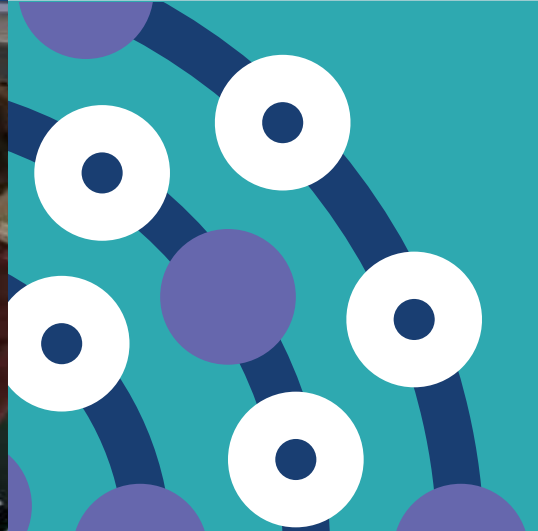
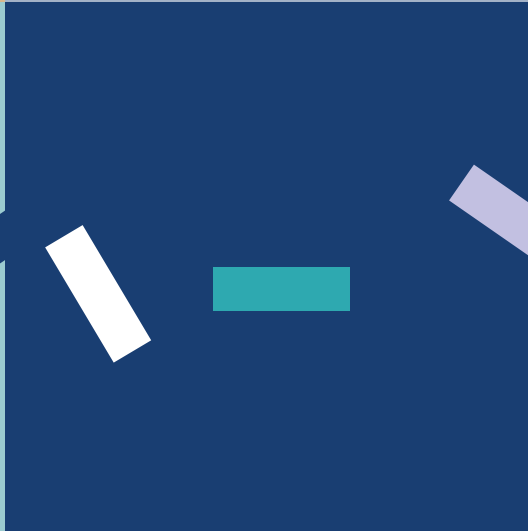
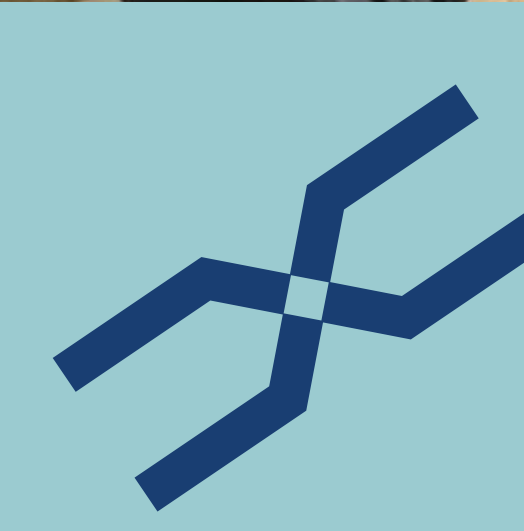
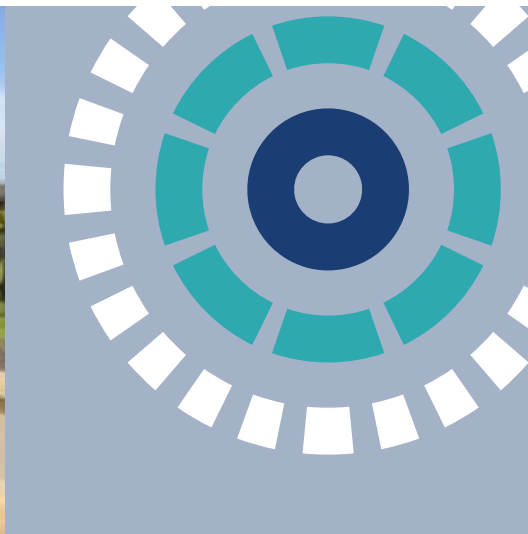


# Co-production in Action

NUMBER ONE



## Acknowledgements

The project team would like to thank everyone who has been involved in the development of this project. Thank you to all those people who took the time and effort to send us their examples of co-produced research. We really appreciate this. A thank you to all those people whose projects are included in the series – we went through several drafts and we applaud your patience!

Thank you to Gill Wren at INVOLVE for proof reading and valuable work on the design of these publications.

And a thank you to Ruth Richardson a public member on the advisory group at INVOLVE who also proof read drafts.

## Introduction

Welcome to the first in a series of three publications highlighting co-production in action. It builds on our earlier work, *Guidance on co-producing a research project (1)*, by showing how the key principles and features identified are expressed in practice. We are responding to feedback from people who called for more information about the ‘how’ of co-producing research. In short, the message was ‘you’ve given us the theory, where’s the action?’ There are many forms that co-production can take and people with greater experience of co-producing research than us. Given this, we thought the best approach was to give the public and researchers a voice by using this set of publications as a platform for sharing examples.

In our earlier work we described co-producing a research project as ‘an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.’ We also noted that some people may want to only co-produce parts of a research project. It’s worth recapping on the key principles and features because they are referred to throughout this publication.

### **When referencing this guidance please use the following:**

INVOLVE (2019) **Co-production in Action: Number One**. Southampton, INVOLVE

## **Key Principles**

**Sharing of power** – *the research is jointly owned and people work together to achieve a joint understanding*

**Including all perspectives and skills** – *make sure the research team includes all those who can make a contribution*

**Respecting and valuing the knowledge of all those working together on the research** – *everyone is of equal importance*

**Reciprocity** – *everybody benefits from working together*

**Building and maintaining relationships** – *an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential.*

## **Key features**

**Establishing ground rules**

**Ongoing dialogue**

**Joint ownership of key decisions**

**A commitment to relationship building**

**Opportunities for personal growth and development**

**Flexibility**

**Continuous reflection**

**Valuing and evaluating the impact of co-producing research**

## Selecting the examples

We issued an open invitation for people to send us details of their co-produced research. This included completing an on-line template which provided information on how the key principles and features found expression. We received 27 examples and our working group (which included staff from the National Institute for Health Research and beyond as well as public members) met to determine which should be included. We were not assessing the quality of the work in terms of the methods used or usefulness of the research. Rather we focused on a) the extent to which the examples addressed the key principles and features identified in our earlier guidance b) selecting a variety of examples (and a maximum of nine) in terms of types of research and regional variation.

