

Full Report

The Value of Co-Production Research Project

Community Reporting Summary of Findings

Version 1.0 [31 October 2022]



This report was co-authored by the 100 people who shared their stories of co-production, and facilitated and curated by collaborative teams from People's Voice Media and Curators of Change. Members of Co-Production Collective provided vital support and guidance throughout the process.









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Introduction

This report pulls together the findings of the community reporting strand of the Value of Co-Production Research Project. People's Voice Media and Co-Production Collective wanted to explore the value of co-production by speaking to those with lived experience of working in this way, and allowing them to share their own stories.

We set-up an open call for people to contribute their experience of co-production - positive or negative - from different types of co-production projects and activities. Through this, we connected with 85 people who agreed to share their stories with one of our Community Reporter peer-researchers, all of whom also were active co-producers. Storytelling sessions were most often carried out 1-to-1, but occasionally people chose to speak as a collective about their projects, in groups ranging from 2-9 people. The story-gatherers recorded dialogue interviews with people over Zoom, using the Community Reporting methodology. This work forms part of the Value of Co-Production Research Project, 31 October 2022 Version 1.0.

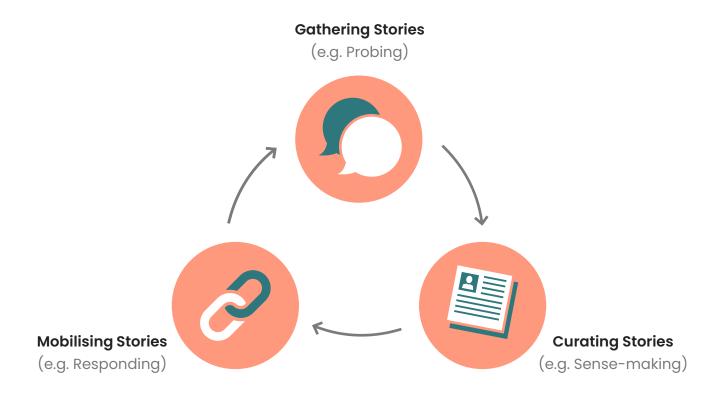
What is Community Reporting?

Originating in 2007, Community Reporting has been developed across Europe as a mixed methodological approach for enhancing citizen participation in community development, research, policy-making, service development, evaluation and decision-making processes. In-line with work such as Glasby (2011) and Durose et al (2013), Community Reporting purports the validity of lived experience and knowledge-based practice in these fields. It uses digital, portable technologies to support people to tell their own stories, in their own ways via peer-to-peer approaches. It then connects these stories with the people, groups and organisations who are in a position to use the insights within them to make positive social change. When used like this, storytelling, as Durose et al (2013) argues, allows for the representation of "different voices and experiences in an accessible way". Central to Community Reporting is the belief that people telling authentic stories about their own lived experience offers a valuable understanding of their lives.

Community Reporting has three distinct components – story gathering, story curation and story mobilisation – based around the Cynefin decision-making framework for complex environments (Snowden and Boone, 2007), as depicted in diagram 1.1. Through gathering, curating and mobilising stories from our growing network of Community Reporters, we seek to inform policy, processes and practice.

DIAGRAM 1.1

Community Reporting Cycle



Probing: Gathering Stories

The stories in this project take the format of peer-to-peer dialogue 'interviews' that do not have pre-determined questions. Instead, an opening question (i.e. a conversation starter) is asked which enables the storyteller to start to tell their story. The Community Reporter recording the story then asks any questions within this storytelling process that naturally occur to them and interacts with the storyteller to support them to communicate their experiences. In essence, the structure of this practice mimics our day-to-day conversations. The storyteller is largely determining the 'agenda' of the conversation, whereas the Community Reporter is the 'agency' facilitating the conversation. Reporters used this question as a starting point:

Can you share with me an experience of co-production? We are interested in exploring what worked well and what didn't. We'd also like to know what changes the co-production process helped to create and what you feel the impact - positive or negative - that the co-production process has had on people, groups, organisations, services, society etc.

We also added to this 15 lived experience stories that were collected using the same method during a previous project with Co-Production Collective.

Sense-making: Curating Stories

For each story, Community Reporters completed a story review sheet which highlighted key quotations, ideas and themes. In particular, we asked Community Reporters to identify any changes that had been brought about to individuals, organisations or society through the co-production experiences described.

We then brought a group of 8 participants together to help us analyse the stories and identify thematic links. These people took part in an online workshop where we listened to the stories together, discussed what we thought were the main messages in the stories, and started to try and group findings together. The results of these discussions have formed the structure and categories used in this report.

We also began investigating what people thought the ideal conditions for coproduction are. We ran a workshop in-person and a workshop online to try to gather initial ideas about this. Paired with the insights from the stories, there are some findings about this work in the final section of this report.

Responding: Mobilising Stories

This report forms one of the initial stages of mobilising the stories, along with its overview document. We have also curated clips from each story into a <u>YouTube playlist</u> for people to watch and learn from.

Who is telling the stories?

We wanted to speak to a spread of people involved in co-production. When people expressed their interest in sharing their story, we asked them whether their experience related to research, policy or services. Participants could select more than one category. The majority of participants selected research (64%) or services (63%), with 43% saying their co-production experience related to policy.

We also wanted to make sure that we had different perspectives and roles in the coproduction process represented. We asked participants whether they were:

- A person with lived experience (55%)
- A facilitator of co-production (62%)
- Involved in co-production as part of their job (55%)

Again, people could select more than one category and it was common in our stories for people to have started in a lived experience or professional role and gone on to get further involved and take up roles as co-production facilitators or specialists. The overwhelming majority of our stories related to co-production in health and social care, with housing, local authorities, communities and education also represented by 5 or more stories each. Equality and diversity, the justice system, and employment also featured as sectors where storytellers had worked on co-production projects.

We wanted to make sure that we spoke to people from a range of backgrounds with diverse life experiences. Our diversity question was deliberately left open so as to avoid the feelings of "labelling" or "being put in boxes". We asked respondents: "We want to make sure we involve a diverse set of voices in this work. Please use the space below to describe yourself in any way that you choose."

People interpreted this question in a wide variety of ways, some people choosing to tell us their demographic data, ethnicity, sexuality, others choosing to tell us about their background, family life, hobbies, and others offering their philosophical approaches to co-production.

From the data that people chose to share with us:

- Approximately 2/3rds of respondents identified as female, 1/3 male. Men were underrepresented in the sample of storytellers, though this may reflect a gender bias in co-production involvement rather than simply in the recruitment for this study.
- 5 people stated they were cis-gendered and 1 person identified as transgender. 4 people identified themselves as gay, and a further 4 as LGBTQIA+. 1 person described themselves as straight.
- 26 people described themselves as having a disability or multiple disabilities. Of these, 13 described themselves as having a mental health condition and 9 listed physical

disabilities. 12 respondents self-identified as neurodiverse or wrote that they were autistic, had ADHD or dyslexia. 7 people described themselves as a carer.

- A total of 27 people chose to give information about their ethnicity. Of these, 13 (48%) were white. The remaining 14 people described their ethnic background in a variety of ways, including: British Pakistani (4); minority ethnic (2); Bangladeshi (1); Black African (1); Arabic (1); Asian (1); Greek (1); Mixed white and Chinese (1); British Nigerian (1) and person of colour (1). [N.B. These descriptors are offered using the language that people self-identified as.]
- 18 people chose to describe their age in some way and these ranged from 20-85.

Aside from the lived experiences covered by the categories above, people also described themselves as having lived experience of: addiction (5); homelessness (4); poverty (3); adverse childhood experiences (2); prison (2); adoption (1); care (1); psychiatric hospital (1) and sexual exploitation (1).

Key Learning from the Stories

In this section, we will share some of the key learning from the stories - the most important benefits of co-production that we discovered through the experiences that people shared. These categories of benefits were developed by listening to a sample of the stories with participants in our deliberative workshops. We then discussed together what the key themes or points were in each story and grouped these together to create these findings.

Diversity of Perspectives

One benefit of co-production is that it brings together people from different backgrounds and with different life experiences. Because of this, our storytellers said one of the most important benefits of co-production is its ability to allow services, policymakers, organisations and researchers to get a variety of viewpoints on a topic from people representing the diversity of the stakeholders involved. The more open the co-production process is and the more people with lived experience that you involve, the greater benefits will be seen here. One storyteller shared the importance of co-production being "available to all people with lived experience, regardless of their abilities", while another felt that "all those impacted by decisions, policies or ideas should have an equal say, so that their needs and opinions are able to shape it".

What value does having a diversity of perspectives bring?

Listening to unheard perspectives

People discussed how the co-production projects they have been involved in made space for the voices of people whose perspectives are often ignored or unheard in wider society:

- "the value to me is in really listening and affording an opportunity to marginalised neurodivergent voices."
- "[the project] has given a voice to people with a learning disability that for sure they did not have in COVID-19."

Storytellers talked about "hearing unheard voices", including categories like ethnicity, age, and the importance of "not talking to the same old people". The benefit of this is that services, policies and research can learn from and be shaped by those voices, reducing the risk of getting things "wrong" and respecting the contributions that individuals can bring.

Cultural inclusion and adaptation

What works for someone from one cultural background or from one set of life experiences might be inaccessible, offensive or traumatising for another. Storytellers described how taking a co-pro approach had helped to make positive, inclusive or culturally-sensitive changes.

- One storyteller described a co-production project in which a group of Asian women got to learn cycling. They described their joy and awe at this "it might not be very unique for a person from the UK but for a person like me Pakistani ladies we always dreamed this is possible!"
- Another storyteller emphasised the positive role that co-production can play in creating equality, diversity and inclusion. Co-pro "helps make sure services are culturally sensitive", they told us.
- Co-production may also help build trust with communities who have been harmed by research, policy or services in the past. "In the populations that I work with... they really have, oftentimes, justifiable reasons not to want to be involved in research... as

communities have not been treated as well as we would like in the past..." said one storyteller.

For organisations, service-leaders, commissioners or researchers, co-production allows them to address issues of equality, diversity and inclusion in meaningful ways that go beyond tokenism or box-ticking - because this way of working allows them to work alongside people with those lived experiences and cultural knowledge.

Multiple perspectives on a topic

Our stories tell us that having a set of very different people feeding in to address an issue or problem offers a greater range of answers and perspectives. This helps researchers, people designing services or policy-makers to understand complexity, generate findings based on lived experience.

- "it was just wow, like there was one question but you think there are a couple of our answers to it but no, every single person there has perspective, has their own side and their own story to tell about that question". This storyteller also told us an analogy of how the humble potato can teach us the value of bringing together people from different backgrounds.
- "It's an opportunity to work with people with a diverse range of experiences. Apart from this forum, where would I ever have met, really, all the people I work with as part of this forum?...It's about generating knowledge and ideas that come from a whole range of different sources. And sometimes people's small parts of their experience link with parts of someone else's experience, and collectively you actually generate a whole range of different ideas that you wouldn't have done on your own."
- "Having that diversity of thinking creates better solutions" offered one storyteller.
- A research team described how they can't affect social change if they only approach the issue from one angle: "we have to bring together people who have different experiences and knowledge."
- •"everybody is unique...you get to meet so many different people, and so many different experiences and get your conscious and unconscious pretty much ridiculed everyday and your assumptions challenged."

Sharing life experiences, suggested one storyteller "helps the organisation to have a fuller, rounder perspective." These contributions suggest that, without taking on a variety of perspectives, the work that is being produced would be less robust - missing important points, working on assumptions, and lacking in diverse voices.

Offers learning opportunities

The stories highlighted how much professionals had to learn from people with different perspectives - particularly people with lived experience.

- "We learnt about parents' experience and that this is critical."
- "How can we do research that better meets the needs of people that are less served by it, and how do we encourage them to get involved?...I knew I had to start from a place of understanding the problem first and understanding the barriers."

Co-production creates plenty of spaces for people to learn from each other - and this is of benefit to individuals, organisations and communities. We discuss this in more detail in our co-learning section.



See things from another point-of-view

Storytellers also described how the diversity of perspectives that co-production had brought them face-to-face with had led to greater understanding and empathy. As well as professionals coming to understand the experiences of people using their services, for example, people with lived experience also learnt about the staff working for organisations and the conditions and restrictions that they worked under.

- "I see how hard this person's job is now. I see how difficult this is, whereas before that they thought, '...they're only interested in saving money'."
- "The idea of listening to other people saying things is an eye opener because I might not have thought that way, and then with that new idea coming through, it's opening doors to new ideas."
- Another person with lived experience described how valuable it had been to them to "understand the why" to be given a proper and honest "explanation of why something you want can't happen" in a service.

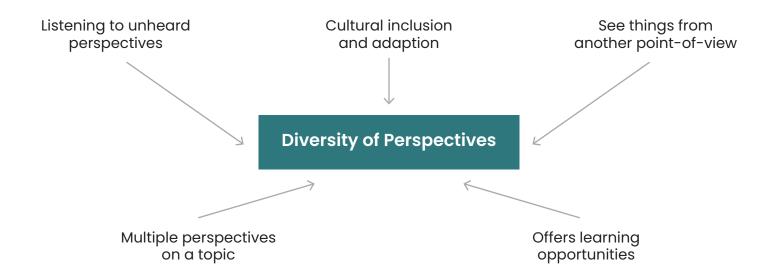
These quotations show the power of co-production to help people hear and understand alternative positions and perspectives. As well as the personal value of this (as one storyteller commented, "I love understanding the minds of people who think differently to me") the stories also demonstrate the value that this has to community cohesion and satisfaction with services. If people better understand and empathise with each other, more productive conversations can be had, and changes can be made that have mutual benefits and with understanding of external restrictions.

Social justice

Several stories also alluded, directly or indirectly, to the idea that having that diversity of perspectives is important for moral reasons as well. Inclusion was an important value to many of the people we spoke with.

