

Co-production in the AMHE QI Collaborative: A step-by-step resource

© Copyright: National Collaborating Centre for Mental Health, 2023

Cite as: National Collaborating Centre for Mental Health. Advancing Mental Health Equality Quality Improvement Collaborative: Co-production in mental health. Version 1. London: National Collaborating Centre for Mental Health; 2023

Contents

Foreword Who is this resource for? What is co-production? Working with people with lived experience Ten steps for embedding co-production i	n your AMHE project P8
STEP 1: Find out what already exists in your organisation	STEP 2: Plan your approach P9
STEP 3: Get people involved	STEP 4: Identifying populations P11
STEP 5: Use co-production as part of the three- part data review	STEP 6: Co-produce asset maps P14
STEP 7: Co-produce the aim	STEP 8: Theory of change
STEP 9: Decide P16 how to measure improvement	STEP 10: P17 Keeping up with co-production
Co-production top tips	
Checklist for the early stages of co-production	
Useful resources	

Foreword

The importance of co-production

There are many reasons that underpin the need for co-production, but the most fundamental one goes to the heart of this project. The reality is that despite the collective efforts of many equality advocates, we have not made sufficient progress in addressing mental or physical health inequality. Indeed, for many people from our diverse communities – including people from racialised communities, disabled people, people on low incomes, people from Irish Traveller communities, people in contact with the criminal justice system, and people who identify as LGBTQ+ (lesbian, gay, bisexual, trans queer¹ and +, encompassing anyone who doesn't feel include in the other categories) - we have seen inequality worsen, with more experiencing long-term and complex mental ill health than ever before. In the year to March 2021 There has been a 24.5% annual increase in the number of referrals to NHS Psychological Therapies.² The Government ethnicity data on detentions under the Mental Health Act showed that in 2020-2021, the detention rate of Black or Black British people was five times higher than the detention rate of white people.³

Mark Farmer and Meera

Patient and Carer Representatives on the Advancing Mental Health Equality Collaborative, The Royal College of Psychiatrists To address this, we need to do something radically different. We believe the best way to do this is for mental health professionals to work in partnership with people with lived experience of mental health inequality and the people that support them in their life – a family member, friend or carer – to change how mental health services are designed, delivered and reviewed.

Co-production is not quick or easy to do. It requires leaders and managers to make sure that any barriers to innovation are removed, and for organisations to take risks and share power. Services and organisations need to build strong working relationships with the people they are co-producing the design, delivery and review of services with.

Co-production is well worth the time and effort. All the evidence shows that when we design, deliver and review services through co-production, they better meet the needs of the people accessing them. This in turn makes services more effective and efficient, enabling us to deliver

good-quality mental health services that respond to people equitably.

1 'Queer is a term used by those wanting to reject specific labels of romantic orientation, sexual orientation and/or gender identity. It can also be a way of rejecting the perceived norms of the LGBT community (racism, sizeism, ableism etc). Although some LGBT people view the word as a slur, it was reclaimed in the late 80s by the queer community who have embraced it.' – Stonewall List of LGBTQ+ terms

2 Psychological Therapies, Annual report on the use of IAPT services 2020–21. By: NHS Digital.

3 Detentions under the Mental Health Act. By: NHS Digital, June 2022.

Who is this resource for?

This resource has been developed to help your own <u>Advancing</u> <u>Mental Health Equality quality improvement (QI) collaborative</u> project team to embed co-production in your AMHE projects.

It contains steps, advice, and guidance on how to work in equal partnership with people with lived experience throughout your work as part of the AMHE Collaborative. While this resource is focused on embedding co-production in your work with the AMHE Collaborative, much of the advice is generalisable and can be applied to other projects.

This resource is for AMHE Collaborative project teams, especially team project leads and sub-team project leads who will be leading on the work. However, the information in this resource can be used in other work, so sharing of this resource is encouraged.



What is co-production?

Co-production defined

Co-production is an ongoing partnership between the people who design, deliver and commission services, the people attending services and the people who need to access them.

Co-production is about a change in the relationships between communities, commissioners and service providers to create a relationship in which people are no longer passive recipients, but are equal partners in the creation, delivery and review of strategies, policies and services. It means that decisions need to be taken by people working together to advance mental health equality in your area.