The use of our key principles and features provided some structure for our conversation and a degree of rigour. However, any consideration of the extent to which the examples addressed our key principles and features clearly involves an element of subjectivity, particularly given the relatively small amount of information the working group had on each example. There is no gold standard of what co-produced research should look like and, at this stage at least, no criteria for assessing co-production. We recognise that, just as with other approaches to public involvement in research, such as consultation, collaboration and user led, what we set out to do can often be constrained by the realities of the challenges involved in undertaking the research. We rarely achieve a 'pure approach' to our public involvement in research but rather a blend of several approaches as we address the challenges and move forward. Indeed, our examples highlight some of the challenges that were faced and compromises that were made. All that said, the working group very quickly came to a consensus on the examples that they felt should be included in this series.

One member of the working group declared an interest in one of the examples we received (she had worked on the project) and so left the room and was unable to comment or vote on whether to include this example. The remaining members agreed that this example should be included.

The authors of the examples selected provided further information in an adapted template and twice at least two members of the working group reviewed drafts. Finally, a small editing team at INVOLVE, including a member of the public not previously associated with the work, worked with the authors to refine further. In the examples, we have tried to preserve the voice of the authors which, in some cases, are members of the public.

## About the examples

Across the publications we have a range of examples, some of which have tried to co-produce a whole project while others have sought to co-produce parts of a project. Some key principles and features have been addressed with relative ease while others have been more of a challenge. We think it important to include information on the challenges of co-producing research and the authors have been open about the extent to which they were able to address them. All research involves challenges which require flexibility, adaptability and compromise on the part of those involved and which, in the case of co-production, may dilute the extent to which we are able to address the key principles and features. Co-producing can be messy. The key is to be transparent about the difference between what you set out to achieve and what you actually achieved.

In this first publication in the series of three, we have three examples of co-producing research. The first example is a collaborative piece from University of Plymouth, together with a volunteer mental health patient research partner and charitable organisations (Heads Count and Care Opinion) in which they sought to improve responses to online feedback from adults receiving mental health care. The second example involves a partnership between University of Bedfordshire and Alcohol Research UK in which they explored the experiences of older adults in residential alcohol rehabilitation services (rehab). The study was co-produced by a team of Public and Expert-by-Experience Researchers (PEERs) and academic researchers. Finally, we have an example from Newcastle University where they developed an intervention to support participation in leisure of children and young people with neurodisability. Young people with neurodisability, parents, and multidisciplinary practitioners were involved in identifying and prioritising the research topic, and preparing the original funding application. Within the research programme, the lead researcher, a participatory artist, and eight young people aged 16-21 years came together to form 'AniMates', a group that makes artwork about research projects. Together they co-produced two stages of the research programme: the data analysis and interpretation, and the dissemination.

Each of the examples also includes references that they found useful when co-producing their research as well as five learning points.

This series of publications show how the key principles and features of co-producing research can find expression in practice. For those people thinking about undertaking co-produced research you may want to copy or adapt some of these examples. Along with the information on challenges and benefits, they may give you the confidence to try a co-produced approach. Finally, these publications are a celebration of co-produced research. We hope then that the examples will be both useful and an inspiration to people considering undertaking co-produced research. Either way please do let us know.

**The project team:** Gary Hickey, Simon Denegri, Sam Goold, Gill Green, Doreen Tembo, Katalin Torok, Gill Wren (all National Institute for Health Research), Sally Brearley (Kingston University), Tina Coldham (INVOLVE Advisory Group), Sophie Staniszewska (University of Warwick) and Kati Turner (St George's University).

1. Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S., Tembo, D., Torok, K., and Turner, K. (2018) **Guidance on co-producing a research project.** Southampton, INVOLVE
2. Hickey, G. (2018) The potential for coproduction to add value to research. **Health Expectations.** 21:693-594

# 1

## What do patients want in a feedback response? Improving responses to patient feedback in an online environment: a coproduction approach.

**John Donovan**, Volunteer mental health patient research partner

**Simon Parham**, Heads Count, Colebrook Southwest Ltd

**James Munro**, Chief Executive of Care Opinion

**Rebecca Baines** and **Ray Jones**, Researchers

### Organisations involved in the research:

Collaboration for the Advancement of Medical Education Research and Assessment (CAMERA), Peninsula Medical School, University of Plymouth, Heads Count and Care Opinion.

### Summary of the research:

Patient feedback is important for service improvement, patient safety and quality of care. However, guidance on how to respond to patient feedback is limited particularly when looking at patient feedback online. The University of Plymouth, together with a volunteer mental health patient research partner and charitable organisations (Heads Count and Care Opinion), sought to:

- 1 Systematically search for stories about adult mental health care on the UK's leading not-for-profit feedback website, Care Opinion, and identify themes potentially helpful in providing a high quality feedback response from a patient perspective. We found 245 stories and identified 19 themes.
- 2 Discuss and test the identified themes with 12 members of a local user-led network for people affected by mental health matters called Heads Count.
- 3 Co-design a best practice response framework based on collaboratively agreed themes.
- 4 Quality appraise 183 existing responses using the response framework to see how well existing responses follow patient desires and expectations.

The framework we developed is the first of its kind to provide guidance on how to effectively respond to patient feedback in an online environment.

### Links to the research:

<https://onlinelibrary.wiley.com/doi/10.1111/hex.12682>

<https://www.careopinion.org.uk/blogposts/698/what-do-people-want-in-a-response-to-their-fe>

<https://vimeo.com/276875542>

## How did the key principles of co-producing research find expression in your research?

People shared power in our research by developing relationships built on mutual trust, acknowledgement of contributions and transparency. Individuals with mental health experiences can often feel silenced or discriminated against. Creating an environment where these feelings were discouraged was therefore really important. We aimed to reduce these feelings by:

- **Establishing ground rules** that we agreed before any data was collected. Our agreed ground rules included the recognition that there was no right or wrong answers, no single perspective was more important or influential than another, **everyone is of equal importance**, and individuals involved were experts in their own right. For people with lived experience, their individual healthcare experiences were their expertise - this was something unique that they brought to the research.
- Holding discussions with the patient research partner and Heads Count members at a time and place where they felt comfortable and empowered. The patient research partner chose for our meetings to take place at the same time every fortnight in his local library. He chose this location as it's not associated with a particular treatment or condition, has good public transport links, and is accessible and familiar. Members of Heads Count chose to have their focus group at their local hospital on the basis of this being their regular meeting place.
- Having the discussion meeting with Heads Count members chaired by a member of Heads Count and not a researcher.
- Involving the patient research partner as an integral member of the research team, throughout the research. This led to **ownership of joint decisions** including designing patient information sheets and consent forms, analysing identified stories, creating questions for the discussion with Heads Count members, co-developing a coding framework and contributing to report write ups/paper publications.
- **Creating an ongoing dialogue** with those involved by providing regular updates about the progress made as a result of people's contributions, ideas and insights. All communication came from one point of contact to help maintain continuity, build rapport and avoid confusion. Methods of communication used included emails, texts, presentations, and social media mentions. Importantly, the team returned to Heads Count to report on research findings before any external dissemination to ensure members were happy with the content, presentation and message.

