as a source of data. Whilst diary entries are often perceived to require literacy skills, texting requires a different type of literacy skill, enabling the inclusion of young people with a range of abilities (Walker et al., 2009). Further, social anxiety may cause some young people to prefer technological communication, rather than face-to-face communication (Pierce, 2009). Text messaging is a particularly important method when researching substance use because most other methods, such as diaries and interviews, require participants to remember and recall events, which can be problematic with memory impairment, associated with alcohol consumption. The date-and time-stamped text messages provide an “experience snapshot” (Plowman and Stevenson, 2012, p. 539) of young people’s alcohol-related, present-tense, actions. Overall, text messaging offered an informal, undemanding, and unobtrusive, means of understanding young people’s drinking practices and experiences, as they unfolded. Text messaging is a research technique in line with many young people’s everyday/everynight practices. For young people in the first author’s study, and as Leyshon et al. (2013) make clear, text messaging is a culturally legible means of communication.

Those researching drinking practices, whether through interviews, diaries, drawings or mobile phone methods, must contend with the issue that people do not always do as they say they do (Holloway et al., 2008). This may be due to the worries about being judged by the researcher or peer researchers, for instance. It is for this reason that the first author also deployed participant observation as a method for young people to “opt into”.

Participant observation

The first author undertook participant observation over a period of 12 months. She observed the drinking practices of seven different young people and their friends participating in the research. She went on 21 nights out/in in total, lasting a minimum of three hours, and up to a maximum of 12 hours. She undertook approximately 96 hours of participant observation in total, in a diverse
range of spaces, including: pubs, bars, clubs, casinos, streets, parks and homes, and for a variety of occasions, including routine nights out, to more celebratory occasions, such as an 18th birthday party. By “hanging out” with participants (Kusenbach, 2003, p. 463), the first author was able to explore young people’s drinking experiences as they moved through, and interacted with, their surroundings. The first author considers that her age, appearance, personality and drinking biography were key factors that enticed young people to invite her on their nights out. We cannot help but think that an older, less fashionable researcher, who abstained from alcohol consumption, for instance, would not have been so openly invited to selectively invited “special occasions”, such as 18th birthday parties. It is worth noting that the first author was going to offer the method of participant observation later in the study, when she had built up a level of trust and confidence with the participants. However, upon explaining the study to participants at a first meeting, one participant stated: “why don’t you just come on a night out with us”? Participant observation, to participants, seemed like a logical way of gleaming insight into their drinking experiences.

By joining young people as they moved in and between different spaces, the first author acquired an understanding of young people’s embodied drinking practices, and the multi-sensory nature of drinking experiences (Langevang, 2007). This included the role of music, the impact of darkness and lightness (see Wilkinson, 2017b), the taste of particular alcoholic drinks, the smell of vomit, and the importance of touch, for instance, when caring for drunken friends. To provide an example, when the first author went out with participants to a club for an 18th birthday party, participant observation provided support for the notion that drunkenness is not about alcohol alone (see Jayne et al., 2010). The music, lighting, (non) alcoholic drinks and bodies were all materials acting on the researcher, influencing her corporeal experiences of space, and making a difference to the social experiences of alcohol consumption (Duff, 2012). The can be illustrated through the following passage from the first author’s field diary:

It is interesting that, despite only having one vodka and coke, I felt drunk. Normally, I require a certain number of drinks in order to have the confidence to dance. However, tonight, being surrounded by other mobile drunken bodies, the darkness of the club, and the thump of the upbeat music, increased my ability to dance uninhibited […] I even found myself participating in the Gangnam Style dance[1] without feeling self-conscious! (Field diary, night out with Maisy, 18, and friends, Wythenshawe).

From the above extract, one can see that the first author experienced a transformation, her body “became” drunk, through its practices and encounters in assemblages with other drunken bodies, the sonic environment, and lighting in the affectively charged space (Waitt and Stanes, 2015). Such visceral insights are not easily obtained through other methods. Having provided an overview of the strengths and weaknesses, and the complimentary nature of the interdisciplinary methods underpinning this study, this paper now concludes.

Concluding remarks

This paper has outlined a substance use study characterised by “pockets” of co-production (Franks, 2011, p. 15). In this paper, we have argued that when conducting substance use research “with” young people, researchers should offer palette of diverse, yet complementary, methods for participants to “opt into”. Such methods could include, but are by no means limited to: interviews, peer interviews, drawing elicitation interviews, diaries, mobile phone interviews, text messaging and participant observation. Combining mixed qualitative methods provided young people in this study with the space and time they needed to communicate the complexities of their lives (Langevang, 2007). This paper has also argued for the need to privilege an open-ended process to conducting substance use research (Gallacher and Gallagher, 2008); for instance, by modifying methods in light of the preferences and characteristics of specific young people (Ansell et al., 2012).

Each method deployed in this study was argued to have its own strengths for researching into young people’s drinking. Interviews offered in-depth insight into alcohol consumption practices and experiences, and friendship group interviews provided a comfortable setting for young people to discuss their drinking stories and have their voices heard. Whilst young people may feel uncomfortable articulating drinking stories to an adult researcher, peer interviews addressed this.
Peer interviews provided interesting data as, whilst young people sometimes fabricated drinking stories, such embellishments illuminated their ingrained assumptions about alcohol consumption. Whilst interviews (individual, friendship or peer-led) often require an immediate response, drawing elicitation interviews gave participants a chance to “think through” drinking practices and experiences. Drawing elicitation interviews also enabled insight into young people’s alcohol-related im/mobilities.

Additionally, diaries were argued to provide a space for more candid drinking accounts. Whilst diaries rely on participants’ writing ability, mobile phone methods enabled those more technologically skilled and minded to participate in the research. Mobile phone interviews enabled young people to “show and tell” the researcher about their alcohol consumption practices and experiences – through a culturally credible medium, whilst text messaging provided real-time updates of drinking practices as they unfolded. Finally, although many methods relied on the participants’ versions of drinking events, participant observation enabled the researcher to both see and feel multi-sensory and embodied drinking experiences. As this paper has demonstrated, by being equipped with a palette of methods, the strengths of one method can offset the weaknesses of another (Cresswell and Clark, 2011).

The palette of interdisciplinary methods deployed in this study enabled the researcher to triangulate the research findings. Importantly, it also gave participants the opportunity to communicate with the researcher in ways they were comfortable with, and found meaningful. By being honest about the successes and failures of deploying specific methods when exploring young people’s alcohol consumption practices and experiences, this paper is valuable for researchers in, and beyond, the field of substance use, seeking to both broaden their methodological toolkit, and research “with” participants in culturally legible ways. We are not suggesting that the methods outlined in this paper should be extracted by researchers for substance use research. Rather, we contend that researchers must be attentive at listening to, and becoming attuned to, the methodological preferences of the specific group of participants in their study, and consequently adapt their methodological offerings to enable participants to communicate with researchers “on their own terms” (Leyshon et al., 2013, p. 180).

Note

1. A pop single by the South Korean Musician Psy, released in 2012, renowned for the choreography and moves in its music video, including gallop, lasso, leg sweep, flick, shuffle, pop and pose.

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Further reading


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Co-production with young people to tackle alcohol misuse

Jill Clark and Karen Laing

Abstract

Purpose – The purpose of this paper is to present the learning gained from undertaking research activities in co-production with young people in order to tackle alcohol misuse in local communities.

Design/methodology/approach – The findings are drawn from an evaluation of an alcohol misuse change programme in which opportunities to learn about and conduct research were provided to young people through co-production. The evaluation was guided by a theory of change, and a portfolio of evidence collected which included feedback from the young people and project staff about their experiences.

Findings – This paper demonstrates that young people can be empowered to take on roles as agents of change in their own communities by learning more about research processes. However, the empowerment does not come from undertaking research training per se, but by being able to work co-productively with researchers on issues and questions that are of direct relevance to themselves and which are framed within a change agenda. Shared values, strong relationships and reciprocal knowledge exchange enabling flexible and relevant responses to real-world problems and questions are needed.

Originality/value – The paper suggests a reflexive and co-productive learning, design and delivery approach to involving young people in research. It challenges notions of young people as a problem in terms of alcohol misuse, and rather situates them as part of a solution that is aiming at longer-term transformational community change. This is significant in that much of the existing evidence concentrates on individual intervention.

Keywords Participation, Evaluation, Young people, Co-production, Agents of change, Alcohol programme

Paper type Research paper

Introduction

The co-production of research and young people’s participation in the delivery of services are not new concepts for researchers in fields that have direct relevance to the lived experiences of young people. However, much of the research that concerns young people typically excludes them from roles other than as respondents, and fails to ensure their genuine and meaningful participation (Daly, 2014; James, 2011; Lundy, 2007; Stafford and Drywood, 2009). Levels of participation vary enormously depending on the ethos of the researcher and the scope of the research being conducted (Clark and Laing, 2012). There has been a change in rhetoric that highlights the value of participation (Phillips and Prout, 2003), but there is less evidence about how this works in practice, and whether such participation, when it occurs, is effective (Todd, 2012; Henricson and Bainham, 2005). The agendas and processes by which young people can engage in service delivery and evaluation are often heavily prescribed by adults.

There is no consensus around how to define co-production, but there is agreement that co-production is multi-faceted and varied (Alford, 2014). In respect of research, it has been described in a number of ways; as co-creation, democratic, user-led or emancipatory research and it is closely associated with traditions of participatory action research (Campbell and Vanderhoven, 2016). There is also a growing consensus about the challenges of co-production, and what it is “not”. This includes indirect service user consultation, involvement in service design or assessment (tokenism) (Carey, 2009) and challenges include the potential to further
marginalise disadvantaged groups (Markkanen and Burgess, 2016) and the cost and time associated with recruiting and training members (Boyle and Harris, 2009). However, co-production can be said to have several important and necessary features, in that it brings people together who have different skills and experiences to work to influence change. In this way, it can be seen as potentially transformative, in that it brings new ways of thinking on the basis of insights into everyday practices (Bergold and Thomas, 2012). The process of co-production itself is one which creates a “boundary space” or “boundary experience” which can enable shared contributions to be understood and facilitated (Clark et al., 2017b). In this paper, ideas of co-production rested on notions of building on young people’s capabilities and providing opportunities for them to recognise and develop their skills and use them in the process of “negotiated activity”, thus becoming agents for change, rather than passive recipients of services (Hatzidimitriadou et al., 2012).

Current evidence focussing on alcohol misuse and young people has tended to explore the relationship that young people have with alcohol and associated risky behaviours. This body of research has frequently situated young people as “the problem”, identifying that the outcomes of misuse and risky behaviour can be severe (Newbury-Birch et al., 2009; Jernigan, 2001; Donaldson, 2009), but rarely enabling their participation in finding solutions. Such evidence does not provide a clear intervention strategy, but highlights the complexity and changing nature of young people’s drinking cultures over time, and the relationship of parents, peers and wider social contexts to their decision-making processes (e.g. Bremnar et al., 2011; Sondhi and Turner, 2011; Valentine et al., 2010; Velleman, 2009; Seaman and Ikegwuonu, 2010; Percy et al., 2011; Atkinson et al., 2011). This point to the need for approaches to tackling alcohol misuse that goes beyond individual health messages, towards interventions that can situate young people as sophisticated decision makers, within the range of contexts that they experience (Sondhi, 2012).

Building on this evidence base, the “Thinking Differently” programme was developed by a consortium of funding bodies in Scotland, to stimulate a different approach. The programme was premised on the idea that alcohol misuse is better addressed by changing general attitudes to alcohol rather than (or, more likely, in addition to) targeting individuals who are individually vulnerable to alcohol misuse (Clark et al., 2017a). The programme trialled an innovative preventative community approach to young people and alcohol. It worked through three very different projects that recognised the more nuanced role of parents, peers, and the community in young people’s decision making about alcohol consumption and attempted to regard young people as potential agents of change rather than as a problem to be fixed. The three projects were developed in collaboration with young people, and each focussed on different processes and outcomes to tackle substance misuse. All three were required to meet two primary outcomes: reducing alcohol-related harm and associated risky behaviour by young people; and, building practical, sustainable skills and knowledge to empower young people, parents/carers and the community to take action to address local alcohol concerns. The definition of a young person was not prescribed and the projects worked with young people of various ages from primary school children through to their mid-twenties.

The evaluation

The programme, and the accompanying evaluation, took place over three years. First, the evaluation team worked with the three projects to develop a theory of change (Dyson and Todd, 2010; Chen, 2015; Laing and Todd, 2015) for their work, based on the actions that young people had suggested, and decide on an evaluation strategy that was bespoke to each project. A theory of change approach to evaluation sets out how an action leads to a longer-term change via a series of intermediate changes. Data can then be collected in order to support, or refute the theory. This approach works well for complex initiatives such as this, aimed at long-term community transformation, where actions are multi-stranded and there are no specific individual beneficiaries.

First, these theories were developed without the input of young people. In the intervening time since the actions were decided, proposals written and accepted, and staff recruited, the young people that were originally involved had moved on and were for the large part, no longer involved
with the projects. This meant that the theories of change needed to be developed in collaboration with staff and strategic leads of projects before other young people were recruited. Data collection was undertaken in order to build a portfolio of evidence for each project. The evidence was used to consider how far the theories of change were supported or refuted. The three projects themselves collected a wide variety of data relating to their work. This included: reports; observations; reflective diaries; visual data (photographs, artwork, video); audio data (adverts and radio shows); notes and minutes; evaluation sheets; and expenditure data. In addition to this data, the evaluation team collected evidence by means of regular interviews with project staff; interviews, observations and focus groups with young people participating in the projects; focus groups with groups defined as "activists" or "action groups" in each project; and diamond ranking exercises (Clark, 2012; Clark et al., 2013). The evaluation team worked with each project and reviewed their theories by drawing on this portfolio of evidence and checked whether their theories still held and whether, in time, they were likely to meet their outcomes.

The Thinking Differently programme rested on the assumption that young people can be active participants in changing not just their own lives, but the lives of those around them including peers, families and communities. Co-production was a key aim of the projects, and they were expected to ensure that their work was "youth-led" and participatory, and that young people were involved in design and delivery. Similarly, young people were given different opportunities to engage with the evaluation and this meant that rather than being "sampled" they participated in ways of their choosing that were appropriate to them. Young people were very welcoming and accepting of the evaluators, and invited them to observe their activities, for example, a climbing wall activity, an animation workshop and a photography workshop. During the evaluation, the evaluation team tried to understand in what ways, and to what extent, young people wished to be involved in design, delivery and evaluation and facilitate this. Early on in the evaluation, the research team offered to work with any of the young people who were part of the three projects to enhance their skills in research, so that they had the capacity to undertake research themselves if they wanted to. This was an idea that was taken up by two groups of young people in two of the three projects and this paper reports on how those young people engaged with the evaluation team, the experiences of working with these young people, and reflects on the lessons that were learned. In that sense, they were not recruited to work with us, but rather were active in suggesting ways that they could learn about research in order to take action in their own communities and the evaluators responded by providing the opportunities for them to do so.

Co-producing research for change with young people

Young researchers research day (project 1)

Project 1 aimed to encourage young people to influence their local community. Their theory was, that by finding out the concerns of the local community and concentrating on addressing them, over time, the wider stressors associated with alcohol misuse would be reduced, and thus alcohol misuse could be tackled, almost by default. Young people were seen as key to understanding the needs and concerns of the local community and mobilising to address them. These young people were involved in a steering group (which also managed a youth café) and a youth activism group. The evaluation team developed strong relationships with these young people during the early months of the evaluation, and noted that they were very keen to become activists in their local community, and felt that engaging in a programme of work which involved them conducting some research within their own community would be a key activity for them. Project 1 staff devised a 12-week programme, including a boot camp, where young people identified key issues relating to community health that they wanted to explore, research and develop key messages about. They identified the best ways to share those messages, to engage the local community, effect change, and increase their own involvement and contribution in positive activity within the local community.