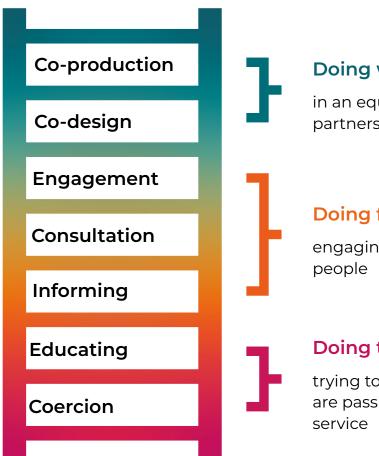


The Ladder of Co-production

The Ladder of Co-production and The Parable of the Blobs and Squares illustrate the shift in the relationship between an organisation and its stakeholders. This model is one of many examples that, can be found on co-production. Co-production is the gold standard that all organisations should aim towards, but full co-production is not always possible.

We recommend starting by coming to an agreement, across all levels of your decision-making structure, on what needs to be done to climb another rung on the ladder of co-production. It will often need a different way of working, and it will mean taking risks to achieve beneficial outcomes.

It is important to remember that co-production is not consultation or engagement. Consultation and engagement can be used to inform the work you are doing; however, they are not substitutes for co-production.



Doing with

in an equal and reciprocal partnership

Doing for

engaging and involving

Doing to

trying to fix people who are passive recipients of

What are the benefits of Co-production?

Co-production enables the resetting and restoring of relationships, by getting everyone to work in partnership together. Relationships between mental health service providers, people using mental health service and their support networks, can be difficult. Service users and their family and friends can often feel powerless in shaping the care and support they receive. People often have not had their diverse needs met may have problems accessing services, or may face discrimination.

Co-production can lead to more effective and efficient services. If people are equal partners in delivering mental health equality and developing services together, people who use or come into contact with mental health services are more likely to have a satisfying experience. Co-production can stop resources being used on services or practices that do not add value for people.

Co-production enables you to meet your legal responsibilities to make sure that people with lived experience are involved in major service changes and are consulted with. It helps you meet the legal requirements that all NHS trusts and integrated care boards are under, set out in <u>Working in Partnership with People</u> and Communities.



Working with people with lived experience

What is lived experience?

In this guide, someone with lived experience is a patient (sometimes referred to as a 'service user') who brings their experience of accessing a service, or is someone with mental ill health who is not accessing services. It is also someone from a person's support network, such as a family member, friend or carer.

Recognising and rewarding people for their contributions

The NHS is moving toward paying or reimbursing people with lived experience (who have accessed services themselves or are part of a person's support network), for their time. Paying or reimbursing people with lived experience for their time helps put all those involved in co-production on an equal footing. It also means you are more likely to attract a diverse range of people who may not necessarily be in a financial position to give up their time for free.

Many NHS organisations now refer to the advice and guidance laid out in NHS England's <u>Patient and Public Voice Policy</u> when paying people with lived experience for their time.

Ten steps for embedding co-production in your AMHE project

The following steps are designed to help your AMHE project team to embed co-production in your AMHE project.

Later, you'll see our <u>Co-production top tips</u> that can be used to guide you through these steps. You'll also see our <u>Checklist for the early stages of co-production</u>, which we designed to help you think about the initial steps to getting started with co-production.

Steps 1–4: Getting started

Co-production is best started before work on the project begins, to encourage maximum buy-in from everyone.



Find out what already exists in your organisation



- You may already know what co-production policies and procedures are in place in your organisation. If you don't, find out if your organisation has any policy or procedures on co-production or involving people with lived experience.
- Find out if people in your organisation have used co-production or already worked with people with lived experience. Ask leaders in your organisation and others in your AMHE project team if any processes exist already. If people in your organisation have used co-production at work before, they may have useful information that may save you time.
- Find out if there are people who can support you, such as a people participation team, service user involvement manager. They may be able to help you recruit people with lived experience and share helpful knowledge of processes.



- Use an AMHE project team meeting to start planning co-production:
 - Your AMHE Quality Improvement (QI) coach can support you – ask them to help you think about your approach to co-production.
 - Involve people with lived experience from the start (as laid out in the <u>AMHE Collaborative</u> <u>Starter Pack</u>) – this is important because those with lived experience can help you plan your approach to co-production.
- Make sure you have senior-level agreement for the project team to be able to take decisions for the project and identify any support that may be required.
- Lay out any parameters to the extent and scope of work from the start. Explain them, discuss them and challenge them.
- Set mutually agreed time and budget deadlines for the project, to make sure your work stays on track.
- Share out responsibilities among your project team
 - Who is going to take a lead on co-production in the AMHE project team?
 - Who is going to be responsible for administrative tasks? Co-production often generates a lot of administration, and it's important to have someone allocated to make sure that tasks are actioned.