The research process was underpinned by tested and acknowledged principles of patient and public involvement (PPI). (1) This included accommodating individual and collective needs to ensure inclusivity and being proactive in our approach.

As a result, relationships have continued to develop both within, and outside, the research setting. This has been facilitated by various activities including the repeated acknowledgement of those involved, co-authorship of open access peer-reviewed papers, collaborative presentation of findings at conferences/events, social media acknowledgements and continued collaboration in ongoing projects.

## Reciprocity

Importantly, co-producing research is not just about the outcome, it is also about the journey or process. While contributing to existing understanding, theory and practice, research should also benefit those involved. Here are some testimonials that describe the reciprocity achieved:

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*“Getting the thing [academic paper] published was a serious, obvious highlight. Going to the Care Opinion event to present, those are highlights, but actually, it is something a little bit more out there for me and that was when I realised that my contribution was actually worthwhile. It was really a big, big highlight for me. It gave me self-worth, and to have self-worth back is critical. You realise you’re a valued person, it doesn’t look all so bad, it can always improve, and when you’re a bit down, you can take solace in that... I have found that my involvement with this research has allowed me to focus on my own issues, so that my own general wellbeing and health has benefited, in particular my intellectual wellbeing... my own health and mental outlook has improved inestimably... it wouldn’t have been possible without all of this [the research], I am indebted to this project...”*

**John Donovan, Volunteer Patient Research Partner**

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*“At Care Opinion we’ve really valued the opportunity to work together to generate research questions, refine methodologies, interpret findings and help disseminate findings. The area we work in is innovative, and so inherently uncertain. We are all learning together and we want our service to create worthwhile benefits for real people. So for us, learning from research findings, hearing other points of view, engaging in critical debate and bringing our own questions to the table has been immensely valuable. The research output to date has supported our sense that we are on the right path. And it has also encouraged us to think about how we can evolve our platform further to support (and measure) evidence-based good practice. Our platform is all about hearing people’s experiences of care, and so it is only right that we hear and act on people’s experiences of our platform itself. This research is one important way we can do exactly that.”*

**James Munro, Chief Executive Officer of Care Opinion**

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## How did the key features of co-producing research find expression in your research?

### Establishing ground rules

At the beginning of the discussions with Heads Count members, ground rules were established by all those involved which included the importance of mutual respect, acknowledgement, confidentiality and anonymity. Ground rules were established before any data collection took place and were regularly reviewed during the research process.

### Joint ownership of key decisions

The local charity and volunteer mental health patient research partner took a lead on designing the response framework with some input from the researchers. For example, the framework was designed by members of Heads Count and the patient partner by listing all agreed themes on individual post-it-notes and arranging these into an order considered meaningful and appropriate to them. The researchers accepted and embraced the idea that the local charity and volunteer mental health patient research partner had the relevant expertise in this area but were still included in the decision-making process.

### A commitment to relationship building

Demonstrating your commitment to the research but also to the individuals you are working with is really important. For the discussion meetings with Head Count members, we found baking home-made cakes and encouraging individuals to request their favourite type of cake was really helpful in building relationships (who doesn't like cake!), and enabling a space to reverse traditional power hierarchies. For example, normally, people are requested to attend a meeting at a specified time and location with pre-defined questions. Individuals therefore have limited opportunities to make decisions, influence change or make their own requests. Requesting a cake flavour is one small, but important, way of changing this dynamic. Cake encourages people to engage in conversation and provides an informal group activity everyone can engage with, helping to lower any pre-research anxieties or tension. Including a photo of the research team can also help personalise the relationship between those in the focus group and research team helping to build rapport and facilitate researcher identification.

### Opportunities for personal growth and development

The volunteer mental health patient research partner has been invited to present at conferences following the co-production of the framework. He was a resident in a homeless hostel when we first met and is now living independently. He accredits his active involvement in the research project to improvements in both his physical and mental wellbeing. For the researcher, this is the best outcome she could ever have hoped to achieve.

## Flexibility

Flexibility was required in terms of discussion meeting dates, location and numbers. Due to some of the conditions people were experiencing, involvement was dependent on the day. Flexibility was also required with deadlines. Co-production almost always takes longer than you think. It is therefore important to build in additional time to account for this.

## Valuing and evaluating the impact of co-producing research

If this research had not been co-produced then its impact, benefits and achievements would arguably not have been achieved. For example, the patients identified the importance of providing two forms of communication, rather than just email, to engage with responders. Patients also identified the importance of providing a named contact to whom they would be sending their response – this helped develop relationships and alleviate anxiety.

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*“I could never have anticipated the impact this research would have on me both personally and professionally. Watching people grow in terms of confidence and self-belief has been hugely rewarding and empowering. This has proved to be influential in motivating me to persevere when things get tough, but has also made me re-evaluate traditional notions of research success i.e. academic outputs. Being alongside John [patient research partner] and sharing the experience of him being able to leave the city and catch a train for the first time in three years to co-present our research was truly an honour and a highlight. This experience has taught me it’s not all about the final output, it’s also about the process you adopt, and the connections you make along the way.”*

Rebecca Baines, Researcher

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## Continuous reflection

It is important to continually evaluate your co-production approach by routinely asking for feedback from those involved, seeking suggestions for any improvements and holding debriefing or ‘closure’ meetings to ensure everyone ends the research project feeling satisfied. We did this through regular informal discussions with John Donovan [patient research partner], having table cloths on which people could scribble their ideas on throughout the discussions and asking people involved at the end of the research activity for their feedback on what they thought had worked well or anything what could be improved – in this way we were able to get people’s reflections in near real time.

## Key challenge: Getting public partners named on publications

We encountered resistance to accept John’s name (patient partner) in a peer-reviewed publication without an affiliation or qualifications. Often, qualifications are equated to expertise. John’s psychiatric care experience and insights are his expertise. No other team members could provide this. John did not fit ‘the template’ of the journal and initially the journal were hesitant in enabling us to register John as a co-author. After some persistence, this issue was resolved by writing to the journal editor explaining the situation and expertise provided by John without which the research would not have been achieved.

