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Involving young people in drug and alcohol research

Original Citation

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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 substance misuse were actively involved in the Youth Social Behaviour and Network Therapy (Y-SBNT) study. This paper explores the impact of that involvement on the study and our understanding of involving young people in drug and alcohol research.

Methods: The initial plan was to form a young people's advisory group, but when this proved problematic the study explored alternative approaches in collaboration with researchers and young people.

Findings: Input from young people informed key elements of the intervention and research process. Furthermore their involvement needed to be dynamic and flexible, with sensitive handling of difficult personal experiences. Engagement with services was crucial both in recruiting young people and supporting their ongoing engagement.

Implications: The dominant discourses and cultures of health services and research (including interpretations of participation in public involvement) often do not sit easily with co-production and young people-centred involvement. There is a need to consider and document how approaches may facilitate exclusion or inclusion of young people in substance use research and more widely. Young people should be involved in influencing how they participate in drug and alcohol research, as well as having the right to choose whether or not they are involved.

Originality/value: The outcomes of this work contributed to innovative thinking and practice and the development of a more flexible and young people centred model for involvement.

Background: young people's involvement in research

The United Nations Convention on the Rights of the Child (CRC) (UN, 1989) has established international recognition that all children have a right to the highest possible standards of both healthcare and involvement (Alderson, 2014). The understanding that children and young people[1] 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). There have also been repeated calls to involve patients and members of the public in healthcare improvement in response to serious clinical and service failings in the UK and internationally (Ocloo and Matthews, 2016). These factors have resulted in increasing interest in children and young people's involvement in the design and delivery of health and social care services (Percy-Smith, 2007; Weil et al., 2015) and research (Kirby, 2004).

Public involvement is now an essential element of all publicly-funded health research in the UK (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). But there has been less attention on the experiences and impact of involving children and young people than the involvement of adults (Bird, Culley and Lakhanpaul, 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 the case for young people deemed to be more 'vulnerable', whose voices are

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[1] Young people were the main focus of this study, and this is therefore the term generally used in this article

often absent from the literature (Richards, Clark and Boggis, 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 problems concerning substance misuse (Brady, 2017).

Involving young people in the Y-SBNT study

The Youth Social Behaviour and Network Therapy (Y-SBNT) study was a National Institute for Health Research (NIHR)[2] funded randomised controlled trial. The study aimed to demonstrate the feasibility of recruiting young people to a family- and wider social network-based intervention (Watson *et al.*, 2015) by testing an adapted version of an established adult intervention (SBNT) (Copello et al., 2009). The Y-SBNT study team aimed to actively involve young people with experience of substance misuse services throughout the study. It was hoped that young people's involvement in the project would ensure that the study, and the Y-SBNT intervention itself, were relevant to, and addressed the issues faced by, young people with substance misuse problems more effectively. 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[3] (Brady, 2017). This article 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).

Methods

The initial plan was to form a young people's advisory group (YPAG) of 10-12 young advisors aged 12-18, working with a national substance misuse charity and other services to recruit young people with previous experience of substance misuse treatment service, and then reflect with young advisors on their experience of this process in order to capture learning. The YPAG is a common model for young people's involvement in health and social care research[4], and we also drew on guidance on young people's involvement (Kirby, 2004; INVOLVE, 2015; Shaw, Brady and Davey, 2011). The aim was for the young advisors to be supported by the study's public involvement leads to work alongside the research team through a series of group meetings. But recruitment proved slower than anticipated, and the first three meetings were poorly attended, and those who attended varied from meeting to meeting. It therefore became apparent that the traditional single-location advisory group format might not be the right model for working with this group of young people.

Adapting the model

We therefore worked with young advisors to develop a more flexible model that focused on fitting involvement activity around what worked for the young people, recruiting young people more locally through services known to the study team and in our localities. Involvement centred on consultations with young people at locations that were familiar to them supplemented with e-mails, text messages, telephone conversations and postal correspondence where these were more convenient for the young people or timely for the project. 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.

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[2] This study was funded by the NIHR Health Technology Assessment programme

[3] Undertaken at University of West of England, Bristol, UK as part of a scholarship supported by Profs. David Evans and Barry Percy-Smith.

