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How to...

A guide to co-production in the NHS

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What is co-production?

The meaning of co-production can be hard to pin down. In its basic sense, it recognises that services depend on input from the people who use them, as well as those who provide them. Co-production recognises the role that people and those who care for them play in their care, for example by creating channels for people to shape services. To be truly transformative, co-production requires relocation of power and control from 'the professionals' towards those who use services, recognising their expertise in their own circumstances. Co-production involves patients and healthcare professionals working together to improve care through small or large projects.

Co-production often happens outside of, and perhaps despite, the administrative systems of public services (1). Within the NHS, a transformative co-production of services can feel very hard to reach. This guide was developed collaboratively by four people, taking on roles as patients, clinicians and researchers. Our aim is to support people on a journey towards co-production, recognising the challenges that we all face day-to-day in our lives and the health care systems we engage with. While we focus on NHS services here, many of the ideas and principles we apply to any engagement between professionals and the communities they serve.

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Why do it?

'No government can be efficient and equitable without considerable input from citizens'

ELINOR OSTROM (1996) (2)

Co-production has the potential to transform both in the end results and through the process itself. The simple act of bringing patients and professionals together as equals can deeply shape us through shared learning and evolving perspectives. The end result is often improved quality of care and increased equity. However, without co-production there is a risk that systems alienate and disempower those who use them – and often those who work in them too. The benefits of co-production for staff are becoming increasingly apparent (3).

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What are the challenges?

Whilst an increased focus on co-production within the NHS and researchers is welcome, there is a risk it becomes tokenistic, especially if easy-to-count measures are prioritised, resulting in a tick-box exercise (4).

Co-production can be a challenging and potentially uncomfortable space for everyone involved. Professionals can be resistant to co-production. It can create challenges around identity, power and reveal issues around staff morale and empowerment. Professionals may struggle when the priorities of those who use services clash with wider structures such as funding and incentive schemes.

Additional resources, time and money are needed, which are hard to find in stretched systems. These are especially important to ensure health equity focus and representation from across the community. If not, people who need more support to contribute may be sidelined. It also depends on long-term relationships, which can be harder in areas where staff turnover is high because organisations are struggling (5). And some policy makers in cash-strapped systems may use it to transfer the responsibility for solving complex problems onto communities themselves or to replace other channels which critique and hold services to account.

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What are the challenges?

It's also critical that co-production isn't a necessary step to accessing services, thereby excluding those who don't have the resources to take part.

People with lived experience may also experience challenges around participation. Balancing co-production work alongside their other roles may be particularly hard for those with unpredictable working patterns and caring commitments. They may have financial barriers to taking part; for example payments received while working on projects may affect benefits (6). Power imbalance is often felt by people with lived experience when they are involved in co-production. For example, professionals may use language or acronyms that make conversations difficult to understand, and it can feel hard to ask questions and hold professionals to account.

While co-production may help to strengthen bonds within communities, it may be more difficult to bridge between communities. Bringing in new voices who may hold different perspectives can be hard and requires building long-term relationships, trust and continuity.

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Questions to ask when planning and engaging in co-production

- **What are the power relationships in the group?** Who is setting the agenda, who is facilitating and who is recording decisions? How can we shift traditional power roles within our work?
- **Have we got representative groups of professionals and people with lived experience?** Who is missing, and why? Whose voices in our group are being heard? Whose voices aren't and why?
- **How are we conducting meetings?** Are they online or in-person? Whose 'territory' is it? Who will struggle to access and what can we do to help?
- **What do we want from co-production?** Are there mutual benefits for everyone? Is anyone feeling like they're being used or taken from?
- **Are we ensuring space to reflect and feedback?** How do we handle sensitive or triggering issues that come up? And how do we handle conflict?
- **How do we create an agreement for ways of working together, and hold ourselves accountable for working in line with this?**

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How to do it: hints and tips for co-production

Staff need support and training to do co-production well.

We suggest a rough approach for work in co-production, particularly when working beyond the individual patient-clinician relationship. We recognise the pressures we are all under in the NHS and so these suggestions are not intended to be prescriptive. Crucially people should be prioritised over process.

1. Language matters

It can be really demotivating when co-production facilitators overly use acronyms or academic language when trying to co-produce with Patient and Public Involvement (PPI) groups. Often you feel silly or embarrassed to give your views in case you have misunderstood what the facilitator is asking. The best facilitators really know how to relate to their audience and get the best collaboration from the public.