### Five key learning points:

- Build a feedback loop – let people know what you have done with the time and information they have shared.
- Work in equal partnerships built on mutual trust, respect and transparency.
- Be proactive. Go out and get involved. Don't expect people to come to you.
- Be resilient and persevere - co-producing research can be challenging but hugely rewarding, it will be worthwhile.
- See it, achieve it, and celebrate it. Decide together how things should work, what you need to do to achieve that, and celebrate all of your successes, no matter how great or small.

## Useful references for co-producing research:

- Baines, R., Regan de Bere, S. (2018) Optimizing patient and public involvement (PPI): Identifying its “essential” and “desirable” principles using a systematic review and modified Delphi methodology. **Health Expectations**. 21:327–335.
- Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. (2014) Mapping the impact of patient and public involvement on health and social care research: a systematic review. **Health Expectations**. 17:637-650.
- Conklin, A., Morris, Z., Nolte, E. (2015) What is the evidence base for public involvement in health-care policy?: results of a systematic scoping re-view. **Health Expectations**. 18:153-165.
- Crocker, J.C., Boylan, A-M., Bostock, J., Locock, L. (2016) Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment: a UK- based qualitative interview study. **Health Expectations**. 20:519-528.
- Domecq, J.P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N. (2014) Patient engagement in research: a systematic review. **BMC Health Services Research**. 14:89 <https://doi.org/10.1186/1472-6963-14-89>
- Gagliardi, A.R., Lemieux-Charles, L., Brown, A.D., Sullivan, T., Goel, V. (2008) Barriers to patient involvement in health service planning and evaluation: an exploratory study. **Patient Education Counselling**. 70:234-241.
- INVOLVE (2012). **Briefing Notes for Researchers: Involving the Public in NHS, Public Health and Social Care Research**. INVOLVE, Eastleigh.
- Jagosh, J., Maculay, A., Pluye, P., Salsberg, J., Bush, P.L., Henderson, J. et al. (2012) Uncovering the benefits of participatory research: implications of a realist review for health research and practice. **Millbank Quarterly**. 90:311-346
- Shippee, N.D., Domecq Garces, J.P., Prutsky Lopez, G.J., Wang, Z., Elraiyah, T.A., Nabhan, M. et al. (2015) Patient and service user engagement in research: a systematic review and synthesized framework. **Health Expectations**. 18:1151-1166.
- Snape, D., Kirkham, J., Britten, N., Gradinger, F., Looban, F., Popay, J. (2014) Exploring perceived barriers, drivers, impacts and the need for evaluation of public involvement in health and social care research: a modified Delphi study. **BMJ Open** 4:e004943.
- Tritter, J.,Q. (2009) Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. **Health Expectations**. 12:275-287.
- Towle, A., Bainbridge, L., Godolphin, W., Katz, A., Kline, C., Lown, B. et al. (2010) Active patient involvement in the education of health professionals. **Medical Education**. 44:64-74.

<http://www.involve.nihr.ac.uk/resource-centre/resource-for-researchers/>

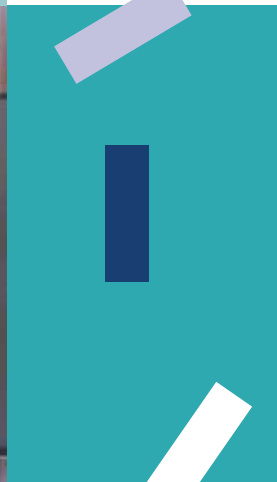
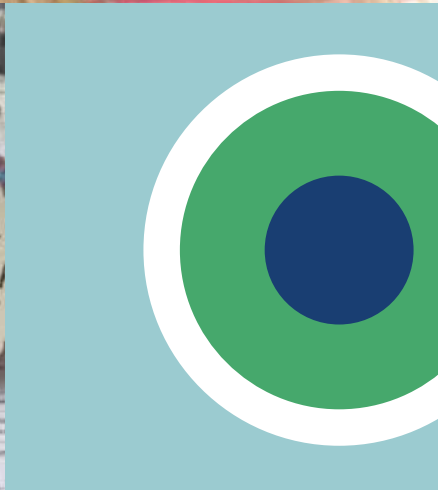
<http://piiaf.org.uk/documents/piiaf-guidance-jan14.pdf>

<https://www.plymouth.ac.uk/uploads/production/document/path/11/11116/working-together-guide.pdf>

Baines, R.L., Regan, S. (2017) Optimizing patient and public involvement (PPI): Identifying its “essential” and “desirable” principles using a systematic review and modified Delphi methodology. **Health Expectations**. 21:327-335

# John and I co-presenting our research at a Care Opinion event.

This was the day John left the city and travelled on a train for the first time in three years...



# 2

## Accessibility and Suitability of Residential Alcohol Treatment for Older Adults

**Maureen Dutton**, Research Assistant Substance Misuse Ageing Research Team (SMART) Bedfordshire University

**Rebecca Jones**, Research Fellow SMART Bedfordshire University

### Organisations involved in the research:

University of Bedfordshire and Alcohol Research UK

### Summary of the research:

This partnership between University of Bedfordshire and Alcohol Research UK explored the experiences of older adults in residential alcohol rehabilitation services (rehab). The study was co-produced by a team of Public and Expert-by-Experience Researchers (PEERs) and academic researchers. The research questions were developed by a PEER who had personal experience of alcohol dependence and who had previously volunteered in alcohol rehabilitation services.

The study sought to answer the following:

- 1 To what extent do residential alcohol treatment facilities have upper age thresholds?
- 2 Are the needs of older adults (for this study people over the age of 50 years) different from those of younger adults aged 18 years and over in residential rehab?
- 3 What are older adults' experiences of these services?

A search of an online directory of residential rehab services was carried out to identify what proportion of rehabs in England had upper age limits. Interviews were then conducted by the PEER with 16 rehab residents to explore older adults' experiences of residential treatment. We found that one in four residential rehabs in England had arbitrary upper age limits and excluded older adults - contrary to the Equality Act (2010).

### Links to the research:

<http://alcoholresearchuk.org/alcohol-insights/accessibility-and-suitability-of-residential-alcohol-treatment-for-older-adults/>

### How did the key principles of co-producing research find expression in your research?

Project lead and PEER researcher, Maureen Dutton explains how the study was co-produced.

## Sharing power

The idea for the research study came from my own experience of volunteering in a residential rehab. Because I was treated as an equal member of the team I felt confident enough to suggest the idea for the study. Like everyone else, I was employed by the university and paid for my time. I was provided with a lap top and a mobile phone, and I received training, support and supervision. The SMART team encouraged this equal power dynamic by using first names, irrespective of our positions or experience, by avoiding academic jargon, and by having each person in the team take turns to chair meetings.

