



# INVOLVE



National Institute for  
Health Research

## Guidance on co-producing a research project



## Foreword

I first heard the word ‘co-production’ a few short years ago. I have been embroiled in the ‘involvement’ agenda as an activist, and working as a consultant on it for many years, and all of a sudden there was this new word and perhaps aspiration?

I have had the privilege to Chair a Co-production Network at the Social Care Institute for Excellence (SCIE) since 2012, as they saw this as a way forward in their work, making sure what they do is grounded in the lived reality of ordinary folk with social care needs. So, it is very exciting to introduce this guidance on co-production in research. We all move forward together.

Going the Extra Mile (2015) set out a compelling vision and clear objectives for NIHR’s leadership in public involvement. That included “Recommendation 6 – Co-production: The public, researchers and health professionals should be empowered and supported better to work together in the future...” INVOLVE has led on establishing the principles for co-production in research, as a simple way to understand their possible importance in delivering research excellence. Indeed, this guidance has been a true co-production effort in itself, an iterative process, worked on by many people together, including and valuing lots of perspectives.

I hope this helps you in your research endeavours.

Tina Coldham

Chair of INVOLVE Advisory Group

February 2018

## Acknowledgements

The project team would like to thank everyone who has given their time and input into this project. A special thank you to all those people who contributed to the workshop we held at which we developed a broad consensus about the key principles and features. Many thanks to the Kent and Medway NHS and Social Care Partnership Trust Experts by Experience Research Group who gave valuable feedback on the first draft. Thanks also to the Public Involvement and Lay Accountability in Research and Innovation (PILAR) Group and the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC) PPI Reference Group for their robust critiques of subsequent drafts. And thank you to all those people who contributed their time and energy, and valuable and supportive comments, to the Twitter chat including the Q Community and the Coalition for Collaborative Care.

We would like to thank Tracey Johns, Research Design Service East of England and Jonathon Paylor, Research Design Service, London for their work on a project that informs this work. Thanks also to Dr Stan Papoulias, King's College, University of London and Nigel Cox, Manchester Metropolitan University for ongoing support and advice.

And a thank you to Gill Wren and Sam Gould at INVOLVE for proof reading.

A full list of the key activities in the development of the guidance is included at the end of this document.

## Summary

Co-producing a research project is 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.

This guidance is a first step in moving toward clarity about what we mean by co-producing a research project. It explains the key principles and features of co-producing a research project and suggests ways to realise the principles and key features. Finally, the guidance outlines some of the key challenges that will need addressing, in further work, to aid those intending to take the co-producing research route.

### 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**

## Introduction

*Going the Extra Mile* (a strategic review of public involvement in the National Institute for Health Research) suggests co-production could be a means of evolving and improving public involvement in research. This guidance identifies some key principles and features involved in co-producing a research project. The term co-production can be difficult to define and pin down, reflecting the wide range of disciplines from which it emerges and the often loose way it is applied. Some people use it to describe a particular methodology. For others, it is a description used when they are often simply referring to some kind of input from public members. Frequently, this means consulting the public, or the researchers deciding in which discreet aspects of the research process the public can be invited to collaborate – old wine in new bottles. But co-producing research means much more than consultation or collaboration.

This guidance, written for the public<sup>1</sup>, researchers and health and social care practitioners (we also recognise that people can wear more than one hat, for example the public can also be researchers) has a focus on co-producing research projects and in particular, how co-producing relates to public involvement in health and social care research. We recognise that some people may only want to co-produce parts of a research project. The guidance here is about co-producing a whole research project.

So what is co-production and what does it mean for public involvement in research?

Co-producing a research project is 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. The assumption is that those affected by research are best placed to design and deliver it and have skills and knowledge of equal importance. Our approach is that co-producing research is principles driven rather than being a fixed set of tools or techniques. It requires that relationships are valued and nurtured and that efforts are made to redress power differentials. People should be supported and enabled to realise their potential in carrying out their roles and responsibilities in the project.

It is not the intention of this paper to provide a blueprint or ‘one size fits all’ approach to co-production. There is no single formula or method for co-production and such an approach would be counter to the innovation and flexibility that is implicit in co-produced research. And we do not want to stifle innovation. Co-producing research can include partnerships between academia and organisations representing the public as well as individual public members working with organisations, for example universities, which undertake research. Nor is it the intention of this paper to provide solutions to all the challenges involved in co-producing research. And co-production does challenge how we think about and do research and the relationships between organisations, practitioners and researchers and the public.