[4] E.g: http://generationr.org.uk/, http://decipher.uk.net/public-involvement/young-people/

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Source material

The methods for the research findings on which this article draws are described in detail in the doctoral research (Brady, 2017) which was underpinned by a participatory paradigm which sought to open up to critical inquiry existing assumptions and practices concerning young people's involvement in collaboration with young advisors involved in the study. Participants in this process were: members of the Trial Management Group (TMG) and Steering Committee (TSC) as active partners and as participants in a focus group to reflect on emerging learning), young people involved in the study as young advisors, and meetings and interviews with organisations supporting the engagement of young people in the study. Material which informed the doctoral thesis (Brady, 2017) and public involvement sections of the study report (Watson et al., 2017) included analysis of transcripts of focus groups with the study's trial management group (TMG) and steering committee (TSC), transcripts of phone and face-to-face meetings with the two young advisors who had long-term involvement in the study, meeting notes of discussions about young people's involvement at TMG and TSC meetings; notes and transcribed conversations from young advisor meetings, and newsletters and other materials developed for and with young people . A thematic analysis approach was used to discover, interpret and report on themes and patterns of meaning within this material (Braun and Clarke, 2013). Ethical approval for the doctoral research was given by the University of the West of England Research Ethics Committee.

Findings

Young people's contribution to the study

Young people contributed to all three phases of the study (see Figure 1). During phase one (intervention development) young people provided input which ensured that the intervention was acceptable and relevant to the Y-SBNT study's target groups, and reflected their experiences as service users. The adapted intervention and training materials for therapists piloting the intervention included examples of processes the young advisors perceived as important to obtaining social network support, good and bad aspects of services, and diagrams of young people's social networks. During phase two (the randomised controlled feasibility trial) and phase three (analysis and reporting) 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 contribution to a regular newsletter for Y-SBNT young advisors, co-presenting at a conference (Brady, Templeton & young co-presenter, 2014) and co-authoring written outputs (Brady, Templeton & young co-authors, 2015; Chapter 8, Watson et al., 2017).

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Figure 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.
- 10 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.
- Seven newsletters were sent to young people with updates on the project, information about how young people had been involved and upcoming opportunities.

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

In the spirit of involving young people in all aspects of the study, this section was written by the two young advisors who had the most longstanding involvement in the project (20 and 23 months), as contribution to the chapter on public involvement in the study report (Watson et al., 2017). An initial draft chapter was prepared and discussed at one of the final young advisor meetings in November 2015, and further developed with input from young people:

"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. Now that we've come out of it we can explain things in a deeper level than adults who've got degrees and read about it in text books. They haven't felt that emotional and physical turmoil, and the same with young people who haven't had drug problems, they haven't gone through what I've had to go through and wouldn't understand what it's like. 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'm involved in the Y-SBNT project so I can pass on my experience and if I can help one person that's another person who might not die and become a statistic. 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. The fact that you've included so much material from young people in this chapter completely personifies the whole point of the project. Reading the chapter and all the findings and the work you've done, and I've done, made me feel quite special. It made me feel like my views are important.

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I also didn't realise just how useful I'd find it, hearing everyone's experiences is wonderful, everyone's unique and that's very comforting. Being involved in the Y-SBNT study makes you think about things, I think about my situation differently now, the way I've isolated people in my life and what factors they had and how they've contributed and everything. It's a good way to detach yourself from it and look at it in a more scientific way but at the same time you are like 'this is my life, this was what was going on with me'. I think it's quite interesting, it's not very often you get to put these things down on paper and step out of your own shoes and look back and say 'let's be honest about this', no emotion. 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 challenged our thinking about involvement. 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 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.

Being flexible in response to the situations of different young people emerged from this study as being important. 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 more urgent 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).

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Keeping in touch was also sometimes problematic, as 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 of the young people we involved did not have regular access to a computer or the internet and/or chose not to use e-mail or social media.

The need for sensitivity

Involvement in the study required young advisors to draw on their own experiences as users of substance misuse services and consider the way in which their family and wider networks had helped or hindered their recovery. Young advisors pointed out that 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).

> "We are young people as well so there's always that level of vulnerability and it's quite a sensitive issue . . . [substance misuse] is quite a shameful thing to some people . . . I find it very awkward to talk about it with people I don't know" (Young advisor B).

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).

Young people with complex needs, especially if they are living in care or in crisis or had co-existing mental health problems, as was the case for several young people involved in the Y-SBNT study, 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, despite various attempts to obtain feedback from young people involved early on in the project, all 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 there was a balance between maintaining contact and leaving the door open, 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 enable and potentially constrain their involvement (Cree, Kay, and Tisdall, 2002; Hood, Kelley and Berry, 1996). We found that services proved to be both barriers to, and enablers of, young people's involvement. 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).

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Some services were also 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. The young people who did get involved in the project felt that it was important to emphasise that this was not in fact the case:

> *"[Tell young people that] you don't have to be a scientist, you don't have to be a genius, all you have to do is have experience of using these services and that's the skill [required]"* (Young advisor B).

This suggests that it is important to spend time preparing young people for their involvement, by establishing relationships of trust and building their own confidence to participate. 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 'got' what we were doing and actively promoted the opportunity to young people and supported their engagement.

