



CO-PRODUCTION EXCELLENCE

SHARING THE POWER OF DECISION MAKING

KATRINA GOODHAND & EXPERTS BY EXPERIENCE: Sam O'Brien, Sarah Wrigley, Pam Callison, Kyle Tofton, Robin Cook, Alicia Clarke
MARCH 2024

What is co-production?

- ▶ NHS England have defined Co-production as: 'a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.'
- ▶ Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective. Co-production is part of a range of approaches that includes citizen involvement, participation, engagement & consultation.'
- ▶ NHS England in 2020 set two Patient Experience goals:
 - ▶ i) Improve the percentage of NHS Staff who report that patient and service user feedback is used to make informed improvement decisions.
 - ▶ ii) Ensure that patients, their families and carers are involved, through co-production, in defining what matters most in the quality of experience of services and improving the quality of NHS services
- ▶ **In the simplest of terms co-production is about sharing the power of decision making from the outset, with people with lived experience.**

How we co-produced this Guide

- ▶ Six people with lived experience of mental illness and myself, the Project Manager for the Health and Care Partnership have been working in a co-produced way since 2021. We jointly co-produced the 2023-2028 Mental Health Strategy alongside partner members of the Health & Care Partnership.
- ▶ Through listening events, consultation, and sessions of joint discussion, people with lived experience known as Experts by Experience were involved in every element of the development of the strategy. This practical guide is the result of a co-produced event looking at how to co-produce effectively and not tokenistic.
- ▶ As we had done previously, we started with a blank piece of paper. The people with lived experience became the organising committee. They had previously used a cake analogy to demonstrate the difference between co-production and other methods of engagement and they decided it would be effective (and tasty) to use it again for the 'what is co-production?' element of their event.
- ▶ Over the past 3 years they have experienced different versions of consultation and engagement described as co-production, in some cases, they felt their involvement was tokenistic. To demonstrate this, we designed a quiz (Appendix A), using real experiences. We asked: 'is this co-production?'. Of the 6 examples given only one was co-production, but it encouraged the audience to question their current practices.

How we co-produced this Guide

- ▶ The next element was the barriers to co-production. Using a blank sheet of paper the audience were asked to discuss and feedback their ideas on what barriers might prevent them from undertaking co-production in their organisation.
- ▶ Through experience we already knew that one of the main barriers, 'the elephant in the room', is the cost of paying people with lived experience for their involvement in meetings, training, workshops and events. The Experts by Experience wanted to demonstrate their value and how little the payment is, in real terms, by acting out a sketch about the elephant in the room. It was an adaptation of the classic Two Ronnie's sketch on class, but instead focussed on education and experience (Appendix B). It was really thought provoking and well received.
- ▶ To reach a position where we could capture excellence, we turned our attention to the value of co-production and what excellent could look like. Using blank sheets of paper the audience, now joined by the Experts by Experience, discussed in small groups the benefits to co-production in practical terms, what the processes might be to undertake co-production well and what excellence would look like. This guide is the result of this co-produced event and the feedback gathered.

The difference of Co-production

Co-Production is all about the cake.

When you hear someone say they are co-producing, think about how they are serving up their cake.

The power to decide and be involved in the decision - making process, is the difference between engagement and co-production

Marketing

“Look at this cake we have baked, it is chocolate with amazing icing and decoration – you will love it.

This is a one way conversation, convincing though it is – it is not community engagement, consultation and certainly not Co-Production.

Consultation

“Look at this cake we have baked, it is chocolate with amazing icing and decoration – you will love it – or will you? Do you prefer lemon? You can tell us which one you like most and even send us a bit more detail, but at the end of the day we may or may not change the cake to go with what you want.

The free text is only about the questions being asked, what about the other things not being asked about? There is an opportunity to respond once.

