

A map of resources for co-producing research in health and social care

A guide for researchers, members of the
public and health and social care practitioners

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About this document

Co-producing research is when researchers, practitioners¹ and members of the public collaborate to develop research. Everyone works together in more equal partnerships and shares responsibility and power throughout the research project (INVOLVE, 2018)².

This document provides a map of practical resources that can help when **co-producing research in health and social care**. It was produced as part of [a project](#) thinking about the challenges of doing co-production in health and social care research. It is not a review of academic papers, nor is it a comprehensive or exhaustive guide to co-production. It provides a selection of resources, toolkits and guidance to help you through the process of thinking about what co-production means in your project. It contains practical information and links which [our team](#) and the people who worked with us thought could be useful. We chose resources that seemed helpful for the kind of research we do. We have included links for ease of use, but we don't have responsibility for them, and they may change over time. We provide references at the end of the document.

The document is set within the National Institute for Health Research (NIHR) INVOLVE (2018) guidance on co-produced research, but it also draws on lessons and good practice from different disciplines so we can all learn from each other. Because of this, you may find contradictory or diverse principles or practices in different resources, because they come from different traditions and may define co-production differently. **You'll need to work out what's most appropriate in your own research context.** Literature and work on co-production is continually expanding. If you know of other resources that you have found helpful, please email Michelle m.farr@bristol.ac.uk and the project team will regularly update this document.

How was this document developed?

This document comes from [a project](#) where we developed a training course and additional materials to support more equal relationships between everyone within co-produced research. We did this by facilitating five workshops with multi-disciplinary researchers, practitioners and public contributors with public involvement and co-produced research experiences. In these workshops we discussed how different co-produced research had attempted to share power and enable more equal relationships between everyone. This document is one of the results of this process. It is intended to be additional materials to support a training course that is run by People in Health West of England and NIHR Applied Research Collaboration (ARC) West. **To access resources developed by this project, please see <http://bit.ly/CoProResources>.**

Who funded this document?

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¹ Practitioners are the people planning and providing services. This could include paid health and social care staff, paid staff of community organisations, health and social care commissioners and policy-makers.

² [INVOLVE](#) is an organisation that supports active public involvement in NHS, public health and social care research, and is part of, and funded by, the [National Institute for Health Research](#) (NIHR).

Definitions

Co-production: an introduction

The word “co-production” is used in a variety of ways. It means different things to different people. It is used across many different academic disciplines including: economics, political sciences, public administration, voluntary sector studies, public management, science and technology studies, services management, public policy, public engagement and participatory action research.



For a great overview of the different conceptual and methodological histories of co-produced research, read ‘There’s no such thing as ‘co-production’: the many faces of collaborative research’ Facer and Enright (2016) Chapter 4

There is a distinction between co-produced research (definition below) and co-produced public services, defined as the activities of public service staff and citizens to enhance public services, where citizens are actively involved in producing services (Brudney and England, 1983, Ostrom, 1996). The NIHR are using co-production principles (see this document p.5) to strengthen public involvement in research (Staniszewska et al., 2018).

This document focuses on co-production in research.

NIHR INVOLVE definition of co-produced 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” (INVOLVE 2018).

Who is co-producing research?

NIHR INVOLVE’s definition incorporates **the public as key collaborators**. Their definition of the term ‘public’ includes 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 includes people who want to get involved based on their personal or family experiences of health conditions. It could also include citizens who are more generally concerned about these issues. Sometimes members of the public who get involved also run community-based or service user-led organisations.

Co-production has also been used to describe research that is developed together with academic and non-academic organisations or communities (Campbell and Vanderhoven, 2016). This stems from a broader definition where co-production is “the process through which inputs used to produce a good or service are contributed by individuals who are not ‘in’ the same organization” (Ostrom, 1996). This means that research has been described as co-produced when all those working together are paid staff from different organisations.

This document focuses on the involvement of the public in co-produced research, i.e. people who are potential/ actual users of a health or social care service, not people in a paid position who plan or provide that service. Involving members of the public in co-produced research, requires different considerations and resources, in comparison to

working only with paid staff or policymakers. The most important thing to think about when you want to do some collaborative research is to think through who you want to involve, how, when and why (see this document p.8).

User controlled research

In contrast to 'co-produced research', '**user-controlled research**' is where people who use a service control, own, and lead research about that service. See [Shaping our Lives, User controlled research: Its meanings and potential](#) (Turner and Beresford, 2005) and [The ethics of survivor research](#) (Faulkner, 2004).

Guiding principles

In this resource we use the NIHR [INVOLVE's \(2018\)](#) guiding principles for co-producing research as we are NIHR funded. The NIHR is using co-production principles (Boyle et al., 2010, Boyle and Harris, 2009) to develop its approach to involving the public in research (Staniszewska et al., 2018). These principles include:

- **Sharing power** – the research is jointly owned and people work together to achieve a joint understanding, people are working together in more equal relationships
- **Including all perspectives and skills** – making sure the research team includes all those who can make a contribution, involving diverse stakeholders and being accessible and inclusive
- **Respecting and valuing the knowledge of all** those working together on the research, building on people's assets and the experiences they bring – everyone is of equal importance
- **Reciprocity and mutuality** – everybody benefits from working together, valuing everyone and supporting their potential
- **Building and maintaining relationships and sharing learning** – an emphasis on relationships is key to sharing power.
- **Joint understanding** and consensus and clarity over roles and responsibilities (INVOLVE, 2018).