This step will look different for different teams, depending on what is already in place in your organisation and how you decide to co-produce. Different teams may have different needs and approaches, so use what your team needs from the points below to meet your aims.

- If your organisation has a process of Patient and Public Involvement, a lived experience advisory group or something similar in place, they will be the people best placed to support you with getting people involved.
- Consider the representation of communities when putting your team together. Does your team reflect the population you are focusing on?
- If you are starting your co-production approach from the very beginning, you can use some of the following methods to get people involved:
 - Ask people accessing your service if they would like to be involved in the project. For example, put a poster up in the waiting room and share information on your organisation's social media accounts to let people know about the opportunities.
 - Discuss ways of working together with people with lived experience, to agree on ways that are most suitable for everyone. In these discussions, consider your meeting lengths and what time they start, if they are face-to-face or online, and where face-to-face meetings are held. How often do you meet? Does anyone need a carer or assistant to be there? Are people with lived experience expected to work on the project between meetings? Reflect on any adjustments you can make to better accommodate community needs and ways of working.

- Co-produce the project team job descriptions for people with lived experience. It's a good idea to have a job description for people to read before deciding whether to join the project team, and give them guidance about the input you are hoping for, because without the input of people with lived experience a power imbalance can occur.
- Find out which local organisations (such as carers' groups, local charities and organisations) you could work with.
- Provide clear information about payment, or if payment is not possible (for example, because it would negatively affect a person's individual financial circumstances) make it clear that the role is voluntary and identify other ways of recognising someone's contributions. It is important to make sure everyone can take part, so carers and support workers should be compensated for their time and costs. Consider the equipment that may be needed for people to take part to enable people to engage effectively and equally.
- As you start to think about populations to focus on first, consider any other points of view you might need to include – your project team members with lived experience can help with this.
- You may need to seek out more perspectives as you work to identify populations. One of the ways you can decide on which populations to prioritise is by engaging with more lived experience experts – how this is done by each team will depend on need and whether any work or discussion on inequalities is already taking place or not.





Steps 5–6: The three-part data review and asset mapping



Use co-production methods as part of the three-part data review The three-part data review, outlined in the AMHE Collaborative Starter Pack, explains that teams will be expected to:

- Listen to the experiences of people in the population you are focusing on, from staff providing services and support to people from this population.
- 2. Review quantitative and qualitative data for the population.
- 3. Identify common themes from both of these.

All of these areas should embed co-production, and this can be done in the following ways:

- By gathering information from the people who belong to the identified populations. You can do this by:
 - visiting local community services
 - interviewing individuals (face-to-face, over the phone or in an online/video meeting)
 - holding focus groups or engagement activities
 - carrying out surveys
 - a combination of the above.

Remember that gathering information doesn't need to start on a large scale at first. First, you could talk to two or three people, to get an insight into the best way to engage with a larger number of people. Speaking to even a small number of people can give you information to make a start with your project – but engaging with the population will not be a one-off event.



- Involving people from the population you are focusing on throughout your project is essential – set up meetings, discussions or drop-in sessions.
- Do you have links with any Voluntary, Community or Social Enterprise (VCSE) organisations that can share their insights? VCSE organisations can have an important role in co-production. Look outside of your organisation, and remember to plan and communicate how you will pay people from VCSE organisations for their time and work.
- By thinking creatively about how you engage people and the channels through which you do this (for example, reaching out to young people through schools, community groups and so on?)
- By responding to the feedback and needs of your communities. If it's difficult to reach people from your population of focus, think about why this might be. Perhaps the approach isn't right for the population you need to work with and needs to be changed. Also consider how they could be represented in the work – perhaps you could involve parents, other family members, or people who have used the service in the past (such as, young adults who used a service as children).

Bear in mind that a person with lived experience cannot represent an entire community or population, but they may be able to suggest ways to engage with that community or population.

- By working in partnership with people with lived experience in any review of data for the population.
- By discussing common themes identified with people with lived experience, to explore their thoughts and ideas.