Engagement

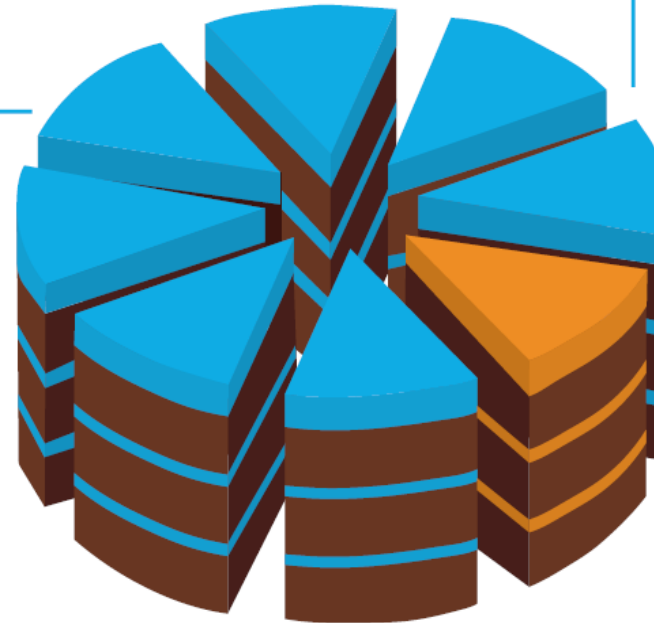
“We are baking a cake and haven't yet decided the flavour or design, tell us which you prefer and we will consider your feedback. There are free text boxes and you are given more choice. You can respond without being limited to questions asked.

They may or may not decide to go with your ideas, but ultimately the decision is with the baker and buyer.

Co-Production

“We would like to serve up something sweet, we are thinking of baking a cake, but we would love you to sit on our board and look at the options we have available and tell us what you think, from your experience, people would like. You may choose something outside of our budget but you will be part of the board deciding what is the best value for the best outcome. It might be cupcakes or a flan and not a cake.

You will be talking throughout the process with free reign to comment. You have equal decision making powers.



If you serve a cake that contains nuts and someone has an allergy you are in big trouble, this is why Co-Production is so important.

Why Co-produce?

- ▶ Co-production is a method of removing assumptions, ensuring that money is well spent, that every option suggested has the voice of lived experience assessing it, that decision making powers and risks are shared, that the benefit of years of experience from a service user perspective is heard and captured, that the aims of providing a better service are focussed, that services are not duplicated and that lessons from past mistakes are remembered and not repeated.
- ▶ Why wouldn't you co-produce?

Barriers & Risks to Co-production

- ▶ Barriers might include accessibility, funding and governance. Also mentioned was a number of assumptions around recruitment and benefits. People with lived experience can be recruited through trusted organisations. It might be a charitable organisation they attend, a clinic or friendship group they are involved with or when treatment has ended. People on benefits can earn supplementary income as involvement workers. They do not become employees, but are paid for their involvement and expertise.
- ▶ Risks include the time it can take to have lived experience participation in a project. If co-production starts from the outset and you already have a panel of experts by experience, it would not delay the project. If co-production is an afterthought, backtracking can cause unnecessary delays. The first time recruitment is undertaken for experts by experience, if done well, it can be the only time it is needed as existing experts by experience will encourage others to participate. Recruitment is not part of the project time, this is an organisational culture shift.
- ▶ Funding for lived experience was also mentioned, but funding is often set aside in bids and budgets for ensuring the community voice is captured through consultation and engagement, this forethought should also apply to co-production. Paying a small amount of money per hour for a person with 20 or 30 years' experience at the decision-making table is a sound investment.

Benefits of Co-production

- ▶ The benefits to co-production are not based on them replacing the other methods of engagement and consultation, they are based upon enhancing the other methods.
- ▶ Co-production removes bias which may be generated by targets, budget constraints, capacity and any other dependency which may focus attention away from what is in the best interests of the service user. Co-production ensures that there is at least one person involved in the decision who has ONLY the best interests of the service user at their heart. Co-production removes assumptions and can avoid unnecessary expenditure on projects that are not wanted or needed.
- ▶ Co-production can be used to interpret the results of consultation and engagement and can be used to write the consultation questions, to bid for the funding and to undertake the research. People with lived experience are in different networks and communities to people without lived experience. Without lived experience you don't sit in that waiting room and listen to the stories being told. Lived experience knows the issues and can think of innovative ways to solve them.