Different disciplines have their own traditions and practices of co-produced research. Co-produced research in the **social sciences, arts and humanities** highlight some similar principles, see bullet points below from a range of different projects (Pain et al., 2015, Facer and Enright, 2016, Campbell and Vanderhoven, 2016, [Productive Margins](#)):

- Academics and community organisations are equal partners in research design and delivery, and everyone's knowledge is valued
- Relationships are based on values of trust and mutual respect
- Co-production builds upon participatory action research and co-operative inquiry that have an ethical commitment to challenge social hierarchies and benefit communities,

and the research leads to action and beneficial outcomes for people with the least power.

Different approaches to co-produced research (Staniszewska et al., 2018, McDermont and Productive Margins, 2018) are connected with wider literature on co-production within public services. Early academic definitions of co-production describe how within public services, recipients can take an active part in producing services; they are not just a passive, consuming population (Brudney and England, 1983). This highlights how service users take a productive role as 'co-producers of the services they receive' (Parks et al., 1981). Applying these principles to research, the public (potential or actual service users) are taking an active role in producing and using knowledge and research.

More recent literature on co-production illustrates how it can be a transformative mechanism in public services (Boyle and Harris, 2009, Boyle et al., 2010, Nesta, 2012, SCIE, 2015, World Health Organization, 2015, European Commission, 2018). Co-produced public services share the principles that are listed above, they also include the importance of:

- Building on people's assets - valuing people, their skills, knowledge and capabilities, and using these to support improve public services
- Blurring roles - reducing boundaries between professionals and people who use services. This may include more peer support roles and building networks and links between people who use services
- Being innovative and creative with room for experimentation.

Research ethics and governance

When do you need ethical approval for co-produced research and what for?

In health and social care research prior formal ethical approval is needed to collect data from patients or service users in a research study. However, a key principle of public involvement in health research is that you do not need to get prior ethical approval to involve the public in decisions about designing and managing the research. This also applies to co-production. This difference is because those members of the public involved in, or co-producing, research are understood to be colleagues working alongside other team members. This role is different from people who are recruited to be research study participants from whom research information (data) is collected. For example, data collection might mean filling in questionnaires or being interviewed about a specific topic. Those involved in co-producing research are providing contributions that include advice and guidance on how to conduct research to ensure that it draws on a public perspective that is often (but not always) based on relevant personal experience. While there is no requirement to seek prior formal ethical approval for public involvement in health research, there is still a need to follow good practice and provide appropriate support and information, and an ethical approach is also key in co-production.

Guidance on when to apply for ethical approval is available from the NHS Health Research Authority: [Patient and public involvement in research and research ethics committee review](#)

What is appropriate ethical guidance for co-produced research varies according to discipline, institution and country. Check your own institution's ethical policies and procedures.

If you're co-producing research and making decisions with everyone involved, you usually find that initial plans and ideas change. You may find that you need to go back to get further ethical approval on some projects several times. The nature of co-production is that you can't always anticipate at the outset how it will develop. Ethical approval may be needed for things that were not initially envisaged at the beginning of projects.

Ethical considerations are part of a process throughout collaborative research. There is **guidance on research ethics** focused on different research methods. Resources include:

- The **National Co-ordinating Centre for Public Engagement (NCCPE)** project on [Ethics in participatory research](#) involved UK community organisations and universities working together to produce resources to help researchers with ethical challenges associated with co-producing research.
<http://www.publicengagement.ac.uk/nccpe-projects-and-services/completed-projects/ethics-participatory-research>
- Easy Read introduction to community-based participatory research:
- Durham University Centre for Social Justice and Community Action (2013). [What is doing research together?](#) National Co-ordinating Centre for Public Engagement.
- [Community-based participatory research: A guide to ethical principles and practice](#) is a guide on ethical principles in community-based participatory research, developed by Durham University and [NCCPE](#).
- Durham Community Research Team (2011) [Community-based participatory research: ethical challenges](#). Also see an account of the 'ethical mess' that can happen in co-produced research (Thomas-Hughes, 2018)
- Faulkner, A. (2004) [The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors](#)
- How can you develop appropriate **data management** guidelines? See [Data management in co-produced research](#) by the Productive Margins research group.

Research methods

Different research disciplines have different approaches to co-produced research, and who's involved in research partnerships and what methods are used to co-produce research are the subject of debate. Social sciences, arts and humanities collaborative and co-produced research has developed from many different research traditions. A great overview is in Chapter 4 '**There's no such thing as 'co-production': the many faces of collaborative research**' ([Facer and Enright, 2016](#)).

Major co-produced research programmes such as [Productive Margins](#), [Connected Communities](#) and the [N8 Research Partnership](#) have drawn on the rich traditions of participatory action research (Pain et al., 2015, McDermont and Productive Margins, 2018). There is a wealth of literature on community-based participatory research, participatory action research and co-operative inquiry where the values and principles embedded in these research methods are in harmony with co-production principles (see page 5). Different co-productive methods are rooted in different critical theory including Marxism, anarchism, critical race theories, feminism, and disability rights (Bell and Pahl, 2018, Facer and Enright, 2016).