• One researcher described how "taking a co-production approach is important to me as I come from a minoritized community. It matters because it's a way of creating justice into the healthcare services."

Often, it was this belief in co-production's power to support social justice aims that had driven people to get involved in this kind of work - whether they were coming from a lived experience perspective, a professional perspective or acting as a facilitator of co-production.



Difficult to achieve the same results without lived experience

Our participants in our deliberative workshop noticed how storytellers discussed their work in ways which showed that the quality of the work produced was better thanks to the inclusion of lived experience. Several of the stories contain acknowledgement that the findings, results or outcomes would have been very different if they had not taken a co-productive approach – and that they potentially would have ended up with "the wrong" types of provision, or results that were missing key points.

What value does lived experience bring?

Richness of insights - leads to greater benefits

Co-production "enables organisations to produce the best work as this will be centred around the living experiences of those that may have been beneficiaries of the offer the particular organisation is delivering", said one storyteller. In particular, co-production can offer a more in-depth and deeper level of understanding than other methods of consultation or engagement like surveys or focus groups.

• Co-production means getting "rich information from real people", which then in turn leads to "mutual benefits for all," described one co-producer, emphasising the reciprocity of relationships in co-production.

It is clear that many of the people that we spoke to co-produce because they feel that other ways of working don't allow them to access or share the same depth of experience.

The expertise of people with lived experience

Underpinning the stories of those working higher on the "co-production" ladder was a deep belief in the importance of lived experience being at the centre of co-production. As many of the contributors pointed out, they are often the people with the most expertise and drive to create change, contribute to research or shape policy about the things that affect them.

- "People who are at the heart of the things that society is trying to change are best placed to help with the change. Beneficiaries of services are best placed to help with that change as they live and breathe these services and know how they should feel, and look, and operate."
- One storyteller shared their belief that every situation "is made better by having the input of the people who will be receiving that process, because they will be able to inform that process better."
- "It doesn't matter how much you learn or think you know, unless you are the person literally experiencing it, you just don't know, and you have to co-produce it."
- Another researcher described how the findings, and photos produced in their research project had more impact because they came directly from people in the community.
- "You can't go in there blindly not knowing what the problems are, what the gatekeeping processes are, and what barriers are facing people" cautioned another storyteller.

These extracts show the value that people with lived experience have brought to coproduction projects. For many, it was a non-negotiable aspect of co-production and the element that they saw as its greatest benefit. However, the Community Reporters on our team also talked to people who described their projects as co-production, but didn't have any people with lived experience working on them. This shows that there is still a great sense of ambiguity around the term, and highlights the need to work collectively towards a shared understanding of what can and can't be considered co-production. This is particularly true as co-production is increasingly becoming a criteria for funding applications. The positive responses of people representing projects based on lived experience highlighted above show what a huge difference this makes to creating change of any kind.

Inject creativity and independence

People with lived experience are often coming from outside the professional or academic framework. This means that they may bring fresh ideas, ways of thinking and working that reinvigorate problems or questions that services, organisations or researchers have become "stuck" on.

- One storyteller discussed how co-production "increases productivity because people come with creative ideas, creative ways of doing things."
- In another project, the co-producer described how the young people involved in the work "came up with solutions", amongst the "noisy", "flexible", "meaningful" sessions they had.

As well as the content of the ideas produced by people with lived experience, the very fact of their bringing original and fresh ideas and energy into a process is a huge benefit of co-production. Storytellers with lived experience also described to us the value they brought as an independent voice:

• "The beauty of people with lived experience. . . they are independent enough to be the angry voice on the periphery. . . and that's quite useful."

Another person with lived experience who had gone on to work in many co-production roles described how his being independent means he can participate in or facilitate co-production projects with an open mind, and give his experience. In the stories, we see that often people with lived experience are good "disruptors" to conventional ways of doing and seeing things, because they come from outside systems.

Finding the unexpected

When dealing with issues around social problems like health, housing, wellbeing, care, inequality, and poverty, researchers, policymakers and service-leaders might struggle to understand where the problems lie. In the stories, we heard how co-production helped working teams uncover hidden issues and contributing factors that storytellers felt might otherwise not have been discovered.

- In one project set up to tackle the issue of food poverty in a community in Bradford, community-led co-production sessions helped identify an unexpected contributor to the problem of food poverty - fear of crime, which was affecting residents' use of cheaper shopping options.
- In another, the young people with learning disabilities working as paid researchers "were picking up stuff [in the data analysis] that us as academic researchers wouldn't have known, yes it's there, but we wouldn't have known the importance without their input."

Again, this seems to suggest that without the collaboration of people with lived experience, important aspects of barriers, challenges and social problems would be overlooked.

Changed understanding and behaviour of professionals

Having people with lived experience as key components of the co-production process is important not just for the value of their insights, but also for the change that learning from them can bring about in others. Putting professionals into non-hierarchical relationships with the people who use their services, or researchers and clinicians in mutually respectful dialogue with the people who have lived experience of their areas of learned expertise can have a transformative impact on those who usually hold the power.

- One storyteller powerfully described how the "depth of understanding and expression" displayed by the lived experience participants affected the professionals: "you can see it on the faces of the professionals...they say, we should have been asking you all along. They feel quite ashamed sometimes."
- Another storyteller said they felt their work has the most impact on clinicians and researchers involved in the work because it uncovers perspectives from the community and patients they couldn't otherwise see.
- "The more that I'm challenged about what I'm doing, the way that I'm working, the more I can learn."
- "What a great opportunity to make sure that we don't make assumptions. The value of co-production would be that as much as possible to bring those diverse views and those diverse experiences...around a table and make sure that we do not make assumptions that, as professionals, that we know best."

- "Academics who co-produce change their mindsets and their work is better for it."
- "I thought I listened to the young children and people I worked with, I thought I advocated, I thought I collaborated, but I think in hindsight, if I was to go back to my job as a social worker, I would do some things different, and better."
- Another storyteller described how it was the emotional and social impact of coproduction that could transform behaviour, as much as what is learnt: "Social workers love the work that they do, nobody comes into social work because it's the most well paid job out there and there's no stress involved. People naturally have something within them that makes them want to help people, if they're in social work, and I think co-production reignites that fire in people and allows them to tune back into that voice that made them get into it in the first place."
- As one storyteller highlighted, this can have long-term positive impacts. They described how medical students attending their workshops said they "would never forget the experiences and us sharing our stories in the workshop and that they will take that into their own medical practice. That every time they're a GP, every time they have a patient with mental health concerns they will always think back to the session that we did. That wouldn't have been so powerful without the framework of co-production."

Building human relationships between professionals and people with lived experience brings greater empathy, understanding and respect, which in turn has a positive impact in changing the practice of professionals. It is not just the individuals in the coproduction project which will benefit from this, but the organisation and wider society will benefit from having professionals change their attitudes and behaviour for the long-term.

Changed process

Our research also uncovered stories of how organisations have recognised this value that people with lived experience bring, and changed their processes to embed coproduction.

• In the forensic mental health services in which one storyteller co-produces, they described how the service has altered to "recognise and demonstrate value of people with lived experience facilitating the process". In fact, they deliberately target the "people with the most reduced opportunities" for this mutually beneficial work.

- A health researcher describes how co-production has allowed them to move to "more evidence-based practice" because "they know they are asking the right questions and asking them in the right way."
- A research team in one story described how having an advisory group "really helped... to develop our thinking".
- More evidence-based practice they know they are asking the right questions and asking them in the right way. They can then feed this into policy.

These examples show increasing numbers of organisations and teams finding ways to ensure that lived experience remains a driver in their work.

Changed outcomes

Storytellers were also often able to point to areas in which the contributions of people with lived experience had decisively changed the outcomes of projects.

- In one story, the speaker describes how a service "made small, easy changes to the services that made a big difference to the people that use them" as the result of a co-production project.
- Another storyteller described how "co-production really changed the course of the overall direction of the project".

Another researcher described how they had expected their project to identify and try to tackle systems-based barriers, but they had discovered a whole different set of issues and then could come up with solutions to tackle these instead. When lived experience is valued, and co-production managed in a way that allows people with lived experience to drive change, the results can be projects that might look different to the original vision, but provide solutions based on real insights.

Influenced outputs

Just as with the outcomes of co-production, storytellers also shared with us examples of how outputs of projects and co-production processes had been influenced by the contributions of people with lived experience.

- One storyteller amended their design for an 3-D autism simulation tool when feedback from people with lived experience told them that they had to make it "much worse" (in terms of what they experienced) than the person had first designed it to be.
- Another person with lived experience told us about the tool they had co-created for discussions around pain between patients and healthcare professional: "It's probably more practical and uses proper language not NHS jargon...you're thinking of you while you're doing it, you're thinking you're a person who lives in a world, rather than a patient seen for 10 minutes."

Bringing the expertise of people with lived experience can help to create outputs that better reflect the realities and suit the needs of the people they are designed to help.

Ability to address needs of different groups

Bringing lived experience to the fore strengthens the ability of organisation to address the needs of different groups.

- As one storyteller points out, the "insight gained from different lived experience recognises that not one size fits all."
- The schemes created through co-production with people experiencing forensic mental health services received *"positive evaluation from service users"*.
- "Our collaborators really helped us understand what would be acceptable for people."

Co-producing puts organisations in a stronger position to understand and be able to address social issues, and also encourages them to think about the complexity of the problem and the different approaches that might need to be taken to suit different stakeholders.

Cautions

While there was overwhelming support and enthusiasm for the huge value of lived experience in the co-production process, a few storytellers did raise concerns that they wanted people co-producing to be mindful of.

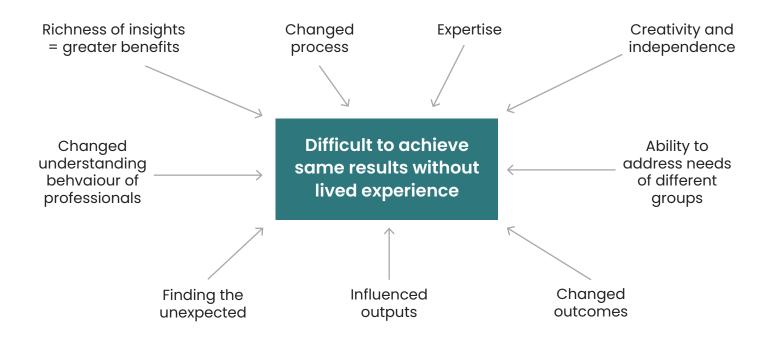
- Co-production can cause harm, one storyteller warned. This is especially true if it involves recounting trauma, if people feel that they have been asked to share stories then ignored or treated poorly, or if change is not forthcoming.
- Another possible restrictor on the success of co-producing with lived experience is
 making sure that people with lived experience do actually have the power and the
 control to create an impact that they are not there tokenistically or to implement
 the agenda of the researchers or professionals. One storyteller felt confident that
 they were contributing to the process that they were involved in doing the work and
 having them there was timesaving for the researchers, but also said they were "not
 100% sure whether my contribution is impacting the outcomes"

Putting lived experience to the fore, for one storyteller, creates fundamental shifts that affect the quality of the work produced:

"Say you've had some kind of service which was being co-designed and co-produced by people who use it, loved ones that have people that have used the services, and also the people around the table, the professionals, that put their heart and soul into this service. It's always going to be better. It's almost like, if you're a good baker...you're making a lovely cake on a Sunday afternoon, you do it through love, and all that love comes out into the cake, it almost tastes better because you've put so much care into it. You're gonna put that little bit of spice into it, lots of fruit, all this sort of stuff. And it's a bit like co-production. If you put your experience into something like that, it makes it feel as if the services are done with love...It's doing it in a way that's going to be right for people in the future, the service or whatever you've done in co-production."

When people with lived experience are listened to, encouraged to take up positions of power and control, co-production can have a host of hugely positive benefits for organisations, professionals, services and wider society. However, this does rely on people with lived experience – and their contributions – being treated in an equitable and respectful way. What this means in practice will be examined in more detail in the "Conditions of Co-Production" section.





Depth of insights

The sections above have highlighted that co-production approaches were associated by our storytellers with gaining a greater diversity of perspectives, noticing things that might otherwise have been overlooked, and changing understanding. Another related benefit that came out through this Community Reporting process was the depth of insights and information that can be gathered through taking a co-productive approach to research, policy or services. "The quality is so much better as a result of doing co-production," one storyteller described the research they'd been part of, saying that this made it have more "impact" on the research organisations involved and, ultimately, services.

What value does co-production bring to the depth of insights produced?

Depth of information and analysis - first-hand, up-to-date

Information can be gathered in great detail, from people with first-hand experience, and generating the most up-to-date learnings - not relying on old data, "commonsense" assumptions or professional perspectives alone.

- "We had amazing in-depth life conversations; the analysis sessions were full of passion and spirit, related to the Equalities Act and hate crime and particularly equalities around education and children and young people's rights and UNCRC [The United Nations Convention on the Rights of the Child], that's in depth, but it was so lively and that's really how co-productive research should be."
- "The value [for services and organisations] is having rich information from the source so we're not gaining this from a spreadsheet or a pool of data, this is coming from real people."

These storytellers both speak to the value of the types and quality of research data and other insights that can be created through co-production.

Outcomes and projects are less shaped by researchers or professionals, less agenda-driven

Undertaking research or change processes in a co-productive way does ask organisations to let go of control and power over the project and its outcomes. This can be destabilising but ultimately some of our storytellers felt that it "removed bias" from research processes and pushed back against service changes where there is a "hidden agenda". Instead, the collaborative approach of co-production can lead to more openness, honesty and creativity.