As part of this process, eight young people (five young women, three young men) from project 1 aged 13-17 were invited by the evaluation team to (Newcastle) university to take part in a day of activities aimed at increasing their research skills, and enabling them to undertake research in their own community. Through practical activities and discussion about the stereotypes of young
people (a topic chosen by the young people themselves), young people explored aspects of research such as: what is research?; what is data?; how to ask a good research question; interviewing and data recording techniques; making sense of data (sorting and coding) and identifying key messages; how to present key messages to others; and, diamond ranking. Part of the day also included a tour of the university, a meal, and a trip to a local funfair.

**Young researchers research residential (project 2)**

The evaluation team also worked closely with an action group in project 2, who were involved in making a film around alcohol awareness and responsible drinking. Project 2 focussed on ways to influence peers and the role of peer relationships in respect of alcohol. The group made two films, with the help of a local film company, and the evaluators met up with them to spend a day working through how they could use those films to make a difference to other young people. Ideas included producing a learning resource to accompany the films that could be used to stimulate discussion in schools and youth groups. The young people realised, however, that they had no idea about how this might be received, or how best to go about this, and decided they wanted to conduct their own research with other young people and staff to discover how this might best work.

Following the success of the work with young people in project 1, the evaluation team invited members of the action group from project 2 to attend a weekend residential in (Newcastle) to learn more about research, and to work on planning their own piece of research to develop the learning materials. Four young women aged 16-18 years, and two project 2 staff members attended the weekend residential at (Newcastle) university, where they learned about: what research is; the role of a researcher; how to plan research; specific methodologies; and how to analyse and use the findings. During the weekend, the young people decided that they needed to conduct research about what young people want in terms of alcohol education and they then planned a piece of work to undertake in schools using visual research methods. Alongside the research activities, the young people, staff and evaluators took part in a range of social activities including exploring the city, going for a meal, and a trip to a bowling alley.

Following this, the evaluators invited them to present at an academic conference and the young people presented about their experiences at the Youth Matters Conference held at the University in June 2016. It was thought that the young people may wish to contribute to a blog about their experiences, but instead, they decided to make a short film that illustrated the impact on them of working with academic researchers. This film was also shown at the conference, alongside a reel of visual images of the activities they had taken part in.

**Findings: exploring co-production with young people**

**Young people’s experiences of participation**

The evaluation of the young researcher sessions undertaken with young people from project 1 afterwards showed that the young people had enjoyed taking part (and some had even found it “fun”):

I like the research task we done today, it was fun!

The researchers were lovely and helpful.

I liked the research activities we took part in today 😊

I really enjoyed the “What’s in it for you?” [exercise] as it was interesting to see other people’s opinions.

The team observed that young people had really taken on board what they had learned, and were beginning to talk in a different way, sounding like researchers, using key terms with confidence such as “data”, “evidence” “questions” and “methods”:

It was interesting how easy it is to research things, and how to split the data into groups (young person).

It was interesting, different ways of collecting evidence for research (young person).

Evidence from the project subsequently demonstrated that five of the young people from project 1 had gone on to conduct research with approximately 60 community members about the use of e-cigs, had successfully developed key themes from that research and produced a radio show in order to
disseminate their key messages into the community. The young people stressed that attending the research training day had enabled research to become more accessible to them and increased their capacity to undertake research within their own communities, which, it is theorised, might in time lead to greater engagement by the community in health concerns.

Feedback from the young people from project 2, who took part in the residential research training, also showed that they enjoyed their experience and learned much:

When I went down to [Newcastle], I didn’t have a clue about research – I thought I did – but I didn’t. When you asked us to get into it, I realised I wouldn’t have known where to start! And if I did start, we wouldn’t have got as far as we are now (young person).

The four young people involved very much enjoyed the experiences they had, and appreciated the chance to make a difference by sharing their experiences from their own perspective with academic researchers. Although initially nervous about presenting at an academic conference, with support from the evaluation team they grew in confidence and felt a great sense of achievement at having presented in front of a whole room full of academics. Their contribution was noted by the organiser:

Having attended many conferences and events which focus upon the lives of young people I feel that one of the elements which made our event stand out was the inclusion of a youth presentation. The young people were able to present to a packed room of researchers, telling us what they feel are the most important elements to consider when undertaking research upon young people. Their presentation was articulate and, above all, funny. They added a unique element to our event (Conference organiser).

The role of project staff in facilitating participation

The intention of the “Thinking Differently” programme was that the projects would be youth led, but what this meant in practice was difficult to define, and open to interpretation. During the evaluation, project staff explained that in a “ladder of participation” (e.g. Hart, 1992; Shier, 2001) levels of participation vary, and perhaps youth led conjured up an image of being at the top of the rung:

I suppose if we say the term “youth-led” it conjures up to me that young people have come up with the idea and they’re steering it.

To me, it’s the top stage of that […] whereas youth participation is a process.

Nevertheless, staff often felt that young people did not have the skills or the desire to help in the running of a project, and the projects instead aimed to ensure that young people were enabled to participate at whatever level suited them, rather than expecting young people to “lead”. Much was based around the relationships and trust that the young people built:

I think, sometimes people assume that youth led, like young people come up with other ideas themselves, and have the skills and the knowledge ability. It’s a load of nonsense, but what they do do is they come and they pick up from the adults who don’t force things down their throat, they just explore things with them, come up with ideas and explain things […] (project co-ordinator).

As young people developed these skills, they were able to act as peer supporters for others. This had to be done slowly and was driven by the needs of the young people:

Given that we’re targeting the people who are not traditionally involved in participation, we have come to accept that it is going to take some time before we progress along those stages, and that our expectations, even if the young people want to be at that top youth-led, is going to take time (project co-ordinator).

Project staff recognised that, without the necessary skills and confidence, young people might not always be best placed to make decisions at certain points in project development, and an element of risk could be introduced if young people were not completely ready. Staff felt that it was more appropriate for them to be constantly questioning young people about their needs, and how they could best be supported. This approach was thus described as:

It’s a participation journey that has the ultimate goal of being youth led, and that participation is at various strands, and it supports young people who want that aspiration to reach that goal, but also support for them while they can dip in and out of the participation.
Some project staff however struggled to move away from notions of the young people they were working with as service users or beneficiaries. Indeed, while planning one of the research sessions, one staff member expressed concern that the young people would find it too hard, or not be able to contribute. After reassurance from the evaluation team, they nevertheless took part, and the staff was surprised but pleased by how well the young people engaged with the research.

**The importance of shared values**

During diamond ranking exercises (rankings of nine statements in order of preference, see, e.g. Clark, 2012) carried out by the research team with the young people, young people demonstrated their desire to have their voices heard. Some young people wanted to change their communities and help others. Their own development was seen as important in the process, but was secondary to wanting to make a difference to others. Identical diamond ranks completed by staff members indicated that the main aim of the staff was to ensure benefit for the young people from participation, rather than enabling them to make a difference to others. This mismatch in the aims of working together was a surprise to staff when it was discussed, and hearing young people’s views enabled them to be much more supportive in facilitating the young people to become more active in stimulating change. Young people expressed their desire to be active in making a difference:

> I think it’s the best reason that I want to help young people make positive choices so we can live in a better environment.

> I’d feel more important knowing that I had made a difference in someone’s life.

Project co-ordinators and young people themselves frequently told us that young people have the ability and desire to get involved, but that they want to be involved in different ways and on different levels, that they choose. It often depends on how interested they are in the topic being addressed, and the agency they feel to make a difference:

> […] unless they really, really care about the issue or feel they can make a change, they will only get so far (project co-ordinator).

Learning how to communicate these different desires and values was crucial to enabling them to be shared. Having shared values enabled activities and opportunities to be more relevant and interesting to young people.

The Thinking Differently programme intended to reduce consumption of alcohol by young people, and to increase community capacity (in terms of young people, parents and the wider community) to begin to address issues with alcohol misuse in their areas. While a laudable aim, the encouragement given to projects in the early months to “think differently” about how to tackle this, and to target ordinary members of the communities for the initial work, led to tensions in whether, and how explicitly, projects identified themselves as “an alcohol project”. Traditionally, many projects badged as alcohol projects seek to work with people already misusing, or at risk of misusing, alcohol in some way in order to address their drinking at an individual level. However, the projects sought to address the underlying societal causes of drinking, rather than the symptoms, and aimed for wider cultural change. In project 3 this meant working with normative groups of young people and parents to tackle the everyday messages about alcohol that portray alcohol misuse in a glamourous, or socially acceptable way. In project 2, community development work was aimed at enabling the community to identify and tackle the underlying causes of alcohol misuse in their area, such as the lack of facilities for young people. In project 2, targeted groupwork was intended to bring together resilient young people and those young people at risk of misusing alcohol to challenge attitudes in peers. As such, although alcohol was central to the activities, these projects did not seek to position the young people they work with as “a problem”:

> The young people and the older people that we’re engaging with, this isn’t an intervention for them, it’s not a service to them. In a way we’re facilitating them becoming community activists, and therefore, actually, we don’t have a right to ask about their personal lifestyle (project co-ordinator).

The evaluation found that talking about drinking can potentially harm young people’s trust in adults, especially if young people suspect an ulterior motive. In project 1, staff made it very clear
that the project aimed at enabling young people to influence adults, and were thus more successful in introducing alcohol as a theme with young people:

[... it came from young people who said] “We want to change the culture, and the way we think we can change the culture is by us telling adults” (project co-ordinator).

In project 2, where a more traditional model of groupwork was undertaken, with issues-based work (including alcohol, but not excluding other topics of concern) happening alongside leisure activities to sustain engagement, the theory was that young people would challenge each other around alcohol use through positive relationships with their peers. Because the young people were not selected for the groupwork based on their alcohol use or misuse (and indeed on questioning, made little use of alcohol), young people struggled to see the relevance of conversations about alcohol in their sessions. This led to a refocussing of the project, so that young people were first supported to gain the skills needed to mentor other young people, so that they did not need to see alcohol as of relevance to themselves, but to their peers, and young people and society more generally. This shift in focus may well have facilitated young people in being drivers of change, rather than recipients.

Valuing knowledge exchange

The co-production approach throughout the programme and the evaluation was a fundamental thread which it was hoped would facilitate and explore new forms of knowledge, values, and social relations that emerged out of the co-productive processes. The Thinking Differently programme was complex, and the dynamic nature of the projects and interactions between the young people and the project (and the researchers) demanded an innovative approach. The evaluation team steered away from a traditional model of doing research “to” and was explicit about these values from the beginning. Young people and their experiences were key and the team was keen to maintain a co-productive process in the evaluation. There are a range of ways in which young people can be involved in evaluation, ranging from participant to researcher (Alderson, 1995; Flutter and Ruddock, 2004; Kirby, 2001). Historically, the extent of their involvement very much varies depending on a number of factors, such as the experience and ethos of the adult researchers, the availability of resources to engage young people effectively, and the willingness and ability of young people themselves to engage and participate. Not all young people will find evaluation interesting or relevant to them, and evaluation is not necessarily seen as a “fun” activity, as one project worker noted:

The focus of the boot camp was data generation and research which are not traditionally thought of as being fun activities.

However, when a topic is relevant to young people, they often want their views to be heard, and will engage at a level that suits them, given the right opportunities. It was always the intention of the evaluation team to involve young people actively in the evaluation wherever possible. Not all of the engagement with young people during the evaluation could be thought of as co-production, but where young people had different choices and opportunities to engage with the evaluation, and chose to do so, co-production was possible.

Discussion

The experiences of the evaluation team in working with young people to enhance their capacity to engage in research in their own communities provided evidence that young people have the desire to make a difference in their own communities, have the capacity to develop the necessary skills and competencies, and can make a valuable contribution to stimulating longer-term transformational change in respect of alcohol misuse. The evaluation team identified several clear messages by involving the young people co-productively in the evaluation:

1. reciprocity and shared values are important;
2. values and aims can be made explicit by effective communication;
3. relationships matter; and
4. young people can, and want to, make a societal contribution.
In any project of this nature, the place of young people needs to be carefully considered and the rationale behind their involvement needs to be made explicit (Clark et al., 2013). There is also a need to be reflexive and recognise that it is not always appropriate to involve all young people and all aspects of research at all times, nor is it always possible, theoretically or practically. In order to facilitate contributions, the evaluation team was able to offer opportunities so that the research the young people undertook was relevant to them, rooted in their own ideas, and based on their own self-identified needs and questions. The active nature of their engagement with us for the research day and residential activity could not therefore be described as recruitment (in the way we normally talk about engaging people for research), but rather emerged through a process of relationship building and dialogue. Throughout, the evaluation team tried to develop an ethos of partnership and co-production with the young people and project staff. The team paid attention to the expectations, interests, and concerns of the participants involved in the research. The team was keen to avoid “extraction” of knowledge from the community to the benefit of the researchers and funders or that the communities were left unchanged or worse off than they were before. Ultimately the team endeavoured to maximise the mutual benefits of working co-productively, especially with regards to the young people in the project. There is a growing theoretical curiosity in health research literature about reciprocity and trust as fundamental health promoting factors that are usually understood in terms of “social capital” on the community level.

Engaging young people, families and communities was a crucial part of all of the projects' theories of change. Without engagement, working towards outcomes was compromised. The projects had different strategies for engagement and learned that where there were existing relationships and a good reputation, and strong partnerships (with a similar ethos) engagement was easier and quicker. The evaluation team also took the time to get to know the young people and supported them, recognising the value and time taken to develop relationships based on trust. Travelling and visiting (Newcastle) (and being away from home) was seen as a benefit by the young people. This, interspersed with social activities and a sense of purpose, and gaining skills, empowered them so that it was they themselves that could make a difference, not the evaluation team as “experts”. A significant achievement was when the young people presented at the conference. This challenged usual academic power relationships. The young people became the “experts” when speaking about their own experiences and this in turn gave them confidence in their own ideas as valuable. This was reported as empowering by both the young people themselves and the project workers.

The research groups undertaken by the young people with the evaluation team acted as “boundary experiences” (Clark et al., 2017b). They were not provided alongside a toolkit, or presented as research training, but rather were flexible spaces whereby young people could share their ambitions, their existing knowledge and their skills gaps, and the researchers could respond with relevant information and knowledge. This two-way reciprocal interchange of ideas and activity enabled an understanding of the perspectives of those that participated, and shared values to emerge: an ethos of discovery rather than one of delivery or deficit. Social activities also cemented relationships and made the engagement fun. The involvement of the evaluation team in such co-productive activity with the young people posed a challenge to some project workers, who had not previously viewed the young people as capable agents of change. They were genuine in wanting the young people to benefit from the activities they participated in, but did not always see the bigger picture of how those young people could contribute to benefitting others.

Concluding remarks

Findings from the evaluation indicate that by “thinking differently”, young people can become a community asset to change the culture around alcohol use (Clark et al., 2017a). This is a different path to take from traditional interventions aimed at addressing youth alcohol misuse. Nevertheless, moving from deficit notions of young people as “problem”, as “risk”, or as “in need” (of intervention), towards notions of young people as agents of change in their own communities is not easy. An attempt was made during this evaluation, very much due to the
ethos of the evaluators and the project designers who had a view of young people as capable, and having valuable skills and knowledge. Young people were further supported by being involved in research that was relevant to them, and drew on their own ideas and questions. This involvement had a specific purpose with the intention of facilitating change to happen.

The evaluators built strong, trusting relationships over time with the young people, and were able to be flexible and offer a variety of opportunities to engage, in ways that were fun and attractive to young people, but that did not shy away from being challenging. The evaluators concluded that young people can be effective researchers in order to stimulate change in their own communities, but challenge notions of formal research training or toolkits as sufficient, advocating rather an approach that incorporates knowledge exchange, reciprocity and co-production that can empower and value young people. Certainly, moving forward, embedding approaches to involving young people in research and evaluation that place emphasis on dialogue and relationship building before the research design phase may enable young people to be more active collaborators, rather than passive participants in the process.