But sharing power within a research team is not only about creating a team environment where people are treated as equals. It also involves ensuring people are given meaningful responsibility and ownership for the project. I had previous experience of interviewing from my time in another role so I was responsible for managing data collection, building relationships with rehabs, conducting interviews and managing a travel and expenses budget. Some elements of the project required research experience, for example submitting ethics applications, coding transcripts and writing the report. These activities were jointly undertaken with an experienced researcher who acted as my mentor. Other tasks were completed jointly, with input from the wider team, a group made up of traditional researchers and those with lived experience.

## Including all perspectives and skills

The project team was made up of PEERs and academic researchers, each of whom brought expertise and perspectives relevant to this particular study. The team included people of different ages, people with experience as service users, a practitioner with experience of working with older adults, and an experienced addictions researcher. The PEER researchers also both had considerable professional experience and transferable skills. For example, I used interviewing skills developed in a previous role in the interviews I undertook.

## Respecting and valuing the knowledge of all

As well as including people from different backgrounds, the team took an inclusive approach to ensure that everybody's voice was heard. For example, to encourage contribution and share decision making, a different team member would chair each monthly conference call. It helped that the team were used to working with each other having developed relationships over several years (see 'Developing relationships' below).

## Developing relationships

In 2015 the Substance Misuse Ageing Research Team (SMART) began involving people with lived experience of addiction in research. As such, relationships and trust have developed over a period of time and beyond the lifetime of this particular piece of research. This research has reaped the benefits of those relationships.

When myself and my colleague first joined the team as PEERs, our role was to advise on ethics applications, review research documents and comment on funding applications. The PEER role has developed considerably since then. This project in particular marked a significant shift in the evolution of the PEER role because it was the first SMART project to be led by a person with lived experience.

## Reciprocity

I was employed as a researcher on a fixed term contract for the duration of this study and my salary was funded by the research grant. As PEERs we also had access to learning and development opportunities, both formal and 'on the job' training. For us, sharing power in the way we conduct our research also involves sharing the credit we get for our work. I was named on the report and the journal article submitted about the rehab study, which made me feel like I had an equal share in the work. I have also been involved in disseminating the findings to practitioners working in rehabs and to the research community through presenting at conferences. This means that I have significant stake in the project from start to finish and am invested in bringing about meaningful change as a result of the rehab findings.

However, it is not only people with lived experience that benefit from this approach. Involving people from different backgrounds also provides useful challenges to research, and the academic community, who sometimes work in isolation. Aside from tangible benefits of producing higher quality and more impactful research, working alongside people with lived experience is also a source of motivation and provides focus for our work. Below Dr Sarah Wadd, the director of SMART describes her experience of working with PEERs:

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*"I feel so strongly about it and get so much from working in this way. It reminds me why I work so hard and keeps me motivated when things at work are tough. It makes me determined in relation to bringing about change. I have learnt not only from the PEERs' lived experience, but also from the skills they bring from their previous careers. I have observed the differences between PEERs and this keeps me focused on the fact that there is a whole diversity of people and experiences out there that we need to consider."*

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## How did the key features, of co-producing research find expression in your research?

### Establishing ground rules

Within the SMART team, many of our ways of working in a mixed team of academic and PEER researchers had already been established by the time this project started. One of the most important things, on this first, service-user led project was creating an environment where everyone was empowered to contribute. On a practical level, this included an agreement to use plain English, avoid academic jargon and acronyms, and encourage the questioning of people when they used terms and phrases with which others were less familiar.



## Ongoing dialogue

On this project the team worked remotely throughout and I travelled around England and Wales to conduct the data collection. To ensure that I was supported, my mentor and I had weekly conference calls where I would provide updates on the project. In addition, I was responsible for updating the wider team on project developments and getting their input through monthly team conference calls. This allowed those members of the team who were not involved in the day-to-day running of the project to contribute their ideas.

## Joint ownership of key decisions and flexibility

Remaining in regular contact also ensured that decisions could be made by those best placed to make them, rather than being made by default by academic researchers. As the team got to know one another better, we were able to identify areas where PEERs had experience that could be used in different ways. Co-producing the research in this way was an iterative process that required a degree of flexibility in how the project was managed. For example, although the initial plan was to use the academic researchers' contacts to identify residential treatment centres to take part in the study, it became clear that the PEERs were well placed to identify rehabs who could be included. As a result, the team decided to use all members' contacts to identify rehabs to partner with. This was useful as it meant that later, when one rehab had to pull out of the research, we had alternative partners we could work with.

## Valuing and evaluating the impact of co-producing research

By working alongside people with lived experience and involving them in every stage of our research, we hope to challenge myths about people with experience of addiction. Even amongst some addictions researchers, there is a sense that people with lived experience of addictions are unreliable and incapable of leading and delivering research. This is perhaps because of stereotypes wrongly applied to people with addictions. This project is an example of how our research aims to explode these myths and promote expert-by-experience led research in the addictions field.

## Continuous reflection

I had regular meetings with my mentor where we would reflect on all aspects of the project.

## Key challenge: Whether or not to disclose lived experience

A key challenge we had to negotiate was whether to publicly identify PEERs as people with lived experience. On the one hand, having people with lived experience involved in research is good publicity for the university and for the SMART team, it helps secure funding and is a unique feature of the work we do. On the other, people who have experienced addictions are often stigmatised as a result, and disclosing a personal history of alcohol problems may not sit comfortably for some people. We realised shortly after we started working together that there were different viewpoints on this within the team. We decided to discuss how to use the fact that we had researchers with lived experience working in our team to our advantage, without making anybody feel uncomfortable about disclosing personal information.

We felt that routinely identifying the researchers who had lived experience could encourage other people with lived experience to get involved with research. Equally it could also make people who do find it embarrassing uncomfortable and by identifying them they may feel vulnerable. We realised that both of the PEERs in the team had different opinions on the situations in which they were happy to be identified as having lived experience. We agreed to leave this decision down to their discretion when introducing themselves in person. When describing the team in writing, we explain that half the team has lived experience, without identifying who those team members are. In certain situations, for example when discussing our approach to involving people in research, it may be appropriate to identify those in the team with lived experience. If this is the case, then this is agreed with those concerned in advance and on a case-by-case basis.

### Key benefit of co-producing your research: More relevant research

People with lived experience bring fresh perspectives and introduce new ideas for research. Put simply, without the involvement of people with lived experience, this project would not have come about. Undertaking research based on the needs and observations of people who have direct experience of addiction treatment and support also ensures that the research we do is meaningful and relevant to the people who access services. Closing the gap between those who conduct research and those who are researched should bring about more meaningful change and increase the impact of research.