- One storyteller was highly critical of research projects that "come in with the idea already in their minds for what they want to do research on and pitch it to you, then ask you if you think, is it a good idea. For me, that starting point should have been at the start before the idea."
- One public advisor described their role as "being a critical friend", and how the
 organisations they work with create space "where they can hear even unpopular
 views and comments, asking awkward questions". This then impacts on the design of
 research. They feel that this is good both for the quality of the research itself and for
 the outcomes of the people involved.
- "I think it just is a way of escaping from the conventional ways of doing things and if you can find some sort of escape from those, and you're not being tied down, you can in this case find out much more about what you can do to help patients or potential patients, than you would do in a conventional way."

The sentiment within these extracts shows the positive, freeing potential of co-production to help organisations, institutions, researchers and professionals step outside the standard ways of doing things and open themselves up to the possibilities of new and unexpected findings and methods.

Research includes evidence from different perspectives

As above, research that is co-produced offers a more rounded view of a topic because it can pull on the perspectives of different stakeholders.

- One co-production team described how their work brought together the understanding of a problem from the perspective of commissioners and the understanding of the same problems from the perspective of young people.
- "I definitely think it's a richer way of working with our communities and it's something that I hope I can extend more in schools, working with parents for example...[this project] has made me realise the value of empowering all voices to bring change, and bring everybody around a table."

In almost every setting, storytellers described how bringing varied viewpoints together helps build an evidence base of quality, in-depth insights that take a rounded view of an issue.

Problems and challenges

While many of our storytellers felt personally, anecdotally and experientially that the quality and depth of insights gained through co-productive ways of working were hugely valuable, a few did note that there are challenges in proving this.

- The "perennial problem around demonstrating impact" was raised by one storyteller, noting that it was hard for them to say what impact the work they'd been part of had had on policy-making.
- Another co-producer discussed how there is, sometimes, however a "hierarchy of research where peoples' experiences are considered based on intuition", seen as "not really facts", a mode of thinking that might make more traditional, conservative organisations or institutions reluctant to try co-production.

There is still more work to do in proving the validity and impact of co-production, and in breaking down some of the assumptions and skepticisms about it (which this report aims to contribute to). However, we also found storytellers who were proudly convinced that co-production gave them solid results that they had confidence in. "We have no concerns about rigour", affirmed one research team, "we constantly review and work together, tweaking and changing things to improve the quality of data and the way that we are working."



Co-learning

Learning is at the heart of many good co-production processes, and our storytellers championed the way that co-production makes space for learning. In co-production, they told us, all parties have something to learn from each other. People can learn, and teach, different skills and types of knowledge. One storyteller described how they saw co-production as a "two-way knowledge exchange, where you learn something from that community, and you pass on knowledge and skills to them as well." The reciprocal element was extremely important to our contributors – it's not about people with lived experience passing on knowledge to professionals for them to take away and share nothing in return. It's also not about professionals imparting their learned knowledge from their socially-ratified position as experts. Co-learning is a collaborative, engaged process with input from all sides, and benefits for everyone. "I learnt as much from them as they learnt from me, being a part of that group," said one storyteller.

Finding the answers together

One of the elements of co-production that generated the most enthusiasm among our storytellers is that co-production provides those spaces for people to come together to find answers. Professionals feel relieved that the onus is not "on them" to come up with all the solutions, and people with lived experience are valued for the education they can bring to others who haven't got the same expertise as they have.

- "The answers are in the room if the space is provided even if what is said is contentious and hard to hear. People who work in services don't have to have the answers."
- One research team described the different facets of knowledge that co-production had brought them: Learning about the research question, learning about generational dynamics and building relationships across age divides, learning about the process of co-producing itself.
- One co-producer described it as "a win-win situation for everyone. They get to
 do their jobs better because they've spoken to me, and I get to live my life better
 because they've brought their expertise and combined it with my experience."
- Another storyteller came up with a wonderful analogy to describe the learning process that co-production takes people on: "I love travelling and I align it to travelling. You go to places you've never seen before, you visit places you haven't seen before and you say, 'oh we'll go down that direction', or 'we'll go round that way', or 'we'll try that'. And you learn more and more as you go along....you don't stop learning. And there are all sorts of things, you get lost on the way, as you do when you are travelling. You come to dead ends, as with travelling. But then you find beautiful views."

These stories highlight the beauty and benefits of learning from each other in co-production, to find answers from people who aren't always asked to teach.

Sharing different types of knowledge and information

People bring different things to the table and co-production allows them to share these skills, knowledge and information. Collectively, the group holds much more than any individual member can know.

• "I suppose the most positive thing is to see what's actually possible when you team

up with people with different skills and different knowledge and how it practically can all tie together to make a potentially exciting and novel piece of work."

"Creating spaces where people share their knowledge and skills can only enrich the
person and the work we are an organisation. People involved in co-production can
personally find satisfaction by sharing their or peoples' living experience and the
different types of knowledge that people hold."

The sharing of this learning can, as the quotations from the stories highlight, have a positive impact on individuals (learning new skills and expertise), on organisations (learning new insights, issues, information) and on the end results of a project (by pooling knowledge and skills, things or change can be created).

Continuous process

Co-production approaches, if properly embedded, also lead organisations and individuals to engage in learning as a continuous process.

- One storyteller comments: "we've spent years honing this skill how to facilitate co-production and we're learning something new every single day", showing that the learning doesn't stop, even when someone might be considered an 'expert'.
- Another person sums up the atmosphere on their co-production project: "everyone's learning from each other, 'how did that work?' 'Just because it didn't work, doesn't mean it's a failure, it means we can learn from it next time'."
- "I think that learning process is essential... never stop evaluating, never stop reflecting, never stop learning."

The value of the co-production approach is that the learning is continuous, on-going, and never stops. The stories we have gathered show that there is the potential for learning at every stage of the process.

Sharing this learning more widely

The learning that happens and is created through co-production can then also go on to be shared more widely.

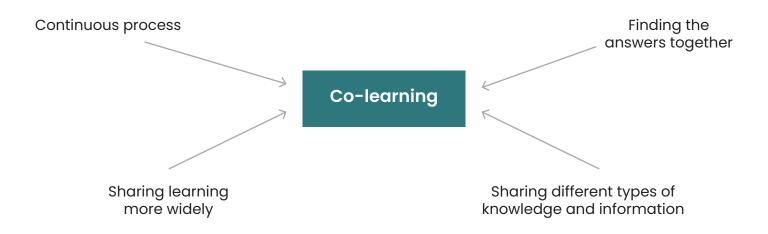
- One storyteller says that the discussion at the exhibition they co-produced was filmed and they are going to share it online so that other people can benefit from the learning.
- Another team describe how excited they are to share what they have learnt about doing co-production with others who might be interested in co-producing research.

When the learning from co-production is shared, this enhances the capacity to create impact beyond the immediate confines of the project, allowing others in the community, organisation or wider society to benefit and learn too. Co-production, or co-produced outputs, were often held up by storytellers as models for others to follow as best practice.

The centrality of co-learning to co-production is summarised succinctly by this storyteller:

"Everything is shared, your knowledge, your values, even your confusion. Co-production is a space where you not only share the things, you also learn the things."

Individuals and organisations can take this forward and make positive changes, using their new skills and knowledge.



Sharing roles, sharing power, striving for equity

Power-sharing was a concept that many of our storytellers regarded as fundamental for co-production to work. Most obviously, this helps to achieve social justice aims, allowing people to take control and responsibility for their own work and making sure people with lived experience are given the opportunity to participate on equal footing

(or as close to that as can be created) with professionals. This also brings value to the outcomes of the projects, and can lead to wider shifts of culture that benefit organisations and society.

What value does power-sharing bring?

Trying to remove hierarchy

Some storytellers described the attempts that had been made during their coproduction experiences to work towards flat and equal team structures, where there is an "equality of status in the room".

- "Because we aren't a group in the full sense, like a work situation, where there's a hierarchy, you've got a boss, you've got people you're in charge of. So all those politics aren't there...I'm not going to kid anybody that it goes smoothly and everything goes right, but I don't think it goes particularly wrong. What happens is you have to find ways of managing these situations in a way you wouldn't in a workplace."
- "All the things I hate about academia the meritocracy and the ranks and elitism, that's not there and everyone can just be themselves."
- "What I like about [co-production] the most is the idea that everyone is equal and everyone has something to contribute and I think that's such an important part of working with people who are underrepresented in research."
- "In the good old bad old days, we as professionals, we had all the power, we knew what was best for you. And just to see that turned on its head."

It's hard, though, some storytellers acknowledged, to get rid of all the pre-existing power dynamics:

• "One of the things that's difficult getting people involved with research is that they feel like the researchers, the scientists, are the ones with the knowledge and the power, and they feel like they're not being listened to or they don't have control over where the research is going...so obviously they're not going to want to get involved, because they don't have that level of agency... I think doing more co-production work is a great way to tackle that because if we can show people that no, you're really

valued in this, you're an equal part of this, in a way you know more about this than we do, so we're learning from you, that could be a way of getting more people involved."

Skilled co-production facilitators can point to different and contrasting ways of achieving this. For example, one storyteller described how she had asked to meet residents of a community without the professionals in the room for one session, in order to shift the dynamics and encourage people to find their own power: "people think for co-production people have to be in the same room all the time and I don't think that's true, because of the power differentials."

Power-sharing - stepping up, stepping back

Storytellers offered insight into some of the ways in which they had experienced power-sharing in co-production situations.

- "Anyone can be a researcher it's about how they can be enabled to become a researcher", reflected one contributor, who wanted to "make research more democratic".
- Another story described a project where facilitators made sure that "families and carers were valued for their assets". They got rid of titles and created "a guideline that no one was going to apologise for themselves".
- "I developed an understanding of power dynamics and how to address them."
- "With co-production, one of the most important things, what it's really good at addressing, is the power dynamics. Especially with some of the projects I've been involved with, you're working with clinicians. And there's often that inherent power dynamic. What I've found working in co-production is it becomes flattened."
- "Until we share a space, equally, with the people that experience social work, with people with lived or learned experience of social work, we're not going to get it right.

 And that's the only way of being better and improving people's lives."

Removing signifiers of power, trying to shift power to people who usually don't hold it were accompanied by professionals themselves learning to cede control to others:

• One professional remembers "having to change my way of thinking", shifting from "having control" to "sharing work and encouraging others to be involved". They describe this as an "important lesson".

• Another professional inverts the idea of communities being "hard-to-reach" and discusses how they have had to "adapt to become less hard to reach themselves."

The storytellers involved in our project were open and honest that power-sharing was a complex process, and no-one claimed to be doing it perfectly or completely. However, all agreed on the importance of striving for and working towards those spaces of equality.

Putting people with lived experience into power-holding roles

One of the most effective ways to address the existent power imbalances is to give people who typically hold less power control over the decisions, direction or management of the co-production project, or elements of it.

- One story described how the co-production project had changed the plan they had planned to bring in external consultants but instead decided that the peer co-researchers should lead the workshops.
- People being given power also need to be properly supported. One storyteller asked "How do we make it easier for people who previously haven't had power to have the confidence to contribute?" They offered suggestions like briefing and debriefing people before and after meetings, or getting rid of meetings altogether and going into the community instead.

When people with lived experience are given power and are properly supported, the stories show that they can make a unique contribution to projects, and surprise themselves and others with what they can achieve.

Being humans together

The idea of "being human" and connecting as people - without the baggage of hierarchies, titles, roles, badges of expertise etc - came up repeatedly in the stories. Co-production reminds professionals that "customers are humans just like us" said one storyteller, proving how restrictive and depersonalising systemic structures can be. Co-production provides a space for another, more human, way of working, the stories suggest.

- One storyteller told us that, although he uses and respects terms like lived experience and living experience, he prefers to share names and interact as people.
- Another person describes how "equality of relationship" was prioritised in the coproduction project they worked on - focusing on connecting and contributing equally.

That these experiences should seem so remarkable and unusual in working cultures for the storytellers points to the transformative potential of co-production to humanise areas like services, research and policy, and make them work for people with human values at the forefront, rather than being subsumed by systems.



People driving change

Many of our storytellers described how they felt true co-production comes when people, rather than professionals, are the ones making decisions, taking action and steering the direction of a project. As a collection, the stories show that this is what distinguishes co-production from other types of collaborative work like involvement and consultation: "Co-pro is more about being the driver, with other agencies, in producing something which is jointly-owned." In another story, the speaker describes their experiences as a lay person on a committee, where they were given a document to comment on. They contrast this to their co-production experience, where there were "patients in the room from the beginning": "The piece of paper that we were consulted about contained ideas that we'd put forward as patients with the different types of arthritis." Having the agency to create change and take control is one of the most important and valuable elements of co-production for these storytellers - and with it come benefits for individuals, organisation and society.

Genuine control over project and process

Our storytellers were able to share examples from their co-production experiences to demonstrate the value in letting people with lived experience and other stakeholders take control of the projects that will affect them.

- One storyteller working in housing described how their project had evolved thanks to the tenants taking control of their own involvement. In the project, tenants were asked to help the housing provider come up with a set of customer promises. However, the tenants felt that actions were more important than words. They agreed to help with the promises on the proviso that some action follows. They are now running a coevaluation project where tenants research, report and present to assess the baseline of how the Housing Association are doing against the promises. By allowing the tenants this voice and control, the housing provider has ended up with something much more than "a set of words stuck up in reception". The plan is to make this an ongoing, tenant-driven annual "health check" process.
- Several storytellers reflected on the idea that it was important to involve a variety of stakeholders right from the beginning not to have a pre-set agenda. As one person noted, "often the things that researchers choose to focus on aren't actually things that are a priority to people."
- This flexibility and ability to drive the direction of co-production should continue throughout the process, agreed one storyteller: "I think it's really important that whatever comes out throughout that process can grow in different directions... it's not about 'come and tell us what we want to hear' it's more about 'come and lead us'."
- A story about a social work group showed how many different areas could be put in the hands of people with lived experience: "The group are involved from the design of an idea, delivery, evaluation not just asked to tell their story. They have been involved in podcasting, webinars, international webinars, they teach in the classroom, and interview the applicants to the social work course."
- "It's the value base behind the co-production ensuring that people not only coproduce but they are co-leading on pieces of work and actually a co-author in papers."
- "Ask people to write their own reports and don't stifle them."
- Another storyteller explained that they thought one of the benefits of co-production was that organisations can "give over" part of services to the people that use them.