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Involving young people in drug and alcohol research

Louca-Mai Brady, Lorna Templeton, Paul Toner, Judith Watson, David Evans, Barry Percy-Smith and Alex Copello

Abstract

Purpose – Young people’s involvement should lead to research, and ultimately services, that better reflect young people’s priorities and concerns. Young people with a history of treatment for alcohol and/or drug problems were actively involved in the youth social behaviour and network therapy study. The purpose of this paper is to explore the impact of that involvement on the study and what was learnt about involving young people in drug and alcohol research.

Design/methodology/approach – The initial plan was to form a young people’s advisory group (YPAG), but when this proved problematic the study explored alternative approaches in collaboration with researchers and young people. Input from 17 young people informed all key elements of the study.

Findings – Involvement of young people needs to be dynamic and flexible, with sensitivity to their personal experiences. Engagement with services was crucial both in recruiting young people and supporting their ongoing engagement. This research identified a need to critically reflect on the extent to which rhetorics of participation and involvement give rise to effective and meaningful involvement for young service users. It also highlights the need for researchers to be more flexible in response to young people’s personal circumstances, particularly when those young people are “less frequently heard”.

Research limitations/implications – This research highlights the need for researchers to be more flexible in response to young people’s personal circumstances, particularly when those young people are “less frequently heard”. It highlights the danger of young people in drug and alcohol research being unintentionally disaffected from involvement through conventional approaches and instead suggests ways in which young people could be involved in influencing if and how they participate in research.

Practical implications – There is an apparent contradiction between dominant discourses and cultures of health services research (including patient and public involvement) that often do not sit easily with ideas of co-production and young people-centred involvement. This paper provides an alternative approach to involvement of young people that can help to enable more meaningful and effective involvement.

Originality/value – The flexible and young people-centred model for involvement which emerged from this work provides a template for a different approach. This may be particularly useful for those who find current practice, such as YPAG, inaccessible.

Keywords Participation, Co-production, Young people, PPI, Public involvement, Children’s rights

Paper type Research paper

Introduction

Young people’s involvement in the Y-SBNT study

Family interventions appear to be an important element of young people's drug and alcohol treatment (Velleman et al., 2005), however, implementation of family approaches in UK services is low (Watson et al., 2017). The Youth Social Behaviour and Network Therapy (Y-SBNT) study (Watson et al., 2015) was a randomised controlled trial (RCT) which aimed to demonstrate the feasibility of recruiting young people to a specifically developed family- and wider social network-based intervention by adapting and then testing a version of adult SBNT (Copello et al., 2009). This involved adapting the original evidence-based family and social network intervention (SBNT) developed and tested with adult alcohol misusers to the youth context. Adaptation of the intervention included the involvement of young people with
experience of drug and alcohol services, as discussed in this paper, as well as consultation with treatment professionals working with young people. A pragmatic, two-armed randomised controlled open feasibility trial followed, based in two UK-based treatment services. In all, 53 young people aged 12-18 years, newly referred and accepted for structured interventions for drug and/or alcohol problems, were recruited and randomised 1:1 to receive either the adapted Y-SBNT intervention or treatment as usual. This paper focuses on learning from one specific element of the study: the involvement of young people in the research process, and the findings of the wider feasibility trial are reported elsewhere (Watson et al., 2017). Overall, the aim was to maximise opportunities for young people’s involvement in the adaptation of the intervention and trial to ensure that both addressed the issues faced by young people with alcohol and/or drug problems. The study was also a case study in doctoral research by one author (L-MB) on how young people’s involvement can be embedded in health services and research[1] (Brady, 2017). This paper draws on this doctoral research and the study report (Watson et al., 2017), and is informed by the GRIPP2 guidance on reporting patient and public involvement in research (Staniszewska et al., 2017).

All publicly funded health research in the UK, including the study discussed in this paper, is now expected to have some element of public involvement (Evans et al., 2014). Involving those who are the focus of research has been found to have a positive impact on what is researched, how research is conducted and the impact of research findings on services and in the lives of those involved (Brett et al., 2014; Staley, 2009). The United Nations Convention on the Rights of the Child (UN, 1989) has established international recognition that all children have a right to the highest possible standards of both healthcare and involvement (Alderson, 2014) as well as a right to have a say in decisions that affect them. The understanding that children and young people should be involved in decisions which affect them has been increasingly reflected in UK law, guidance, regulation and policy in relation to health and social care (Department of Health, 2013; Franklin and Sloper, 2005). But there has been less attention paid to the experiences and impact of involving children and young people than the involvement of adults (Bird et al., 2013).

Involvement should lead to research, and ultimately services, that better reflect young people’s priorities and concerns (Brady et al., 2012; Fleming and Boeck, 2012). This is especially important for young people deemed to be more “vulnerable”, whose voices are often absent from the literature (Richards et al., 2015). For example, users of mental health services (Mawn et al., 2015), those who are looked after (in the care system) (Powell and Smith, 2009) and young people with alcohol and/or drug problems (Brady, 2017). The work discussed in this paper focussed on involvement as commonly defined in health and social care research as “research […] carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (INVOLVE, 2016). But the terminology of involvement, participation and engagement can be contradictory and opaque, compounded by the increasing popularity of co-production, which is becoming an increasingly popular term in policymaking, governance, and research (Filipe et al., 2017). However, work by National Institute for Health Research (NIHR) INVOLVE found that:

[…] (co-production)’s application in health and social care research varies, revealing a lack of consensus around the concept. Some argue that co-production in research is just “really good PPI [patient and public involvement]”. For others it is very different: a much more deliberative process which requires public members and “professionals” to be involved on an equal footing throughout every stage of the design and delivery of research (www.invo.org.uk/current-work/co-production).

Furthermore, there are tensions between the participatory intent of co-production and the “expert”-driven notion of RCTs. The paper explores the lessons emerging from the involvement of a group of young people who are “less frequently heard” and was conducted as part of a PhD that focussed on understanding what it means to embed young people’s participation in health services and research. The main aim was to explore whether and how young drug and alcohol service users could be meaningfully and effectively involved in an RCT.

Methods

The initial plan for young people’s involvement in the Y-SBNT study was to form a young people’s advisory group (YPAG) of 10-12 young people with previous experience of drug and alcohol treatment services. The YPAG is a common model for young people’s involvement in health and
social care research (http://generationr.org.uk/; http://decipher.uk.net/public-involvement/young-people/), and we also drew on published guidance (Kirby, 2004; INVOLVE, 2015; Shaw et al., 2011). The original aim was for the young advisors to work alongside the research team, supported by the study’s public involvement leads, through a series of group meetings. But recruitment proved slower than anticipated, and initial meetings were poorly attended.

We therefore worked with young advisors to develop a more flexible model that focussed on what worked for the young people, recruiting through services known to the study team and in our localities. Involvement centred on consultations with young people at locations familiar to them, supplemented with e-mails, text messages, telephone conversations and postal correspondence. Young people were given the option of ongoing involvement as a young advisor, without obligation to do so. Regular newsletters, with contributions from young advisors where possible, were sent to all the involved young people, with the aim of keeping them informed even if they were unable to attend meetings or be involved in other ways.

**Source material**

A range of qualitative data was collected to inform our understanding of, and learning from, young people’s involvement. Data collection included transcriptions of focus groups with the study’s trial management group (TMG) and steering committee (TSC), phone and face-to-face meetings with the two young advisors who had long-term involvement in the study and conversations from young advisor meetings. The analysis also drew on TMG and TSC meeting notes, newsletters and other materials developed for and with young people, and notes from meetings with organisations supporting the engagement of young people in the study.

A thematic analysis approach was used to discover, interpret and report on themes and patterns of meaning within all of this qualitative material (Braun and Clarke, 2013). Informed by Eisenhardt’s (1989) paper on building theory from case study research, this involved initial thematic maps structured around research questions, a review of the literature and initial reflections. Transcribed materials and other qualitative documents were then coded to test the “fit” of the data with the initial themes identified, refining the thematic maps and identifying broader patterns and themes in an iterative process (see Brady, 2017, ch.4). Ethical approval for the Y-SBNT study (including young people’s involvement) was given by NRES Committee West Midlands – Coventry and Warwickshire, and for the doctoral research by the University of the West of England Research Ethics Committee. All contributors gave informed consent.

**Young people’s contribution to the study**

Young people contributed to all three phases of the study (see Box 1). During phase one (intervention development) they contributed to the design of the intervention, ensuring it was acceptable and relevant to the Y-SBNT study’s target groups. During phase two (the randomised controlled feasibility trial) and phase three (analysis and reporting of data from the feasibility trial) young people’s involvement included input into the design of recruitment and training materials, data collection tools, data analysis and interpretation, reporting and dissemination. This included co-presenting at a conference (Brady et al., 2014) and co-authoring written outputs (Brady et al., 2015; Chapter 8, Watson et al., 2017).

**Box 1: Summary of young people’s involvement in the study**

In total, 17 young people were involved as young advisors in some capacity. The young people came from five areas of England (the West Midlands, the North East and the West of England, London and Oxfordshire). The 17 young people included 12 females and five males ranging in age from 16 to 21 years, with an average age of 18 years. Ten young people were involved in the study once, five twice and two on five or more occasions. We met young people face-to-face on 20 occasions. Contact was also maintained by post, text message, e-mail or telephone call, depending on the preferences of the young people involved.
Findings

"Why we got involved": young advisor’s perspectives

In the spirit of involving young people in all aspects of the study, these findings start with the views of the two young advisors who had the most long-standing involvement in the project (20 and 23 months):

I think it’s important to involve young people in the Y-SBNT project because it’s actually about young people, and I think they should have an input into it and not just the adults. I think it’s important to involve young people who have used drug and alcohol services as they can understand what it’s like for others who are in the shoes that they’ve been in – no offence to people that have got degrees! We have sort of walked the walk, so we know that stuff that other young people using services have to go through on a daily basis.

I wanted to get involved with this project because I’ve always wanted to do something like this to show others that it is possible and there is light at the end of the tunnel – and that no matter what circumstances they’re in they’ve always got a voice. I want to make things better, I actually don’t care as much what I get out of it, I just don’t want to see any other young person suffering the way I had to, or end up dead or in prison. If I can help develop something that prevents that then I will (Young advisor A).

I got involved in the project because I think that it’s important that young people can get the help that they need in the most helpful and supportive way so it doesn’t damage them. I think I’ve gained an insight into research with young people and the opinions of young people held by social agencies and professional networks. A project for young people should definitely consult young people and should be based around their views. Young people who have used drug and alcohol services will be able to reflect on their past use of services and give relevant feedback. Reading the chapter [on public involvement in the study report] and all the findings and the work you’ve done, and I’ve done, made me feel like my views are important. It’s the first time a group of professionals have taken things I’ve said and made use of it, and benefited from it, in an academic project. I’m very much used to discussing my substance use history in a very negative light with no real benefit at the end, but this project has helped me realise that a negative experience has made me wiser (Young advisor B).

The need for flexibility

The young people’s perspectives above highlight the benefits as well as the challenges of working with a group of young people who had complex lives and little or no experience of either involvement or research. This challenged our thinking about how young people were involved in the study. We found that facilitating the input from young people needed to be dynamic and flexible in relation to the rhythms, preferences and commitments in their own lives:

Perhaps that sort of [YPAG] group structure isn’t going to work with these sorts of young people in a project like this. And I think it is good to have a group and people fire off each other […] but I still think the individual-level stuff that we’ve had has been really good and that’s worked well and in a more natural way and perhaps this group need that level of support […] because they’re pretty chaotic, [with] multiple problems (Research team member, TMG focus group).

My mental health has sometimes made it difficult for me to be involved [in the project] […]. But I like how, if I can’t come to a meeting, we can have a phone call instead or you’re just a text [message] away, or we can do stuff by post. I’ve not always been well enough to come and see people face-to-face but that doesn’t mean I couldn’t be involved in things, whereas some organisations I’ve been involved with would have said ‘you’re ill or you couldn’t come to a meeting so you can’t be involved (Young advisor A).

What I’ve liked is the flexibility. I’ve never had to make my own way to one of these meetings […] of course it is a research project so there is a certain amount of formality about it but [individual involvement] keeps it relevant and convenient for to the young person which is always good (Young advisor B).

However, the individual model of one-to-one work with one of the public involvement leads, supported by group work where possible, could lead to some young people being more isolated. One young person, who was mainly involved in this way because of availability and geography, said that, although she appreciated the flexibility and convenience of meeting at a time and place that suited her, she would have liked to meet other young advisors and more members of the research team.
Whilst adults think it is useful for young people to participate, and indeed young people may perceive benefits to involvement, we found that the young advisors often had other priorities:

Young people in my age group are in a very transitional stage of life, it’s hard to commit long-term. Some young people relapse, or simply don’t like discussing their problem in depth (Young advisor B).

Keeping in touch was also sometimes problematic; many of the young people we worked with were in hostel or other temporary accommodation, moving several times during the course of the project, as well as changing mobile phones. Lack of internet access and other personal reasons also meant that many did not have regular access to a computer or the internet or chose not to use e-mail or social media. We addressed this by working on young people-centred ways, discussing with the young people how best to keep in touch.

The need for sensitivity

Involvement in the study required young advisors to draw on their own experiences as users of drug and alcohol services, as well as considering the ways in which their family and wider networks had helped or hindered their recovery. Young advisors pointed out that, in this context, individual involvement may sometimes be more appropriate than group meetings:

This project talks about really personal stuff and the only way I can talk openly and honestly is because I’ve had a chance to get to know you [public involvement lead] face-to-face and because I trust you. It wouldn’t work otherwise (Young advisor A).

The skills and experience young people can gain is often cited as a benefit of involvement, but we found that in a study such as this crediting young people’s involvement can be problematic:

As much as I would love to put on my CV that I’ve been involved […] people might wonder why I’ve been an advisor to a drug project […] it just raises a few question marks […] I do always have that worry that they’re going to think ‘Oh she was a druggie’ and yes it’s the truth but I don’t want every employer knowing that stuff (Young advisor B).

Several of the young people involved in the study were living in care or in crisis, or had co-existing mental health problems. Young people with complex needs may feel powerless about decisions affecting their life and found it difficult to actively say “no” to involvement, instead opting out by remaining silent or not responding to contact (Waldman, 2005). This was certainly our experience as all the young people who opted out of further involvement did so by not responding to contact rather than actively opting out. However, both of the two long-standing young advisors had periods when they were unable to be involved in the project but subsequently re-engaged with it when their circumstances changed. We found that it was important to maintain a balance between keeping in contact and leaving the door open for future re-engagement, and not making young people feel “hassled”.

The role of services

Adults, either parents and carers or professionals, often act as “gatekeepers” to young people and can either facilitate or constrain their involvement (Cree et al., 2002; Hood et al., 1996). It was sometimes difficult to engage the interest of services in the potential opportunities that involvement could provide for young people:

Some professionals don’t see the value of these projects and don’t commit to recruiting young people. Without this you just can’t engage young people and do projects like this (Young advisor B).

Some services were reluctant to pass information on to young people because they were concerned about young people being too vulnerable or, conversely, because they thought that young people might not be “academic” or reliable enough. But when we were able to successfully involve young people in the project, the role of services was crucial both in recruitment and in supporting their ongoing engagement. The young people who become engaged almost all did so because someone in a service understood what we were doing and actively promoted the opportunity to young people and supported their engagement.
Developing a different approach to involving young people

Despite the challenges we faced in identifying and recruiting young people with experience of alcohol and/or drug problems for ongoing involvement in the study, young people were actively involved through all stages of the research. Being a doctoral case study also created the opportunity for additional reflection and learning. Towards the end of the study we worked with the young advisors to reflect on what we had learnt and how we might best involve young people in future studies. Both researchers and young advisors felt that, ultimately, some form of ongoing group was the best way to involve young people; but one that was more flexible and young people-centred than a fixed-location YPAG with a largely static membership. Instead what emerged was the need for a more fluid “community of practice” (Wenger, 1998) in which young people can gradually develop capacity for engagement on their own terms, in what Lave and Wenger (1998) refer to as “legitimate peripheral participation”.