Whilst co-operative inquiry and participatory action research are strongly aligned with the principles of co-production, in health and social care research there is a hierarchy of evidence and a culture of evidence-based medicine. Randomised controlled trials (RCTs) sit at the top of the evidence hierarchy with a stronger claim to be implemented in health policy and care, whereas qualitative approaches and participatory action research can be less valued. In healthcare research, findings from randomised-controlled trials, can be more influential than other kinds of evidence. This increases the challenge of co-producing research in this context, as the values, principles and ways of doing health and social care research may be less in tune with co-production principles. Below are a series of health and social care papers and resources, where people have used different methods to co-produce research:

Qualitative, community-based and participatory action research

In health and social care, people who have written up how they have co-produced research have often used qualitative research (Norah Fry Centre for Disability Studies, 2018) and community-based participatory research methods (Aabe et al., 2019, King and Gillard, 2019).

- Durham University has provided a range of [toolkits, guides and case studies](#) in community-based participatory research including a [Participatory action research toolkit](#) (Pain et al., 2011) and an overview of the ethical challenges involved in community-based participatory research (Durham Community Research Team, 2011)

Other types of research methods

There are examples of systematic reviews that align with the principles of co-production (Jackson et al., 2018, Rose et al., 2003, Rose et al., 2004, Merner et al., 2019) and useful resources to support public involvement in systematic reviews (Pollock et al. 2018, Pollock et al. 2019):

- INVOLVE provide [guidance on public involvement in systematic reviews](#) (Vale et al., 2014). This document also includes references and other resources about public involvement in reviews.
- The Cochrane Collaboration is a global network that produces high quality systematic reviews and evidence syntheses. They have a learning resource to involve public contributors and healthcare teams throughout the review process, including best practice and practical suggestions (Pollock et al., 2015):
 - Pollock A, Morley R, Watts C. [Involving people: A learning resource for systematic review authors](#). London: Cochrane Training

We have found one example of a co-produced **randomised controlled trial** (RCT) (Goldsmith et al., 2019), and reflections on using co-production in RCTs (McConnell et al., 2018). Please tell us of others!

Who's involved and when in a project

In an ideal world (and in the NIHR INVOLVE guidance) co-production should take place at every stage of a research process. When beginning to think about and plan a co-produced project it is important to include partners (or people who may be representative of partners) at the early bid stage to develop the project. The priorities for the project need to come from the people who you will be co-producing with (Cameron et al., 2019).

- **Working in partnership with user-led organisations:** [Getting Things Changed](#) (Tackling Disabling Practices: Co-production and Change) was a co-produced research programme, and one strand worked in partnership throughout the project with Disability Rights UK, an organisation led by people with diverse experiences of disability and health conditions, from different communities (Sass, 2019). Disability Research on Independent Living & Learning ([DRILLUK](#)) is a major research programme led by disabled people, with [resources](#).
- When thinking about who should be involved, you can use a planning tool like **stakeholder analysis** to help identify key people and groups who have an interest in your topic (stakeholders): <https://www.odi.org/publications/5257-stakeholder-analysis>
- [Resource on planning and recruiting a co-production team](#) by [Iriss](#).

When thinking about how to involve people, you will need to consider:

- Co-production adds time to a research project to build relationships and trust and understand the priorities and norms of different communities. This time must be costed appropriately.
- Sometimes co-production may happen at just some stages of a research process
- Have clear roles for everyone and enable people to use their strengths and skills. Co-production shouldn't be about everybody doing everything.
- Academic leadership in co-produced projects requires negotiation and socio-political skills, not just technical research skills (Campbell and Vanderhoven, 2016).
- Provide opportunities for people to develop skills and share expertise. Include a training budget.
- Keeping group membership stable can be helpful, but this can be difficult if you are working with people who have health conditions that fluctuate and may impact the extent to which they can get involved. It is important to discuss the extent to which people want to get involved, and manage and review what support people need to keep being involved if they want to be. Have regular conversations about this and think about how to support people.

- Can you involve a balance of people with different backgrounds and expertise? [McPin](#) suggest for example, a group with 3 practitioners, 3 people with experience of mental health issues and 3 researchers (while acknowledging people can have multiple expertise) (McPin, 2019)
- Have research decision-making roles distributed across the research team (Gillard et al., 2012). Decision-making needs to involve those who'll be affected by decisions, and those who are willing to take those decisions. Information needs to be shared to make decisions. Clear communication about which decisions can be co-produced is essential, as is understanding the implications of decisions for the project (Goldsmith et al., 2019).

Working with community researchers or 'peer' researchers

Members of the public who are involved in carrying out research can be called public contributors, community researchers and peer researchers. Peer researchers can have personal experiences of a particular health issue, which is the focus of the research, and have had training, support and skills development to conduct research. Community researchers may be people from a particular community or social group working as researchers. People in this role may need honorary contracts, criminal records checks if they are working with vulnerable people and appropriate payment. Resources include (and see additional references p.15).

- <https://productivemargins.blogs.bristol.ac.uk/co-production-hub/peer-research-training/>
- Thomas Hughes, H (2018) [Critical Conversations with Community Researchers: Making Co-production Happen?](#) Further information at [Connected Communities website](#).

Sharing power

Health and social care research, like many other forms of research, is carried out within a context of embedded hierarchical inequalities in universities, public service institutions, and research funding systems - as well as in society more broadly. Sharing power within co-production demands critical reflective practice, and consistent attention to fluctuating power relations (Farr, 2018, Bell and Pahl, 2018). Understanding how power dynamics are working in practice can be difficult, as power relations are working everywhere, which makes them tricky to grasp.

Power can be understood in different ways:

Power to: Our individual ability to act. We can be active, creative and can reflect on and attempt to change situations (acknowledging that there are social constraints). Everyone can make a difference in some way. In co-produced research, how can we empower people, using power to act and achieve goals in ways that are productive, transformative and achieve social change?