Co-produce asset maps

Community Mapping (sometimes called asset mapping) is all about involving residents in identifying the assets of their neighbourhood, looking at opportunities and creating a picture of what it is like to live there. The exercise is a valuable and effective method of community engagement simply because maps are visual and easy to relate to; like photos and videos they cut through communication difficulties to reveal feelings and ideas which otherwise might be hard to express.

East London NHS Foundation Trust – The Community Mapping Tool Asset maps⁴ are key in the AMHE Collaborative, and looking at asset maps by other AMHE teams can help you think about how to develop your own.

Here's an example of an <u>interactive asset map for</u> Newham, East London NHS Foundation Trust.

With your team, explore the local community assets in your area – and remember that asset maps should be co-produced with people with lived experience who are from the population(s) you are focusing on.

- Set up asset mapping forums, workshops or meetings together with people with lived experience.
- Request information from local community or VCSE groups that you want to include, and find out if they have examples of other community assets to include.



4 Examples of asset maps used by teams in the AMHE Collaborative are being sought for inclusion in the next version of this resource.

Steps 7–10: Using co-production as you start your QI project

As we've talked about above, co-production starts long before the QI work starts, and by this point you will already be familiar with working in co-production on your AMHE journey. Your QI coach will support you to develop your team aim, theory of change (including change ideas) and your measurement strategies.



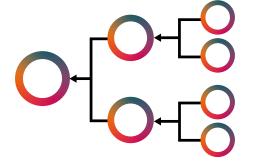
Co-produce the aim



- It can take a little more time and work to identify your aim, but don't worry if it's not clear at this stage. Start with an initial aim, such as to improve access for the population you are focusing on. That is enough to get started with your project, and can be developed in time.
- To develop your aim, have team meetings that include lived experience team members and are focused on aim development. You may also want to invite other people with lived experience to collaborate and work together to develop the aim. You could include people with lived experience who have been involved in Steps 1–6.
- Adapt the process and strategy, to enable and allow people to be involved in development of the aim.
- Over time, you will develop a co-produced Specific, Measurable, Achievable (but also aspirational), Relevant and Time-based (SMART) aim. Starting with SMART aims has been found to lead to better results in healthcare.
- Send drafts of your aim to people who represent the population (the more people, the better!) and ask for their views. Then, make changes to your aim to bring in the feedback they send you.



Theory of change





Decide how to measure improvement (and co-produce measurement materials as needed)

- Work with people from your population(s) of focus to adapt the programme-level theory of change and create a co-produced theory for how your organisation can improve access, experience and outcomes for the population(s).
- To start with, you may want to focus on one part of the programme level theory of change. For example, if you chose to focus on 'access', developing your aim with people with lived experience and from the communities you want to focus on may reveal big topic areas you need to focus on. It may also help you think of ideas that you can test out. By developing a theory of change on 'access' alone, you can start to see how your project is taking shape and keep focused on working towards your aim.
- Involving people from the population(s) in the work and the project team will make sure you are generating and testing ideas that can help you achieve the aim of the project.
- Your theory of change will evolve over the course of your project as you continue to learn and adapt to the needs of the population.
- It is key that you promote meaningful discussion, partnership working and equal opportunity for involvement and decision-making, for people with lived experience.
- Work with people with lived experience to identify existing measures, and whether you need to develop new measures. If new measures are required, co-produce them with people from your chosen population.
- When planning which methods you'll use, work together with people with lived experience to design questionnaires, or enable them to lead on developing topic guides for focus group discussions. Topic guides can include suggested questions and prompts that can be used when running a focus group.
- As your project progresses, you will identify what data will help you determine whether the changes you are testing are having an impact.



Keeping up with co-production

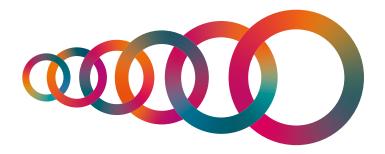
Co-production is not something you do once or just at the start of a project. Keeping up with co-production throughout the project is vital, and allows you to embed it in your processes. This can be done in the following ways:

- Set up regular co-production-focused meetings to:
 - assess your progress with actions
 - determine where change might be needed
 - keep track of co-production in practice.

The meetings should take place at least every 6 months, on top of informal check-ins with relevant people and addressing any challenges that have come up.