Shabir Aziz

Co-production facilitators need to use language that everyone can understand, especially those who may not have a university education. I often felt that I didn't understand what the facilitator was saying but didn't want to ask because I thought I was the problem.

Tasleem Aziz

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2. Plan well, co-produce well

Considerations:

- **Begin thinking about co-production as early as possible**

> It's hard to make a positive contribution when you don't really understand what's going on in the research project - this becomes even more difficult when the project lead is reaching towards the end of the project and our input seems tokenistic rather than collaborative.
>
> Shabir Aziz

> Sometimes, it feels more like ticking boxes than really trying to co-produce. This is because at that stage a lot of the work has already been done.
>
> Tasleem Aziz

- **Map out who is involved and impacted by the work you are planning**
  - Potential impact across the communities you serve, e.g. demographic groups or inclusion health groups.
  - Balancing staff and patients that contribute: a larger group can mean more perspectives are heard, if everyone is able to speak, but can make it harder to build trust and relationships.

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Co-production facilitators really need to be more creative when co-producing with larger groups where it is difficult to engage with everyone. I remember the feeling of being quite frustrated and disappointed in those kind of groups and have thought – there was really no point in coming. In larger groups it's essential to break down the group and feedback.

Shabir Aziz

I find it harder to concentrate and focus in larger groups. You simply don't get enough time to think about questions and give opinions. When I do think of something, the group has usually moved on.

Tasleem Aziz

- Drawing on existing networks can give work a head start as relationships are already established – but risks missing diverse and new voices.

There have been times when our PPI group has been quite resistant to new members – whilst having the same group enables us to gel better, having new voices would perhaps gives us a better range of opinions and views.

Shabir Aziz

Whilst I prefer small groups as they are more comfortable and familiar with each other, having the same people means hearing the same opinions. This is not always healthy.

Tasleem Aziz

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- **Anticipate sensitivities**
  - Plan for support if a project may trigger sensitive or painful memories.
  - Be aware of cultural sensitivities.

During a research session on prostate cancer, some of the men from black and Asian groups were reluctant to speak whilst women were present. Later, the sessions became men only and I noticed a visible difference in the amount and depth of discussion from the participants.

Shabir Aziz

When discussing sensitive subjects such as contraception or breast cancer, researchers need to be culturally sensitive and allow women to have separate, safe spaces in order to discuss freely.

Tasleem Aziz

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3. Align the right resources

- **Training and skill development:** For example facilitators/chairs need skills such as active listening, empathetic understanding, acceptance of diversity and understanding of the complexity of privilege and discrimination.
- **Funding:** For example, venue hire, expenses and providing involvement payments.
    - It is vital to be aware of potential risks to participants as involvement payments may impact on benefits, see NHS England guidance.
- **Digital inclusion:** Training, equipment, data, community resources such as libraries (see https://www.goodthingsfoundation.org).
- **Translation and interpreting services**
- **Staff and patient time**

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4. Make sure meetings are enjoyable and meaningful

- **Outreach:** Actively reach out to communities and grassroots organisations to build broader participation.

- **Establishing the team:**
  - Agreeing a charter at the beginning may help and being open to amend it throughout the project.
  - Roles and responsibilities.
  - Processes for feedback and evaluation avoiding 'bean counting'.
  - Support and mentorship.
  - Explore different communication needs.

- **Meetings:**
  - Think creatively about how and where you work (sharing food!)

> Eating together, sharing food with people, it makes such a big difference. Something really important happens, to do with trust and connection.
>
> Amy Dehn Lunn

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- For face-to-face meetings, venues should be accessible – physically (e.g. wheelchair access) and culturally (whose 'patch'?)
- If online, be aware of the risks of digital exclusion.
- Check in at the start and end of meetings.
- Who is facilitating/leading discussions? Having co-chairs may make it easier to check language.
- Who is recording what is said, and the decisions? How is this shared back and agreed?

> More than often, co-production facilitators come to get our opinions and run! There is rarely any summary of what was discussed and we may never see them again. This does not feel like co-production.
>
> Shabir Aziz

> It's really useful when the facilitators come back or send us feedback via email about what was discussed and what they gained from talking to us.
>
> Tasleem Aziz

- Listen to what community members have to say and take seriously – try not to select only ideas and comments which appeal or are convenient.

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5. Always reflect and share

- **Constructive criticism is key:** We all make mistakes, we all have bad days, none of us are perfect – we should aim to create a space in which we can all learn and grown.
- **Sharing power in new ways may feel uncomfortable/challenging** – reflect on your power, your privilege, your needs within the group.
- Facilitators and chairs need to reflect on and address the power imbalance between co-production members in order that all have an effective voice.