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<sup>1</sup> When using the term ‘public’ we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.



This guidance is a first step in moving toward clarity about what we mean by co-producing research. It articulates the key principles and features of co-producing a research project. Also included are some suggestions – by no means an exhaustive list – of ways in which the principles and key features might be realised. Finally, the guidance concludes with some of the key challenges that will need to be addressed to aid those intending to take the co-producing research route. The next steps will be taking these key principles and features as the basis for the development of tools and techniques which can address these challenges.

## Key principles

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

This is the key principle and the one from which all others lead. Research becomes a shared responsibility rather than the preserve of researchers and practitioners.

Co-producing research means that relationships and systems are horizontal rather than vertical. Often there are differentials in power between researchers and practitioners on the one hand and public on the other. This inequality in power can be rooted in wider social and economic differences which need to be recognised and this inequality needs to be continually addressed in the ongoing relationships.

It should also be noted that ‘sharing of power’ does not mean that everybody is involved in every decision and every part of the project. People working on a project will still have different roles, for example there will still be a ‘leader’ on a project – and this can be a member of the public. Sometimes this leader, for example the Principal Investigator, may be the person who is ultimately accountable. However, they can still share the responsibility and key decisions with others.

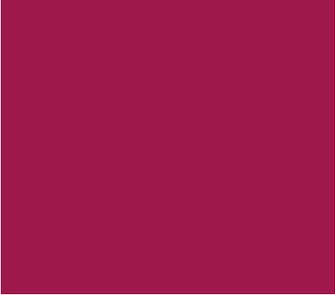
And there is also recognition that during a project power between individuals will fluctuate depending on the expertise required at any particular stage. The approach however is more consensual, power relations are more equitable than hitherto and there will be joint ownership of key decisions on a project as people work toward a **shared understanding**.

With shared power and ownership of key decisions comes **responsibility**. There needs to be **defined roles** for everyone with each team member holding **real responsibility**.

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

Co-production requires a research team to ensure that **all the necessary views, experiences, skills and knowledge are included**. This encompasses the different types of expert, for example members of the public who have knowledge and expertise about their own experiences of services or a condition, researchers with skills and knowledge of relevance to the research approach and/or service or condition, and practitioners with their expertise of the service or condition.

It also involves embracing **diversity** and developing structures and practices to enable the involvement of all those people required for a particular project, including underrepresented groups. This **inclusivity** requires the research to be accessible. As well as physical access to, for example meetings, this includes ensuring information is accessible, for example documents are in an appropriate format and language.



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

The starting point is that everyone working together on a research endeavour is of equal importance. Everybody on the team is recognised as an **asset**. Traditionally practitioner/ research expertise carries greater value than other forms of knowledge, for example experiential knowledge. Co-producing research requires that the different knowledge bases, experiences and perspectives of all involved in the enterprise are afforded **equal respect and value**. Additionally, we must provide the space and opportunity for all voices to be heard.

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

The contributions of people should be **recognised**. Everybody working together on a research project should **get something back** from contributing to that project. This could take many forms, not just financial rewards. For example, the development of social networks, increased confidence, new knowledge and skills and access to courses and training.

## **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.*

The evolving relationships between the various people working together on a research enterprise are key to co-producing research. It is the evolution of these relationships and of **trust** that enable co-production to happen. In order for trust to develop individuals need to **reflect** on the knowledge, assumptions, preconceptions and biases that they bring to a research project. There needs to be an acknowledgement and mindfulness of the complexity involved in ‘power differentials’.

## Key features

This section outlines some of the key features that you might expect to see in co-produced research. Each key feature is followed by some suggestions as to how it might be achieved. These are some pointers rather than an exhaustive list.

### Establishing ground rules

Establishing ground rules at the beginning of the project can help create an environment where all voices can be heard and treated with respect. These ground rules, developed by the group working on the research, would set out **expectations**, in terms of the **roles**, **responsibilities** and **behaviours** of all.

#### How might this be achieved?

A useful starting point would be the work INVOLVE, along with partners, has been doing on values, principles and standards. Getting consensus on the values and principles will provide guidance on behaviours expected, while the standards provide more detail on how these values and principles might find expression.