Box 2 summarises the model which we developed in collaboration with the young advisors.

Discussion

While the evidence base for public involvement has expanded over the past decade, the quality of reporting is often inconsistent, which limits understanding of how it works, for whom, and why (Stanszewska et al., 2017). There is a need to collate, understand and disseminate more evidence on the nature, extent and impact of young people’s involvement in research (Brady and Preston, 2017). The Y-SBNT study sought to explore ways in which young people with experience of using substance misuse services could be involved in all aspects of a study of this nature. It provided an opportunity to reflect on how the rhetoric of involvement was operationalised in reality, and to reflect on the learning that emerged from this process.

The Y-SBNT study, as with many studies involving young people in health research, began with an adult-led set up in which plans for involvement were established before young people became involved, rather than collaboratively exploring with young people what would work best for them. In this case, the time taken to establish a group of young advisors and the lack of established YPAG members with relevant experience meant it was difficult to involve young people in the initial stages of the project. If the primary purpose of young people’s involvement in research is for them to comment on how to make research materials more “young people-friendly”, this is nearer to consultation than authentic participation (Cockburn, 2005), co-production or emancipatory models of involvement (Beresford, 2013; Gibson et al., 2012). The dominant discourses and cultures of health services and research often do not sit easily with partnership initiatives with young people (Todd, 2012). Although consultation can be helpful, it can also be an easy way for researchers to “tick the public involvement box” and could also exclude those young people who are less frequently heard, such as those with experience of alcohol and/or drug problems.

**Box 2: A new model of involvement when working with young people**

Hub and spoke model with a core ongoing group of young advisors, who might change over time, alongside one-to-one and small group work and one-off consultations. Working in partnership with services, who would recruit and provide ongoing support to young people. Involve young people in recruitment for public involvement, both initially during visits to services and through “snowballing” through young people recruited as advisors. Establish a group of young advisors before a project started, so that young people are able to be involved in the development of the proposal and support the recruitment of a new group of young advisors. Provide opportunities for young people would be involved at all stages of the research, but recognise that not everyone will want or be able to do so. Varying levels of involvement, from consultation to co-production, determined by young people’s interests and availability as well as the views of researchers. Public involvement lead(s) with relevant expertise supporting all members of the research team to embed public involvement into their work. Linked to wider discussions within the NIHR and elsewhere about making public involvement in research more inclusive, diverse and accessible.
Furthermore, focussing just on consultation limits the extent to which young people are able to participate more fully as partners in, or coproduce, research.

Y-SBNT young advisors spoke about the benefits of involvement for their wider peer group as well as personal benefits, including being able to use difficult personal experiences to create positive change: but doing so safely, required building trust and being sensitive to individual circumstances. Young people have a right to be involved in matters that affect them, but in exercising that right, they should be able to influence how they participate as well as exercise the right not to be involved. Individuals who may be under significant stress might see limited personal benefit of being involved as a research collaborator (Beresford, 2000). It can be particularly difficult to involve young people in research on sensitive topics, such as those that are private, stressful or “potentially expose stigmatising, or incriminating information” (Lee, 1993). We found that inclusive involvement requires providing opportunities for young people who want to be involved to do so in ways that work for them. But if, when and how they can be involved is ultimately a matter of individual choice. The model which emerged from young people’s involvement in the study recognises this and makes a wider contribution by highlighting processes and dynamics relevant to young people’s involvement in substance use research, as well as more widely in public involvement in health and social care services and research. We found that involvement needs to be embedded in everyday practices, systems and cultures, but at the same time young people and those facilitating their involvement need to be able to be “critical friends” and to have the independence and resources to be able to drive a more participatory and inclusive involvement. However, this requires careful consideration of the scope and context for the involvement, including the requirements of an RCT by NIHR regulatory and commissioning bodies, available resources and the limits of young people’s possible influence (Brady, 2017).

There is currently no systematic way of knowing which young people are involved in research, let alone assessing what form that involvement may have taken or any impacts from involvement (Brady and Preston, 2017). There is also uncertainty about how to increase the diversity of young people involved in health and social care research (Brady, 2015). Therefore, it is important to consider how approaches to involvement and co-production may exclude or include young people in substance use research and more widely, as well as to document that involvement. This paper contributes to this body of knowledge, both through the model which emerged through this process (Box 2) and our reflections on the learning which emerged during this process.

Note

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References


Further reading


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David Evans is a Professor in Health Services Research, University of the West of England with a strong focus on patient and public involvement. He initiated People in Health West of England, a collaborative initiative on public involvement in research with the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC West), the West of England Academic Health Science Network, the Clinical Research Network West of England and Bristol Health Partners (http://www.phwe.org.uk/). He was the Principal Investigator on a study on public involvement in research for the NIHR Health Services & Delivery Research programme.
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Co-producing and re-connecting: a pilot study of recovery community engagement

Michael Edwards, Josie Soutar and David Best

Abstract

Purpose – The purpose of this paper is to discuss the design and methodology of the REC-CONNECT project and to determine whether a co-produced approach to research in this area between those with lived experience, those delivering recovery support, and those investigating recovery evidence, generated greater project impact.

Design/methodology/approach – A co-productive approach was taken during project planning, training delivery, data collection and community connecting activity. Workshop evaluations were collected at each training session that provided data on worker/peer volunteer wellbeing, workshop efficacy and organisational factors. Community connectors used REC-CAP for evaluating improvements in clients’ community engagement.

Findings – Whilst co-production as a research approach broke down barriers between theory and practice and delivered a wider community asset map, a number of hurdles emerged: buy-in of all participants; culture/competing agendas; overcoming sense of disenfranchisement of people in recovery; and resources, tools and timescales of research requirements.

Research limitations/implications – This is a small study in Sheffield. As such, data are limited. However, the implications spread to other vulnerable groups in other areas are evidenced, and the principles offer sustainability and partnership that go beyond time-limited projects.

Social implications – Co-production as an approach to research in the substance misuse field has a meaningful impact on the “end-user” of people in recovery through empowerment, better connected recovery pathways and evidence-to-practice-based support models.

Originality/value – The project advanced the emerging principle of reciprocal asset-based community development and designed a co-produced model to create a team of professional, volunteer and peer community connectors to engage and connect new individuals to recovery with existing community assets, and who themselves emerged as a community asset through the project.

Keywords Recovery, Co-production, Assertive linkage, Asset-based community development (ABCD), Community connectors, Quality action research

Paper type Research paper

Background

“There is no doubt that the idea of ‘co-production’ has arrived in the UK”. (Boyle and Harris, 2009, p. 3). Beresford (2013) outlines two significant concerns in co-production: who gets to be involved and how. For this paper, the “who” will focus on stakeholders involved within the substance misuse field (both drug and alcohol), including those with lived experience along with professionals from the voluntary, health, statutory and academic fields, working together on a research project called REC-CONNECT. All stakeholders brought their own agendas, responsibilities, perceptions and motivations for taking part; therefore, the study’s “how” examined their level of buy-in and engagement to a co-producing approach and what impact this had on the research outcomes.

Boyle and Harris (2009) point out that co-production has “emerged as a critique of the way that professionals and users have been artificially divided”, in part by managerial practices. This has resulted in co-production coming more naturally within some sectors, for example, public and voluntary, rather than others, like the researcher/subject of Academia or doctor/patient in Health (Realpe and Wallace, 2010). Imperative to a co-production approach is the blurring of
boundaries between the user and the professional (Nutbrown et al., 2015); therefore, stakeholder buy-in and engagement with co-production can vary depending on a particular sector’s culture of acknowledging the importance of the expert by experience. This dynamic is particularly relevant in the substance misuse field, where the principles for recovery care are undergoing a transition from “expert-patient” relationship to one based on equal partnership, while acknowledging the importance of peer and lived experience (Sheedy and Whitter, 2009).

Co-production and the recovery community

Confronting the stigma of addiction is a significant hurdle for those who seek to embark on a recovery journey. A study in the USA found that within the general population addiction was more stigmatised than smoking or obesity (Phillips and Shaw, 2013). Against this backdrop, Beresford (2013) talks about the most disadvantaged people often being excluded from co-production projects due to an unfair assumption that they are not able or interested in being involved. However, it could be argued that co-production has been embedded for some time in community-based addiction support, albeit restricted amongst people in recovery and described under different terms. The validity of the “lived experience” as an authority and the role of peers in co-producing social groups is well established in peer-based recovery communities and mutual aid groups like Alcoholics Anonymous. White (2004) chronicles as far back as the 1700s, where Native Americans were using group-based recovery “circles” to achieve sobriety. Co-production in substance misuse as a method for reciprocity and mutuality is as relevant today as it was then. Valentine et al. (2007) assert that a core element of any vibrant Recovery Community Organisation is an authenticity of voice, in that “the voices of people who have experienced all forms of recovery are heard and embraced”.

Pestoff et al. (2010) outline three key motivations for people willing to be involved in co-production: self-interest, civic obligation and belonging to a co-producing social group. What is significant about the substance misuse field is that all three of these motivations are already firmly embedded within the recovery community culture. For people with a history of substance related-harm, engaging in research activity that explores models to improve sustained recovery is not just altruistic but serves some form of self-interest, and fulfils a broader principle of “giving back” that is seen as critical in mutual aid recovery groups. The recent UK Life in recovery survey (Best et al., 2015) highlighted that 79.4 per cent of the 802 respondents felt a civic obligation to volunteer in community groups or civic groups and at least 70 per cent had attended mutual aid groups.

Co-production and substance misuse treatment

On a UK policy level, the importance of the lived experience in substance misuse treatment has been acknowledged since Professor Strang’s (2011) recovery-orientated drug treatment report on behalf of the (former) National Treatment Agency. Peer-based approaches to both drug and alcohol treatment have subsequently become an expected part of more formal, medically-driven treatment pathways. With this, focus has a significant shift in the dynamics between service user and service provider, with the former considered an asset that can help shape, the latter into agents of change rather than simply being deliverers of a service. However, on the ground, this redistribution of power can cause tensions within long-standing organisational hierarchical structures, posing challenges in terms of partnership working and co-production approaches that may be perceived as infringing on areas of clinical expertise and knowledge.

Co-production and research

The co-production of knowledge has an emphasis on the need to understand the research subject’s experience and context (Pearce, 2008). Co-production in research has been described as facilitating empowerment and providing opportunities to learn and reflect on “lived experience” – a move away from just a “dialogical” approach between researcher and subject towards “transformative research” (Durose et al., 2011). This directly challenges the positivist tradition in academia where truth is believed to only be found through objectivity and standing separate to the subject (Pearce, 2008). As with clinical expertise, co-production in research has implications on power dynamics as it asks the academic to relinquish their role as the creator of knowledge and value “experiential expertise” (Porter, 2010).
The subject of this paper, REC-CONNECT (recovery connections), is a research project that was not specifically focused on examining co-production within substance misuse research; rather, it was about identifying and tapping into community resources for those early in their recovery journeys. Funded by the Health Foundation, REC-CONNECT is a pilot project to test if a recovery connector model improves the engagement of vulnerable populations in community groups, starting with a group in early recovery from alcohol and drug problems (McKnight and Block, 2010). Dennis et al. find that two-thirds of people seeking recovery relapse within the first year (Dennis et al., 2007), but risk gradually reduces across the first five years of the recovery journey. There is clear evidence, for both alcohol and drug use, that changing social networks to those supportive of recovery and engaging in meaningful activities is highly protective of recovery from substance dependence (Longabaugh et al., 2010; Best et al., 2014; Best, Beckwith, Haslam, Haslam, Jetten, Mawson and Lubman, 2016).

REC-CONNECT utilised people in recovery, as peer delivered support has shown to be a key evidence platform for effective recovery (Humphreys and Lembke, 2013). Engaging in such positive social networks has been associated with the development of coping skills necessary for long-term recovery (Moos, 2007, 2011). Furthermore, the value of connectedness is underscored by the “CHIME” mental health recovery model that identifies connections as one of the five core components of effective recovery support (along with hope, identity, meaning and empowerment; Leamy et al., 2011).

**Asset-based community development (ABCD) and assertive linkage**

Referred to as “beyond co-production” (Russell, 2015), REC-CONNECT uses an emerging literature about ABCD (Kretzmann and McKnight, 1993), specifically for alcohol and drug using populations (Best et al., 2013). The model, “reciprocal community development”, was developed by one of the project teams and piloted in partnership with the Salvation Army Eastern Division in Australia. The success of the Australia pilot has been published in a peer-review journal (Best et al., 2014), where the indicators of success included increased staff participation in community activities and greater partnership working between staff and service users.

**Paper aims**

This paper aims to reflect on the co-production element of the wider REC-CONNECT research project. It will focus on the dynamics between the researchers, organisations involved and people in recovery during each stage of the project (design, delivery, data collection, analysis). The paper will reflect whether the project achieved increased staff participation in community activities, better partnership working between different fields and greater results through co-production, without compromising the integrity of the research design.

**Method**

Sharing many philosophical elements, quality action research (QAR) provides a natural platform for designing co-production projects. Whilst defined more as a style rather than method of research, QAR is the term used for “research in which the researchers work explicitly with and for people rather than undertake research on them” (Meyer, 2000, citing Reason and Rowan, 1981). Common elements to QAR are its participatory character, democratic impulse, critical reflection on both the process and the outcomes and parallel contribution to social science and social change reflecting the interface between research and practice development (Meyer, 2000). REC-CONNECT was in intent, design and structure consistent with the aims of QAR. The project adopted the view that co-production was less a method for study and more a way of thinking in order to break down barriers.

What makes REC-CONNECT relevant to co-production practice is bringing together professional and recovery peers to jointly train in assertive linkage and ABCD mapping, supporting and growing a “mixed” group of community connectors and assessing their impact on wellbeing of the target population. In other words, what is unique about this model and separates it from prior
ABCD initiatives is that it has the goal of building community engagement in all participants (both professional and service user) – the research is applied and has a clear legacy. The experiential knowledge is found, not just in the lived experience of the service user or practice experience of the professional, but on the equal and shared experience of being a citizen of Sheffield. Thus, the method should not only improve outcomes for people in recovery but also improve feelings of efficacy in staff, and through this increase wider community cohesion and wellbeing.

**Phase 1: design**

A project lead group was formed with representation from academia, NHS, public and voluntary sector (see Figure 1). The project lead group agreed the purpose and process of the study, establishing context and methods for staff and service user (people in recovery) participation.

REC-CONNECT researchers consulted Sheffield Addiction Recovery Research Panel (ShARRP) to ensure Public and Patient Involvement (PPI) at design stage. ShARRP consists of people in recovery, carers and family members who learn about and review research projects that have a specific focus on addiction and/or recovery, and they have a key role in quality assuring and supporting the feasibility and the application of addiction research projects in the city. Its observations and contributions informed the project’s design throughout its stages.

**Phase 2: delivery**

For service users (experts by experience), participation was fully voluntary and was planned for Phase 2 onwards.

Project delivery was segmented into three parts. The methodology is based on exposing both statutory, non-statutory organisations and those in the recovery community to both train and work together to improve the health and social capital outcomes for all, by:

1. Training 20 alcohol/drug practitioners and service users in the principles of assertive linkage into communities and how to build links with positive social groups. Workshops included the mapping of community assets through co-production in order to:
   - establish as wide a map of assets as possible;
   - raise awareness of local recovery resources; and
   - identify community connectors to support people new to recovery to engage in community groups and events that will build their personal and social recovery capital.

**Figure 1  Project phases and partner engagement**
2. Facilitating community connector recruitment, training and support, based on the assertive linkage model, which was co-designed by a mixed group of practitioners and service users. It was imperative that this stage of delivery was guided by participants in order to establish ownership of the model and encourage cross-sector partnership working. This is consistent with the work of McKnight and Block (2010) who identified connectors as critical to the ABCD approach.