Power over: Being controlled by someone, a group, or organisation. It includes getting someone to do something that they would not have otherwise have done. In co-produced research, this could relate to who makes the rules and decisions and owns the resources.

Power with: Collective action. The collective power that can emerge through our ability to act together (Arendt, 1970). In co-produced research this could include conversations between different people to facilitate shared understandings of common concerns. From this enhanced understanding, how can we take action? How can we achieve more together than on our own?

For ideas of how these different sources of power can be used in workshops, see the Carnegie Trust's report on [Power and making change happen](#) (Hunjan and Keophilavong, 2010).

[Powercube.net](#) is a website full of resources to help understand power relations when you are trying to bring about social change. It has both practical and theoretical materials and resources to help think through and respond to power relations within organisations and different social and political spaces. It includes guides to:

- [Plan a workshop](#)
- [Analyse power](#) basing work on theoretical notions of power, but providing handouts and illustrations to be practically useful
- How you can develop [strategies for action](#) to create social changes.

The [Powercube](#) has been developed as a way to understand and analyse different forms of power. Building on the theories of power (Lukes, 2005), it illustrates how power can be **visible** (through rules, institutions, resources), **hidden** (through the setting and manipulating of agendas, ensuring some voices are heard more than others), or **invisible** (embed in beliefs, language or assumptions).

Academic publications that include practical guidance on how to understand and disrupt embedded power dynamics include:

- An analysis of different public involvement frameworks, including those that explicitly tackle issues of power (Greenhalgh et al., 2019)
- A review identifying the “10 best resources on power in health policy” (Sriram et al., 2018)
- A table of reflective questions based on different understandings of power dynamics within co-production projects (Farr, 2018, p.639)

The idea that co-production and the sharing of power can actually happen within mainstream University spaces has been challenged (Rose and Kalathil, 2019). The authors argue that changes need to be made in the way different knowledges are valued, aligning themselves with local grassroots practices and discourses. Co-production can be used as ‘jargon’ which in reality does not reflect guiding principles (see p.5), and leaves power with research institutions, not the people who use health and social care services and wider members of the public.

Meetings

Co-production meetings will involve a diversity of people. Points below are compiled together from [resources](#) including from the Social Care Institute for Excellence (SCIE), a [blog from McPin](#) (McPin, 2019) and other references (INVOLVE, 2019, INVOLVE, 2018, Goldsmith et al., 2019).

Preparing for meetings:

- Ensure that everyone is asked about their access needs
- Be flexible in terms of meeting dates, location and numbers. Hold meetings somewhere that public contributors will feel comfortable. Ask public contributors where they would like to have meetings. Think about public transport links, accessibility, familiarity, who may need childcare and if people have caring responsibilities. Help to organise transport if people need it.
- It helps to have food at meetings, for convivial and comfort reasons and especially if people are on low incomes. Encourage people to take away any food that's left.
- Video/ phone conferencing/ Skype may enable some people to join– but this may not be accessible for everyone.
- Prepare people in advance - send easy to read minutes and agendas, explain who is coming and why and be clear about expectations.

In meetings:

- Ask people how to format the meetings so they are accessible. Ask people for agenda items.
- You could 'check in' with everyone at the start of a meeting and ask what do you need today (maybe tired been up all night etc.). Be honest as an academic/ practitioner about how you're feeling, this will help to create trust and openness within a group.
- Slow down – allow more time for meetings so that they are not rushed and there is plenty of time to talk about things. If people's involvement is occasional, make sure you do an update at the beginning to ensure everyone knows what's happening. Make sure everyone understands.
- Take regular breaks when people need them for food, drink, cigarettes and toilets.
- Always make time for the 'quiet voices' and support them to be heard.
- Ensure that people have claimed their expenses on the day or know exactly how to do this. Providing shopping vouchers can mean that people get paid on the day. Ask public contributors about the best way to recompense people for their time. Some people may be put off by forms.
- Use plain English, avoid academic jargon and acronyms, and encourage the questioning of people when they used terms and phrases with which others are less familiar.
- Include some time to socialise and catch up
- Is it appropriate to change who chairs at different meetings, or to share the role?

- Change how a room is set up to make sure people sit in different places – you don't want academics in one place, public contributors and practitioners in others.
- Use more group work and have fewer presentations, as this will enable people who don't like speaking in front of a big audience to give their opinions more easily
- Have a documented way of making decisions so that they are clear and transparent
- Try to create an environment where power differentials can be honestly acknowledged and challenged. Be creative, try different facilitation techniques (see p.11). Include reflection time.

[Shaping our Lives](#) have developed an action list to improve involvement, developed from a user-led research project carried out by disabled researchers and a disabled people's organisation (Cameron et al., 2019): [A Guide for Service Providers and Practitioners Organising Involvement Activities with Disabled People](#) (applies equally to researchers)

[A Guide for Disabled People who are Interested in being a Service User Representative](#)

This SCIE webinar helps to make sure that meetings allow everyone to take part, you don't exclude anyone, and your meetings support project progress:

<https://www.youtube.com/watch?v=NdVuR9oW7KU>

Remote co-production during (and beyond) Covid-19 pandemic

In response to Covid-19 we have all been finding out more about how to stay in touch without meeting face to face. This section provides some information on different ways that this might be done, consideration of access and costs for public contributors, and support and safety issues. These pages have been pulled together quickly to help in these unusual times, please be aware that external sites are likely to change and be updated.