### Ongoing Dialogue

There should be dialogue between all those working together on the research project. This dialogue should begin prior to the start of the project, to help identify different types of knowledge, roles, responsibilities, expectations and establish relationships.

#### How might this be achieved?

Dialogue needs to be built into the governance of the project. It should continue throughout the project as project plans, ideas, research tools and knowledge that emerge from the project go through various iterations and are influenced and shaped by those involved.



## Joint ownership of key decisions

It is the 'joint ownership of key decisions' which helps differentiate co-producing from collaborating. It is not that everyone needs to be involved in every decision or every aspect of a piece of research but rather that the group, **working together**, decide and agree who should be involved and when, in terms of the management, governance and undertaking of the research.

### How might this be achieved?

One approach is for everyone 'around the table' to outline, at the beginning of the project, what they do know and what they don't know about a given topic area – the intention is to pool together the collective knowledge and move researchers and practitioners away from the position of determining what is and isn't important knowledge. If researchers and practitioners put themselves in the role of 'experts' then the inference is that others are not. This sharing and enabling everyone a voice creates a building block from which to progress.



## A commitment to relationship building

Embracing and embedding the principles really requires a coming together of the organisations which host research projects and the communities within which they exist. Addressing power differences and developing relationships requires the development of **open, honest, trusting and reciprocal relationships**.

Trying to create a level playing field and emphasising the development of relationships have implications for both the culture and processes and procedures of organisations – many of which will take time to implement. Co-production won't 'just happen'. Organisations and researchers need to shift from being not just 'doers' of research but to being proactive in encouraging and **facilitating** public involvement and developing relationships beyond the research community.

### How might this be achieved?

Sometimes there will need to be a commitment to relationships beyond the life span of an individual project. One approach, which may not be appropriate for every research project, would be to establish and cultivate a research reference group<sup>2</sup> which is attached to the organisation undertaking research (rather than just an individual project). This reference group could meet regularly with staff, and its members could undergo any necessary training and be regarded as an asset in the development of research ideas. Over time the reference group could help shape for example the research strategy of the organisation, and members could work on individual projects.

Organisations which undertake research could provide induction training to their research staff and public members on co-producing research. This would, at the very least, raise awareness of what co-producing research entails and the likely challenges.

Safe spaces could be created to enable people working together to step outside of their official roles and develop quality and trusting relationships. These safe spaces might involve people sharing information about themselves that is not project related, for example their interests or engaging in activities away from work. The key is to change group dynamics and communicate on a more level playing field.

All of the above require time – which must be built into individual projects and/or become part of the 'way of doing things' in those organisations which undertake research.

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2 the membership of a reference group is not static and will, periodically, need new members to ensure diversity and inclusivity



## Opportunities for personal growth and development

There is an emphasis on **supporting** individuals and unlocking the potential of individuals to contribute to the project. In this way people are treated as **assets** with the skills, knowledge and experience to help develop solutions to issues.

Project leads need to facilitate the involvement of the public effectively and manage the flexibility and uncertainty that are often involved in co-produced research projects.

Members of the research team need to be willing to **relinquish power** and accept **reciprocity** of experience and expertise. This may require a cultural change in the research team and/or the organisation hosting the team.

### How might this be achieved?

An obvious mechanism is the provision of training and support – for the public, researchers and practitioners.

Researchers will need to learn how to effectively facilitate the involvement of the public and manage the flexibility and uncertainty that are often involved in co-produced research projects.

The public may require training and support to enable their voice to be heard, take responsibility and facilitate their involvement. People need to be equipped/trained with the necessary skills and knowledge to co-produce. Providing the training and support encourages an element of reciprocity which can ensure that people are more actively involved as they are being supported as required.

## Flexibility

A research project usually has a pre-determined project plan. However, a co-produced research project should provide opportunities for an iterative, fluid, open ended, experimental and interactive process; there should be opportunity for solutions and innovations to **emerge from the relationships developed**.

### How might this be achieved?

Devolution of decision-making power is required. Co-producing research challenges the top down approach to research; in co-produced research decision-making is devolved and shared.

It is important to provide opportunities for discussing ideas, assessing progress and reflecting on the research project.