Benefits of Co-production (cont)

- ▶ It would be possible to list pages of benefits to co-production, including appropriate challenge and thinking outside of the box, but one of the main benefits of co-production mentioned by people with lived experience is that of transparency. It is a demonstration of honesty for it to be OK for people who receive a service to see first-hand and participate in decisions which include budgets and resources. This in turn builds trust in the integrity of the organisations willing to co-produce.

What is Co-production Excellence?

- ▶ Co-Production Excellence is embedded. It is a culture, it is 'how we do things here'. Co-production is unapologetic. It is involvement of people with lived experience as soon as the problem is posed.
- ▶ Excellence is when a person with lived experience helps to define the problem, writes the research brief and questions, supports the consultation and looks at the results to decide a solution alongside others. The person with lived experience looks at the budget available and best value for money and once decided helps to decide on implementation. They help to develop the marketing, engagement and communication strategy. The person with lived experience undertakes evaluation at milestone points and reports findings. They support the end evaluation and share in the success or lesson learning.
- ▶ A person with lived experience has the same power as any of the other project board participants and is not 'stand alone' from employed staff.
- ▶ Co-production excellence is from start to finish in all things from recruitment to new projects, to bid writing and customer service. From policy making to reviewing processes, from complaints to awards, people with lived experience can help an organisation to be honest with itself and improve.

How did we do it?

- ▶ I have never trusted a phone number on a poster asking for my personal details and nor should anyone.
- ▶ A) To recruit people with lived experience we asked trusted organisations working with our cohort to recommend us.
- ▶ B) We knew what they would be paid and had a budget ready. We contacted the local DWP explaining what we were doing and asked them for a single point of access for the people with lived experience to talk to.
- ▶ C) We interviewed and ensured that it was clear that it wasn't a complaints process, that the purpose was to look to the future and how we could participate in developing improvements and how they could be listened to and present their experiences in a constructive way.
- ▶ D) We encouraged partners to invite the experts by experience to attend their decision-making boards, asking for two places so that they could attend with another expert by experience so that they wouldn't be intimidated.
- ▶ E) We asked that they were given questions to answer, problems to solve, not solutions to rubber stamp.
- ▶ F) Word got around how useful their input was and they were trusted to help develop the Mental Health Strategy. They got to work from a blank sheet of paper to an excellent Listening Event, based upon doing the exact opposite to all of the 'bad' events they had been to.
- ▶ There would be no 'death by powerpoint'. We had keynote listeners not speakers. The statistics were made real, because they are real to people with lived experience.

How could you do it?

- ▶ A) Start at the top – encourage Senior Leadership agreement to change the culture of the organisation to be one of embedded co-production.
- ▶ B) Find a small Co-production budget – look at the marketing and communications budget if you must.
- ▶ C) Decide who will manage / support your experts by experience
- ▶ D) Write a co-production policy using people with lived experience who you currently work with (if you can, if not make it a temporary policy)
- ▶ E) Recruit a small group of people with lived experience from a charity or your own organisation and look at your policy. Decide further recruitment and bids for more funding and start to implement co-production across all areas of business
- ▶ F) Give your experts by experience some introductory training and access to what they need. (There are some charities offering laptops to people without IT access)
- ▶ G) Look at all streams of work and decision meetings and invite two of your experts by experience to attend and when they feel confident to participate fully.

It costs less than you think

- ▶ Rethink pay their Experts by Experience £15 per hour
- ▶ An average meeting lasts 2 hours = £30
- ▶ Decision Making Boards are usually every month = $12 \times £30 = £360$
- ▶ If you have 2 Experts by Experience at this Board it doubles to £720 per year
- ▶ If you have 4 x 2 hour board meetings each month for a year with two Experts by Experience at each it would cost only = £2,800.
- ▶ If you utilise an existing member of staff as their manager and support, it costs nothing additional.
- ▶ Experts by Experience may require some training and it will cost only for their time if they train alongside existing staff. Equally staff learn from learning alongside experts by experience.
- ▶ Experts by Experience might also help to develop some training packages with you, their expertise costs only for their time, where a consultancy will charge £1,000s