It is important to offer people choices about whether and how they might contribute. Some people may well prefer one to one discussion on the telephone or sending their comments or feedback by email or text. Not everyone will feel comfortable taking place in a teleconference or videoconference meeting, particularly if they do not know others involved. If people are willing to contribute in these ways, it is important that those attending know what is expected of them, and what they can expect from the organisers.

What platform do I use?

When deciding what platform to use, check your own organisational policies about the security features of the platforms, and which platforms they support. If you're discussing sensitive issues you need to use an appropriately secure system.

The National Service User Network has developed some helpful guidance about [Keeping in touch with each other when we can't meet face to face](#) which goes through the different options for keeping in contact with people, including guides on setting up WhatsApp groups (with WhatsApp people will be sharing their mobile numbers which may not be appropriate, and not everyone may want to do), Skype, Facebook (think about privacy issues), and Slack.

[The Big Hack](#) has provided information on [different accessible online platforms](#).

[Traverse Ltd](#) have also summarised some features of [different online engagement platforms](#)

The University College London (UCL) Centre for Co-production has produced useful blogs to [Carry on co-producing: handy hints and tips to help you out](#) and [Locked down, but not out of co-production](#)

Other collaborative platforms include [Miro](#), [Mural](#), and [Stormboard](#).

[Hyvr](#) is an online social media platform for healthcare users and healthcare innovators, so if you have concerns about how and where your data is held, this platform could be helpful.

Instructions to support public contributors to use online meeting platforms

The national [School for Primary Care Research](#) has created some excellent guides to support public contributors to use online platforms effectively for meetings. These are helpful to give to public contributors; they are also useful for everyone to learn more about these online platforms. See the full range of tips and resources for public contributors on [virtual involvement](#) as well as specific guidance for different platforms.

[How to use Zoom for meetings \(for computers\)](#)

[How to use Microsoft Teams for meetings \(for computers\)](#)

[Link Age Network](#) have developed some very visual and helpful guidance on [how to join a call using Zoom](#)

The [Co-production Network Wales](#) have also developed some [guidance on how to use Zoom](#)

How to facilitate public involvement online

The national [School for Primary Care Research](#) has some useful tips for facilitating online public involvement meetings: [How do I hold a PPI meeting using virtual tools?](#)

The National Co-ordinating Centre for Public Engagement (NCCPE) has developed a guide: [Online Engagement: A guide to creating and running virtual meetings and events](#).

[Sarah Knowles](#) from the University of Manchester has developed a public shared document on [digital co-design and remote public involvement](#). Lots of information on different resources and online platforms.

The [Shared Learning Group on Involvement and Charities Research Involvement Group](#) had developed a document with guidance on [Involving people when you can't involve them face-to-face: Sharing experience](#)

More general advice on hosting web meetings is available from [Full Circle Associates](#) at: [So You Want to Host a Web Meeting?](#) by Nancy White, with Pete Cranston, Susan Stewart and Bonnie Koenig,.

Facilitation tips: Smaller meetings – up to about six people – work well online, and conversation/discussion can take place normally without too much facilitation. However, bigger groups need more management, and sometimes it is helpful for all participants who are not talking to mute their microphones. This stops any background noise from different rooms being projected into the meeting. Meetings online need to be shorter than face to face, an hour is probably the maximum length without a break. Therefore, managing time in meetings is important, and it is probably useful to send information out in advance, and to ask people to prepare so that the time together is used most effectively. Tips to make all telephone and online meetings work well include:

- Ask people in advance how they'll be accessing the meeting. Will it be through mobile phone/ home PC. Does the equipment have a microphone/ video? (see also costs below)
- The organiser should open the meeting a couple of minutes before it is due to start.
- If anyone expected is unable to join for any reason, ask them to let the organiser know in advance. The organiser should provide a phone number and/or email to attendees so that attendees have a way to contact them.
- If anyone is having technical difficulties joining, they should know who to get in touch with and how. Again, a specified person by phone, text or email.
- While people can leave at any time, ask people to not just drop out. This is very important as it leave the organisers unsure about what has happened and whether someone needs support. See the support and safety section for more below.
- For meetings over an hour, regularly change the format to keep people engaged (e.g. breakout rooms) and have short breaks.

Chairing a large online meeting can be a challenge. Some tips to make bigger meetings work well include:

- Making sure that every person has some time to speak and asking people specifically if they would like to contribute something. No single person should speak for a long time - making sure everyone can contribute is even more important and needs to be facilitated and managed.
- Discuss how to indicate you want to speak, e.g. participants putting up their hand or waving if they would like to speak, and to use the thumbs up sign when asked for agreement (or not – thumbs down).
- Give an overview of meeting structure at the start for a sense of purpose / direction
- Having a co-chair to help to read any chat messages and questions and help to notice who wants to speak.
- Having someone attend whose job it is to take notes, particularly if you are not recording the meeting.

Costs of online and telephone meetings

Before the meeting it can be helpful to ask people what devices and connection they will be using, so that you can make sure that people won't end up with a bill for getting involved. It is important to consider the costs of taking part in telephone or online meetings. The costs of phone calls or data used should be covered, how this will be worked out and payment should be agreed in advance. While some people may have broadband packages at home that allow them unlimited usage, this will not be true for everyone. If people only have data on a mobile phone, using any online conference meeting will eat into their data. Turning off the video function will reduce the data used, but will still use data. Phoning into a conference call may use up people's minutes or mean that people face call charges. You need to look into this for the online platform/ conference call that you are using. If public contributors have limited data and minutes on their phones you may need to make sure that they have access to free phone numbers e.g. beginning 0800 or 0808 as these will mean that public contributors do not need to pay for calls or data. Alternatively, make sure that public contributors can get recompense for the charges for any calls they make. Asking people to dial 141 before the phone number means that their phone number will not be shared with the group, which is important for safeguarding, unless the group have explicitly consented to share phone numbers.