3. Providing on-going support for 15 community connectors so they could engage with 20 people new to addiction recovery in Sheffield. The connectors assertively linked people into local resources and pro-social groups and activities, increasing their social and community capital resources, supporting them to engage with pro-social groups and to sustain their connections to maximise the benefits accrued. The aim was to map the growth in recovery capital in the new to recovery group to assess the benefits and impact of reciprocal community development work.

Phase 3: data collection

The project used two forms of data collection:

1. During stages 1 and 2, data were collected related to worker/peer volunteer wellbeing, workshop efficacy and organisational factors using a bespoke evaluation form adapted from the Texas Christian University Organisational Readiness for Change workshop evaluation (WEVAL). Evaluations were collected at each of the training sessions. Additionally, the maps of community assets that emerged from the workshops constitute an additional source of “data” for research and for application purposes (see Figure 2).

2. During stage 3 the REC-CAP (Recovery Capital; Best, Edwards, Mama-Rudd, Cano and Lehman, 2016; Best, Irving, Collinson, Andersson and Edwards, 2016) instrument was utilised as a way to establish baseline data at the point of connection with people in early recovery, and was administered by the community connectors to add to their ownership of the project. REC-CAP evaluated whether the REC-CONNECT model improved engagement in community groups and improves a range of recovery outcomes. The REC-CAP involves a series of

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Figure 2  Peer and community support

![Diagram of Peer and Community Support](image)

Spaces
Assessment and rehabilitation centre (ARC)
Food halls
Emmaus charity
Slimming world
Model aeroplane club
Families together
Women in recovery
Together women
Fitzwilliam centre
Sleaford centre
Spar charity
Weight watchers
Royal society of the blind (RSB)
What about me (WAM) sheffield

St. Mary’s church
Sheffield alcohol support services (SASS)
Recovery coaches
Somali centre
Buddhist centre
Netheredge cooking classes
Mosque
Camraders
Commas
Sheffield working women’s opportunities project (SWWOP)
Sheffield hallam university (SHU)
Corner project
Ben’s centre
Sheffield addiction research recovery group (SARRG)
Hospitals
Buddhist centre
Sheffield alcohol support services (SASS)
St. Mary’s church
Royal society of the blind (RSB)
What about me (WAM) sheffield
questions designed to capture recovery capital, defined as “the breadth and depth of internal and external resources that can be drawn upon to initiate and sustain recovery from AOD (alcohol and other drug) problems” (Cloud and Granfield, 2008). Best and Laudet (2010) identified recovery capital in three broad categories – personal, social and community resources – and the REC-CAP seeks to identify what capital an individual possesses that acts as strengths to an individual’s recovery. The community connector was responsible for working through the REC-CAP both at the baseline collection stage and three-month follow-up.

**Phase 4: analysis**

All data were entered and analysed by the researchers at Sheffield Hallam University. The WEVAL was summarised and shared with partners and community connectors. Completed REC-CAP questionnaires, both baseline and follow-up, were anonymised and sent to the researchers for quantitative analysis. In total, 63 WEVALs were received, which broadly endorsed the value of training, benefit to job and increased knowledge.

**Findings**

**Co-production during design phase**

The three non-academic, lead organisations were selected based on their expertise in the recovery field; their focus on the Sheffield community and representation of cross-sectors. Although partners were from different fields, all were members of the Sheffield Addiction Recovery Research Group (SARRG), a multi-agency/peer group which aims to support recovery-focused research activities; therefore, they had well-established relationships with each other and the researchers.

Senior representation was sought and provided, which facilitated strategic ownership to the approach and a commitment to sharing power/project decision making through co-production. Lead organisations were involved from the planning stages, which proved invaluable to helping to ensure aims were representative of all agenda’s and a collective approach taken to project design.

**Co-production during delivery phase**

At each delivery stage, co-production was implemented to design subsequent stages:

- **Information sessions** – 3 sessions were held with 52 attendees, to introduce the project rationale, model and methods.
- **Workshops** – using the feedback from the information sessions, the research team subsequently designed workshops around ABCD and assertive linkage, delivering them to 41 workers and service users. Workshop participants completed ABCD maps and identified attributes of a community connector, thus co-designing the “job description” for their role. At the conclusion of the training events, participants registered to become community connectors.
- **Community connector training events** – 30 connectors attended.
- **Connector launch event** – 20 connectors attended and completed the design of the project.

From the 21 community connectors who were ultimately recruited, 7 were NHS staff, 7 were voluntary sector staff and 7 were people in recovery (the recovery status of staff members was not investigated). Although evaluation feedback was quite positive, there was a significant withdrawal rate from practitioners who attended the information sessions to those signing up to become community connectors. This meant the aim of increasing staff participation in community activities was limited to the 14 staff who became connectors. However, accounting for repeated attendance of some of the participants, about 100 workers, volunteers and peers were exposed to the project’s principles and methods over the course of the project. But better communication about research design, pre-training would have potentially led to more sustained buy-in from staff in some of the participating organisations.
There was very little evidence of stigma or exclusion between the professionals and service users. Challenges around stigma were more self-determining limitations of the people in recovery around their own identity, validity of voice and confidence. People in recovery tended to fall within two-groups: the gatekeepers (Pearce, 2008), who were very vocal throughout the project and wanted to do everything; and the passive consumers (Realpe and Wallace, 2010), who were looking to be told what their role and their usefulness was.

During the design phase much was discussed amongst the project leads about service user motivation and ensuring that the “hard to reach” voices of people in recovery were included. What was overlooked was establishing buy-in from staff participants, with a “presumed” motivation. Some were simply told a time and place to attend mandatory training, with little pre-information on the aims of the project or the co-producing nature. In particular, NHS staff appeared less motivated to participate as a result of going through a significant internal restructure. A few participants described feelings of “suspicion” around the aims of the project and refused to complete the WEVAL evaluation (even though it was anonymous), as it asked for feedback on any organisational barriers to implementation. When planning the training sessions, researchers were unaware of these organisational challenges and the impact this would bring to levels of trust for the project. Equally, NHS professionals struggled with the project dynamics and reported a lack of clarity, feeling frustrated with the “woolliness” of the co-production approach, the impact on their already-stretched time and a constant cycle of reflection on both the process and outcomes. This suggested that one of the major challenges and future questions is around how professionals can reconcile their professional roles and identities with partnership and participation in community engagement and co-production activities.

To this end, the voluntary sector staff were, on the whole, more comfortable with the user-led mechanism to planning, delivery and management. As a result, early on in the delivery phase (when service user recruitment was initially low), we were able to expand participation to additional voluntary sector organisations, which greatly aided connector recruitment, engagement and retention.

A main challenge faced was simply coordinating schedules between a fragile cohort of participants and extraordinarily busy staff and service users. The community connectors met regularly once client recruitment was underway and the meetings were pitched as the coming together of “experts” to build focus on group skills to empower individual capability and confidence. These meetings involved senior representatives from the lead partners, in addition to community connectors from various organisations. This was an invaluable opportunity to share and reflect on experiences, receive project updates on timescales and recruitment progress and address any project challenges as they arose.

**ABCD mapping exercises**

The ABCD mapping exercises generated a substantial body of data creating an asset directory identifying 134 community assets. The mix of sectors and professional/service user participants provided broad range of knowledge and networks of city assets. These were classified into four domains – education, training and employment; sport and leisure; mutual aid and recovery; and peer and community participation – with 22-35 community assets identified per domain (see Figure 2). That directory is a living document and a core component of the project learning sustainability within substance misuse services and groups in Sheffield.

**Co-production during data collection**

The original research design had to evolve due to the co-produced approach to data collection. The research goal of achieving REC-CAP follow-up evaluations from all service users was not fully met, partly because of the challenge of reconciling quantitative methods within a co-production process where some connectors felt uneasy about the amount of data collection. The REC-CAP was designed, not just as a research instrument, but a tool with practical applicability in peer treatment and recovery settings (Best, Edwards, Mama-Rudd, Cano and Lehman, 2016; Best, Irving, Collinson, Andersson and Edwards, 2016). However, feedback from some
connectors was that the REC-CAP was quite lengthy when conducted in conjunction with the other outcome monitoring and assessment requirements already embedded within individual agencies. This led to recruits not being as willing to engage in these follow-up activities because they perceived the research aspect, i.e. REC-CAP survey, as interrupting their “recovery time” as they were actively connecting and engaging with community assets. One service user expressed the sentiment by stating that he “just wants to get on with it”, as reported by his connector. With the primary goal being to assist people in recovery to make connections to community assets, this “failure” is only insofar as the research is concerned.

**Co-production during analysis**

Broadly speaking, there was an element of co-production in some of the data analysis as the connectors analysed and collated the community assets identified during the ABCD mapping exercises. However, Phase 4 was the only stage of the project that did not involve any substantive form of co-production, with university researchers being responsible for analysis and then sharing findings with participants. A requirement of the grant funding was completing the project within a 15-month timeframe that practically would not allow for training non-academics in research techniques. Consequently, this did add some form of separation between connecting theory with practice for wider participants. It also raises questions about relinquishing power and academic authority in the co-production of knowledge (Porter, 2010). However, participants were involved in a project ending celebration event and dissemination strategy discussion, along with assisting the project team in making contacts for project spread.

**Discussion**

**Co-production as a research method**

The project was hugely successful and accomplished its goals of educating workers and peers and connecting people new to recovery services. The project developed a large and engaged cohort of great connectors, an extensive network of community assets to link into, and a strong organisational partnership between the local government, third sector and academic communities. Hindsight tells us that the project could have been transformative if participants had been involved from the beginning through to the analysis stage, for example, designing simplified data collection mechanisms or training non-research participants in data analysis techniques. This raises challenges around resources and timescales, but nevertheless is an important barrier to consider. One of the key successes of the project was the university becoming a visible and accessible resource that vulnerable populations could access without fear.

The project benefited from the presence in Sheffield of the multidisciplinary SARRG and the PPI ShARRP. The formation of SARRG and ShARRP reflects that both higher education institutions in Sheffield (Sheffield Hallam University and University of Sheffield) have a commitment and acknowledgement of the usefulness of interactive knowledge production in the field of substance misuse research. Universities and research departments should consider implementing similar structures to widen potential audiences of their research findings in their specialist field of research to facilitate co-production and encourage the change processes needed for progress in our societies.

**Breaking down barriers**

Valuable feedback from participants included the success of the project in connecting previously siloed agencies and organisations. The relationships formed or enhanced within the project team and the lowering of the separation between researcher, professional and peer-driven services is a project success that will be key for sustainability. What the project has done is a partnership for co-production that involves statutory organisation and NGO’s, with a local university at a strategic level and engaged a range of individuals who are both professionals and volunteers to work together to generate and link to community resources. The project demonstrates how the university is a valuable physical community resource and provides a venue for breaking down barriers.
Sheffield is fortunate to have a vibrant and robust recovery community that was able to leverage their existing assets and relationships to promote, advance and sustain the project. This was facilitated by the strong online presence of the Sheffield Recovery Community, and its active Facebook page. What the project added to this was the generation of both a network of cross-sector connectors (brining with them existing social resources) and a clear collective purpose that included training and team-building to develop a visible and meaningful identity and presence in the city.

In other areas of the UK, drug and alcohol services are provided by a myriad of NHS and non-NHS organisations and the project approach used in Sheffield may result in starker improvements in building networks and cross-working. Having the collective purpose of researching new recovery models can break down barriers between sectors, with Universities acting as a catalyst in the bringing together of interested parties. The project evaluation and learning could also be explored as an approach to aid networking and increasing social capital in other vulnerable cohorts.

**Vulnerable subjects**

Purely viewing the people in recovery as the “vulnerable subjects” was a significant oversight of the planning stage. The project relied on staff being motivated to make a difference or bring about change, which Pearce (2008) outlines can have the opposite effect if participants feel it is meaningless or they are focused on “survival”. Staff do not operate in a vacuum and there were challenges around the timing of the project. Nationally the NHS interest in co-production has coincided with significant internal changes and new models of health services as a response to the consequences of modern lifestyle (Realpe and Wallace, 2010). Co-production requires the redistribution of power between all stakeholders involved. In the pursuit of ensuring the experience was meaningful and non-tokenistic to people in recovery, the project failed to nurture similar feelings of empowerment in staff (pre-delivery) causing tensions from the outset. This demonstrates that when determining the “vulnerable subjects” within the researched, researchers may need to look beyond assumptions of disadvantaged groups and consider objective conditions, competing agenda’s, sector cultures, funding regimes and other factors.

Another learning point from the design phase regards the non-inclusion of people in recovery. It could be argued that power was delegated to this group through seeking feedback and approval of project design through ShARRP. However, certain challenges faced during delivery and data collection phases may have been identified earlier if those with lived experience had been part of the project lead group during the design phase. Lead organisations found that motivation for engagement in the project amongst users of their service was high. It was, therefore, determined early, following a project team meeting, to include service users in the training cohort to join the alcohol and drug workers targeted in the model.

**Sustainability**

The REC-CONNECT project, partnership and produced resources could be sustained and accommodated by existing services in Sheffield, albeit without on-going evaluation of outcome measures in the robust and systematic manner that Sheffield Hallam University has provided during the course of this project. The network of community connectors and partners may benefit from attending existing service-user focused forums where information on latest developments in the recovery community are shared or further social mapping with input from research organisations maybe incorporated. This will help the project to be embedded within the Sheffield recovery community. The project has created a vibrant network of connectors through a process of co-production and social network building and this is a hugely valuable resource that could be applied in a wide range of areas.

**Summary**

The project has highlighted the opportunities for partnerships to generate co-production by building existing networks and challenging partners to design and contribute to new ways of
working together to support the recovery journeys of vulnerable populations. In the paper, we have shown how a model designed to train and support community connectors has generated a diverse network of community assets and has created opportunities for a consortium of volunteers, peers and professionals to contribute to recovery by building networks, generating community and social capital and creating a model for supporting community growth.

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**Further reading**


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Abstract

**Purpose** – The purpose of this paper is to report the findings from reflexive data collection on the evolving co-production research relationship between the two “worlds” of community and academia: people with lived experience and their community intermediaries and academic researchers. It reports analysis of reflections on experience as the different partners explore and evaluate their own experiences of co-productive research within the context of substance use recovery co-production research.

**Design/methodology/approach** – The research uses reflexive data from perspectives of an intermediary community partner, academic partners, and community researchers on experiences of a series of co-productive research projects. The aim is to identify thematic features of the co-productive experiences from different positions and through the process of adaptation to a co-productive relationship.

**Findings** – This paper outlines what has been learnt from the experience of co-production and what has “worked” for community and academic partners; around the nature of co-production, barriers to performance, and its value to participants and the wider recovery research agenda.

**Originality/value** – This paper reports a unique perspective on a developing methodology in health and social care, contributing to a growing body of knowledge pertaining to experiences of co-production research.

**Keywords** Reflection, Community, Co-production, Recovery, Research, Substance use

**Paper type** Research paper

Introduction

This paper reports the findings from reflexive data collection and analysis on processes of co-production research from the diverse world-views of community recovery partners and academics involved in a series of co-production research activities, collectively titled “Recovery voice in action”. The project series was an exploration of the meaning of recovery as understood by people with lived experience of substance use recovery. It involved community organisation to facilitate data collection via participant-controlled computer-assisted structured interviewing (The VoiceBox) (see Cox et al., 2016), using a co-production approach to method design, data collection and interpretation. Involved partners were academic researchers, in-recovery community members and a community intermediary. A key aspect of this series was the incorporation of people in recovery as VoiceBox, “crew” as community researchers; design consultants, recruiters/outreach, interviewers and data interpreters. “Recovery voice in action” was a community project of involvement and engagement, consisting of a loose affiliation of in-recovery members around the VoiceBox (Crew), community intermediary (AC) and academic facilitators (LW and NC).