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

It is as important to value the impacts of working co-productively that come from the research process as it is of the research findings or outputs. For the research process, some of these impacts will emerge rather than be planned: new relationships, expanded social networks and increased confidence of members of the public may be some examples. In terms of the research findings or outputs, working co-productively will produce knowledge and an end result that will often be different from that produced by a conventional academic process.

### How might this be achieved?

In order to build up the evidence base around the impact of co-producing research, it is important to put in place mechanisms to evaluate, measure or assess this. Using reflective processes (see section overleaf) is one example: another may be keeping a co-production log throughout the project.

Some tools for evaluating impacts can be found at <http://piiaf.org.uk/resources.php>.

Although the responsibility for co-producing research – and evaluating its impact - should be shared and owned by all members of the team, it is helpful to have one or two people whose particular role in the project is to steer, guide and advise on working co-productively throughout.



## Continuous reflection

Reflection is a process whereby research team members have the opportunity to look at and reflect on **how they are working together**, how they might be using their particular expertise and perspective in the project and how this might impact on the research process and findings/outcomes.

### How might this be achieved?

There are many different kinds of reflective approaches. Research teams should think carefully before the start of the project and agree on what approach might best fit both the type of research they are doing and the way the team is structured. For example, team members might keep individual reflective diaries pegged to each research stage or there might be team meetings held every few months with a specific reflective focus.

Using reflective approaches such as these are a helpful way for a research team to keep continually and collectively aware of how they are working together, what is working well and where there are tensions or sticking points. Creating safe and supportive spaces which enable team members to openly and honestly reflect on challenging issues such as power dynamics and inequalities is an integral part of co-producing research.

This kind of reflective process should not be confused with supervision or an annual review/appraisal provided by a line manager as a part of someone's role and career development.

## Conclusion

Co-producing a research project has implications for the processes and procedures and cultures of organisations and their relationship with the public. Indeed, it has the potential to transform how we 'do' and think about research.

This guidance identifies some key principles and features involved in co-producing a research project. These principles and features are just the beginning of a pathway for those considering taking a journey on the co-production route. They are the first steps from which we can go on to develop further tools and techniques to enable co-producing research.

The extent to which research projects and organisations embrace all of the principles and the depth to which they go in embedding the principles will vary. The more principles that are adopted and embedded the stronger will be the co-production of the research. The intention is that organisations, researchers and the public can use these principles to critique their own (and others') practices and further evolve and improve public involvement in their research.

Co-producing research requires a shift in how we approach and think about research. However it is likely that efforts at co-producing research will usually build on existing public involvement frameworks in organisations. Indeed, when reading the guidance some readers will recognise principles and key features which already exist in the public involvement frameworks in their own organisations or organisations with which they have worked. Sometimes these involvement frameworks will provide firm foundations for building co-produced research while at other times these frameworks will require modification.

This paper also raises many challenges that will need to be addressed to really prise open the opportunity of co-producing research. Though by no means an exhaustive list, below are some of the key ones:

1. How can we ensure that power is shared in a research project (given how research is currently funded and organised)?
2. How can we allow for the greater flexibility often required in a co-produced research project (given the way that research is usually governed)?
3. Can we develop criteria that would enable funders/reviewers to determine if a project has been co-produced?
4. Can we develop tools or guidance on how to co-produce knowledge?
5. How do we assess and evaluate co-produced research? And how do we ensure that it is regarded as 'credible'?

In short, this guidance is the beginning of our work on co-producing research. It is not the final word.



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

### **How was this guidance developed?**

This guidance has been co-produced by the following: Gary Hickey, Simon Denegri, Gill Green, Doreen Tembo, Katalin Torok (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). These people form the working group on this project.

This guidance was developed via an iterative process. The table opposite outlines key activities in the development of the guidance:

| Activity  | Date                          |
|---|-------------------------------|
| Round table held, with working group members, to kick start the project and identify key principles and themes in 'co-producing research'   | November 2016                 |
| Research: Literature review of key text on co-production and interviews with people involved in co-produced research.<br><a href="https://tinyurl.com/yconqp8y">https://tinyurl.com/yconqp8y</a>  | November 2016 – November 2017 |
| Workshop, with researchers and the public, in which the key principles and themes identified from the round table and research were used as the building blocks, to gain consensus on the key principles and key features of co-producing research. | May 2017                      |
| Working Group discuss and revise first draft of guidance  | June 2017                     |
| Consultation with Kent and Medway NHS and Social Care Partnership Trust Experts by Experience Research Group  | July 2017                     |
| Consultation on draft guidance with Public Involvement and Lay Accountability in Research and Innovation (PILAR) Group  | July 2017                     |
| Working Group discuss and revise second draft of guidance   | August 2017                   |
| Working Group email comments on third draft of the guidance   | August 2017                   |
| Consultation on draft guidance with National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NETSCC) PPI Reference Group  | September 2017                |
| Consultation on draft guidance at Conference: Global perspectives on research co-production with communities: ontologies, epistemologies and methodologies  | September 2017                |