Using social media

NIHR INVOLVE has developed guidance [for the use of social media to actively involve people in research.](#)

NCCPE have developed [a guide for engaging the public through social media](#)

Sharing learning

The NIHR Research Design Service has created a blog on [public involvement](#). [Steven Blackburn](#) has developed a Google document to share what's being done around online involvement:

https://docs.google.com/spreadsheets/d/1NlpGGtJIAe4rxbTVr_8DvIlk4XOiQnP9luHNnSlk-4E/edit#gid=0

Support and Safety

It is important to think about the support and safety of telephone and online meetings and agreeing some expectations in advance is helpful. Guidance might include:

- Offer a practice/test session in advance.
- Asking people to dial 141 before the phone number means that their phone number will not be shared with the group, which is important for safeguarding, unless the group have explicitly consented to share phone numbers.
- Having a bit of informal time at the start for people to join and say hello before the meeting proper starts.
- What to do if people have technical problems joining or during a meeting. Agreeing that someone will phone, email or text one of the organisers if they have problems is useful. Someone running the meeting may need to help with any problems if they can. If someone leaves by accident or for a technical reason give them a contact name, and phone, mobile/text or email contact.

- Letting people know they can leave at any time if they need to or feel distressed, and if they do to let one of the organisers know they have done this.
 - Ask anyone leaving to either send a private 'chat' message to the organiser in the meeting, or to let the organiser know that they are OK by text or email after they have left.
 - If the organiser does not hear from someone who left a meeting unexpectedly, they will email and/or telephone to check that they are OK. If this happens and no contact is made, the organisers may need to think of additional steps, for example contacting a partner or family member.
- If those attending might be particularly vulnerable, or the topic is likely to be distressing the organisers may need to provide additional support, for example access to information about support services available, or access to a named person who can offer follow up support.

[Against Violence and Abuse](#), a UK charity committed to ending gender based violence and abuse have produced a [digital safeguarding resource pack](#) to support online working.

Online working with children and young people

Many of the issues described for all telephone and online meetings are also relevant for children and young people. As usual, it is important that those attending know what is expected of them, and what they can expect from the organisers. However, there are some additional suggestions for ensuring the safety and support of children and young people:

- Guidelines for meetings should be agreed with children, young people and their parents in advance.
- One of the adults running the meeting should have an enhanced DBS clearance certificate.
- At least two adults should be present in any online or telephone meeting from the start. Children should not join until two adults are present.
- If a group member is under 16, please make sure a parent or guardian is with them when they initially join the meeting. They can leave once you are confirmed in the meeting.
- The second adult facilitator should be able to communicate with, and provide initial support to, a group member who leaves the meeting unexpectedly.
- If a child or young person is expected and they do not join the meeting or call within 10 minutes of the planned start, someone will contact the parent/guardian to make sure they are OK.
- As always, a child or young person can leave any meeting at any time. However, ask them to not just drop out. Ask them to let the organiser know if they are leaving the meeting. If they would rather not say this out loud, ask them to either use the "private" chat function or text/call the organiser immediately to let them know.
- If they leave by accident due to a technical issue, ask them to text the organiser to let them know otherwise someone will call their parent or guardian to check they are OK or if they need support.
- If they become distressed for any reason and need support, ask them to let the organisers know by text or "private" chat function so they can make sure they have support.

For resources on how to work with people safely online, please see [Youth Work Support](#). Their [Safety guidelines for online youth work](#) can support safeguarding and procedures to develop for young people's involvement.

[People, Dialogue and Change](#) have created information on different [Online hangout on tools for working with young people online](#), and these resources on [Online youthwork and participation](#).

Making decisions and participatory techniques

Here we provide a selection of practical toolkits and facilitated exercises that people can do in meetings and workshops, to engage people in more participatory approaches and to try and disrupt the usual hierarchies and ways of speaking in traditional research meetings.

Research prioritisation processes

The [James Lind Alliance](#) has well developed [methodologies and guides](#) to support public involvement in research prioritisation. They aim to enable clinicians, patients and carers to work together to identify and prioritise the questions they would like answered by research and have various [resources and publications](#).

Developing research partnerships and tools for engagement

- [Rethinking Research Partnerships: discussion guide and toolkit](#) provides a wide range of tools to help understand how power flows between people and organisations in research collaborations.
- The **Patient-Centered Outcomes Research Institute** ([PCORI](#)) is working to ensure patient-centred research with meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders through the entire research process. It has a range of [resources for public engagement](#)
- The **National Co-ordinating Centre for Public Engagement** ([NCCPE](#)) helps universities engage with the public and has a range of useful [resources](#)
- The Social Care Institute for Excellence (SCIE) has a range of [resources](#) and training on co-production. This includes guidance on how to co-produce with [different groups of people](#) and how to [make events accessible and pay public contributors](#).
- The [Participatory action research toolkit](#) guides you through the process of working together through participatory action research (Pain et al., 2011)
- [The Recovery Library](#) at the University of Melbourne, has developed [Coproduction: Putting principles into mental health practice](#) which includes a framework to map power, icebreakers, and questions to bring co-production partners together.