**Co-production**

Co-production is becoming increasingly important to healthcare research as it meets the current requirements for patient and public involvement and the need to produce impact which is meaningful to end-users of services (Department of Health, 2006). As an approach to evidence-based practice, it has become part of the UK health policy that adopts a “citizen consumer” approach, ensuring that end-users of services and the community are involved in commissioning, prioritising and collaborating in health research (Shippee et al., 2013).
Co-production is becoming adopted across the public sector in the UK in recognition that it improves service planning, local representation and the adoption of local knowledge, and improves engagement and ownership among community members (Coote, 2002; Needham and Carr, 2009). The key principles of co-production research are argued to be mutual consultation and decision making between stakeholders, resulting in a sharing of diverse knowledge between professionals and the communities affected by the research (Nowotny et al., 2001). However, co-production methodologies are said to be challenging for a number of issues. Co-production challenges the conventions of “traditional” research by being trans-disciplinary and removed from traditional academic organisation (Gillard et al., 2012), with few models or guidelines for its performance (Kothari and Armstrong, 2011). However, Durose et al. (2011) argued that, while it also challenges conventional methodologies by its reflexivity, it has become a vehicle for social justice, enabling democratic knowledge production and grassroots representation. In this way, for Durose et al. (2011), it reduces the power differential between the expert and the layperson.

There are many examples of co-production in mental healthcare, and a growing body of knowledge which explores methods and challenges. For example, Manikam et al. (2016) used co-production to determine community mental health priorities among UK South Asian families, finding themes emerging from the community researchers not anticipated by the academic partners. Reeve et al. (2016) collaborated with voluntary sector and primary care providers to roll out a complex care model, finding the need for ongoing flexibility in response to challenges encountered. It is, however, recognised that co-production is demanding of time, resources and commitment (Walter et al., 2003; Sadler et al., 2017), and requires leadership, purpose and the right mix of partners and roles (Hunter and Perkins, 2014). For people with alcohol use problems, it is recognised that, while involvement in research can be part of the recovery process, stigma and the risk of relapse makes this group of co-producers particularly vulnerable and presents additional responsibility to academic partners in research (Alcohol Research UK, 2017).

Agreed key principles across different areas of healthcare co-production are the reduction of the power differential between agents and equal exchange of knowledge. For Boyle et al. (2010), this means recognising and valuing the assets and strengths of end-users, addressing whole person (and community) contexts and adopting holistic approaches to solutions.

Co-production principles and challenges

The discussion paper by Boyle et al. (2010) reports on an exploration with co-production practitioners in the UK to identify key approaches in making co-production a mainstream method for inclusive approaches in public service development. They suggest that co-production demonstrates specific elements in recognising people as assets and enhancing these, working equally and in partnership (mutuality and reciprocity), working with peer support networks, and having integrated partnership working between different agents. For the academic partner, the role should be one of facilitating rather than leading or delivering.

In the N8/ESRC-supported exploration of co-production research projects, Campbell and Vanderhoven (2016) described co-production as a meta-methodology in which boundaries between pure and applied research are blurred, and a process that confers public benefits beyond academia or professional practice. They argue that co-production research should not only still strive for academic excellence but should also present flexible working between partners to produce inclusive and actionable evidence.

The principles of co-production present a challenge to conventional research for Pain et al., (2015). They suggest that the “donor-recipient” model (Pain et al., 2015, p. 12) of top-down, academically informed practice or policy recommendations, is not compatible with co-production methodology. It could be argued then that co-production requires an epistemological paradigm shift especially, as Pain et al., (2015) argued, to capitalise on the value-added aspects afforded by co-production.

The mutuality and reciprocity principle of co-production suggests, for Boyle et al. (2010), a sharing of responsibility and expectancies and, as expressed by Wehrens (2014), an interdependent flow of knowledge in which partners are not seen as existing in different, rigid, domains but where boundaries become negotiated and flexible. To achieve this principle,
the research process should involve all relevant partners (Hunter and Perkins, 2014) and be meaningful (Garfield et al., 2016), so that the research question and project planning are as much driven by the community members as professional researchers or policy-makers.

Durose et al. (2015) suggested that the credibility and methodologies of co-produced research impact on the quality of the evidence. As co-production lends itself to qualitative approaches, evidence produced would not be highly rated in traditional research hierarchies. However, this may be part of the paradigm shift of co-production in that the evidence should strive to have greater strengths in its applicability, especially as it can lead to stronger ecological “ownership”. This also means a different approach to dissemination. Durose et al. (2011) indicated that there is accountability to, and within, the partner communities, that dissemination may inevitably become activist in promoting change in the light of community-produced evidence. This has implications for the researcher who is more normally charged to remain the objective, reflective scientist.

While co-production addresses the problems of injustices of representation, and offers a methodology for research to broaden the knowledge capture, its adoption as a legitimate and valued contribution to actionable evidence currently outstrips the recognition of, and response to, the ethics challenges it presents. Vayena and Tasioulas (2013) and Durose et al. (2015) all recognised that the methodology first is required to be scientifically rigorous, and this is to meet an ethical consideration of research burden on participants as much as a research quality need. However, it is also argued that researchers often under-appreciate why people engage in research by ignoring altruistic motivations, and base participant involvement on a protectionist approach, so presenting barriers to valuable and ethically appropriate research insights (Cox and McDonald, 2013). Therefore, the qualitative nature of the evidence should be valued as research evidence, and that co-production has the potential to contribute value-added authentic and trustworthy evidence that has applicability.

It is suggested here that the overall challenge for co-production research is managing the conflicting demands of conventional research with effective co-production methodologies. The demands of co-production research may be incompatible with traditional forms of research (Pain et al., 2015) that best utilise the expert-participant/subject forms of methodology such as comparison and experimental studies. This paper collates reflections of researching co-productively in the field of recovery from problem substance use to address the challenges found from the experiences of co-production partners. The aim is to create a working aide memoire, using accessible language, for the process of co-production research between the two worlds of academia and those who are often marginalised and stigmatised, such as people with lived experience of substance use recovery.

Recovery voice in action

Evidence for this paper came from multiple reflexive data sources within the “Recovery voice in action project”, conducted over a three-year period (2013-2016). VoiceBox Inc, a community research organisation and the project intermediary, undertook a commissioned evaluation of The Brink, a dry bar in Liverpool, run by a national drug and alcohol treatment service. The evaluation gathered a range of digital assets including film, photography and audio recordings of interviews, stories and testimonies relating to experiences of recovery. After completion, the participants and VoiceBox Inc continued working together forming the “Voices from the brink” community research “Crew” to explore the value of the digital assets in providing a better understanding of the meaning of recovery. Academic researchers were invited to join the project and a relationship was developed based on knowledge exchange and asset sharing. A series of questions were developed by the Crew that were then explored through a traditional sequence of engagement, data collection, analysis, and dissemination/showcasing, with over 300 people at diverse recovery events. Both event attendees and the recovery community researchers themselves were interviewed as part of this research. Interview questions were specific to each event and focused on the experience of recovery, recovery identity, and mutual aid. The data were captured in video diaries, blogs, and recorded interviews.

At the same time, there was a rolling programme of data capture of participant action research (PAR), using both formal and informal critical reflection to monitor and observe the process of co-production work. This set of data occurred in the form of de-briefing discussions,
dissemination planning and informal reflection, and captured as video diaries, written notes, blogs, or recorded interviews. Through reflection on the PAR process, research members thus explored “what works”, identifying barriers, facilitators and practical and theoretical constructs that help explain, critique and define co-production research.

Methodology
Gillard et al. (2012) suggested that reflection on the processes of co-production research presents an opportunity to explore stakeholder involvement in research, and that reflexive approaches offer a useful tool in exploring this methodology. In this paper, we have adopted a reflexive process through the collection and analysis of the documented experiences of co-production research during the “Voices in action project”. Ethnographic reflexive strategies during research procedures allow the researchers to reflect on the experience in process (Pelias, 2016). This approach to ethnography meets co-production research principles by acknowledging that all informants are knowledgeable of the context, it accommodates the temporality of the social context and ensures that the data (text and digital formats) are part of the social context (Smith et al., 2006).

Data collection and analysis
Reflexive material was collected from all three partners (community researchers, academic researchers, community intermediary) over the three-year period in the form of individual and group reflections, gathered contemporaneously in written and digital formats, including diary entries, showcasing presentations, film and audio recordings. As described above, reflections on the process of co-productive partnership working were continuous throughout the whole project between academic, community intermediary, and partners with lived experience. The project series afforded opportunities for all partners to discuss methods of working, identify barriers, and to problem solve, while exploring and testing the principles of co-production and reflecting on the barriers and facilitators.

The principles of co-production underpinned the analytical approach. Partners met opportunistically during research project and dissemination events or meetings at which reflections were recorded. Analysis of material was iterative: over the duration of the meetings consensus-seeking discussion took place which enabled participants to organise and “make sense” of experiences of the co-production process. Analysis of reflexive material took into account contexts of data collection and the impact upon each set of partners. At the same time, informal discussion took place throughout the project series to address issues arising from the friction between co-production and conventional research processes.

Findings
The reflections identified “clash points” of the different ways of understanding (Popay, 2006), termed here “rub”, where co-production methodology and procedure clashed with traditional research methods, producing barriers to inclusion, empowerment, representation. The reflections also served to identify the problem-solving approaches used to ensure the research process adhered to co-production principles while ensuring quality findings. From this came the “R” themes; a checklist of consistent themes in co-productive accessible language that illustrate the challenge to more conventional research; how it is valued, assumptions of what research is, procedural barriers to authenticity and representation, and issues of participant engagement and meaningful inclusion. They are placed in alphabetical order as the research team concluded that no one was more important than any other.

The “R” themes of recovery co-production
Reach. A key factor from the outset was that the outcomes of co-produced research would be shared with a wider group of stakeholders than would normally have access to “traditional” research outlets such as peer-reviewed academic papers. As the community researchers
(people with lived experience) were actively involved in the research process, they had a stake in the research and understood it. Channels of communication and research translation became embedded in the co-productive process throughout, with community researchers extending the methods and routes to dissemination. Snowballing became commonplace, working through recovery communities and networks (face to face and virtual), enabling the research to get very close to the issues through the people experiencing them:

This research means something to us – it’s grounded in who we are and what we know – we want people to hear about it and to learn from it – me taking this to the services and groups that I know or talking to others and getting them to talk about it is important to me – I want to get this out there (community researcher).

Reason. Our reflections highlighted that reasons for initial and ongoing participation varied considerably for different people and changed over time. For community researchers, the fundamental reason was predominantly to promote recovery and help others. This was clearly a positive factor in sustaining the research process and “pushing” for the activity to be extended wider than the original focus. Whilst it is not the intention to negate personal motivations of academics, the agenda was inevitably linked to the university role and the need to demonstrate research activity. Motivating factors for academic researchers and their institution were to produce research for career purposes or for the organisation to improve its Research Excellence Framework (REF) ratings. It was also clear that research activity goals can often be governed by the funder. During the life of the project, some funding was accessed, but most was without external resources. This led to different outcome expectations. Where funding was secured, traditional research outcomes (practice recommendations, reporting, dissemination) continued to be used as benchmarks for success, and to signify the completion of the research activity. Therefore, funders’ expectations were privileged over community needs and goals. Although a lack of funding presented significant barriers for community researchers, it afforded a level of flexibility and freedom to enable the partners to allow the research agenda to unfold. Overall, the sense was that the challenges and implications of co-production were poorly accommodated by the university’s institutional processes, which meant support was experienced as tokenistic and even obstructive.

Reciprocity. Community researchers appeared less comfortable with sharing knowledge than academic researchers. This illustrated an issue particularly with working with communities in which low self-esteem and stigmatisation are barriers to inclusion, such as a recovery community. Although community researchers initially struggled to acknowledge their power in the knowledge they possess through their experience and its value to the research, there was a clear shift over time as a co-productive culture “bedded in” and a co-producing research group identity (communitas) (see Cox et al., 2016) emerged.

Recovery. The process of being involved in research made a positive contribution to people’s recovery. This included people’s understanding of themselves as people, and as people in recovery, with many examples pointing to individuals’ self-learning, the impact of sharing experiences and the self-esteem that came with realising the importance of their role in the research:

What comes up for me is the level of growth, for me personally and for others in the Crew. When we first talked about the idea of research, I thought it was something that people from universities did and came and asked questions [...] I wasn’t long out of treatment and my recovery was my priority, not talking to people about research. I now know that it’s not like that. Being part of this has been part of my recovery [...] I’m a researcher in my own life and helping others in similar situations to me [...] that’s so good for my recovery (community researcher).

I’ve been in recovery for a while [...] I’m used to talking with people within the groups I go to and sharing my story, my expertise. But this has taken me outside of that and connected me with people who don’t know about recovery. It’s shocked me how much I’ve grown and how my thoughts have broadened (community researcher).

Relationship. This area was the one that had the most impact for all of the partners. The growing relationship between each of the participants was crucial to the whole approach to delivering something that had been genuinely co-produced. Relationships formed and were based upon a
real and deep understanding of each other as individuals and also their positions and experiences (academic and lived). It allowed all parties to take risks and created a richer dialogue and led to the robustness of the data analysis and understanding of the material produced.

**Reward.** The principles of co-production emphasise the essential element that everyone benefits from the involvement (Boyle et al., 2010). It proved important that all partners acknowledged and shared what the benefit was for them. These rewards were naturally different and reflected the reasons partners wanted to be involved. In recovery from addiction, a key “reward” appeared to be enacting the principles of recovery through helping others, combating stigmatisation and having a voice. Other types of “reward” included the perceived credibility of being associated with a higher education institution and engaged on “proper” research. Although this was identified as a positive outcome to an extent, it also stimulated feelings of “rub” (see below) where the perceived status of each partner was different.

**Risk.** Here, risk is seen as encapsulating the experience of feeling unsafe or threatened by the research process. Feeling unsafe for community researchers was described as being out of their comfort zone, and feeling inadequate or being judged in academic environments. However, risk and threat were experienced by academic researchers too and this suggests the discomfort of being beyond the power relationship of being “the expert”:

> I noticed I got panicky thinking that we had to be doing this and this otherwise the funders get upset and the Dean gets upset. It felt “risky” to be letting go of this control and allow other people to take over. Even talking about it in this way just shows how the traditional research relationship starts getting into a power relationship (academic researcher).

Risk was also identified with “rub” (discussed below) where conflicting notions of ethical risk emerged from different values among the different partners.

**Robustness.** Here, the concern was always around how much the research would be seen as robust in conventional research terms, for example, having a research question in mind that could be tested through well-established research approaches in data collection and analysis. What was found was that robustness came from the authenticity of the data collected by being able to get “up close and personal”; a key benefit of the co-productive research process allowing the research team to reframe what was meant by “robust”. By using each person’s experiences as a resource, the whole process was more robust than it otherwise would have been as there were more checks and balances, particularly in relation to the authenticity of the data and its interpretation.

**Rub.** These clashes between the partners often came from different background experiences, training and organisational culture. These became a valued and valuable part of the research process leading to more discussion and debate than otherwise would have happened. Language was identified as a key exemplar of power “rub”; while community researchers initially felt depowered by use of research and academic language, academics felt challenged to “give away” the power it conferred, and equally experienced recovery language and exclusiveness as a barrier. Over time, the process became one of more shared understanding rather than merely translation and terminology:

> I used to switch off when they started talking about data this and data that, but I noticed now that it was my stuff – I knew what it meant but thought it was all “poncy crap” and better than me. Talking about how we talked about things was what made the difference (for us all) […] we all learned new words and stuff (community researcher).