These stories show that giving control over to people with lived experience creates new opportunities, gives space for innovation and supports professionals and organisations to deliver, based on the expertise and experience of people.

Change in attitudes - recognise capacity to create change

Some of the stories showed that putting people in positions of power and allowing them autonomy and control had a knock-on effect. As people recognised their own capacity to create change, their attitude became more positive and their actions grew in scope.

- "The thing that I love about it is the infectiousness, or the enthusiasm, and the sense of actually this is the way to do things, you can see that emerging in these groups and across other partners who perhaps before might have been sceptical," one storyteller told us.
- "By the fourth session, the dialogue was really different, and they were saying 'we'll organise our socials, but we don't have a social space so what we want you to do as the HA [Housing Association], because you've got clout and budget, we want you to find us somewhere, a space that we can gather. We'll sort the rest...we just need you to find the space and we're very capable'...they really swapped from like 'how are you gonna solve all our problems' to 'we can do all this stuff but this is the bit that you can do', which was amazing. And that complete transformation in four sessions which when you think about it isn't that much, is like 8 hours total."
- Another storyteller described how residents organised a series of community meals to discuss the issue [of food poverty] and come up with solutions. Ideas included: more police in the area, council support, more local buying options.

These examples show that unlocking that recognition of people's ability to take control and change things in their community or organisation can have a positive "snowballing" effect, where the validation of successful change spurs further will and action.

Professionals changing practice to put others in control

In order to achieve this momentum of change, people need to be given authority to make decisions and take actions - to lead projects or parts of projects. Many storytellers noted that this requires professionals to change their practice or step back to allow others to take control, where they may be used to managing and directing the actions of others in the course of their job.

• "What I hadn't realised until we did this project was how much I focus on the outcome that I need young people to achieve and how tightly I direct them towards that outcome without really meaning to do so. And working on this project...this kind of this idea that we ask young people how they want to approach things, which sounds like a really obvious thing to do, was I'll say, a revelation."

In this example, the process of co-production has made the storyteller, who considers themself "a very open minded person who likes to try new approaches to educating young people", to have a realisation about their previous practice. The self-reflection that has been prompted here leads to positive change in their behaviour and outlook. There are similar examples throughout the stories of professionals confronting their own need to be in control of situations and learning to let go through co-production:

• "At the start, I thought that the young people on the panel would need a lot more support and guidance from me than they actually do need. I was really concerned with having a structure for them to follow, and I felt nervous when I didn't know what to ask them, or how our meetings were going to go, because I felt like it needed to be very controlled to sort of guide them through it. But actually, the more meetings we had together and the more we worked together, the more I realised that they could lead better than I could, and actually direct the conversation. They came up with some ideas that I wouldn't have thought of for the project."

In this instance, the young people suggested that they could do some of the interviews with their peers, rather than the PhD researcher carrying them all out. This was taken on board and the storyteller believes the research is better as a result.

People feel ownership - buy in helps you achieve more

In another example of an attitudinal shift prompted by a change in way of working, several stories described how putting people in control through co-production encouraged them to take ownership of the project - which might be research, improvements to a service or development of policy. Storytellers spoke of how this creates investment and buy-in from the community of stakeholders, which helps to achieve more

- "[students] knowing that they have a say in how they can move forwards with things just increases that ownership that they feel for their learning so much and then impacts on their buy-in to what we're doing and their pride in what they actually achieve."
- "When they feel that their voice matters and they're actually leading research, and they're integral to it, so without them we can't move forwards."
- A person with lived experience explained how being in at the beginning of the project has made a difference- they feel that they've been able to shape it.
- "No one wants research to succeed more than the people living with conditions."

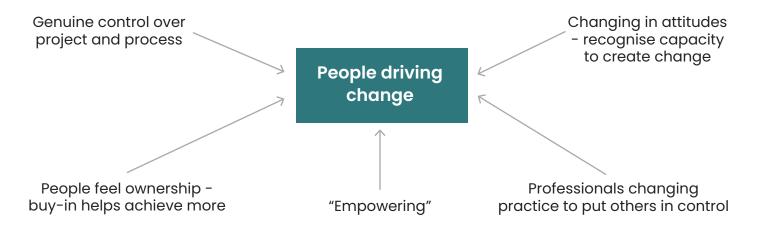
The increased self-belief and investment in the project makes people with lived experience important actors in the change-making process. This sense of responsibility keeps people engaged in the project and gives it momentum and drive, which in turn helps achieve things.

Empowering

The word "empowering" can be a controversial term in co-production circles. For some, it represents a "doing-to" approach, and can be seen as reflecting a paternalistic attitude. However, for others, it is a word with positive connotations - about a feeling of self-confidence and belief in one's own abilities. It's included here in our analysis because it's a word that came from our storytellers time and time again.

- One storyteller described their co-production experience as "positive, empowering, uplifting".
- "Being part of that change that has been empowering."
- One storyteller describes feeling "empowered because the decisions were made with us, not without us".
- Another storyteller felt their lived experience group "enables people to find a sense of individual agency and more so their own sense of power."
- "Your experience is as valuable as any qualification or training out there...don't feel like your voice isn't valid or is less valid."
- As a comparison, one storyteller described their experiences in non-co-productive
 work or in work that they felt was "fauxproduction": "I can't get involved unless
 someone chooses to involve me, I don't often have control over the terms of my
 involvement." This was disempowering and left the person feeling emotionally
 exhausted.

Empowerment in co-production, then, can be seen as a first step to helping people find their own power. Giving space and handing over agency creates conditions for people to feel a sense of their own power in all sorts of ways, from leading projects to "refusing to have words put into your mouth".



Collective action and connections

Storytellers emphasised how much of the power of co-production resides in the ability to work together to create change: 'The single most important thing is the building of relationships,' one storyteller told us.

Connecting with power

Co-production creates connections between people with different levels of power, and gives marginalised groups the ability to speak to and influence decision-makers.

- "We've got those direct conversations between young people and also members of the government."
- "One of the most interesting things in those conversations between young people and commissioners is really seeing people look at a problem from each other's perspectives."

Co-production is a productive space where people can have two-way conversations with people in positions of power and influence. This means that decision-makers and policy-makers go forward with new understanding, and people with lived experience have a greater ability to raise issues and solutions directly to those "in charge".

Connection and support = power and opportunity

However, what the stories also show is that it's not necessarily talking with the most powerful people that create change - the power and opportunity for change often lie in the collective action taken as a group working together.

- One storyteller described how "peer support groups enable people to find their power, to find their voice because it's a step towards, then when we do bring them together, they are primed to have much more constructive conversations."
- This person also told us how people involved in co-production then go on to spread power through their community: "[The] group felt empowered to help others in the community as well as themselves, because they realised their own assets and knowledge".

- As a result of co-producing, one storyteller described how their link clinic set up not only enables them to engage with the community that they want to serve, but also "helps with community cohesion".
- "There are lots of serendipitous opportunities that come about from mixing with random people and forming new networks."

In these examples, the value is in bringing people together to form stronger community links and through the power of collective action. People feel stronger working together as a group and have an enhanced ability to create change, both through bringing together their knowledge and skills, and by collective representation rather than acting as individuals.

Growing empathy - learning to work together

Our stories also show that co-production supports cohesion, empathy and compromise in communities, groups and organisations.

- One person with lived experience told us about the people skills they had developed during their extensive co-production work: "Learning to work with others, understanding others, being empathetic and it makes you grow". They described the process of working on a co-produced manifesto, where "people [came] with all sorts of kind of priorities that they wanted on the manifesto but then people realised, hang on, this will only benefit this small group of people, but we want it to benefit the majority, so maybe I should change my mind in look into that instead."
- "A sensible compromise around pet policy was reached and a mutual understanding among the community around how to live together."

In the examples above, the close connections, shared dialogue and equal working relationships of co-production create a space in which compromises can be found, views changed and shared goals developed. These are the building blocks of strong community relationships.

Social connection has an impact on mental wellbeing

Storytellers also told us that the kinds of personal connections between human beings that are created within co-production spaces have a positive impact on the wellbeing of participants in the process.

- "That social value...human connection...agency...that power that the residents found in themselves going, 'now we can do this'. There is huge value there in their sense of self, being, they're looking out for each other, we have value in this community, there's a value there that's really hard to quantify. For me that's everything and what matters in co-production."
- "It's definitely that social connection and coming together and meeting and learning."

Feeling connected to others and having supportive community links enhances the wellbeing of individuals involved. On top of this, the sense of accomplishment and strength enhances this further, leading to more resilient and happier communities.



Enhanced ability to create change organisationally and in the community

The sense of connection and the building of capacity for collective action described above had a knock on effect in many of the stories. Storytellers described how coproduction had enhanced people's ability to create change in organisations, services, systems and in their local communities, the benefits coming both within coproduction projects themselves and diffusing through indirectly by upskilling, providing models for change and shifting cultures.

Benefits to communities

Communities benefit from the outcomes and outputs of co-production projects, but also, by seeing their peers work in co-production, even those who were not directly involved can be positively impacted.

- One storyteller reflected that "people in the community who did not take part in the project can look at the outputs and see that getting involved in research was a good experience for their peers, which might encourage them to get involved too…or at least they can recognise some of their own experiences and feelings in the findings". This has the effect, the storyteller felt, of bringing the research closer to communities "not paywalled in academic journals".
- Another story had a similar message: "People who have been involved can take the positive health messages to their communities, families and friends and influence others".

Both of these storytellers reflect the importance of peer relationships as influencers. In the first one, seeing members of the community creating something new through co-production helps them understand the potential for change, and engages them in finding out more. In the second, the storyteller feels that the community links could lead to positive behavioural change. In this way, co-production makes "hard-to-reach" institutions like research and health services more relatable and potentially more accessible to people in the community. As one other co-producer pointed out, this model of "community development reduces cost".

Meaningful connections that increase community cohesion

The peer relationships built through co-production also have a positive impact on the way people relate to each other within the community.

- "I definitely think it's a richer way of working with our communities...the way that this project has been done has made me realise the value of empowering all voices to bring change."
- "It's much easier to have a conversation with somebody around the fact that you live in this community and this is what people have agreed about how to live together."
- "They valued that I had lived experience...not just a professional, I get it on a personal level."

Having the shared knowledge, understanding and empathy built through co-production gives a more secure basis for difficult conversations and collective decision-making.

Sharing resources, findings, tools

Concretely, co-producers were also able to point directly to outputs, resources and insights they had shared with other agencies or organisations.

- One storyteller described how their co-produced Diagnosis Support Packs for autism/ ADHD were shared and embedded within local schools, and they are in discussions to roll out the resource more widely through NHS England.
- "We will share our findings with local leadership and policy-makers about what needs to change and [the young people's] recommendations."

Co-production produces new findings, models, ways of working and tools that can be replicated or shared by others - offering value more widely than the confines of the original project. Contributors to the project also spoke of how co-production allowed them to raise "greater awareness" of the issues that they set out to tackle, and to win "hearts and minds", which again enhances the capacity to create change around these topics.

Organisations changed to become more dynamic and people-focused

The stories also contained examples of how co-production had impacted upon the organisations taking part, allowing them to adapt. The transformations that co-production brought about in these systems left them more able to create change and act dynamically, and with a focus on people.

- One team described the big "culture shift in way of working" that they had observed through their co-production project.
- Another storyteller shared a positive example of measuring work with a council where they developed "a level of continuity and local connection embeddedness". The speaker felt that this needed to become the "norm" in local government.

This is another one of the more intangible and indirect benefits of co-production - it is difficult to measure shifts in attitude and working practice (particularly if nothing has been officially set up to monitor such changes). However, the stories provide evidence that this is happening in the experience of co-producers, and it is easy to see the huge positive potential that these types of shifts hold within them for achieving social change and creating organisations and services that better serve the needs of communities and work more effectively.



Trust

The concept of "trust" – both as an outcome and a process – came out in many of the stories as a hugely valuable and important aspect of co-production. Many stories described the time spent "building relationships and developing trust", but also the positive results that can be achieved once those mutual relationships of confidence and care are established. As our storytellers described it, trust is one of the outcomes of co-production that can be beneficial long after the initial stages of a project are finished.

In services

- The trust built through co-production can positively affect people's experiences of services. One storyteller told us their view of co-production as "inclusive, builds trust, [leading to a] better journey through health services".
- Another story described how a co-production project around catering allowed them
 to "take off the 'professional mask' and build trust and have a laugh with tenants".
 Good facilitation was key to this it was achieved through fun and thematic exercises
 in the sessions.

In communities

• One lived experience storyteller described co-production as key to "building trust within communities."

In research

- "Having the involvement from the people in the community also built trust in the research and I think that people were more willing to come and talk to the research team... because they knew that it had that authentic input from people with that lived experience."
- "The photos really helped to open up that discussion and for us all to get to know each other, and I feel like it really helped with the discussion about the health research, because people had already opened up and shared something, and so it was much easier to talk about those difficult things as well."
- Another storyteller described how they had worked co-productively with the Gypsy and Roma community, where there were "high levels of mistrust based on previous history and experience." This storyteller pointed out that it would be "disrespectful to expect them to join willingly". Co-production can help overcome these misgivings if a lot of time and care is placed into building trust, but the storyteller urges other co-producers to "be mindful that communities aren't all able/ready to engage in the same way."