### Five key learning points:

- Get the right people involved: identify what skills and abilities you are looking for
- Consider the long term: be transparent about how long you want people to be involved for
- Treat people as individuals: people with shared experience may have very different views on how and why they want to be involved
- Be open to change: reflect on the way you are involving people and revise when needed.
- Don't forget the boring stuff: ensure finance is in place, provide remote working support and material/equipment

### Some useful references:

Alcohol Research UK (2017) Public Involvement in Alcohol Research,

<https://alcoholchange.org.uk/publication/public-involvement-in-alcohol-research>

# 3

## Developing an intervention to support participation in leisure of children and young people with neurodisability

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**Lucy Barker**, Participatory Artist/Creative Producer

**Organisations involved in the research:** Newcastle University

### Summary of the research

In the United Kingdom, 1.1 million children and young people are disabled – approximately 8% of 0-19 year olds.(1) Neurodisability is one of the largest populations of disabled children and young people, and describes a group of congenital (i.e. inherited) or acquired long-term conditions that are related to impairment of the brain and/or neuromuscular system.(2, 3) Common conditions include cerebral palsy, autism, and learning disability, although a specific diagnosis may not be identified. The impact of neurodisability may include difficulties with movement, cognition, hearing and vision, communication, emotion, and/or behaviour.(3) The number of children and young people in the UK affected by neurodisability is unknown. Approximately 182,856 UK children aged under five years (4.7%) have developmental disabilities; however, this figure underestimates neurodisability because it does not include prominent conditions such as cerebral palsy.(4)

For all children and young people, including those with neurodisability, participation in leisure is an important health outcome. Leisure contributes to physical and mental health, subjective wellbeing, social inclusion, and academic achievement. However, children and young people with neurodisability are restricted in their leisure participation compared to their non-disabled peers. This can mean they miss opportunities to experience the developmental benefits of leisure activities, which in turn further disadvantages their wider health and wellbeing.

In the NHS, allied health professionals – occupational therapists, physiotherapists, and speech and language therapists – support children and young people with neurodisability to participate at home, at school, and in the community. However, there is limited evidence about how they can best support participation in leisure. To fill this gap, the National Institute for Health Research funded a three-year research programme investigating:

- 1 What factors influence whether children and young people with neurodisability participate in leisure?
- 2 What intervention techniques can allied health professionals use to target and change these factors?
- 3 How should they go about delivering these intervention techniques in the NHS?

To guide our thinking in the research programme, we drew on the World Health Organisation's International Classification of Functioning, Disability, and Health, a framework that brings together biological, psychological, and environmental perspectives on health and disability. Our research methods were based on the UK Medical Research Council's guidance for developing complex interventions, and theory and evidence about

health behaviour change. First, we reviewed the current evidence about factors influencing participation in leisure, focusing on children and young people's personal factors (e.g. emotions and goals), and social environmental factors (e.g. support and relationships within the family). Then, we talked to children and young people, parents, allied health professionals, sports coaches, short breaks professionals, and researchers about their experiences of intervention techniques for supporting participation in leisure (e.g. providing emotional support, or adapting activities). Finally, we integrated the current evidence and people's expertise into a practical manual for allied health professionals to use in the NHS. The next step is to investigate the feasibility and acceptability of actually using the manual in the NHS, and to evaluate whether the techniques in the manual are effective in supporting participation in leisure.

### What stages of your project were co-produced?

Young people with neurodisability, parents, and multidisciplinary practitioners were involved in identifying and prioritising the research topic, and preparing the original funding application. Within the research programme, the lead researcher, a participatory artist, and eight young people aged 16-21 years came together to form 'AniMates', a group that makes artwork about research projects. AniMates members have first-hand experience of neurodisability, or supporting people affected by neurodisability. Together we co-produced two stages of the research programme: the data analysis and interpretation, and the dissemination. Here we describe how we developed an animated film to shape and share the results of the research.

### How did the key principles and features of co-producing research find expression in your research?

As a research team, we were inspired by projects where creative arts had been used for **including all perspectives and skills**, particularly those of young people perceived as vulnerable. We had budgeted for public involvement in our original funding application, and we needed to access methodological expertise to support a co-production project. So, our first step was to commission an experienced participatory artist, and orientate her to the research programme and preliminary results. Initially, the lead researcher and the participatory artist decided to co-produce an animated film to share the results of the research programme. We chose animation because of its successful impact in other co-produced research with vulnerable young people. (5)

To get people involved, we contacted individuals from our previous project, and began a new collaboration with Pyramid of Arts, a collective of artists with and without learning disabilities. Eight young people aged 16-21 years got involved in the co-production: three young people with neurodisability and their three personal assistants, and two artists, one of whom has a learning disability. We visited young people at home to introduce the idea of the animation and gain their initial consent to be involved. The home visits helped us to start **building and maintaining relationships**, and to prepare an inclusive and accessible co-production environment. We practised interacting through the young people's high-tech communication aids, worked out how to operate their other assistive technologies (e.g. powered wheelchairs and hearing aids), and learned how to carry out essential support tasks safely (e.g. assisting one young person to have a drink of water). The young people

were all in education, so we worked around college terms and family holidays to set the date for our first co-production workshop. We sourced a suitable venue with a Changing Places accessible toilet, level access, and parking, and booked wheelchair-accessible taxis.

Our co-production took place within five one-day workshops over ten months, mostly in the school holidays and occasionally at the weekend. We made a conscious decision to ensure we were **including all perspectives and skills**. For example, we valued the contribution of personal assistants because, as well as supporting the young people to take part, they had experiences and views in their own right, and we wanted them to have a stake in the co-production. We believed that having young people as the predominant age group throughout the process would set the right tone, and create an environment where individuals could be vocal, and feel confident and in control. It was important that the young people with neurodisability could attend without their parents, and that – as much as possible – we communicated and made arrangements with them directly. This was more developmentally appropriate for their age group, and we wanted to avoid adding to their parents' workload. To help build relationships, we agreed initial ground rules (Figure 1), and created a giant timeline where we plotted everyone's birthdays, exams, holidays, and other important events (Figures 2-3). In the workshops, we devoted the first hour to socialising and catching up on timeline news. Between workshops, we used social media (e.g. SMS text messaging, WhatsApp groups, email, Instagram, and Doodle) to share photographs of our activities (including with parents), keep in touch with each other, and decide when and where we would next get together.