Power is also pre-eminent in research language and processes: co-production research is still research and as such may still become entwined by academic processes. In order to meet the needs for research excellence, there remains a requirement to either identity methods for methodological rigour (i.e. respondent validation) that are appropriate to co-productive enquiry, or deploy concepts that emphasise the particular strengths of co-production, such as authenticity and applicability. Ethical considerations, too, provided friction points that exposed the power differentials between academic and community researchers (see “risk” above). Academia is charged with responsibility for participants of research via ethical oversight. Academics often want to commit to the ideals of co-productive research, but they are professionally accountable and are locked into institutional – and not community – notions of risk.
The two communities (community and university) frame risk differently. This responsibility inevitably puts the academic partner into a paternalistic role, held institutionally responsible for the safety of partners and involved others. Having to impose ethical procedures on to participants emphasises the “them and us” relationship, but at the same time, training community partners to become researchers and comply with research processes felt less like empowering participants as making them more like “us”:

It’s not that there’s nothing to learn but the most important thing that I bring is my experience and that, when I share it and use it, it’s good for the research. I sort of get the thing about being anonymous but sometimes I thought it was over the top – I didn’t need to be protected, it was about visible recovery (community researcher).

The use of “R” to identify the themes has been useful to support a need for creativity to the process of reflection. It becomes a tangible product of the reflection process which is intended to be a useful “checklist”, or an aide memoire, for when the different “worlds” of recovery community and academia struggle to share the same language and perception of the co-production research process. The reflection process identified these common themes not only from the experiences of difficulty, but also from the problem-solving process, working together over time enabled us to resolve some of the tensions outlined here and find common ground.

Discussion

The purpose of this research was not to reduce the notion of co-production to a definitive set of variables, but to explore the experience of doing co-production research. This formed the “R” theme checklist. This experience opens up fundamental questions about the very nature of research, the relational essence of co-production and its practical challenges for individuals, organisations and systems.

The “R” theme contents are not exhaustive but are ones that occurred across a range of contexts or were considered to have a significant impact by the project team. The intention is not to describe “good” and “bad” approaches to co-production but to reflect upon the experiences of engaging in this methodology in a manner that models co-production itself.

In these reflections, the “reach” theme illustrates how our co-production enquiries achieved the “as close to the actors” authenticity as recommended by Ostrom’s (2005) definition of co-production. This appears to have been achieved through the snowballing afforded by the natural networking of community researchers and the commitment engendered through having ownership of the process and the outcomes. The commitment of people in recovery to give back to others and use recovery as mutual aid felt particularly relevant to the “reasons” for engagement and willingness to make use of the opportunities to promote their own and others’ recovery. This appeared to be the altruism identified as under-appreciated and under-used by Cox and McDonald (2013). The “fit” between mutual aid and co-production research, however, presents a different form of ethical responsibility for academic members, in ensuring that benefits (rewards) and power are shared equally (reciprocity).

During this project series, it was clear that the “rub” of the co-production process stemmed largely from the clashes between the co-production methodology and conventional research infrastructures and processes. Both Hunter and Perkins (2014) and Campbell and Vanderhoven (2016) recommended that universities should change their understanding of research to incorporate the wider eco-system of co-production and take active steps to develop and encourage community partnering, including financial support. This means widening the boundaries around research processes to recognise that co-production starts with the formation of partnerships rather than a pre-determined research question. Issues with adhering to university ethical constraints, institutional budgeting requirements to pay expenses, and even sub-contracting arrangements were all experienced as disempowering and patronising for both the community researchers and the intermediary.

The research partnership resonates with the “relationships” theme from our reflection. We identify “relationships” as a vital component to the co-production process. Without developing a trusting relationship and engaging in reciprocal working, decision making could have become dominated
by academic theory rather than bottom-up community-driven ideas. As identified by Hunter and Perkins (2014), relational factors between research partners are more important than the structure of the partnership, and, as Manikam et al. (2016) found, community researchers often identify different needs and agendas to academic researchers. Hunter and Perkins (2014) suggested that partnerships can be “over-engineered” (p. 15) which can reduce flexibility and reduce the space for people to think and explore. While our academic partners experienced the co-production as, at times, messy and out-of-control, this may have been the essential creative space required for community partner exploration and thinking.

This broadening of boundaries should also to extend to greater sensitivity in ethical oversight, recognising the rights of representation and self-determined risk taking of community partners/ participants. As our evidence of “reciprocity” and “risk” suggests, community partners can feel constrained by the processes of research ethics, and that their choices are not taken into account. While right to representation is part of the Social Research Association (2003) ethical guidelines, current practice and protectionism favour risk aversion over facilitating representation. It could be suggested that another “R” in the aide memoire could be “respect”; respect for the right of community researchers to represent themselves and be self-determining.

Commissioners and funders of research are also recommended by Campbell and Vanderhoven (2016) to widen their recognition of what constitutes research and evidence generation. Co-production represents a wider way of knowing (epistemology) that in many ways better meets the needs of policy and practice commissioners. Boyle et al. (2010) also identified that co-production requires change in the systems and structures of public services to enable co-production to work effectively in changing services. As we found in our “robust” theme, co-production research can identify community-generated key problems, and problem-solving strategies, and establish a receptive bed for implementation through community ownership and ecological validity (Durose et al., 2015). It has been found in this reflection (“reason” and “risk”) that, when funder expectations set the agenda for the research, this can be at odds with the direction co-produced research may take and what it may produce. Therefore, co-production should involve consultation between all stakeholders at an early stage that incorporates agreed aims, objectives, and wider community impacts.

It is helpful that the REF in England has widened the measurement of research activity to include “wider impact” (HEFCE, 2017). The REF is the instrument with which UK universities receive research funding from the Higher Education Funding Council of England. Therefore, the REF standards dictate university structures to support research. REF impact allows universities to widen the required outcomes for their researchers to include activities with social benefit. However, as Pain et al. (2015) identified, parameters of “impact” must be wider still to accommodate the evidence that co-production can generate.

Conclusion

The “Recovery voice in action project” series provides useful insights into a number of key questions. What do we need in order to “do” co-productive research? What gets in the way? What are the key threats? What are the benefits and why bother? The emerging themes point to a willingness to challenge ourselves, as academics and community researchers, and to remain open and explorative. Whilst the commitment to see everyone involved as an “asset” may be increasingly prevalent in the narrative of co-productive research and public involvement, the reality of what this means in practice is less clear. Mutuality, trust, and partnership are easy to say, but investment in the building blocks of this requires sustained investment and a level playing field to avoid these principles becoming tokenistic. Rigid research infrastructure and lack of support for community partners pose a real threat to the potential of co-productive research to help explore the issues and impacts of drug and alcohol problems for individuals, communities, and society as a whole.

At the heart of this is the requirement for a continued and sustained interrogation that explores the potential imbalance of power. This is manifested through access to and control of resources to further develop understanding of the nature of co-produced evidence and recognise its value. But this needs to be not simply a contribution to the research “system” but a recognition of its contribution to a real and equal relationship that results in social change.
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Further reading


About the authors

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Participatory action research (PAR) research: critical methodological considerations

Wulf Livingston and Andrew Perkins

Abstract

Purpose – The purpose of this paper is to explore a range of key deliberations with regards to adopting participatory action research (PAR) and privileged access interviewer (PAI) approaches and methodologies within research on substance use.

Design/methodology/approach – This paper is a reflective piece; it adopts a mixture of applied practice and theory considerations. These conceptualisations capture what are still relatively early understandings and uses of such methodologies, acquired across several decades of research and service provision experiences. The paper is structured around some of the sequences of the research process and as such provides a broad framework for such approaches.

Findings – PAR and PAI approaches utilise several key theoretical considerations. There are many critical issues associated with adopting these approaches, including those of ethics, funding, involvement, language, resources and support. Three key principle reasons (moral, political and research based) help explain why the authors should see more adoption of such approaches in substance use-related research.

Research limitations/implications – This paper represents authors’ views which are by their nature very subjective.

Practical implications – Implementation of the key considerations highlighted within this paper can lead to an active adoption of PAR and PAI methodologies within alcohol and drug research. Increasing the use of such methodologies will allow commissioners, researchers and service providers to develop a more nuanced understanding of the experiences of and responses to alcohol and drug use.

Originality/value – This paper captures critical conversations at a time of increased calls for service user involvement across all aspects of alcohol and other drug provision, including evaluation and research.

Keywords Participatory action research, Involvement, Research methodologies, Substance use, Research ethics, Alcohol and drugs

Paper type Research paper

Introduction

This paper is explicitly the current views of its named authors. However, like all research papers, it builds upon previous experiences and projects (e.g. Biskin et al., 2013, Livingston et al., 2011) and previous writing (Livingston, 2016, 2017). Therefore, much of what is offered emanates from co-production activities with other actors which have influenced its formulation. Given its nature, it would be inappropriate to not start by stating that this paper is the consequence of all the generous sharing by and with all those we have worked with across numerous years in research and service provision. We are grateful to them for educating us and as such we feel advocates rather than originators of the sentiments contained within this paper.

Participant action research (PAR) combines two separate research concepts:

1. participation – active involvement of “subjects” in the research process; and
2. action – defining social problems and solving them.
It sits within a spectrum of what is considered patient, public or service user involvement. The movement to increased participation is not only concentrated on provision and receipt of health and social care services, but also includes research into the effectiveness of services too (Brett et al., 2014, Voorberg et al., 2015). An early defining model of this spectrum was Arnstein’s (1969) ladder of citizen participation which suggested a full spectrum from manipulation to citizen control. In research terms, we might suggest some of the positions along the spectrum as:

- Non-participation (manipulation) – service users partake purely as respondents from whom data are collected.
- Degrees of moderate involvement – consultation or involvement in steering groups only.
- Significant involvement – delegated and designated roles within the research as researchers.
- Participatory research – involved in the need for and commissioning of research, and/or as full team members from research bid through to final report.

The two concepts of PAR bring different elements and understanding to the research process, including that of alcohol and drugs.

First, participatory – this is what Gilbert (2008) referred to as doing with and for, rather than on others. It is thus concerned with definitions of expertise and knowledge and who controls these. It comes with what Humphries (2008) identified as having several principles:

- a bottom up approach with a focus on locally defined priorities, processes and perspectives;
- striving for equalising power among researchers and researched;
- a process characterised by a genuine dialogue between researcher and researched;
- control over definition of problems, methods, analysis and actions is with those most affected by the study;
- the emphasis is on processes as much as on outcomes; and
- the role of the researcher is one of facilitator and catalyst rather than director.

Second, action – proposes that action researcher and members of a social setting collaborate in the understanding of a problem and in the development of a solution based on this understanding (Bryman, 2008). This is supported by an emphasis on:

- nonintrusive collaboration (including ownership of the project by the group);
- mutual trust and genuine respect;
- solidarity (all humanity is connected by a common journey and shared destiny);
- mutuality and equality (everyone’s interests are important);
- a focus on process (informal interaction that goes beyond a detached working relationship and respects others’ cultures); and
- language as an expression of culture and power.

Action research seeks intended consequences and expects elements of change to be experienced by all. It pursues to overtly improve the social situation with explicit practical application and political activity. It can occur across several activities, for example: organisational change, community development, new projects, practitioner research and social injustice.

The overall approach can be summarised as concerning itself with “People, Power and Praxis” (Gilbert, 2008), where traditional academic researchers translate their role into one of facilitating the goals of their co-researchers. Carey (2010) echoes these sentiments in which three key considerations are raised: practical impediments, ethical implications and political dilemmas. He goes onto caution that there are possibilities that participation in research can mirror some of the current preoccupations in wider policy and provision, where participation maybe encouraged or increased but not necessarily be successful in addressing the power dynamics; and may even exasperate them.

Privileged access interviewer (PAI) is a term that best captures why such methods are especially well suited for research inquiries into areas of activity and with people in experiences that are
subject to societal marginalisation and often referred to as “hard to reach”. These include those of substance use. The approach is political apposite where there is a need to reach into certain populations that are perhaps not readily captured by traditional research methodology. There are distinct overlaps with the ethnographic approaches drawn from social anthropology (Fine and Hancock, 2017), and the essential role of those with access as established through Whyte’s (1993) seminal text and his relationship with Doc. Ennis and Wykes (2013) concluded that such involvement of service users in the research process enabled greater levels of recruitment to projects. Further, participatory approaches (i.e. those emphasising what can be considered as co-production) have a resonance and value in understanding the experiences of marginalised populations (Tedmanson, 2016), including alcohol and drug use.

The principles of these approaches like most research techniques are applied to a range of design, data collection and analysis methods. This said, there is to some degree an inherent bias towards the subjective rather than the objective. Thus, many articulate for the use of an extensive range of qualitative written, visual and textual data collection methods (Bryant, 2016) to compliment the traditional dominant paradigm for random control trials, statistics and surveys.

Within these discourses the use of terminology implies ontological and methodological positions. The ethical, morale and methodological implications of this language are explored further on; but for consistency this paper, from hereon in, refers to those whom are actively involved in the research as participants and those who contribute or offer data examples as respondents. For expediency, it adopts substance use to capture the diversity of both “substances” (alcohol, illicit, legal and illegal drugs) and “use” (dependency, excessive, harmful, hazardous and recreational).

Starting points
These approaches have several assumptions (or givens) that might be considered as pre-existing contextual considerations.

Whilst the idea that a group of alcohol and drug service users will just wander up to a university and ask for assistance in a research project might sound like the optimum and theoretical starting point (and indeed does occasionally happen), it is likely (and should be likely if co-production is indeed an increasingly wider commissioning, policy and service provision norm) that ideas are generated from within existing involvement activity. This could or should happen in substance use organisations or fora, where meaningful participation is already well established with regards to other business or activities. This methodology therefore demands that initial conversations have been reciprocal and not unduly led by agencies/researchers to meet their own agendas. Thus, involvement prior to design or research bid application moves research further along the possible spectrum of participation.

From here, it is appropriate to have one or two dedicated conversations/meetings that scope out a project. These might well want to involve others not deemed as participants as well as early project initiators. This is important to ensure that the research is supported, welcomed and has a good level of stakeholder engagement and involvement from the start. These early conversations need to include explicit exploration of ethical and resourcing issues. Such solid foundations of shared understanding are important to help ease future resistance when goals are directed towards political change.

It is likely, if not desirable or expected, that such a stage maybe the precursor to a formal funding application. Although, as outlined below, acquiring funding is not without its difficulties. Ideally in such instances applications are made with participants rather than on their behalf.

It feels important to emphasise that, in these early meetings, service user and participant voice is strong and not of a singular or representative type. Indeed, some might argue that they need to be the majority for it to be truly participative, and the involvement of other professionals and researchers is for consultation (McLaughlin, 2010).

Identifying and recruiting participants
In many instances, those individuals involved in the initial and scoping conversations may well be those identified as the participants or PAs. It feels important that potential participation is invited across many roles and responding to a variety of interest and skills, such as: project advisories or
consultants, full blown participants, advertisers, recruiters, respondents and supporters. While initial conversations may generate enough involvement, in many instances there is likely to be the need for further recruitment – especially for PAI type projects. This will need to follow a purposeful sampling methodology, using a combination of targeted advertisement (with active consideration given to mobile and social media methods) and snowballing through existing substance use networks, relationships and recovery organisations.

There comes a point in participatory methods, if this has not happened fully at inception, where any project needs to ensure that its direction is highly participant led. At this juncture, the research team (PAI and supporting academics) needs to possibly withdraw from wider stakeholder discussions and begins to enable an approach which is very much service led, rather than informed. The role of the (academic) researcher here is to facilitate discussions and understanding among the participants, and supports them to agree upon the specific methods of inquiry.

Substance use research has the possibility to see co-production beyond the service user group and partnership could see carers, families, practitioners or students become the participant population.

### Language and terminology

Early formulations of this paper were borne out of and reflect struggles with language. Much research literature frequently refers to participants. When in the context of an understanding of genuine partnership involvement, what is being referred to is those from whom data have been collected. The use of participant almost seems a hangover of a subject involved in a controlled experiment, rather than any sense of any co-production; the exceptions perhaps being those engaged in ethnography or discourse analysis. For us, the ambiguity and confusion were cleared by choosing to be firm in distinguishing between those from whom we collect data (respondents), and those who actively participate in the other aspects of the research process (participants).