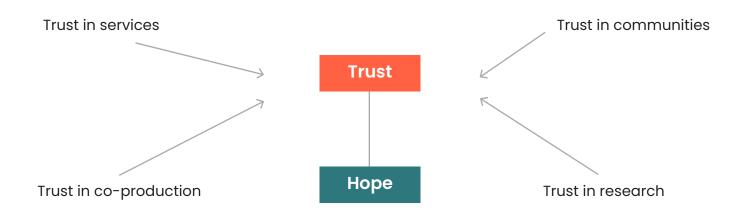
In co-production itself

- Time taken to build trust is an important part of the co-production process. "Building trust and a space where people feel valued and equal in terms of the decisions that are taking place" is what makes co-production work, according to one storyteller.
- This means that co-production often happens more slowly than other processes of change: "You can't go from 0-60, you need to build relationships, and gain understanding of intent".
- "The really nice thing is that it has allowed us the opportunity to build relationships with each other, and to trust each other because you talk about some quite personal things sometimes within the group."

Trust is important in connecting with "seldom-heard" groups and those for whom services, research and policy are distant and hard-to-access. But for any co-production group working together, storytellers felt that trust was both an important aspect of the work of co-production and a lasting outcome of the process.

Hope

A related element that participants in the deliberative workshops noticed linked several of the stories was "hope" - where the trust, relationships and change brought about by co-production led to them feeling "uplifted" and "excited" by the possibilities, often from situations which had made them feel powerless, frustrated or harmed in the past.



Challenges

While the sections above detail what storytellers told us about the positive value of coproduction, people were also open and honest about the barriers they face in doing coproduction. This section covers some of the most common challenges or cautions that co-producers offered up to us in their stories.



Ambiguity and confusion about term

Storytellers described their frustration and annoyance at having been involved in or recruited into projects that described themselves as co-production, but were not. One problem with working in this way, one storyteller said, was that there is "not a generalised understanding of co-production."

- People with lived experience in particular described having been involved in "co-production" projects that were "informing rather than involving, tick box exercises, done insincerely". Indeed, even some of the experiences that were presented to us in this project described actions on the "bottom rung" of the co-production ladder or labelled themselves as co-production but didn't involve people with lived experience.
- "When there is the illusion that people with lived experience and carers are involved but the decisions are actually being taken by professionals or managers, that can be quite disempowering. You're just there to nod your head and agree, rather than challenge and put things forward."
- A PhD researcher storyteller described how she had discovered that what she sees as the "gold standard of co-production" is very different from what normally co-production means to her colleagues and peers. She describes being told that if she'd "talked to 3 or 4 patients" she had done it."

While not wanting to be prescriptive about or to gatekeep co-production ("we're not the co-production police!" was a phrase that came up a few times in our discussions as a research team), it is also clear that there is an ambiguity around the term. While some of this is necessary because of the nature of what co-production is, this also leaves it open to (sometimes) misrepresentation of projects that are actually involvement, consultation or other related terms. Storytellers felt this was occasionally malicious or at least deliberate (from organisations that don't want to be challenged in this way), but more often through misunderstanding or a lack of resources and expertise. Whatever the cause, it is clear that there is value in making sure that the key conditions of co-production are understood among people involved in services, policy and resarch.



Systemic and organisational barriers

Even where the intent, will and understanding of co-production was there, what co-production looks like in an "ideal" state came into conflict with the lived experience of co-producing in the real world. Many of the co-producers described the systemic barriers they had come up against while trying to create change through co-production.

- Working against systems is like "running through treacle" said one experienced coproduction facilitator.
- A team described having to have a "candid discussion" in their action group about the "organisational structure and its limitations" that shaped their project.
- "In a co-production project, by its nature, you can't exactly say what's going to happen at the end at the beginning. And in handing over that power to the people that you're working with, you come up against this tension between between wanting

to do what's right for them, and acting according to their needs and wishes and interests, and really listening and responding to that those voices; and the formal ethics procedures which the university would like you to take, which are baked into the university protocols."

- "Organisations who have what I call a co-production ceiling you can only go so far. Some systems are so rigid they are impossible to penetrate they're not flexible enough to change."
- Another storyteller described the rigidity involved in the university criteria for employing researchers and "what they consider to be research". They felt that "there are a lot of hurdles to overcome if co-produced research is to become common practice."
- Echoing this, one storyteller spoke about how "very often the outcomes are funding dependent and very much dictated by the funders."
- "Academic systems and structures are not set up for co-production, so in a lot of the projects that I work with where they're genuinely co-produced... I wanted to apply for funding collaboratively, but often when you're applying for funding it has to be through an academic institution so the power automatically goes to the academic even though the whole principle of co-production is about sharing power."
- Another person described how, because of university ethics procedures, the research
 question existed before the young people in their project came on board. Because this
 was not co-produced, they describe feeling a "niggle" about whether this is even a
 relevant question to young people. They would prefer to co-design the question and
 build the research project together to make sure it's as relevant as it can be.

These testimonies all show that co-production and the outcomes it can achieve are often hampered, sometimes severely, by the institutional constraints in which people are collectively operating. This can be frustrating at best, and at worst create harm for people with lived experience, some of whom described the experience of being retraumatised through telling their stories but not being given any power to create change. However, one speaker reflected that the process of mainstreaming co-production will take a long time, and was hopeful that they could see steps in the right direction: "I'll always take the tiny bit of co-production over no co-production because it's just setting an example of changing the tone changing the culture just gently, gently shifting things."

Still not a standard way of working

Part of the problem that co-producers are facing in these challenges is that co-production is still not a standard way of working. Our storytellers described the barriers to understanding, implementing and finding the time and space to carry out this type of work.

- "I think working in a different way is difficult because they have constraints themselves, and a lot of the time when I work with clinicians or researchers, they kind of do this separate to their work."
- Another storyteller pointed to the lack of co-production in wider society, whereby most things are still run with a "top-down hierarchical process", as a reason for poor take-up of newer, collaborative ways of working.
- There may also be fear about reputation or opportunities that will be open for work that is co-produced: "There is a lot of emphasis in research on traditional methods... it's harder for co-produced projects to get recognition and into prestigious journals."

These storytellers all identified that co-production is still a niche way of working, and this can present practical, organisational, and gatekeeping barriers which may put people off, or make the projects that do exist more difficult to run.

Resistance from staff, managers, academics

Systemic intractability can hamper co-production, and the people and individuals acting within those systems may also be institutionalised in ways that make them resistant to change and the relinquishing of control required for co-production.

- "Some will embrace it and some will be threatened by it."
- One storyteller felt that middle and senior managers resist co-production because they think people "will just sit and moan."
- One co-producer described how evaluation in one of the organisations they were working with had found that senior level staff "fail to put time into the relationship" with people who are not influential.
- "Some people get a lot of strength from being that professional and being the one in the room that it is in control."

- "I think it's always there at the start of any co-production project what is this? What's my role? Well, your role is the same as everybody else's - that's going to take a bit of a shift in mindset."
- Researchers "can get caught up in their academic background."

As the quotations demonstrate, most of these reflections were offered with empathy for the individuals caught up in systems, but there was consensus that changes to the behaviour of professionals were necessary in order for co-production to work. As the storytellers have demonstrated though, these types of shift in attitude and practice can also be brought about through the process of co-production itself.

Power of the system to corrupt

However, one co-producer also cautioned that developing the links to power-holding organisations and services can subsume co-producers into the system. There is a "danger that you can become 'one of them' rather than 'one of us'", they reflected.

Products or findings of co-production not embraced by professionals

Another, related problem that we heard repeatedly from storytellers was that the outputs of their co-production processes were not always respected, well-received or used by professionals in the ways that they were intended.

- One storyteller described their disappointment with the take up that the tool created by their project had had. "It's very innovative, user-friendly," they said but it has "not been embedded or introduced to patients". They felt that this was not a deliberate action but that it came up against the pressures that NHS health workforce are under, highlighting the need for all parts of an organisation to be onboard for a coproduction project to be successful.
- Another storyteller described how their research is designed to be practical the
 development of a new service but that it will be up to the organisation to take the
 service and implement it. This decision is out of their hands and they described the
 difficulty, pain and frustration in having to be upfront with their co-producers that their
 research might just stay theoretical.

 "Whilst co-production clearly has an impact on individuals representing organisations in a co-production group, they don't always have the mandate to make changes even if they can see the value."

The evidence from these stories indicates the importance of people within power-holding and practical roles from organisations and institutions getting involved in the co-production process, or at least being committed to implementing and enabling the changes that are the desired results. Without this, co-production can get stuck at the point of having theories and suggestions for change, but only able to make limited actions and therefore not have as great an impact in the "real world".

Time

An underlying theme running throughout many of the stories was that co-production takes time - often more time than other methods and sometimes more time than is available within the institutional and systemic structures in which people are trying to create change.

- The "amount of time needed is a concern" said one co-producer, who felt that they didn't give enough of their time over to it.
- Co-production is "time consuming," another research team reflected, saying they "spend a lot of time on building relationships."
- "I wouldn't say it's an instant fix, because it takes time. It can be hard work."

Some co-producers reflected on the reasons why they felt under such time pressure, and thought about causes and solutions.

- One co-producer pointed out that the devolved legislation they were working under in Wales says that public bodies need to do co-production but they are not given the time. They felt there was an ongoing need to "shift the culture to get it right."
- Another storyteller said that in co-production "things take more time but that can be okay". They argued that they would "rather spend time on a job well done" but acknowledged that "organisations can have different pressures."
- Another storyteller felt a big problem hindering co-production was "short-term funding" schemes which "impose a timeframe". They described how this was restricting how much feedback patients could give into the project, and made it less likely that their recommendations could be implemented.

• Another storyteller echoed similar sentiments, arguing that commissioning cycles need to run in ways that account for the time needed for relationship-building.

Inadequate time to explore, build relationships and trust, work in a collaborative way, and engage people in all stages of the process makes co-production less effective and more difficult. Time is one of the biggest constraints on co-production, and adequate time would be one of the most important conditions for co-production to flourish.

Cost

A related point that some storytellers made is that co-production costs money - it needs to be adequately resourced.

- One storyteller describes feeling like charities had no interest in supporting their research, because there's no money attached to it. They also noticed a "lack of avenues to take funded research from the community". This places a barrier on co-production projects that are truly grassroots and bottom-up, as money is concentrated and held further up the chain of power.
- "Co-production often seems to be an add-on, not an essential part of some projects". They criticise organisations that "do the plan and then realise that they need lived experience to get the funding", as this often results in quite superficial treatment of those contributions reflected one co-producer.
- This person was also critical of the lack of payment for people with lived experience working on co-production: "With all the will in the world that this isn't happening even though some researchers are trying, it feels very tokenistic". They describe often having to really persist in order to secure payment for people with lived experience. Seeing what people with lived experience bring to co-production as work is a crucial part of levelling the power differentials, and payment is an important factor in this (see the Conditions of Co-Production section for more detail).

Difficult to prove impact

Perhaps one of the trickiest aspects of co-production, and one that is certainly linked to the financial side described above, is how difficult it can be to prove the impact that co-production has made.

- "It's very difficult to assign success factors, because it's about feeling"
- "The difficulty is that it's hard to quantify aspects of co-production," said one storyteller, pointing to things like the value of networks. In their experience, "most organisations want more tangibles or quicker financial gains."
- "The thing that struck home to me was how complex evaluation of co-production and research can be - because co-production in itself is a very multi-dimensional and very complex thing."
- "It's too early to tell what the impact of the research will be or whether co-production will have impacted it," reflected another storyteller.

In part, these ideas mirror the rationale for this project - that it is difficult to measure all of the impacts, values and changes brought about by co-production. There could be an argument for further research, skills sharing and development of resources and training around different evaluation methods that might be suitable for co-production - but any one method in isolation is unlikely to catch them all, and the most suitable tools are likely to be a mix of quantitative and qualitative methods. Implementing an evaluation strategy effectively is likely to take extra time and money, which may put pressure on the change or action that can be created.

Complex and messy

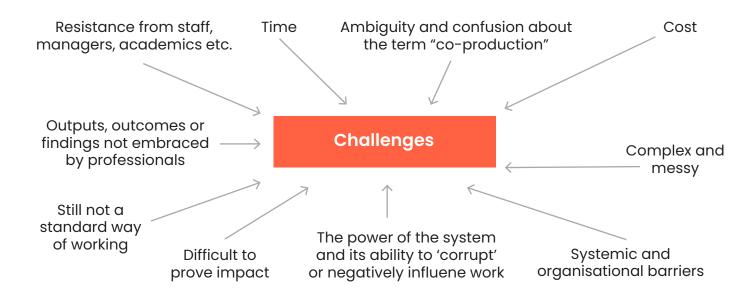
Another challenge described by the people who shared their co-production stories with us was the confusion, complexity and "of the process. The creation of a comfortable, power-sharing space to solve problems collaboratively can be a positive environment for some, but create anxieties for others (or people may feel both emotions at different stages of the project).

- "Some people like order and structure," noted one storyteller, but in co-production "you have to sit with mess for a while".
- "It can be quite intimidating. In fact the opposite of, if you go to a formal meeting at work, that's intimidating to me. Well, it can be equally intimidating to be part of a coproduction, because you've got no idea what this is about."
- "Co-production is hard work...it's not an easy fix."

The removal of structure, clearly defined roles, pre-set agendas is what allows co-production to strive for meaningful, people-driven change. However, it is clear

that this can be a challenging environment for some people and they will need to be supported through that. Peers or colleagues looking in from outside might also be intimidated by what they see as "messy" ways of working, so may be put off from taking up the methods themselves.

Overally, there are numerous challenges to co-production, and most of our storytellers did not shy away from confronting these head on. However, with a few exceptions, most people felt that the value that they saw from co-production was worth facing these challenges: "It does have its challenges, but the benefits are more important than the barriers!" one co-producer enthused.





Value for all - individuals, organisation and society

In this section, we explore the (sometimes overlapping) benefits that co-production has provided to people, the systems and organisations in which they live and work, and to society more generally.