Figure 1



Figure 2



Figure 3

We soon began to realise that researchers and artists bring very different knowledge and skills to the co-production table. Researchers generally use pre-determined protocols that lay out the steps they will take to deliver their aims and objectives. Artists create spaces and processes for exploring ideas, seemingly without a fixed agenda or purpose, and respond to what emerges. For our co-production, the participatory artist envisaged loosely structured workshops, with time built in for young people to play, experiment, bond, and process the density of the research. She was confident – and creatively, she thought it was important – to take risks and see what happened. From a researcher's point of view, this felt risky and uncomfortable. How did such **flexibility** and open-ended approaches fit with funded deliverables and fixed timescales? At this point, it was critical to step outside the comfort zone and be open-minded about diverse methodologies. In the end, creative approaches proved to be one of the most important mechanisms for enabling **sharing of power** with the young people, by giving them real responsibility and more control over the co-production process.

The young people were confident and enthusiastic about taking responsibility and control straight away. They got started by watching a diverse selection of short animations, analysing their content, tone, accessibility, and format, and deciding on a shortlist of desirable features (Figures 4-5). They preferred animations that had a clear message and a target audience, were humorous, accessible for people with hearing loss and those with reading difficulties, and were based on real-life people and places. We realised that real-life stories would be a good way of opening up the research for young people, so the lead researcher went back to the research data and extracted participants' quotations, stories, and examples for the young people to explore in more detail. Simultaneously, the group experimented with different art forms, including light painting, animating, and printing (Figures 6-7). Combining the art with the research was refreshing. Making things gave us all time to reflect on the data, and sparked off conversations about how health and social care policy and practice actually played out in the young people's day-to-day lives. They made connections between the issues in the data and their own views on leisure, short breaks, direct payments, accessibility of buildings, and rules and regulations in leisure centres. Their views challenged the research team to think about whether and how the results of the study might help to address the issues they were describing.



Figure 4

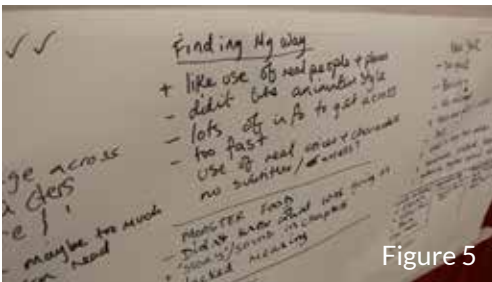


Figure 5



Figure 6



Figure 7

There were around six weeks between the workshops, and this gave the lead researcher and the participatory artist time and space to take an iterative approach to the co-production. We reflected carefully on the young people's views, went back to the data for more analysis and interpretation in light of their perspectives, and planned the next workshop in direct response to their ideas. We created an **ongoing dialogue** by following the threads of the young people's views in and out of the data, and bringing back further quotations, stories, and examples focusing on the issues they had identified as important.

By halfway through the co-production, we were collectively taking **joint ownership of key decisions**, particularly the main messages for the animated film. The young people wanted to focus on tensions around 'hanging out with friends', because this topic resonated with their own experiences. On the one hand, they believed hanging out with friends to be an important aspect of participation in leisure contributing to health and wellbeing. On the other hand, within the research data they had explored problems with NHS and Social Care support for hanging out with friends (e.g. professionals' beliefs that hanging out has limited value, and that participation in sport is more important). These tensions have been highlighted in other studies, but – prior to the co-production – had not been part of the research team's main focus. **Ongoing dialogue** with the young people enabled the lead researcher to analyse the thread of hanging out with friends in more detail and with more nuance than she had previously. This meant that she could appreciate its importance to one of the key stakeholder groups (young people), and highlight its significance in the write-up of the research programme. In short, collectively we were **respecting and valuing the knowledge of all those working on the project**.

In co-production, **reciprocity** means that everybody benefits from working together. In this project we emphasised **valuing and evaluating the impact of co-producing research**, not just in terms of project outputs, but also the personal development opportunities that came about for all of us. The lead researcher learned how to open up the research data and preliminary results to people outside the academic research team. On a practical level, this meant getting better at communicating in plain English, and working out how to condense a large volume of information to something that the participatory artist and the young people could actually access, whilst simultaneously preserving its nuance and meaning. For example, the research programme had generated approximately 1,000 pages of interview and focus group transcripts. It was overwhelming to think about how to even start to make these data accessible and interesting. The solution emerged from listening and responding to the young people: they could relate to stories about real-life people and places, so extracting participants' verbatim stories and examples from the data set was the best place to start. Opening up the research meant the lead researcher had to become less protective of the data set as a whole, and more willing to separate out individual sections and stories for scrutiny in the co-production workshops. The temptation was to try and control other people's understanding of the research. It was important – but challenging – to resist the urge to over-explain the data, and give other people time to digest it all and come up with their own interpretations.

The creative arts methods we used emphasised exploring and experimenting, seemingly without a fixed agenda or purpose related to the research data and results. The idea was to embrace uncertainty, follow the threads in different directions, see what happened, and



Figure 8



Figure 9



respond. For the lead researcher, who was responsible for delivering and managing the project, and would be judged on its success, this was challenging. What would the funder and the wider academic community think about the outputs of the co-production? How was all this going to help disseminate the research? However, as the co-production progressed, the creative methods were the very aspects that freed us up to take a fresh perspective and play with the research in different ways, for example through comedy, movement, and metaphors. Although this approach was unfamiliar to the lead researcher, it was natural and interesting for the young people. It played an important part in getting them involved in the process, because it encouraged expression and autonomy, and enabled them to take more control over the co-production. Sharing control with the young people generated uncertainty, which meant that a supportive and respectful relationship between the lead researcher and the participatory artist was key. Through **continuous reflection** on our ideas, concerns, and anxieties, we developed a shared sense of responsibility for the success of the project, and became more confident and willing to take risks.

Throughout the co-production there was a **commitment to relationship building**, breaking down boundaries, and gaining a better understanding of the young people's worlds. The lead researcher and the participatory artist experienced first-hand the considerable logistical challenge of organising accessible co-production workshops, particularly the limited availability of level access venues with Changing Places. Although this was time-consuming and often frustrating, it was also fundamentally important to making the co-production happen, and it gave us a taste of the reality that the young people and their parents navigated each day. We learned more about how health and social care policy and practice actually played out in the young people's day-to-day lives. These insights enabled us to explore the relevance and use of the research results, and come up with new ideas for research that would inform positive changes in policy and practice.