While such deliberations may appear of semantics, they are in fact rooted in issues of power. They challenge perceptions of “us and them” populations. At the heart of them lies a transparent declaration of whether researchers are distinct from (expert and controlling), or sharing in the same human experience (indeed most alcohol researchers are drinkers). The latter position begins to ask fundamental questions of whether one truth or measurable actuality exists, rather than being a construct of any given (research) process. Furthermore, it raises questions of who is the expert and in what capacity. It also suggests the equal validity of all research methods, rather than supporting a hierarchy of the traditional or dominant. Finally, it implies the assumption of a sharing of access to resources and rewards from the research process.

### Ethics

As research, normal ethical considerations and processes must be accounted for. Projects will need to undertake appropriate due research ethics processes. It is possible that where ethics boards are predominantly used to, or dominated by, traditional positivist and experimental type research approaches, understanding of (and support for) PAR approaches maybe more limited. However, it is our experience that ethical approval is gained when attention is paid to specific key considerations; notably issues of boundaries and researcher confidence.

These approaches have a resonance with ethnography, which in turn helps to inform the management (or not) of boundary issues. Researchers are considered, if not expected, to be an active part of the community. Indeed, it is the opposite of aloof non-participatory observation which, in terms of the politics of involvement, might be considered a more exploitative and unethical approach. Active researcher participation offers the opportunity of more realistic, transparent and trustworthy interactions. It works with continuums of populations and communities, rather than suggestions of “us and them” populations. Working within discreet populations (as accessed via a PAI) challenges the boundaries of what is considered normal confidentiality for other research methodologies. Tolich (2004) acknowledged that an overt understanding of this helps accept the limits in the principles of confidentiality. Insiders are more likely to recognise what other insiders have said. He concluded that internal confidentiality is
distinct from external confidentiality and suggests the assurances for protection against identification is with those who were not subjects of the research, rather than within the discreet population cohort or community.

Because the methodology described here is not as deterministic or predictable in its course of action and process orientated, then the ethical requirement is for confidence in the researcher and/or research team (as much as the prescription of methods) and the successful management of what can appear as more fluid boundaries between the researcher and the researched. Ethics committee confidence is often, as with other methods, about any relevant prior experience of the researcher. One of the authors (as a registered social worker) has found that it is important to stress equally the oversight of practice and research ethics. Thus, the process of being held accountable to a professional regulatory body complement those of research ethics, as might a social work qualification compliment a PhD. This is because many of the research ethics issues are foremost practice dilemmas.

As might be expected, there is also regular concern raised about the use of payments for participants in this area of research. The ethical concerns often fall into two considerations: those of undue incentive to participate (Ritter et al., 2003), and/or payment leading to risk of harm, notably with the possibilities of monies being spent on substances. However, many researchers have now clearly articulated why genuine participation (issues of power) requires this group of users to be treated the same as others and that payment is a requisite (Fry et al., 2006; Neale et al., 2017; Sandberg, 2008). Fry et al. (2006) in their paper concluded “[...] research payments are ethically acceptable in most circumstances of addictions research, but should be closely scrutinised in situations where these may exacerbate existing harms or create additional risks for participants and investigators” (p. 21). This counter argument therefore stems around payments as justifiable and fair reimbursement for time given and expenses occurred. The concerns about cash being spent on substances are usually compromised by providing individuals with high-street shopping vouchers that cannot be exchanged for alcohol or cigarettes. Participants in research studies have expressed that the use of vouchers can present implied lack of trust or feel paternalistic and may even in some instances increase (not decrease) risk (Neale et al., 2017). For some individuals (i.e. street drug dealing or use of drugs by sex workers), payment maybe the only way individuals can viably participate without loss of income earning time; and reimbursement in cash rather than vouchers will be a necessity to enable participation (Sandberg, 2008).

Funding and research bids

If a bid for a participatory project is to be made with clear evidence of involvement having informed it, then this involvement also needs funding. For traditional research, bid preparation activity is part of the paid job role for academics. To ensure a parity and active involvement of others, it seems to be an important and logical consideration that some of the substance use commissioning, policy and organisational fora (referred to above) are also able to create funds and resource capacity for appropriate involvement to inform potential research project starting points (Minkler et al., 2003).

Even assuming this informed prior application involvement, one of the biggest barriers to getting such research projects off the ground is often the successful acquisition of external funding. Research funds often sit in a competitive bid process, including blind peer review processes. These processes aspire to establish exactly what a research project is going to do, so how well detailed and predictable and/or reliable the methodology described is. These scoring methods often have a bias towards predictive/positivist experimental research over methods where determining the methodology is a part of the process and not fully determined prior to. Truly iterative and participatory approaches cannot provide such clarity before they have begun. In addition, and much like the ethics committee, the bids are assessed by panels of experts whose own experiences and understanding lie with controlled experiments, quantitative surveys and statistical modelling rather than qualitative involvement. Thus, there is a more inherent bias where participatory action approaches are neither understood, nor valued by those responsible for making such judgements. Typical of those
sentiments is the following example that these authors received from a recent “friendly” reviewer post an award being made:

The use of participant researchers looks innovatory but pretty risky, and the sample size is very small. A small and potentially contentious methodology [...] is unlikely to make a big difference to conclusions even if it worked.

This situation was recently acknowledged at the 2017 Alcohol Research UK Annual Conference, which in part has led to this special edition[1].

Data collection and analysis

Whilst all forms of data collection tools can be used within participatory approaches, there is often an inherent leaning towards the intrapersonal and relationship-based inquires, so frequently qualitative methodology. Whilst this may regularly be done through focus groups and interviews with schedules and a range of semi-structured questions, participatory approaches also lend themselves to the use of arts and other creative data capture approaches (Bryant, 2016). Iterative approaches (typical of highly qualitative methods to data collection and analysis, whereby the experience of one element feeds into and refines the next) feel highly resonant with involvement approaches that are seeking to develop collective understanding and inform change.

It is possible that PAIs will at these junctures require some formative input from the academics or others within the research team. Thus, some of the research team need at times to translate facilitator into educator roles. So, the stage here is the sharing of expertise and knowledge about research techniques. Active consideration must be given to how material often used in other classroom settings might need to be adapted for different audiences and learning needs.

It can be useful for PAIs to conduct the data collection method on each other. This provides: safe space to practice and receive feedback on, and refine techniques; and potential initial data that can be used within the wider data collection set. It might be that where data have been collected via film or audio, the experienced researcher facilitator also watches and listens to the data to provide supportive feedback to PAIs. Similarly, methods of analysis might need to be explained or adapted to suit the needs of the PAI population. Consideration needs to be given to how best to support PAI involvement in analysis, so without assumption about access to and competence in IT. Some PAIs will want to be actively involved in the use of say SPSS or NVivo; but for others, a paper based or aural process maybe more suitable. Added reliability can occur with dual analysis approaches and then comparison of interpretations, so one approach for some PAIs and then a complimentary or additional one from the experienced or academic team members. An active but supportive role of experienced researchers within the cohort can act as an additional process of quality assurance.

Recruitment of respondents is likely to follow the same purposeful sampling methodology, using a combination of targeted advertisement (with active consideration given to mobile and social media methods) and snowballing through the existing substance use networks and relationships used in PAI recruitment. Research that utilises peer and recovery groups means that individuals are known to each other within the community. Reflexive considerations of insider research approaches are required. Within this, identification of what proximity to potential respondents the PAIs are should be undertaken and used as inclusion or exclusion criteria; or passed onto another PAI within the project. As PAIs spread out into the respective community and collect data, the experienced members of the team must be available for ongoing mentoring and support.

Post data considerations

Like other research methods, it is good to find a process by which emerging outcomes can be “tested” out with those most likely to be impacted, and their responses to this can shape any final conclusions. This could include taking initial findings back to any initiating substance use fora or project advisory group. Active recovery communities are also likely to provide ongoing spaces, where PAIs can test and make sense of emerging findings and conclusions.

It is likely that commissioners of research will want to see traditional “research reports”. Further, any academics involved will want to, and be under pressure to, publish within peer review journals. In both
these regards, it is important that the opportunity to participate in “writing up” is extended to PAIs, and irrespective of their involvement in the writing up, they are fully acknowledged (with consent) as co-authors. However, some projects, some groups, etc. may also identify other non-written ways of wanting to present research findings. The adoption of these seems important, especially when considering research as both involved and action orientated. The change implied in action is likely to come from the widest of dissemination approaches.

The implications suggest that this paper, like other papers cited of the authors, might have involved some other substance use individuals as co-authors. However, we elected to be transparent in this being our thought piece and not a shared research project, but as in the introduction, to be clear we were not claiming originality of thought and indeed owed a debt to a vast number of previous collaborators.

Part of an action-orientated methodology, which has process as important as outcomes, and considers outcomes for all, is about establishing sustainable PAI populations to then advise and support commissioning of future research, get involved in other projects, and act as peer mentors for future PAIs.

Applied framework

It is possible to synthesise these considerations into a broad or proximate framework (model) comprising multiple stages (Table I).

Applied considerations

This paper has been influenced by a diversity of previous and ongoing research projects. However, given the considerations described, it has equally (if not more so) been informed by: many unsuccessful research bids, policy conversations, recovery group deliberations and reflections on the limitations of other research (including ours). This final section offers some of the learning we have acquired through these experiences.

PAR projects require a lot of (and at times freely given) energy and time, to ensure that they are successful and sustainable. Several of the recent projects we have contributed to have come out of long-term prior existing relationships. In other words, we have been actively involved in

<table>
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<th>Table I</th>
<th>Model of stages of participant action research approach</th>
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<td>Stages</td>
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<tr>
<td>Early and formative</td>
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<tr>
<td>A</td>
<td>Agreeing scope of project and initial starting points (including resources and research bids)</td>
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<tr>
<td>B</td>
<td>Recruiting PAIs (within inception fora and beyond where necessary)</td>
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<tr>
<td>C</td>
<td>Broad agreement on research question and preferred methods</td>
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<tr>
<td>D</td>
<td>Developing detail of data collection methods (including PAI training sessions)</td>
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<tr>
<td>E</td>
<td>Piloting</td>
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<tr>
<td>F</td>
<td>Revising data collection skills and tools</td>
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<tr>
<td>G</td>
<td>Respondent service user recruitment</td>
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<tr>
<td>H</td>
<td>Data collection and analysis (ongoing training and support to PAI from experienced team members)</td>
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<td>End games and impact</td>
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<td>Output production</td>
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<td>L</td>
<td>Dissemination</td>
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<tr>
<td>M</td>
<td>Commissioning, policy, organisational and service provision change (Next project)</td>
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Notes: Stages are iterative and overlap. *These stages involve processes and organisations that are possibly external to the research team, so not fully within projects influence
those fora discussed in the earlier part of this paper. This requires the academic researcher to spend time out and about in the community. Notably, we have been active members of recovery group networks and partnerships, often giving skills and time just like any other volunteer. Successful bids and projects are far more likely to come from already established and trusting relationships. We have, as is consistent with other research approaches, spent time doing early, small and unfunded pilot formulations. There is a need to continue especially in economic climates, where organisations and universities increasingly seek to restrict activities to those associated with computerised workload management agendas, for researchers to articulate that such time spent is necessary and valuable – especially as this is required to be off site. There is scope here to use organisational good citizenship or social good agendas to help meet these goals.

That participatory research, especially that involving action (for change), is as much a political as it is research activity, has therefore been one of the earliest and consistent messages. Biskin et al. (2013) identified how even the simple task of social work students being encouraged in the classroom to expect service user and carer involvement then meet resistance when wanting to account for whether they actually experience such in practice through a research project. So, whilst the service user involvement agenda is well established in substance use policy and provision agendas, it has yet to fully impact on the research world. Service user involvement has tended to primarily focus on the active participation of “users” within treatment policy and provision agendas, rather than all users and ex-users and including evaluation and research activities. In a recently completed review of the Welsh Governments 10-year alcohol (and drug) strategy, there was no PAR material amongst the relevant data sets and evaluations (Livingston et al., 2017).

PAR and PAI approaches require inclusivity (and measured risk taking) if they are to succeed in being different and provide alternative explanations. We have had expressed to us concerns about PAIs interviewing those who are still actively using and exposing their own vulnerability to relapse (which assumes that PAIs are abstinent – which need not necessarily be the case), and how rigid (or not) any criteria for PAIs needs to be. This, in turn, raises concerns for us about whether researchers could be tempted into using PAI recruitment methodologies which are too strict (or too controlling) unless they themselves are prepared to take a few risks. PAR research ought to have the capacity to involve the whole spectrum of use or not. It is by its nature risk taking rather than risk adverse. When working with those in recovery as PAIs, it seems important to entrust to their already successfully developed notions of management and networks of support, rather than impose secondary researcher led frameworks. In fact, this makes us think that the success of PAI methodologies is also shaped by the characteristics of the research facilitator as it those of the PAIs recruited. Inclusivity and risk taking is thus required by those commissioning, evaluating, overseeing and undertaking research. This seems to be only a fair and reciprocal to the risk we ask of others in entrusting and sharing their experiences with us.

It feels as if over the last decade that the tide is finally turning. Indeed, the ARUK conference that is the precursor and inspiration for this special edition is one obvious marker in this evolutionary journey. The explicit requirement to demonstrate involvement now appears to be a more regular element of research bid application and journal submission (i.e. British Medical Journal) process requirements. Indeed, we have had more bid success of late (albeit maybe it is just that we have got a bit better at that bit). Notably, and very recently, an acceptance of the validity of the contribution these methods can make to enhance a complexity of methods in understanding national policy has been acknowledged by Health Scotland in its commissioning of participatory methods as one of the streams within the evaluation of the impact of minimum unit pricing on harmful drinkers (NHS Health Scotland, 2017).

Concluding discussion

At one level, there is nothing revolutionary in the principles of PAR or the methodological considerations explored within this paper. In part, they just feel like good conscious and reflexive research practices. However, at another level, they seek to comprehensively resonate with aspirations for greater service user involvement in policy, practice and research activities.
They have a feel of the ideological, a set of best laid aspirations and intentions. In this sense, the revolutionary comes from trying to meet as many of the ambitions as possible within each project, while contributing to an overall picture of change and challenge to an existing order that places expert led controlling experimental research at the pinnacle of perceived research hierarchies.

It is possible to reduce these complex discussions into three clear reasons why we should do and see more PAR/PAI research within alcohol and other drug studies. First, this feels like a moral imperative. It is just the right thing to do. There has been an explosion in service user involvement in policy and service provision for substance use, and this needs to be matched by those researching such. Substances are widely consumed in society, including by researchers. The boundaries between an “us and them” population often maintained by researchers in this instance seems particularly false. It maybe that we need to turn the traditional research ethics preoccupation with protecting the vulnerable on its head and into one of entrust, empower and respect. Second, this is a political issue. It raises fundamental questions of ontology and epistemology. A challenge to a dominant and vested interest about who does research and how. It asks questions of who is the “expert”. It asks that research has an impact beyond the vested interest of the academic career and the research frameworks that academic institutions are increasingly judged by. Finally, and this is the purpose of research, new methodologies help create new understanding. There is more than one way to know how. It is a direct and appropriate response to Orford’s (2008) seminal paper that argued for substance use research to move beyond its preoccupation with the randomised control trial. These are methodologies that enable us to gain a greater insight into the nature of experiences and relationships that are at the core of understanding why individuals develop difficulties regarding their substance use and how they might best be supported in developing healthier lifestyles.

It is possible to see two overlapping “new” waves at work here. Where research has accepted the role of the sociological and qualitative to compliment the experimental and quantitative, it has yet to fully embrace moves to take this outside of the academy. Similarly, where substance use has embraced harm reduction and whole population agendas as a response to narrow disease model understandings, it has yet to fully reconcile itself with some of the newer debates and understanding about recovery and the increased control and involvement of those most affected. This paper simply seeks to contribute to these journeys.

Note

References


Further reading


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