Impacts on individuals

Developing skills and knowledge

Storytellers listed a huge range of skills that they'd learnt or saw others develop during the co-production process: clinical skills, research skills like interviewing, presentation skills, photography, video, facilitation, leadership, and people skills.

- "A student whose attendance to lessons was limited...chose to be involved in filming... started to make decisions...even to the point where, in spite of his difficulty in spoken communication, he was then willing to go on the camera and speak and allow us to put that onto the website, which was just an amazing thing for him."
- Another co-producer explained how their group undertakes skills audits with experts by experience coming on board and works with them to develop in areas where they want support.
- "I've learnt so much through co-production work", shared one storyteller, who also discussed how co-production had inspired them to do research on topics like colours, and disability, which they had learnt about through working as a group with others with different knowledge and skills.
- Another powerful story described how the language and behaviour of a set of school children changed after their co-production experience: "even in their relationships with each other, in other aspects of the school day or school matters has really changed. Because you can hear them use the language of "actually, I think there's...", "but maybe it's because of", "that might have caused this", or "it's okay to change your mind about this" and just that whole ethos of actually, my decision matters and I'm going to be listened to."

Developing emotionally and growing in confidence

A huge number of storytellers spoke of how they felt their own confidence grow throughout the co-production process, or how they had witnessed others develop in confidence.

- One storyteller saw the "self-esteem and confidence" of a group of residents grow as they gained awareness of their abilities.
- "It's definitely made me a lot more confident as a person, it's made me less undervalue my voice and given me more of a motive to use that voice to help others."
- Another contributor described how co-production had given them a lot of confidence to use their own skills and knowledge to make a difference locally, as well as increased confidence in their lived experience. They told us they could use this confidence "on a daily basis" and it was "transferable to all areas of my life and work".
- "I personally think it's opened up my world to things that I wouldn't have touched two years ago. It's made me more of a confident person, I'm more outgoing, I blog post more. It stirs things up. It's made me more of a passionate person, I mean in the way that I'm passionate about something I believe in."
- In another co-production project, the storyteller described how one of their peers, a person with hearing loss, gained confidence and took a new role as the group's photographer.
- This was true of professionals and researchers as well as people with lived experience: "The key thing that I've had from co-production is that it's really improved my research, not just on the projects that I've co-produced but generally changed my outlook on the way that I do research. It's given me more confidence to take risks."

Career and Employment

Storytellers described how getting involved in co-production brought opportunities for further employment and learning for participants, particularly people with lived experience.

• People gained new contacts/networks, references, things to put on their CV, which one person described as "opening doors".

- People described how being involved in co-production had inspired or led them to enter higher education or gain employment, e.g. as researchers or public advisors.
- People also gained career support. For example, one storyteller described how they were given a mentor to support them in their role as a public advisor at a university.
- Co-production also offered opportunities for professionals to develop or change the direction of their career:
 - "having to change my way of thinking, having control, sharing work, encouraging others to be involved, was an important lesson and made me think of a career change, so now I am employed as a user-researcher."
 - "Being recognised with an OBE, not only for me, it's for all the women that we have tried to make a difference for."
- Many described seeking other co-production-related jobs after experiencing what it is like to work in a co-productive way. Some storytellers told us that they found it hard to go back to other ways of working.
 - One storyteller described how they have chosen to continue initiating coproduction projects instead of seeking more financially stable work.
 - "You can't walk away once you've started doing it."
 - "I can't seem to find the other ways of working just as stimulating, just as interesting, just as progressive, as co-production."
 - "I can't see another way I would ever want to do research now...It wouldn't feel like I was doing a project justice."
- People brought the things they had learnt from co-production into other aspects of their professional lives. For example, one person told us that they had learnt about values-based facilitation and now takes this into their teaching.

Emotional value - satisfaction and feeling of making a difference

People described a deep emotional value in co-production. Working in a genuinely co-productive way has positive impacts on an individual's sense of wellbeing, purpose and self.

- One storyteller described the sense of satisfaction in "knowing that you have made a difference to people and the life of people through co-production."
- "I found it fantastic, it gave me a purpose, I felt really motivated...What people overlook is the incredible benefit to the individual involved in co-production...It gave me a purpose, it gave me confidence, it allowed me to network."
- "It gave me back my life."
- "I'm really proud to say that I am a little part of making such a big change locally, standing proud of my contribution. I find it individually really rewarding, sharing my experience which means the system has changed."
- "Co-production personally has changed my life. It's given me a lot of purpose, a lot of grounding and acceptance. And to see what it does for the people around as well, it's really really powerful."
- "The sense of making a difference and what this does to an individual's own emotional well-being. It makes you feel good, and you are contributing to the lives of others and making a difference."
- "It's quite positive and rewarding in yourself, because you feel like you've got something to offer."

People feel good about themselves when they get to use their expertise. A few coproducers even described the process as being "like therapy" - to them it feels good to work with others and make a difference.

Friendship, connection and networking

People described the friendship and network connections that they had developed through their co-production experiences. For some, this was the first time they had felt connected to others in this way.

- "I came from being a person who never really interacted with society. I was quite an isolated individual, very muted and not really interacting at all. I had never done any online talks, and this gave me an opportunity to be able to go for the first time ever and speak with other people."
- Another co-production team described their joy at seeing young people connecting with people they wouldn't normally meet.

 Another researcher working with young people and teachers expressed a similar sentiment: "I also feel really proud of the young people and the relationship we have, building that makes me feel warm." They described how doing a PhD is usually a solitary activity, but they had built "these really strong connections with people that I just never would have come into contact with."

Feeling of having a voice

Being listened to and heard was also a major personal benefit to many of the storytellers, particularly those with lived experience and from marginalised groups.

- People are "able to contribute and be listened to."
- "The social work group finds it cathartic to be involved in. It's healing for them to be heard in a way that they haven't been heard during their social work journey."
- "My whole power and acceptance of my background, what happened, even working through my trauma, came from co-production, the power that is given to me, the power that I'm able to give to other people through creating a space where they can co-produce as well."
- "Patients who have a say in their healthcare feel better and respond better to treatment."
- These benefits were felt by professional staff too: "It made me feel valued as an individual, not just a staff member." They described this as their favourite bit of work because it was "professionally-personal".

Practical benefits and the benefits of co-production outcomes

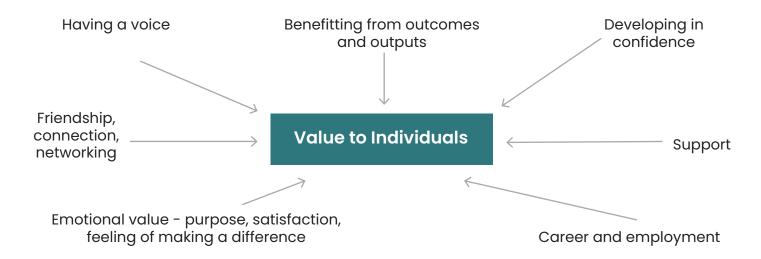
- Of course, the outputs and outcomes of co-production were also described as providing personal benefits to individuals both those involved directly, and those who are the target group for the services, policies, products or research developed.
- One storyteller described the impact of the access to tablet and internet that they had worked to achieve for forensic mental health patients: "it's actually helped them, it's broadened their lives, it's helped them to access things about their communities."

• Another example already discussed - the cycling lessons for women of South Asian origin - also fits into this category of people benefitting from co-produced outputs.

Support

Some of the co-production projects that had the most impact on individuals were ones in which support for the people involved had been well-thought through. Getting involved in co-production often enabled people to access information, guidance, opportunities or community support that they might not otherwise have been able to get. This has a positive impact on inclusion.

The stories show that co-production can have powerful impacts on individuals, creating changes in their career trajectory, self-belief and relationships. The feeling of power and agency can be unleashed in people with lived experience and professionals alike, giving them the confidence to speak up and create positive change.



Impacts on organisations

Impacts on organisations

Co-production and the insights it generates can help organisations make decisions with the right information, so that they can address the needs of the people they are trying to support or the things they are trying to change, with the most effective use of resources.

- "We might be coming at something with completely the right intentions, but unless we're opening up and having discussions with people who are going to be impacted by what we're doing, then we don't know how that's going to be received, we don't know that we're taking all the relevant information into account. In terms of effectiveness of running an organisation, I think co-production is huge."
- "[Co-production] helps organisations by informing the decision making, and how to involve people who are impacted by it. It improves the quality of the decisions the organisation makes."
- One person described how the co-production work they'd been involved with had helped "ensure that the local commissioners meet the needs for individuals" and that support "targeted the needs of community members."
- "Who are the best people to improve services? People that use their services."
- "As a result of co-producing, the organisation is not only enabled to engage with the community that they want to serve - they want to provide services to individuals which meet their needs - but it also helps with community cohesion." This helps the organisation as well as the people who need the support.
- Another story describes how co-production was instrumental in "getting the right service, at the right time at the time when it was needed". The input that they got from everybody involved was crucial: "If you design a service without service users, you don't know if that's the service that's needed, or if you are marketing it in the right way, using language that people understand."

Less waste - saves money

Storytellers pointed out that although co-production is sometimes seen as more costly than other ways of working (because of the amount of time involved), because the outputs have been co-designed, they are more fit-for-purpose and therefore can save money in the long term.

- "The impact is that if we don't do it...we're potentially wasting scarce public money coming up with the wrong solutions for people. If you can quantify that in pounds, shillings and pence, I suspect there's huge public service savings to be made by co-production."
- Co-production helps organisations to "get it right first time", so that "helps with the finances."

- Co-production "removes wastage, because from the start you are involving people and asking them what would work and what wouldn't work."
- Co-production results in "services that meet the needs of the people that they are designed for, less waste if you want to talk pounds and pence."

Producing better outcomes using shared knowledge and experiences

The conversations and insights that come about through co-production help organisations find ways forward and support their practice and decisions.

- Collective agreements about the way forward can be produced, such as in one project where the team described how they "took time to have conversations about the agreed priority of digital."
- Conversations were "eye-opening for professionals" when they valued the assets of people with lived experience.
- This bringing of "varied views together to problem solve, drive adaptability, learn from each other" is a key benefit of co-production to organisations trying to tackle issues in society.

Inclusion: "Nothing about us without us"?

"Nothing about us without us" - a slogan associated with the disability movement - was repeatedly invoked by storytellers in the project. Co-production is a way of working that allows organisations to be true to the idea that no decisions should be made without the direct involvement of those most affected by them.

- "Individuals are at the heart of everything we do, to coin a phrase: 'nothing about us without us'. Absolutely, people are at the heart of the decision-making process."
- As well as allowing organisations to fulfil an important criteria of social justice and inclusion, this also makes their provision and working cultures better for those with lived experience: "Somewhere in the co-production experience, people have thought about them because there is lived experience in the team."
- Organisations can also recruit people with lived experience onto their teams through co-production, therefore expanding the experience, knowledge and skills of their staff.

Changing the way things are done

"The value of co-production is the ability to create change," one storyteller said, expanding to discuss how co-production can "provide the evidence and the will in the community, and the mediums to create that change." One of the biggest values of co-production to organisations is its ability to activate change.

- Storytellers described a whole host of tangible outputs and concrete changes that had been co-produced, including, but not limited to:
 - Diagnosis packs, conversation tools, information packs, online content about different health conditions including eating disorders, pain;
 - Co-produced hospitals, link clinics and inclusion projects, such as a project offering hearing in an empty unit in Dalston Shopping Centre;
 - Digital tools such as video games, virtual school tours and a 3D autism simulation;
 - Papers published in peer reviewed journals;
 - Contributions to conferences/seminars/workshops online and in person
 - Education and training e.g. for social workers, cycle training for South Asian
 Women
 - Customer promises and evaluation process for housing association
- However, the value of co-production was not limited to the outputs themselves, but often in the wider changes that the process brought about.
- One co-producer discussed how co-production "stops some of the narrow and rigid thinking in organisations, adding that "I have so much more respect for the professionals I work with once they've laid the cards down and said, 'let's put that title here...I respect your view'."

People with lived experience being part of that change

Taking a co-productive approach made organisations put people with lived experience in the driving seat of change.

- "Too often people with lived experience are asked to tell their story and then aren't involved in follow up, [so they] don't know if change is ever made. Whereas in coproduction they get to be part of creating that change. Not just sharing your story and hoping for the best."
- "Without co-production," one storyteller reflected, professionals "can talk about people as if they don't exist". They argued that co-production improves organisations because it forces staff and managers to "confront and change and adjust." They describe how when they were sat in a board meeting as a person with lived experience, their very presence made the panel members realise that they were speaking about people in a way that wasn't appropriate. This awareness prompted by working with people rather than working for them can change behaviour and institutional cultures and attitudes for the better.

Putting recommendations or learning into practice

There was evidence in the stories of participating in co-production having led to changed practice and behaviour of staff or other individuals in organisations in response to what they've learnt or experienced.

- For example, one storyteller described a shift in language that had come about through co-production, where "doctors' reports will always include strength-based discussions in consultations".
- Staff in schools reported changes in their behaviour, and one story demonstrated the impact that co-production has had on social work training in one local authority:
 - "And we've got someone who has had a huge number of social workers in her life, and she says that she can tell categorically where a social worker has qualified from...what she's telling us anecdotally is that she can tell if they've graduated from the University of Suffolk by the way they stand in her kitchen, by the way they approach a relationship, by the way they interact with her and her son, and that's quite incredible."
- Co-production also harnessed organisations with innovative tools and new ways of doing things:
 - The creation of new emojis with young people with additional support needs who experience emotions differently, which according to the storyteller offered "so much more colour, insight, and imagination" than the existing tools.

• A project looking at hearing loss took their exhibition to Dalston Shopping Centre, and offered hearing checks to passers-by set in an empty shop unit.