Tools to facilitate group discussions

- The [Leapfrog toolkit](#) has methods to facilitate creative and engaging discussions
- The [Scottish Health Council Participation toolkit](#) has a range of techniques to more effectively involve patients and service users, carers and members of the public in decisions about care and the design and delivery of local services. Some of these techniques could easily be used in research meetings as well.
- The Institute for Research and Innovation in Social Services ([Iriss](#)) has got a very detailed [set of resources](#) including a range of [participatory exercises](#) and a [co-production project planner](#)
- The [community planning toolkit](#), supported by the Big Lottery, provides guidance on planning and designing [community engagement](#) processes
- A [Dilemmas café](#) is where people come together to discuss choices between different courses of action, when it is not clear which is right to choose. [Guide for facilitators](#) available from Durham University.
- [Liberating structures](#) provide a series of simple and practical methods to help facilitate discussions and collaborations.

Co-implementing findings and co-producing dissemination

There are fewer examples of where co-production has extended to the implementation stage of research (Halvorsrud et al., 2019). The implementation of co-produced research is covered less extensively within NIHR INVOLVE guidance on co-producing research (INVOLVE, 2018). However, by involving practitioners and the public within co-produced research, this can provide more opportunities for focussed and implementable research findings. We have found less practical resources in this area (please let us know of others), so we have also included references to some current projects we are aware of and academic publications.

There are some key questions to consider when thinking about how the findings of a co-produced project might be implemented. They are:

- How can your partners support the implementation of the research that you have co-produced with them?
- Have you discussed what information or product will be generated? How will it be shared with people beyond your project team?
- What Intellectual Property (IP) have you created together? Who will own any information or products that you have generated together?
- When writing up, discuss who will be co-authors of papers. If you have genuinely co-produced work, then your partners and public contributors may well meet the [International Committee of Medical Journal Editors \(ICMJE\) guidance on authorship](#) and be co-authors.

- Make sure research findings are available to public contributors (e.g. not behind a journal paywall) and involve them as co-presenters at academic conferences.

Co-producing dissemination materials

- **Making media with communities:** As part of the [AHRC Connected Communities](#) research programme, a guide on [Making Media with Communities: Guidance for Researchers](#) provides a framework for the development of community media projects.
- **Films** have been co-produced with communities including [autism in a UK Somali community](#) (Aabe et al., 2019), [training videos for dementia communication](#) (Webb et al., 2019) and one for [people with learning disabilities and their personal assistants](#).
- **Plays and theatre** have been co-produced with [local communities](#) (Barke, 2017).
- A [practitioner's guide to collaborative fiction writing with community groups](#) has been developed (Satchwell et al., 2019).
- **Co-designing health messages:** Public contributors have been involved in co-implementing research findings. Examples include the [Co-design of harm reduction materials for people who inject drugs](#) (Hussey et al., 2019) and [co-designing physical activity](#) messages that have been derived from previous research, so that messages are more tailored and effective with different communities.

The impact of co-produced research

The [Connected Communities research programme](#) has explored how experimental research and co-production practices have impacts when working towards social justice (Ersoy, 2017), and how the value of collaborative research can be accounted for (Facer and Pahl, 2017).

Impacts from co-produced research can occur in unplanned and unanticipated ways which are responsive to current situations and aim to empower research partners (Darby, 2017, Evans, 2016, Pain et al., 2015).

To account for the fact that co-produced research can have long-term and unpredictable impacts, a social impact framework has been developed to account for different changes that occur as a result of co-produced research, at different levels, including the individual, the organisational and societal (Beckett et al., 2018).

Reflecting on and evaluating processes and impacts

To reflect on the process of co-producing research, our [project team](#) has developed a self-reflective tool which is available here (<http://bit.ly/CoProResources>).

Some additional resources to support reflection are:

- The International Collaboration for Participatory Health Research ([ICPHR](#)) have developed various [resources](#) including [quality criteria for participatory health research](#), that can be used as a reflective tool to consider the extent to which people are equitably involved in a research process

- A [Co-production Evaluation Schema](#) has been developed by Nathan Eisenstadt, based on co-production work from the [New Economics Foundation](#) (Boyle et al., 2010)
- The Economic and Social Research Council has developed lessons for collaborative research, derived from their funded projects:
 - <https://esrc.ukri.org/collaboration/guidance-for-collaboration/lessons-for-collaborative-research/>
 - <https://esrc.ukri.org/collaboration/guidance-for-collaboration/>
 - <https://esrc.ukri.org/research/impact-toolkit/tips-for-doing-knowledge-exchange/>

Evaluation and reporting on public involvement and engagement

The evaluation of co-production is still at an early stage. Beckett et al. (2018) have developed a '[social model of impact](#)' to capture and evidence the multi-layered impacts of co-produced research.

More generally, there are a variety of ways of evaluating public engagement and involvement activities. Here are some different resources that may help.

- The Research Councils UK (RCUK) have developed practical advice for evaluating public engagement projects [Evaluation: Practical Guidelines. A guide for evaluating public engagement activities](#)
- The National Co-ordinating Centre for Public Engagement (NCCPE) has developed [guides and courses](#) to support researchers and public engagement professionals and practitioners to develop their evaluation work including [Impacts Arising from Public Engagement with Research](#)
- The [GRIPP2 reporting checklists](#) (Staniszewska et al., 2017) gives a set of reporting criteria for how you have involved the public in your work. This could also be used as a reflective tool to think through how, where and when you are involving public contributors in the research process, the contextual factors affecting involvement and the outcomes of public involvement.
- The [People in Health West of England \(PHWE\)](#) public involvement team provide a training workshop on practical approaches to evaluating public involvement in research. The PHWE workshop outlines three approaches.
 1. Keep a simple log of public involvement activities and the impact they have had
 2. [The 'CUBE' framework](#) (Gibson et al., 2012) evaluates how different people's knowledge and experience is valued and used within health services research. This has been translated into a [practical workshop](#) process (Gibson et al., 2017).
 3. The [Public Involvement Impact Assessment Framework \(PiiAF\)](#) is a comprehensive framework to assess the impact of public involvement.