- Keep up to date with the latest resources and guidance on co-production best practice: one of the best ways to do this is by attending AMHE Learning Sets, in which project teams and coproduction experts share the latest information, resources and guidance.⁵
- Evaluate your co-production efforts: review and consider the impact that co-production is having on your project.

In the next section, our <u>Co-production top tips</u> provides some guidance that can be used across the AMHE Collaborative as you continue to embed co-production principles and methods in your work.



5 You can watch presentations and download materials from past AMHE Learning Sets on the AMHE Collaborative Events web page.

Co-production top tips

The 'top tips' below are can be applied while doing Steps 1–10, and will help you follow co-production principles and best practice in your work.

The top tips are derived from:

- a. Lived experience advisers working on the AMHE Collaborative
- b. The <u>AMHE Resource</u> (updated and re-worked for this document)
- c. AMHE Team
- d. The NCCMH Equality Advisory Group (EAG)

Area	Top tips ⁶
General	
Accessibility	Are your meetings held in accessible venues, with hearing loops, wide accessible spaces or dimmable lighting? And, think about the time of day when you hold meetings.ª
	Work together to understand the team's needs and put in place a plan to meet them: Everyone will start the project with different levels of understanding and knowledge about co-production. Ask people what support they might need to participate to the best of their abilities – would they like to read documents in advance? Would they like to debrief after a meeting with a member of the team? ^a
Communication	Don't use jargon in meetings and documents, so that everyone can understand and contribute fully: Don't put people on the spot or ask them to publicly share details of their experiences. ^a

Area	Top tips ⁶
Equality and respect	Don't let a hierarchical structure form in the team: Everyone is there as an equal partner, and the team should make decisions together about who is leading on which aspect of the work. ^a
	Approach co-production with an open mind: Working with different people in new ways can use resources differently. Bear in mind that there may be impacts on other areas, such as budgets and timelines, and remember to enjoy the process and celebrate the results. ^a
	When preparing for co-production activities, the whole team should develop and agree a shared set of values, principles and ways of working: The aims of the project should be co-defined, and repeated at the beginning of each activity or meeting. ^b
Recognising and rewarding people's contributions	Pay people for what they do and for their time: This might include for attending meetings and events, giving feedback on draft documents or planned actions, and co-producing written materials or leading meetings. People should also be given support with their travel expenses. ^{a,b,c}

Understanding and identifying inequalities

Use existing data and resources



Meaningfully include and involve people with lived experience in decisions about changes to data collection processes: People with lived experience can help identify gaps in these processes and make informed suggestions for updating indicators. This could involve inviting them to data improvement meetings in the same way that you would invite clinicians and health professionals.^b

Anecdotal data (from individual experiences) is valuable: Don't let worries about not having the 'right' kind of evidence prevent you from implementing new ideas – remember, lived experience colleagues are experts by their experience, and should be listened and responded to.^a

Area

Top tips⁶

Work with communities



The environment should be safe and inclusive: Consider any ways in which the environment could act as a barrier to contributions (for example, a person may not feel comfortable sharing personal or traumatic information with people from the same community as them for fear of judgement).^b

Don't disengage from communities: Follow up in a timely fashion, and let people know the outcome of their contributions. Make sure you action what you say you will. These are classic pitfalls that lead to mistrust and disengagement, but are also easy to avoid. Consistency is key to building productive and trusting relationships.^a

Make sure that the working group's diversity and protected characteristics reflect the community of interest.^b

Generating ideas and problem-solving

1. Ask the community



Discuss and agree on the preferred language and terminology that will be used, to ensure activities are accessible to all and respectfully handled.^b

Be prepared to hear criticisms about your services or current ways of working: Differences in opinion, experience and perspectives are a key factor in co-production and are a sign that the process is working. Create an environment where it feels safe to share these differences, and they are explored and addressed in a positive and professional way.^a

Co-develop the strategy with meaningful input from stakeholders, including people with lived experience: They will be able to offer unique contributions, based on their experiences, about what works and what doesn't work. Treat all consultants as equal, valued members of the team.^b

It might not always be possible to reach full agreement: But it is still important to respect the views of the community you are working with and commit to working productively together.^a

Top tips⁶

space.^b

2. Training



Provide training sessions in which everybody can spend time listening to people with lived experience: Talk to them to learn about their experience of services.^a

I would make part of the training for everybody to spend time listening to experts by experience. Talking to them about good experiences and bad experiences that those people have had with the services, to give them pointers on how to handle people in crisis. I would make it compulsory in training for all professionals."