> It's really important to be really clear in your own mind and with the group about what is and isn't possible to change. Otherwise it can get frustrating all round – I've definitely been there! It's worth thinking beforehand about how you can feed back those things that need to change that are outside the group's decision-making.
>
> Amy Dehn Lunn

> I have had the opportunity to co-chair a PPI meeting where I was able to lay down some ground rules. Although I was worried that this would upset people, I got positive feedback and the meeting proved successful.
>
> Tasleem Aziz

> Being open to different ways of communicating is so important – not every co-production meeting needs a strict agenda that must be followed.
>
> Lucy Johnson

> Sometimes, I feel like facilitators are like 'rabbits in the headlights' when it comes to dealing with continuously vocal members of a co-production group. Out of fear of upsetting the group they will allow the status quo. This has to change if all members are to be equal in collaboration.
>
> Shabir Aziz

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- Feedback during the project: what impact are we making? How are we changing things?

> The best kind of co-production has been where the facilitator has come back to us and fedback the impact and value of our collaboration. At those times it feels like you have made a little difference.
>
> Shabir Aziz

- Create opportunities to share with the wider communities, both professional and community groups.
- Formalise the end of a project. For example, this could be through sharing written and verbal feedback, or a farewell meeting. Make it a celebration!

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Perspectives on co-production

We have written down some perspectives on our experiences of co-production – we've found stories very powerful in our discussions.

> As a relatively experienced public co-producer over the last four or five years, the idea/value of co-production seems to override my actual experience of it. What I mean by this is, basically, that co-production is great in theory but not always so great in reality. This may sound quite negative but I mean to say that true co-production is slowly improving but still has some way to go. The best facilitators, in my opinion, are those who are able to listen, observe, empathise, and review. Further to this, those facilitators who are able to address issues of group dynamics, diversity, power, inequality privilege, etc seem to make the better co-productionists. The job of a good facilitator should be to get the best outcome for the whole group.

Shabir Aziz

> One of my best experiences of co-production was when I was asked to produce a video for promoting physiotherapy in GP surgeries. I role played a patient who had multiple conditions whom the GP could no longer help and was referred to physiotherapy. This was an issue close to my heart as I had lived experience of similar issues. My empathy for the role, I felt made this co production more effective and realistic.

Tasleem Aziz

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A notable memory for me was when I visited a local community centre. I stepped into the centre not knowing exactly what to do, who I was looking for, or what I was hoping to find out. In my calendar I had neatly noted down an 'appointment' that ran for an hour, across lunchtime. I soon realised that the encounter marked in my diary was a full meal, cooked and served by attendees at the community centre. The food was brilliant. I spent a couple of hours talking to strangers and getting to know more about their involvement with the centre. I learned a lot. Good co-production requires a relinquishing of control. By letting go of how researchers think things 'should' be, we can move incrementally towards a democratic approach to research, service design, and service delivery.

Lucy Johnson

Before I worked in this way, I felt quite worried about starting. I felt out of my comfort zone. But once you've built relationships and trust, you realise how valuable it is to work together on a project. Not only does it strengthen the work, it's also a lot more fun.

Amy Dehn Lunn

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Useful links and resources

- **Co-production: what it is and how to do it.** Social Care Institute for Excellence guide: https://www.scie.org.uk/co-production/what-how/
- **Co-production Influence and Participation toolkit** (includes useful case studies). Mind https://www.mind.org.uk/workplace/influence-and-participation-toolkit/how/methods/co-production/
- **Co-production webpage and Working Together Guide.** Oxfordshire County Council https://www.oxfordshire.gov.uk/residents/community-and-living/our-work-communities/co-production
- **Reimbursing expenses and paying involvement payments**. NHS document containing financial considerations when working with patient and public voices including useful practical guidance on, for example, the impact of involvement payments if person on benefits: https://www.england.nhs.uk/wp-content/uploads/2017/08/B0869_Working-with-patient-and-public-voice-partners-reimbursing-expenses-and-paying-involvement-payments.pdf

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About the Health Equity Evidence Centre

The Health Equity Evidence Centre is an academic collaboration hosted by Queen Mary University of London which seeks to build the evidence base of what works to address health and care inequalities. Decades of evidence has shown that the structures and systems within society lead to health inequalities. We believe that it is only by tackling the unequal distribution of the social determinants of health will we achieve health equity and that the benefits of health care should reach the most marginalised in society.

Our How-to guides aim to provide practical guidance for policymakers and practitioners across a range of topics.

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