Putting recommendations or learning into practice

Making sure things can continue once the project or funding has ended In the stories we gathered, there was also evidence that co-production was helping organisations think in a more long-term way.

- One co-production facilitator explained how they tried to build this sustainability and longevity into the process: "What we tried to do is to build in sustainability so that they could keep having those kinds of discussions, we built a toolkit with them to give them ideas of how to support those discussions to continue without us, and we tried to put a volunteer in place to continue once we withdrew."
- Another person spoke about how organisations could use "co-production as a starting point for something, for potential to develop".
- One storyteller described their belief that "the changes that come from co- production will continue to change and will help people that come along after us."

Embedding co-production as a standard way of working - for the long-term

As above, it is not just discrete co-production projects that offer the potential for long-term change. Rather, many of the stories that were shared with us showed how organisations were deliberately changing to embed co-production itself within their everyday practices.

- One co-production team discussed how they were looking into the potential for the entire development of their school curriculum to be co-designed and user-focused.
- Another example discussed with us was a co-produced link maternity services clinic, which is still running today after being set up in 1998 - and the community are still able to influence it.
- As one person who had had a positive experience of co-producing reflected: "Moving forward, I don't think that there would ever be a decision that we've made in school

not ... through co-production... I think it is really the way forwards to doing everything with children, particularly in school communities, with parents. I can't imagine that there's a more engaging and respectful way to lead change more than co-production."

Organising services and decision-making around co-production principles

In order to achieve this model for co-producing change in the long-term, organisations have had to change their systems and structures to better support the ways of working that co-production requires.

- "Co-production should be the starting point, not an add on."
- In our stories, we heard examples of services, research and policy starting to be co-designed, planned, commissioned, and evaluated. One storyteller described the development of a new kind of commissioning structure which "challenged the traditional NHS way of doing things which is top down, and to think about something that is grassroots and bottom-up."

As well as (or perhaps even before) these practical or structural changes, co-production was also shown to bring about changes in culture that improved organisations.

- "Co-production can create a culture within organisations, it also changes the way organisations work and see the involvement of people's lived experiences. It changes an organisation and staff thinking. It enables organisations to produce the best work as this will be centred around the living experiences of those that may have been beneficiaries of the offer the particular organisation is delivering...Co-production has a snowball effect on people in organisations and they see the benefits of co-production and then want to start doing it themselves. Even if they don't really know what it's all about!"
- "The beauty of co-production is it could change the whole culture of an organisation, not just make services and provision better, if we understood how important it is for us to be is to be open."
- "I actually think that the people who are a bit more sceptical are actually the biggest converts in a way. I've worked with some really senior people and one guy said to me 'I can't believe we haven't done this before'."

The stories show that co-production can bring powerful changes to the ethos, community and working practices of an organisation, while also enabling them to achieve better outcomes and make decisions that are based on evidence and centred on the people involved - whether that's staff, students, patients, residents or other stakeholders.



Impacts on society

Many of our participants had stories to tell of how the direct and "ripple" effects of co-production had created change in wider society. In particular, many of these linked to the idea of "social capital" - where the community networks and relationships built between individuals bring knock-on benefits:

"Communities who have social capital - can engage with each other, services, councils etc enjoy better health and outcomes, and are better funded. Co-production is a vehicle to produce social capital - harness people to be "bothered".

A fairer society

Co-production becoming a more mainstream way of doing things had the potential to create a fairer society with greater involvement from citizens in decisions.

- The overarching approach of co-production means it's "fairer for all" and "better decisions are made for everyone," said one storyteller.
- Another spoke about the way in which co-production allowed people to access what they called "meaningful citizenship". They felt that co-production "enables everyone to feel that they have ownership and stake and investment in decisions that need to be made, services that need to be designed."
- Co-production can create a "more open society", another storyteller argued, through "building bridges and learn to work things out together."

Addressing stigma, discrimination, inequality

Earlier in this report, we described the centrality of diversity and inclusion to many of our storytellers' conceptions of co-production. The value of this to wider society is that co-production can be a vehicle to address inequality. By placing people from different backgrounds together and giving voice and power to marginalised groups, the storytellers often discussed how they had seen co-production "break down barriers of stigma and discrimination."

- One storyteller working with people with learning disabilities described "the impact on society is that no one is left behind and a more inclusive society."
- "It demonstrates to society the importance of empowering women and girls."
- "Challenging stigma and raising awareness more people talking about it, investing in it, willing to make change," said one storyteller of their work around the subject of eating disorders.
- Co-production is important for "equality, diversity and inclusion", one co-producer stated, because "it values and validates people's experiences."
- One research team described how they had used "creative participatory methods" to help adults see things through the eyes of young people. Through this they had been able to "[raise] awareness of young people's skills and abilities" and offer the "right support" to young people, recognising them as "citizens today, not the citizens of the future."
- Another example of co-production bringing about a shift in attitudes towards
 a disadvantaged group is described in one story where the person describes a
 community where some tenants were living with dementia. Initially people were afraid,
 but after training sessions with the wider community, including local shopkeepers and
 taxi services, people were educated on dementia; "Fear and hostilities diminished and
 it became a dementia friendly neighbourhood."
- As one person with lived experience of adoption and the social work system noted, "most stories are lifelong, so if there are positive changes for a person the ripple effects of that can extend for a long time."

Employment for disadvantaged groups

One way in which co-production contributes to addressing inequality and discrimination is through opening up access to employment for marginalised groups. These seldomheard voices are then represented among professional teams and within organisations, offering the potential for further change.

- One storyteller described how the project they had been working on offers opportunity for employment: "that's where it does start to impact on society because forensic mental health is not well represented in the workplace. It's not an easy barrier to overcome when going into the workplace and society. Learning skills which require removing your own self-stigma...being able to harness that expertise is really exciting and the fact that we are building skills and confidence there."
- Another co-production team described how the opportunities for people with learning disabilities and autism in their project had led to a "change in attitudes."
- One storyteller celebrated the fact that, after their project had ended, two of the
 young people with learning disabilities went on to other research jobs. But they also
 acknowledged that there was still more progress that needed to be made: "because
 there are generally severe barriers to the job market for people with learning
 disabilities, some of the other researchers had to go back to volunteering work which
 was frustrating."

Awareness-raising

Co-production gets people talking about social issues which are sometimes hidden, stigmatised or overlooked. This can ripple out through communities, or the new outputs produced through co-production can spark conversations in new areas. Through these channels, storytellers described co-production as a way to raise awareness.

- "We are talking about eating disorders more, because there is that passion there from everyone," one co-producer reflected, "more people are talking about it, investing in it, willing to make change."
- Another discussed how their co-production project had got the issue of arthritis "on the political agenda" by bringing together "health professionals, MPs, and people with arthritis to try and raise the profile of the issue."

Taking power to grassroots

When people see co-production in action, they recognise the power of people acting collectively, which in turn may make them more likely to take community-organised action in the future.

- "People are more aware of their rights," reflected one storyteller.
- "When someone is valued, they start realising things, which is the gateway to opportunities like education."
- However, co-producers also felt there was the potential to do more in this area. One person described how they want to "change research practices so that they're not created in a vacuum but reflect what the community would like to see".

A model for others to follow

- Co-producers were keen to spread the potential and findings of the work they'd done by offering it as a model for others to follow. This opportunity for replication holds within it the potential for the benefits of co-production to spread further through society and be adapted for use in different geographical areas or by different groups of people beyond those immediately involved in the initial work.
- One co-production team felt that their work shows the potential for the development of school curriculum to be co-designed and user-focused. In this example, both the approach, design and behaviour used can be copied and taken up by other schools.
- Storytellers also offered examples of where people who have experienced coproduction spread the benefits and learning to others: "this is making a big difference and for me in my own practise in the classroom" but also "makes a difference for me as the curriculum lead influencing other members of staff."
- "More people are responding to the research ultimately meaning that people are more likely to engage in this research, this has an impact on society and uptake of research."
- Another researcher hoped that if they are able to co-design a hybrid model for the service through co-production then this could be a model for other services.

Sharing learning more widely

One of the simplest ways in which co-production has positive value for wider society is that projects can share their learning with others. The people we spoke to were able to give concrete examples of this happening in practice.

- One storyteller co-producing around the issue of hearing loss described the various ways in which the project had reached out to the wider community and produced shareable assets to distribute the learning: a YouTube video created during lockdown; newspaper articles in East End press and radio appearances to raise awareness; an in-person exhibition in a shopping centre; and an app under development to mirror the experience of the exhibition. They also had evidence of the impact of this sharing, their evaluation found that a "high proportion of visitors to the exhibition declared an intent to seek help and knew the route to seeking help via the NHS."
- Another co-producer described how they had filmed the discussion at their exhibition and they are going to share it online so that other people can benefit from the learning.

Positive impacts on wellbeing

- Many co-producers referenced in their stories the benefits that co-production brought to well-being, not just of individuals but how these changes added up to an overall healthier and happier society. "Better overall well-being is difficult to quantify," one co-producer acknowledged, but like many of the storytellers, they felt they had experienced this among the people they were working with in their local area.
- "It shows the society, shows lived experience and how involving individuals is good for health and well-being and has such an impact locally and nationally."
- Another storyteller talked through the way in which co-production had led to a better way to improve outcomes around sensitive topics like smoking during pregnancy or infant feeding. In these areas, there are health implications of decisions and behaviour. The person described how the temptation is for "health professionals to want to educate people to make positive changes," but entering a conversation from that position can feel patronising and intimidating to people. If people feel like they are being talked down to, this can actually have quite a negative impact, the storyteller said. "The challenge is to have conversations...how can we have open and honest conversations that aren't about telling people how, but are about curiosity and not trying to fix people". Co-production led to a change in approach which then has benefits for parents, babies, and the healthcare service in the long term.
- Co-production's flexible and participant-led approach meant that wellbeing often became a focus of projects that were not originally set up with this aim in mind. For example, in one story, people were keen to learn more about mental health and more trainings were introduced as a result.

Another storyteller described their belief that the library of lived experiences will
definitely support the public, adding that their own experience of pre- and post-natal
depression would have benefited from a living book or similar ability to connect with
someone who'd experienced the same thing.

Services that better meet needs

One huge benefit of co-production mentioned by many of the storytellers is the creation of services that better meet the needs of the people who use them. This has value to organisations, as discussed above, but also to wider society as social issues are better addressed and people are better supported.

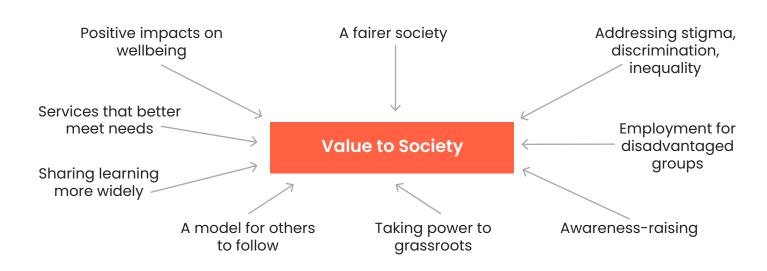
- One co-producer described how involving young people in their project had enabled them to have a wider impact on the community. They spoke to police and crime commissioners in Gwent about when bullying turns to hate crime, and what can be done about it in community settings. The commissioners' office have changed their reporting mechanisms as a result.
- Another storyteller working for a local authority shared how "The value for people is getting the right support, for example, housing pods that meet the needs of the homeless community, ensuring that there is an appropriate offer for groups of people that the system may find it challenging to support." Co-production helps ensure "that the local commissioners meet the needs of individuals."
- This also has financial benefits to the public purse, noted one contributor, because "funds can be used and targeted effectively". This helps local authorities, health services, universities and other providers make the most of limited budgets.

Co-production is becoming a more normal and mainstream way to do things

One final point that was raised in relation to the value of co-production to society was that, as more people are getting involved and taking up the method and its ethos, it is gaining in popularity and becoming a more mainstream way to do things. This in itself brings the potential for all the benefits described above to be multiplied and have a bigger impact on more people.

- One storyteller noted that things have changed over time and that, in comparison to other countries, the UK is at a more mature stage with co-production work.
- Conversely, the products of UK co-production can also be spread for global benefit: "Some of the work that has been done with the patient and public involvement group has gone international."
- One storyteller from a local authority describes a new "multi-million-pound contract being commissioned, that has clauses about what people say and need."

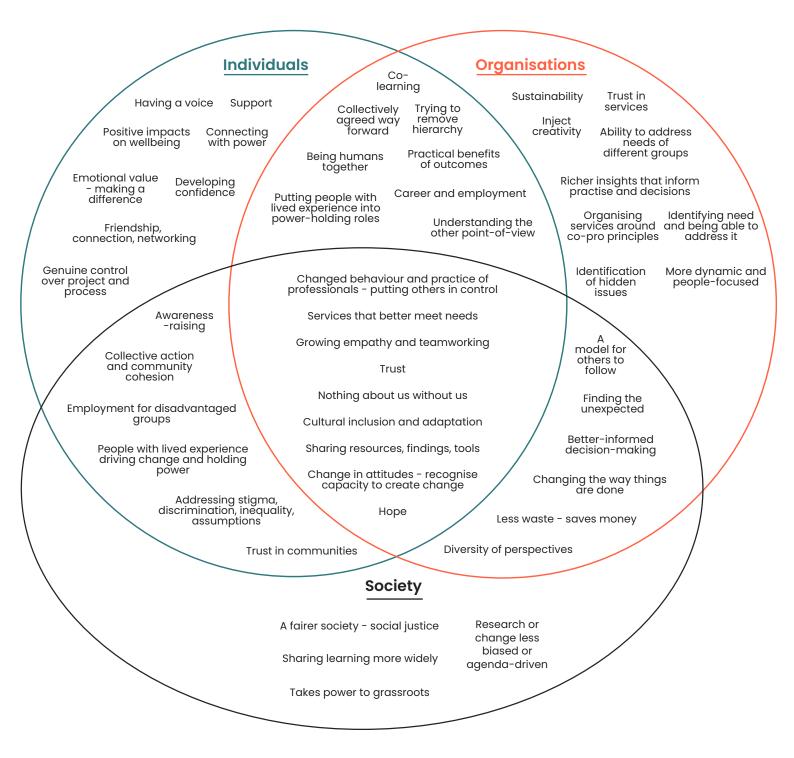
No co-production project exists in a sealed bubble, and so each attempt at coproduction can have positive ripples that touch wider society to create changes. Whether it's sharing learning; offering new research, tools or services; or activating communities, co-production's effects can reach widely.