For a variety of resources and references on evaluating public involvement see: Kok M. (2018) [Guidance Document: Evaluating public involvement in research](#). UWE Bristol.

General resources on co-producing research

Below are resources that cover a wide range of different aspects of co-production and centres that specifically focus on co-production.

Facer K and Enright B (2016). [Creating living knowledge: The connected communities programme, community–university relationships and the participatory turn in the production of knowledge](#) This research provides important lessons about how to fund, conduct and sustain high quality research collaborations between academics and civil society in the arts, humanities and social sciences.

[Co-production Network for Wales](#) Knowledge Base. There are many resources mapped and linked by this network. When you click on a section heading numbered 1-14 there are the titles and descriptions of various resources. This network mainly focuses on co-producing services. There is a section on research, but it doesn't differentiate between research on co-produced public services and co-produced research.

Facer, Keri (2018) provides some top tips for engaged research projects:

<https://kerifacer.wordpress.com/2018/01/20/12-top-tips-on-submitting-proposals-for-engaged-research-projects/>

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 available from:

<https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/>.

INVOLVE also have a web page on co-production <https://www.invo.org.uk/current-work/co-production/>

Middlesex University have a Centre for Co-production in Mental Health and Social Care. The link to their web page is <https://www.mdx.ac.uk/our-research/centres/centre-for-coproduction-in-mental-health>

University College London have a [Centre for co-production](#) see this blog:

<https://blogs.ucl.ac.uk/public-engagement/2019/10/14/whats-next/>

Extra resources that focus on public involvement practice

Co-production can be seen as building on and extending existing good practice guidance for all public involvement in health and social care research. Some elements of good public involvement practice become more important, if not essential, if you are co-producing a project. For example, having clear roles and expectations agreed in the team, everyone having a voice, and providing accessible information and feedback/follow up. Co-producing research extends good public involvement through sharing power, ownership, and involving public contributors to plan and run a research project, producing it together (see definitions p.4).

INVOLVE the national advisory group for public involvement in research provides lots of advice and guidance on public involvement. See <https://www.invo.org.uk/resource->

[centre/](#) The National Institute for Health Research (NIHR) also provides links to training and resources for public involvement in research. This searchable resource is available here: <http://learningforinvolvement.org.uk/> If you are in the West of England (where our team are based) more guidance and information about public involvement is available from People in Health West of England, a regional public involvement network, see <http://www.phwe.org.uk/>

The NIHR has developed a set of national standards to improve the quality and consistency of public involvement in research: [National Standards for Public Involvement](#). They have also published a set of links to resources to support working towards these standards: [National Standards for Public Involvement: Resources to support working towards the standards](#)

There is involvement guidance developed by organisations in mental health. The [NIHR Mental Health Research Network](#) works with everyone who needs to be involved in research projects – researchers, mental health professionals, people with experience of mental health problems, their families and research and development staff based in NHS trusts. [Good Practice Guidance for Involving People with Experience of Mental Health Problems in Research](#) includes practical guidance to involve people with lived experience in mental health research.

- The [National Survivor User Network \(NSUN\)](#) is a network of people who have experience of mental distress and who want to change things for the better.
- [4Pi National Involvement Standards](#) was developed by people with lived experience as part of the National Involvement Partnership (NIP) project, the 4Pi National Standards ensure effective co-production, thus really improving experiences of services and support.
- Mind <https://www.mind.org.uk> have also developed an influence and participation toolkit available here: <https://www.mind.org.uk/workplace/influence-and-participation-toolkit/#>

Imperial College London PPI (Patient and Public Involvement) toolkit developed by the Biomedical Research Centre is available here: <http://tiny.cc/r9yr7y>

[CLAHRC East of England](#) developed guidance for researchers on giving feedback to public contributors: [Patient and Public Involvement \(PPI\): Feedback from Researchers to PPI Contributors](#)

Peter Beresford's (2013) "[Beyond the Usual Suspects: Towards Inclusive User Involvement: Practical Guide](#)" by Shaping Our Lives Publications, is a practical guide to help develop more inclusive involvement.

Additional resources on peer and community researchers

Clough, R., Green, B., Hawkes, B., Raymond, G. and Bright, L. (2006) Older people as researchers. Evaluating a participative project. Joseph Rowntree Foundation. Available from: <https://www.irf.org.uk/report/older-people-researchers-evaluating-participative-project>

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Salway, S., Chowbey, P., Such, E. and Ferguson, B. (2015) Researching health inequalities with Community Researchers: practical, methodological and ethical challenges of an 'inclusive' research approach. *Research Involvement and Engagement* 1:9 DOI [10.1186/s40900-015-0009-4](https://doi.org/10.1186/s40900-015-0009-4)

Searle, M. (2016) Running a peer research project with offenders in the community: A handbook for staff *Revolving Doors Agency*. <http://www.revolving-doors.org.uk/file/1865/download?token=mrEpVlaa>

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