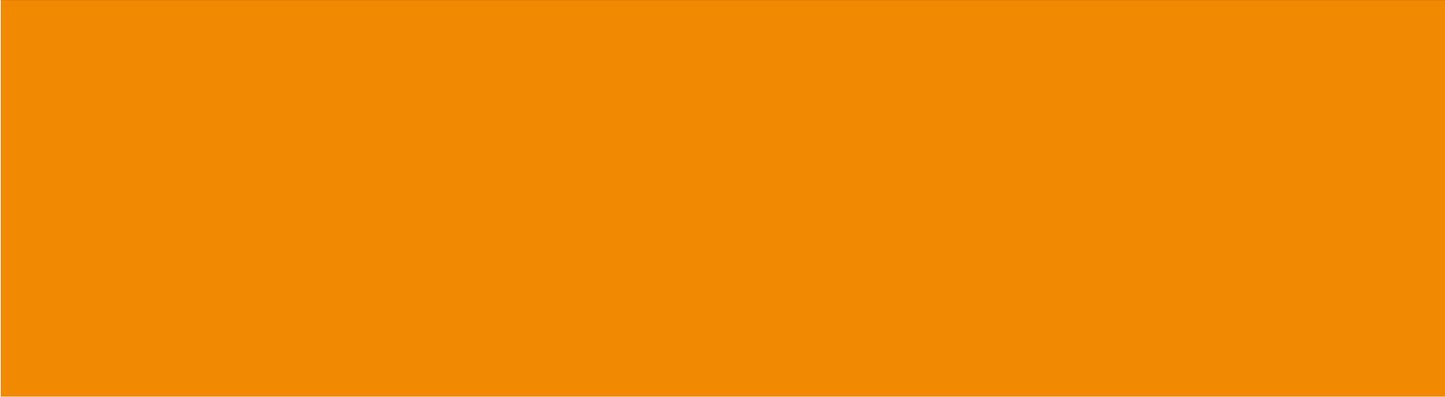
| Activity (continued)  | Date          |
|---|---------------|
| Presentation and discussion on draft guidance with Research Design Service Public Involvement Community <sup>4</sup>                    | October 2017  |
| Consultation on draft guidance with Collaboration for Leadership in Applied Health Research and Care Shared Learning Group <sup>5</sup> | October 2017  |
| Twitter chat on draft guidance  | October 2017  |
| Working Group discuss and revise fourth draft guidance  | October 2017  |
| Working Group email comments on fifth draft of guidance   | October 2017  |
| 'Sense checking' draft guidance at RDS Staff Training Day   | November 2017 |
| Working Group email comments on sixth draft of guidance   | November 2017 |
| 'Sense checking' draft guidance at INVOLVE Conference   | November 2017 |
| 'Sense checking' draft guidance NETSCC PI Leads Group   | November 2017 |
| Working Group sign off guidance   | December 2017 |

3 Membership of the group is open to those who have a lead role in promoting and supporting public involvement in research funding and commissioning within the National Institute for Health Research (NIHR) e.g. NIHR Central Commissioning Facility, NIHR Evaluation, Trials and Studies Coordinating Centre, the NIHR Trainees Coordinating Centre, the NIHR School of Primary Care Research and NIHR School for Social Care Research, and the NIHR Research Design Service. In addition, membership also includes representatives from other organisations that also promote and support public involvement in research funding and commissioning e.g. the Medical Research Council, the Economic and Social Research Council, and some of the major health charities.

4 Each Research Design Service is represented by a member of staff or their deputy with strategic responsibility for public involvement in their region.

5 Each Collaboration for Leadership in Applied Health Research and Care is represented by a member of staff with responsibility for public involvement in their region.





**INVOLVE** is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

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