Barriers are just
challenges we haven't
yet made the effort to
overcome

(K.Goodhand 03.04.2024)

Appendix A Co-production Quiz

(only Question 3 is co-production)

- ▶ Question 1: You are an Expert by Experience and you have been invited to a meeting to discuss a topic you are particularly interested in. You are sent a strict agenda and some of the topics you think are important are not on it and nor is there an agenda item for Any Other Business. Is this co-production? If not, then what?
- ▶ Question 2: A partner organisation is completing a bid for funding for a new project. On the bid there is a section for Co-Production, the bid is sent to you as an EBE to proof-read and your name is included on the co-production section as having input. Is this co-Production? If not, then what?
- ▶ Question 3: You are an expert by experience and you have been invited to a meeting to discuss the development of an action plan. You and other experts by experience and experts by training are presented with a blank sheet of paper and are asked for ideas how to develop the action plan. You are told what the plan needs to do, but not what it should say. You are told the problems that need solving, but not how to solve them. You make suggestions and they are written down, but not everyone including other experts by experience agree with what you have said. Some, but not all of your suggestions are altered. Is this co-production? If not, then what?
- ▶ Question 4: You have lived experience of mental illness and you have been asked to sit on an interview panel two days before a face to face interview is being held with a candidate for a receptionist position. The role is very customer focussed. The interview panel ensure the room where the interviews are being held is accessible and you are given a script to read from one day prior to the interview, to familiarise yourself with your questions. The scoring is being done by everyone. Is this co-production? If not, then what?
- ▶ Question 5: You are an expert by experience as a carer of a person with dementia and you are asked to support the development of an information leaflet. You agree and at the first meeting you are presented with a draft version of a leaflet to read through and agree. You don't think the content is worded very well for people with dementia, so you make suggestions for alteration, but the deadline is too soon to make the changes. You are promised they will try though. Is this co-production? If not, then what?
- ▶ Question 6: A supermarket chain have invited you to an event where the purpose is to capture your voice as a person with lived experience of neurodiversity. They tell you the room is fully accessible and ask about your dietary needs. When you arrive there are loud Christmas songs playing and flashing lights in the foyer, you have a sensory overload and cannot proceed into the event. Is this co-production? If not, then what?

Appendix B: The elephant in the room

- ▶ In the case of Co-Production it is the cost of paying Experts by Experience for their involvement. We have a little sketch written to demonstrate our response to the elephant in the room.
- ▶ **Kyle:** Good afternoon – I am a consultant psychiatrist and I have 20 years of experience. I went to medical school to study as a Bachelor of Medicine for 6 years and undertook further years of work experience. I am paid around £120,000 per year, I can earn more if I work for an agency. People always listen to me because I am a consultant psychiatrist, I dress smartly, I am qualified and have lots of experience and I have gone through the ranks to achieve my position and I am now in charge.
- ▶ **Pam:** Good afternoon – I am a psychiatric Senior House Officer, I have been to medical school to study as a Bachelor of Medicine for 6 years too and I have 7 years of experience. I support my consultant and I earn around £60,000 per year. In clinic and on wards people listen to me because I am a doctor and I am qualified, I have experience and a degree. I listen to my consultant because he has more experience than me and he is in charge.
- ▶ **Sam:** Good afternoon – I am a patient of Kyle and Pam's, I listen to Kyle because he is a consultant, he has a qualification, dresses well, has experience and he is in charge. I listen to Pam because she is a Senior House Officer, she is qualified and can help me if I need support. They rarely ask for my opinion because they have previously seen me when I am unwell. It is important to distinguish between when I have an episode of mental illness and when I am well as I appreciate my decisions may be affected by illness. Like Kyle and Pam I studied at university for 4 years and I have a university degree. I celebrate 30 years of lived experience of mental illness this year and **if I am lucky** I am paid £15 per hour for my expertise. I am an expert by experience for Rethink and some people do listen to me. If we base our listening values on expertise and education, **they should both** be listening to **me**.