From the outset, it was essential for the young people to get something back from the co-production, and our first priority was for the workshops to be enjoyable and challenging, as well as inclusive and accessible. We had learned to have high expectations of the young people's abilities, and we wanted to make sure their contribution was meaningful, substantial, and challenging. We wanted to avoid falling into the trap of merely 'entertaining' them, or asking them for feedback on – or endorsement of – research results that had already been decided upon by the adults. The co-production was an opportunity for combining academic and creative thinking, exploring young people's perspectives on live research data, and experimenting with art forms they had not previously experienced. We believed that this approach would lead to **opportunities for personal growth and development** for all of us, by using and extending our existing knowledge and skills.

The co-production also provided a context for forming friendships and developing a sense of group identity. Partway through the workshops, one young person named the group 'AniMates' – a play on our animation work and the social aspects of getting together regularly. Two artists in the group designed an AniMates logo capturing the ideas of asking questions, having fun, voicing your opinion, making things, and being together (Figure 8). As a group, we socialised outside the arena of the research programme by visiting one of the young people's first exhibitions as a solo artist and having a celebration lunch (Figure 9). Socialising both within and outside the workshops was pleasurable, and helped strike a balance between having more challenging academic and more laid-back aspects to the co-production.

Our co-production project gradually became a springboard for new ideas about how young people can make a much greater contribution to neurodisability research. To begin to realise our ideas, we needed to be able to sustain what we had achieved in AniMates. However, as a research team, we were all too aware of the challenge of keeping up momentum between funded research programmes. We successfully applied for sustainability funding from EngageFMS at the Faculty of Medical Sciences, Newcastle University, which enabled us to develop a strategic plan for maintaining and developing AniMates in the coming years. By this point, we understood the individual young people's talents, interests, and capabilities, so the funding also enabled paid leadership roles for AniMates members on various projects. For example two members designed a Facebook page to describe our co-produced projects, introduce AniMates to the world, curate our artwork, and get more people involved in the future. One young person was interested in exploring career options in health and social care and research. She contributed to two successful funding applications to the National Institute for Health Research and the British Academy of Childhood Disability, and became a paid co-investigator.

Looking towards the future, one next step is for AniMates to connect with other researchers and young people's advisory groups. We would like to further explore how meaningful and reciprocal involvement of people who are seen as vulnerable can best be embedded within, and sustained between, research programmes. We are also interested in how co-production itself could have a positive impact on young people's friendships, peer support, work experience, and employment, all of which are more restricted for young people with neurodisability. And we have started working on plans to further evaluate both the impact of our co-produced artwork and events, and of the co-production methods and processes themselves.

### Five key learning points:

- Flexibility is the cornerstone of inclusive and accessible co-production. Practicalities and logistics are a demanding but fundamentally important part of making co-production happen.
- Interdisciplinary collaboration with participatory artists enriches co-production methods and outputs, particularly with groups of people seen as vulnerable. Researchers can build opportunities for diverse methodological approaches into their funding applications.
- Co-production is characterised by relationships that bring the best out in people. But co-production relationships, as well as processes, are often messy, emergent, uncertain, and emotional. Researchers may need to transgress traditional boundaries, and the unwritten rules about how to interact with public advisors may need to be challenged. Crucially, this may introduce ethical complexities that will need to be carefully navigated, and critical reflection and peer support will be essential.
- Researchers should make it a priority to look for opportunities to sustain and fund co-production relationships beyond individual research programmes, particularly with people with long-term conditions.
- Co-production may introduce ethical complexities that will need to be carefully navigated, and critical reflection and peer support will be essential.

## Useful references for co-producing research:

- Chesworth, L. (2018) Embracing uncertainty in research with young children. **International Journal of Qualitative Studies in Education**. Available from: <https://doi.org/10.1080/09518398.2018.1499982>
- Dovey-Pearce, G., Walker, S., Fairgrieve, S., Parker, M., Rapley, T. (2019) The burden of proof: The process of involving young people in research. **Health Expectations**. 22: 465-474
- INVOLVE (2012) **Briefing notes for researchers: involving the public in NHS, public health, and social care research**. INVOLVE, Eastleigh. Available from: [http://www.invo.org.uk/wp-content/uploads/2014/11/9938\\_INVOLVE\\_Briefing\\_Notes\\_WEB.pdf](http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf)
- INVOLVE (2018) **Updates on welfare benefits regulations**. INVOLVE, Eastleigh. Available from: <http://www.invo.org.uk/wp-content/uploads/2018/01/REVISED-Jan-2018-INVOLVE-Updates-on-welfare-benefits-regulations.pdf>
- Johannesen, J. (2017) Exploring the purpose and meaning of patient engagement in paediatric neurodisability research. Available from: <https://johannesen.ca/2017/11/exploring-purpose-meaning-patient-engagement-pediatric-neurodisability-research/>
- Liddiard, K., Runswick-Cole, K., Goodley, D., Whitney, S., Vogelmann, E., Watts, L. (2018) "I was excited by the idea of a project that focuses on those unasked questions": Co-producing disability research with disabled young people. **Children and Society**. 33: 154-167.
- Maguire, K., Britten, N. (2018) 'You're there because you are unprofessional': patient and public involvement as liminal knowledge spaces. **Sociology of Health and Illness**. 40(3), 463-77.
- Madden, M., Speed, E. (2017) Beware zombies and unicorns: Toward critical patient and public involvement in health research in a neoliberal context. **Frontiers in Sociology**. 2(7).
- Starling, B., Tanswell, J. (2018) Diversifying audiences and producers of public involvement in scientific research: the AudioLab. **Research Involvement and Engagement**. 4(39).
1. Department for Work and Pensions. **Family Resources Survey: financial year 2016/17 2018** [2 May 2018]. Available from: <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-201617>.
  2. Department of Health. Annual Report of the Chief Medical Officer 2012, **Our Children Deserve Better: Prevention Pays**. Crown Copyright; 2013.
  3. Morris, C., Janssens, A., Tomlinson, R., Williams, J., Logan, S. (2013) Towards a definition of neurodisability: a Delphi survey. **Developmental Medicine & Child Neurology**. 55(12):1103-8.
  4. Olusanya, B.O., Davis, A.C., Wertlieb, D., Boo, N-Y., Nair, M., Halpern, R., et al. (2018) Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. **The Lancet Global Health**. 2018.
  5. Breaking Through Moving On from Child Sexual Exploitation, University of York and Basis Yorkshire: <https://basisyorkshire.org.uk/training-resources/breaking-through-moving-on-from-cse/>

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