The Value of Co-Production:

Individuals, Organisations, Society

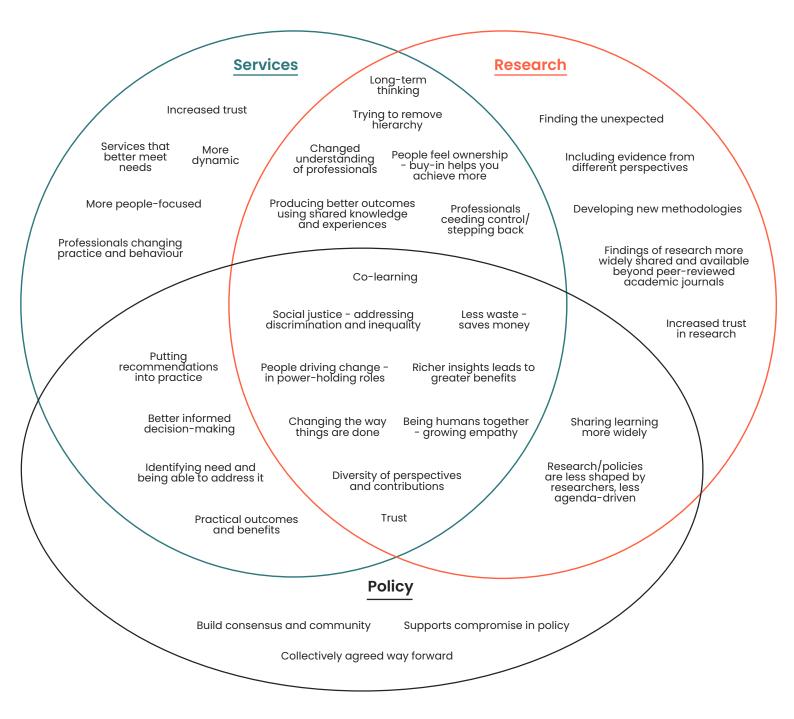


Impacts by sector: research, policy, services

This section organises the values identified in the previous sections in terms of their benefits to the three primary areas in which co-production has been mobilised as a method of working: research, policy, and services. Participants in our workshops discovered that these overlapped greatly so we have chosen to display the findings here as a diagram to display these interconnections.

The Value of Co-Production:

Research, Policy, Services



The conditions of co-production

Through the stories, many people brought up the issue of "buy in" to co-production and discussed the context and conditions in which they think co-production works best. We also explored this question, using extracts from the stories as prompts for a more indepth discussion, in participatory workshops in-person and online. In these sessions, we asked people to think about the "ingredients" of co-production. In combining the findings from these methods, a set of ideal conditions for co-production has started to emerge. This area needs more research, but this section of our report outlines some of the most common answers and starts to provide an idea of the building blocks needed to make co-production happen. Here, we outline the key conditions that emerged from the research, backed up with some supporting quotes from the people who contributed their stories and ideas.

Intent

Co-production should be undertaken for the right reasons. This means not as a box-ticking exercise or to validate pre-approved plans.

• "Do it for the right reasons...do it because you're curious and you're interested and you want to hear from people that you're researching."



Embed from beginning

Co-production needs to be a part of the project and its intentions from the very beginning.

- "Embed co-production from the very beginning."
- "Write into tenders and bids, to make sure it happens from the very beginning."
- "Co-produce from the start, even though that's scary."
- "Involve people as early as possible."
- "When I've started with programmes where people have been involved really early on, and there's not a lot of preconceptions about the end result or the outcome, so there is an open curious mindset. Beginning with where people who are involved are genuinely saying, 'we need some help with answering this problem'."
- Aim for co-production as "an everyday practice" like mindfulness.

Flexibility/openness to change

Co-production projects are unpredictable, outcomes are undetermined, and work with real people as human beings interacting together. Therefore, co-production requires flexible conditions. Things such as timescale and budget might change, and the outcomes or even the topics might end up being different to what was originally envisaged.

- "Flexibility to change original proposal."
- "Ability to push back against deadlines."
- "Not a linear journey."

Open culture and attitude - don't have the answers

Co-production works best when there are no pre-set answers or agenda. A culture of openness to ideas and suggestions helps projects thrive.

- "Create spaces for innovation, prototyping things, you know listening and having the humility that we don't have to have all the answers, let's figure it out together."
- "Start with a blank sheet of paper."
- "Be open people are on that journey with you."
- "Be positive!"
- Things that don't work very well are things where there is always that agenda: we're not telling people the 100% truth about this, this is what we've got in mind and we want to steer it this way. That doesn't work for me, and it's not true co-production, that is a little bit sneaky and I don't really like it. What works well is saying, "look, cards on the table, this is what we can offer, this is what we're doing, and can you help us with this?". And help us, I'm talking about that on the same level as everyone around the table. Because co-production isn't only about the user-carer or consumer or customer, or whatever you want to call us, it's about staff as well."
- "Being open minded and ready to learn from others."

Honesty

Co-production works best when people communicate honestly. That involves creating a space where people feel free to openly express themselves, and being upfront about any parameters or restrictions.

 "Honesty about not being able to fix everything, going into the conversation with an open mind."

Share power and remove hierarchy

Co-production involves trying to share power. This might mean professionals stepping back and letting go of control, and people with lived experience stepping up into positions of influence. In order to do this, co-producers need to take steps to remove markers of hierarchy.

• "Both medicine and academia are hierarchical institutions - getting rid of titles and qualifications is less alienating."

Live with discomfort

Co-production will present moments where people feel challenged and out of their comfort zone. This is necessary for change and understanding to develop.

 "Be prepared to be uncomfortable - it is necessary to let go and you have to trust the process."

Facilitate well or get a trained facilitator

To support power-sharing, an open culture and to make everyone feel safe, co-production needs to be well-facilitated. Someone external or independent can help to work through conflicts and support the process. If someone internal is facilitating, it's a good idea to get training.

- "We've spent years honing this skill how to facilitate co-production and we're learning something new every single day...if you're not sure, get a facilitator in who can help you do it well."
- Importance of facilitator: "transforming a room full of strangers into a room of people that were comfortable with each other."
- "Get training and advice from people who've done it before."
- One storyteller said the most useful thing was having someone experienced in coproduction who actually showed them how to do it - modelling the activities to do with children.
- "Need skilled facilitators power dynamics need to be understood and acknowledged."
- "Have training on co-production."

Human

Co-production depends on strong, supportive relationships being built between fellow humans.

- "Bring kindness this is about building relationships."
- "Good work comes from strong social ties when you work together as humans, rather than resources, when you give power to people."
- "Treat people like people."

Be open to learning from mistakes/ongoing evaluation

The best co-production projects are based on ongoing learning and evaluations. Mistakes are inevitable and valuable, because you can learn from them. The co-production process itself has to be open to change.

- Things will happen that are "not planned...make mistakes and learn from it."
- "Take time to explore the things we need to do...what's working well..space to learn more."
- One project described how obtaining feedback constantly ensured that change and learning was built in. For example, moving to small groups meeting face-to-face for reflection on the request of the young people taking part.
- "We changed what we did based on the earlier project we developed different options with the help of young people."
- Another storyteller shared how they changed their approach for a co-production project working with older people. Initially "it was more consultation in a way ... we were trying to reset, we were trying to co-produce what would then happen so this became really powerful... because what they said was the activities what we had done were fun but maybe a bit patronising cos they're not kids, so why do they just want to do arts and crafts?...We listened and had to let go of prior ideas."

Listen to and value each other

Co-production requires people to listen to others and care about their point-of-view. A good co-producer is careful to value people's time and contributions.

"Valued as a person. You are listened to."

- "Some of the most powerful moments that I've ever remembered, whether I was a social work student or a social worker in practice, was when I listened to someone's story. And we forget the power of our listening skills and how important they are."
- "Co-production does cost, so please value people's time, their expenses...make sure no one is there being taken advantage of."
- "Pay people for their time and coach where necessary but you are not the expert."
- "Value the people that are taking part."
- "Reflection time before and after each focus group was built in. Mutual respect..valuing that ..being open minded and ready to learn from others."
- Reciprocity: "What is in it for the communities? Because we know what's in it for us, because we need to meet certain targets or we need to deliver on certain budgets or we have to meet certain criterias. Communities don't think like that they want the best for their areas or for the issue that is at hand."

Support

Co-production can be an intimidating and even harmful experience, especially for those from marginalised communities or those who have experienced trauma. Support for people taking part must be offered in a thoughtful manner.

- "Support people really well to help them to be involved. Have a safety net."
- One storyteller described some of the minor accommodations that they might need because of neurodiversity, saying they found it bad when this doesn't happen. "It's easier to get these things in a co-produced space."
- "Co-production needs thought and care."

Money

Co-production needs funds to be successful. Everyone involved should be paid for their time, as this is one way to create parity between professionals and people with lived experience.

- "Ring fence co-production money so it's a must-have, not a nice-to-have."
- "Write co-production into bids."
- "Pay people for their time."
- One storyteller described how challenging it can be to attempt co-production whilst also balancing childcare and caring responsibilities. "Adequate funding makes a huge difference."

Time

Co-production needs time to be successful. It may take longer than other ways of doing things, and might need to overrun set timescales to get the best results.

- "Make time don't rush things through."
- One storyteller described how their previous work had a tight timescale which limited involvement of people with lived experience through the lifecycle of the stages. In their subsequent project, they made sure to "build in time to analyse the data together and think about ways to share the findings with different stakeholders."
- "The time investment really pays off."
- Another storyteller reflected that it wasn't so much the time taken to do co-production itself, but the time taken to adjust ways of working and learn about it as a way of being: "A lot of people will think that co-production will take a long time it doesn't take longer to do co-production. But I think to master co-production, or master your understanding of co-production can take a bit longer... you just need to immerse yourself in it really, you can't just necessarily read a book on it... you just need to get your hands dirty."

Appropriate spaces and forums - both physical and digital

Co-production needs space in which to happen, to bring people together to work in collaboration. These can be physical or online spaces, but have to take into consideration the needs of the people involved.

- "Spaces for joint ventures need to be discovered. If we start finding places or venues, we can go to the communities who are in need and who want to learn. There are a lot of spaces that can be used."
- "Many people were able to do co-production online it was good for carers, for example."

Be creative

Creativity is an essential ingredient of co-production.

"Think outside the box - post-it notes, paper, crafting - so that people can contribute in ways they feel comfortable with."

"Be challenged in such a constructive way, to think outside the box."

Action - make change

For co-production to succeed, something needs to happen. It must be action-based. Just talking is not co-production.

"Do something - even small, minute changes."

There is more work to be done here to understand – and perhaps even test – what the ideal conditions for co-production are. Many of these are abstract concepts so it would be interesting to explore what the concrete ways of achieving them are – what does power–sharing look like in practice, for example? One of our storytellers stated that "the time has now come for co-production and we need robust and rigorous systems for it being implemented." Further work in this area would contribute to the ability of organisations and individuals to mobilise co-production in the right way to create positive, collaborative change.

Conclusion

Our 100 storytellers offered a variety of different co-production experiences and - as the length of this report shows - an extensive list of benefits. Whether their experiences had been positive or negative, almost every participant had something good to say about co-production as a way of working. The language that was deployed by people during the sessions was full of enthusiasm, positive emotion and joy.

People were also able to point concretely to differences that had been created through co-production. They were able to gesture to less tangible, but in some ways even more essential value that had been added - such as professionals describing the way their practice had changed as a result of working with people with lived experience. There was shared learning, exchange of knowledge and new ideas generated by bringing people from different perspectives together.

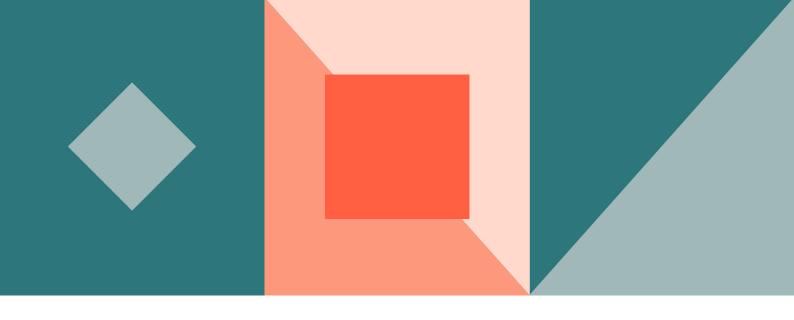
People did not shy away from telling us the challenges of co-production, but most felt the benefits were worth some of the extra work, effort, time and battles against "the system".

Co-production, described by one participant as "a way of being, not a way of doing" has value to individuals, organisation and society. We will leave the final words to one of our storytellers - with great thanks to everyone who shared their experiences and insight with us:

"It's the feeling that you get when everyone involved in a project is bringing their own different set of skills... and it's working in harmony... we all have our own different areas of expertise we bring to a project, so it's not that anybody is of higher value or lesser value... when that works really well and we're all treating each other as equals in that project... we've all got our own areas of interest and agency in tasks that we're dealing with delivering on those - that feeling when that project comes together at the end is just amazing. Because we've all contributed equally in our own way and the end piece of work - it really does feel collaborative - it feels like we've all inputted into this equally."







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