Developing a different approach to involving young people

Towards the end of the study we worked with the young advisors to reflect on learning and consider how we might best involve young people with experience of substance misuse 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 that this needed to be 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 1991) in which young people can gradually develop capacity for engagement on their own terms in what Lave and Wenger (1991) refer to as 'legitimate peripheral participation'. Based on learning from this study a number of key principles emerged, which we hope will underpin involvement in other studies (see Figure 2):

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

1. 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.
2. Working in partnership with services, who would recruit and provide ongoing support to young people.
3. Involve young people in recruitment for public involvement, both initially during visits to services and through 'snowballing' through young people recruited as advisors.
4. 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.
5. 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.
6. Varying levels of involvement, from consultation to co-production, determined by young people's interests and availability as well as the views of researchers.
7. Public involvement lead(s) with relevant expertise supporting all members of the research team to embed public involvement into their work.
8. Linked to wider discussions within the NIHR and elsewhere about making public involvement in research more inclusive, diverse and accessible.

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Discussion

The time taken to establish a group of young advisors and the lack of established YPAG members with relevant experience meant that it was difficult to involve young people in the initial stages of the project. So the Y-SBNT study, as with many studies which involve 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. 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, Britten and Lynch, 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 substance misuse (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. 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. 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 are able to be involved is ultimately a matter of individual choice. 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, cited in Powell and Smith, 2009, p.128).

Researchers' access to young people generally requires the permission of adults (Hood, Kelley and Berry, 1996). Young people can be powerless in this process and reliant on significant adults to decide what information they should be given and whether they can participate (Powell and Smith, 2009). Although gatekeepers often play an important role in safeguarding the interests of young people *"they can also act to exert power over young people to prevent their voices being heard"* (Moules, 2005, p.142), and may have reservations or concerns about young people's active involvement (Coyne ,2008), particularly when those young people are felt to be 'vulnerable' which need to be addressed in order to facilitate involvement.

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 (Staniszewska et al., 2017). Comprehensive and comparable data on the nature, extent and impact of public involvement in health research is currently considered to be lacking and there is a need to collate, understand and disseminate evidence on the nature and impact of young people's involvement in research more efficiently (Brady and Preston, 2017). Embedding young people's involvement requires critical reflection and shared learning, and we therefore hope that this article will make a contribution to the wider evidence base.

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Acknowledgements

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Involving young people in drug and alcohol research

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 (Y-SBNT) study. This paper explores the impact of that involvement on the study and what we learnt about involving young people in drug and alcohol research.

Methods: The initial plan was to form a young people's advisory group, 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'. 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.

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 young people's advisory groups, inaccessible.

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, Templeton and Copello, 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 social behaviour and network therapy (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 article, 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. 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 article 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 article 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 article, 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 (CRC) (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, Culley and Lakhanpaul, 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, Clark and Boggis, 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 article focused 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 , Rened and Marston (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"[2]

Furthermore, there are tensions between the participatory intent of co-production and the 'expert'-driven notion of RCTs. The article 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 focused 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.

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[1] Undertaken at University of West of England, Bristol, UK as part of a scholarship supported by Profs. David Evans and Barry Percy-Smith.
[2] http://www.invo.org.uk/current-work/co-production/

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[3], and we also drew on published guidance (Kirby, 2004; INVOLVE, 2015; Shaw, Brady and Davey, 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 focused 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 were 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 Figure 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, Templeton & young co-presenter, 2014) and co-authoring written outputs (Brady, Templeton & young co-authors, 2015; Chapter 8, Watson et al., 2017).

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[3] E.g: http://generationr.org.uk/, http://decipher.uk.net/public-involvement/young-people/

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Figure 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.
- 10 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 longstanding 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, Kay, and Tisdall, 2002; Hood, Kelley and Berry, 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 1991) in which young people can gradually develop capacity for engagement on their own terms, in what Lave and Wenger (1991) refer to as 'legitimate peripheral participation'.

Figure 2 below summarises the model which we developed in collaboration with the young advisors:

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

1. 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.
2. Working in partnership with services, who would recruit and provide ongoing support to young people.
3. Involve young people in recruitment for public involvement, both initially during visits to services and through 'snowballing' through young people recruited as advisors.
4. 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.
5. 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.
6. Varying levels of involvement, from consultation to co-production, determined by young people's interests and availability as well as the views of researchers.
7. Public involvement lead(s) with relevant expertise supporting all members of the research team to embed public involvement into their work.
8. Linked to wider discussions within the NIHR and elsewhere about making public involvement in research more inclusive, diverse and accessible.

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 (Staniszewska 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, Britten and Lynch, 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 (Brady, 2017). Furthermore, focusing 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, cited in Powell and Smith, 2009, p.128). 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 article contributes to this body of knowledge, both through the model which emerged through this process (Figure 2) and our reflections on the learning which emerged during this process.

Acknowledgements

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