A person with lived experience working with NCCMH

Enable and empower people in the community, those with

lived experience and family and carers to contribute to the

(not tokenistic) and getting feedback from communities

service evaluation process: Engagement should be meaningful

could take place in an appropriate local setting, to encourage attendance and enable people to contribute openly in a safe

3. Consultation Which issues need more immediate action. They can also help identify small changes that can be made quickly to make improvements.^b

4. Service evaluation



5. Deciding on tools and measures to assess impact



6. Designing an evaluation

Whether its deciding which existing tools and measures to use in an evaluation of the service or of an intervention, or developing new ones, this process should be done in collaboration with the people with lived experience in the AMHE project team: For example, when planning which qualitative methods to use in an evaluation, involve lived experience experts in the design of questionnaires or enable them to lead focus group discussions.^d

In your project team, set up an evaluation sub-team or a meeting so that there is dedicated time for planning the evaluation. Try to involve people with as many different experiences as possible.^d



Checklist for the early stages of co-production

This checklist outlines how to include co-production at the heart of your project from early stages of scoping, recruitment, developing a shared aim and theory of change.

With this checklist, you can check your use of co-production at several different stages of your AMHE project (for example, when you're identifying populations, identifying inequality issues to prioritise, or completing the three-part data review, and so on).

Checklist	Notes
Identify a person who will lead the project and champion co-production.	
Develop a co-production plan and include an approach to engaging people from the community you are working with.	This should be culturally sensitive and include consideration of travel, language barriers and geographic location – anything that might make it harder for people with lived experience to share their voice
Recruit people with lived experience as equal partners in the project.	
Check if there are already networks for peer support, 'Experts by Experience' or Lived Experience Advisers in your organisations.	
How has your organisation engaged with people with lived experience, inside and outside your organisation? What can you learn from this? How can you adapt the learning to your approach?	

Identify people who are likely to be impacted by your project or your identified population through an equality impact assessment.	This may include people who come into contact with, use or have used your services, family and friends, carers of people with lived experience and residents). This can be revisited as and when needed to review impact.
Seek advice and talk to staff, volunteers and people working in local organisations who work regularly with people from the community you are working with.	This may include people who come into contact with, use or have used your services, family and friends, carers of people with lived experience and residents). This can be revisited as and when needed to review impact.
Consider how people with lived experience can contribute to the work.	This may be in person, by phone, virtual meetings, group discussions, workshops, surveys and using interpreters. Pay attention to any barriers to participation, and work with people to address and break them down.
Make sure that enough resources/ budget have been allocated for co- production.	Including payment for people with lived experience, travel, and learning and development opportunities (for example, attending learning sets).
Co-produce a shared understanding and aim for the project including people with lived experience, frontline staff, project staff and local stakeholders.	
Do all partners understand their role and responsibilities?	Roles and responsibilities should be documented in the Terms of Reference.
Co-produce a process to enable everyone to feel safe, empowered, and able to express their views, stories and lived experience.	The process should be included in the Terms of Reference.
Develop a mechanism to reflect on and evaluate partnership working at various stages of your project.	This may include peer support for people with lived experience.

Useful resources

<u>Policy on payment of fees and expenses for members of</u> <u>the public actively involved with INVOLVE</u> [Organisational policy document]. By: INVOLVE Coordinating Centre, Scott J; Southampton, 2016.

AMHE Resource: Advancing Mental Health Equality: Steps and Guidance on Commissioning and Delivering Equality in Mental Health Care. By: NCCMH, London, 2019.

AMHE Resource Appendices: Advancing Mental Health Equality: Appendices and Helpful Resources. By: NCCMH, London, 2019.

Working Well Together: Evidence and tools to enable co-production in mental health commissioning. By: NCCMH, London, 2019.

<u>Payment Guidance for Researchers and Professionals</u>. Version 1.3. By: National Institute for Health and Care Research (NIHR), London, 2022.

<u>Payment Guidance for Members of the Public Considering</u> <u>Involvement in Research</u>. Version 1.3. By: NIHR, London, 2022.

<u>People not process – Co-production in commissioning</u> [Web page]. By: Think Local Act Personal, hosted by Social Care Institute for Excellence, Egham.