

Co-Pro Stories

Exploring lived experiences of co-production / November 2020

As part of the celebration of their launch in October 2020, Co-Production Collective wanted explore the co-production experiences of their community. People's Voice Media were commissioned to gather these Co-Pro Stories using a Community Reporting approach. Community Reporting is a pan-European storytelling movement that supports people to use digital technologies to tell their own stories. Originating in 2007 and developed by People's Voice Media, Community Reporting has been developed across Europe as a mixed methodological approach for enhancing citizen participation in research, policy-making, service development, and decision-making processes.

We used dialogue interviews to gather the stories, then analysed them together as a group in a sense-making workshop. We spoke to 15 people with lived experience of co-production to find out their Co-Pro Stories. The storytellers come from different sectors, work on different projects, and participate in different ways, but all share the identity of "co-producers". In this report, we explore what these stories as a collective can tell us about co-production: what it is, what it feels like, and what it can achieve.

"We're all people": What is co-production?

People articulated their understanding of "co-production" in a variety of ways. Many people stressed the need to not be purist or worry too much about a strict definition of what co-production is in practice. Instead, they emphasised that co-production is "value-driven, and that's important". One storyteller offered up the sentiment that co-production is "a way of being, not a way of doing". Many others echoed this in their willingness to talk about the values and ethics that underpin co-production, suggesting that these are more important to co-producers than any strict methodology or way of doing co-production.



People expressed ideals of **democracy** and **equality** – of contribution and of treatment – as underpinning the co-production process. Indeed, one storyteller mused that in co-production you "create the values together". The language of equality was frequently invoked. "No one is of higher or lesser value", said one storyteller. Another emphasised the need to set up the infrastructure to "enable people to take part on an equal footing, as equal partners". Co-producers felt strongly that their ways of working should allow for equal treatment of everybody in the co-production team.

For this to happen, storytellers discussed the importance of **sharing power**. In order to give people "equal value, equal agency", you have to give people equal opportunity too. This is the difference between co-production and consultation – in co-production you "have things to go away and work on", said one storyteller. Similarly, it was felt that people needed "control" over the terms of their involvement. Storytellers discussed practical things they have done to try to correct the power imbalances that exist in their groups. One said that in their work they try to "lose the job titles, remember we're all people, we all have names". A storyteller with lived experience reflected that they had fallen into the habit of "filling introductions with my qualifications and experience", a trait they called "jockeying for position", but co-production had made them realise that we need to do away with all this to make things more equal. Storytellers reflected on their own power relative to others, and tried to come up with ways to distribute power more evenly.

It can be challenging. "Sometimes people have worked very hard for power and don't want to let that power go", said one storyteller. Another observed that people feel "nervous about giving away control". The stories emphasised that this was one of the most effective vehicles for change. "When people give away that power and other people see them do that, then people believe we are on this journey together", one storyteller told us, urging other co-producers to "spread the power around". Another person's advice to co-producers was to "hand over power, go with the flow and see what happens". The stories



acknowledge the personal risk felt with sharing power, but advocate strongly for the benefits of stepping back and sharing it. One person told us their best moment in co-production was joining community co-producers in a meeting with senior, very vocal academics and seeing them speak up and question, making the team think in a way they probably hadn't expected to. This provides a concrete example of how a value enacted - sharing power - can lead to a shift in the direction of a co-produced project.

One of the fundamental values of co-production articulated in the stories was the importance of "recognising that **lived and learnt experience are both sets of knowledge**", and trying to value those equally. There is an imbalance in how different types of knowledge are valued in society and in institutions like medicine and universities. One interviewee admits "medical researchers have tended to think we know best", while a co-production partner has learnt that "there are people in the community with their own expert knowledge". Co-producers were keen to stress the need for revaluing types of knowledge usually disregarded in society. As well as showing respect for each other's knowledge type, one contributor added that "we all have more than one knowledge type". For co-producers, knowledge is multiple, it is learned and lived, and all types should be valued equally.

Fundamentally underpinning this is a growth mindset of "I'm still learning, we're all still learning". Co-production is a process of **collaborative learning** underpinned by strong values. This was summed up by one co-producer, who said that there is "mutual recognition that none of us own all the knowledge, all the skills, all the experience – we each have a set of those things...by sharing it we may be able to bring more to the table". The stories show that co-producers value not just the knowledge itself, but the way that by bringing it together and listening to different perspectives, everyone is able to learn something and take that forward.



"Putting people first": How do you do co-production?

As well as the values described above, discussions of co-production often highlighted particular ways of working that the storytellers felt created the conditions for good co-production. Whilst, as one contributor emphasised "there's no one way to go about it", there were several key themes that emerged in the stories.

Language of **collaboration**, **relationships** and **community** was used across all the stories. At its heart, co-production is about **people working together**. One contributor said the best thing about co-production was "the feeling that you get when everyone in a project is bringing their own set of skills and it's all working in harmony". Words such as "partnership", "collaborative", "relationship", "connection", "together", "compromise" and "conversation" appear throughout the interviews. Relationship-building forms a huge part of the work of coproduction from all sides, and it is through this that "trust" is created. In addition to this, some of the stories also emphasised the "diversity" of voices as being important – "having conversations with people that you wouldn't normally". Coproduction, therefore, is not just about working as a team. It's about building a team out of people who wouldn't normally work together.

Many of the storytellers made reference to **working practices** that create the conditions for good co-production. One described how attending an event run by the UCL Centre for Co-Production in Health Research (the former name of the Co-Production Collective) had given them an idea of what co-production looks like in practice, showcasing "the concept of a team" and how the way the event was run "enacted the principles" (e.g. in the way the room had been set up). Organisational culture was important, the need to create "a safe space", "a culture of working together and making mistakes". Some had group agreements or guiding principles that were there to remind people of the environment in which they wanted to work. This was something to be celebrated as a powerful aspect of co-production. "I'm fed up of playing by other people's rules that have been set over decades or even centuries, I think we should be



able to make up our own rules, together, in whatever space we've created, to get the best outcome," spoke one storyteller powerfully. Storytellers saw coproduction as a chance to create different working practices that enacted the values described above.

Involvement of people with lived experience at all or several stages of a project, from idea genesis to final product or service, was emphasised in the stories. The metaphor of co-production as a "journey" was used several times, where co-producers were "guided" by others, where you "take people with you", ask others to "come and lead us", and go "on a journey of discovery together". Having ideas generated from the community of experience and not just in a top-down way was seen as essential for some, a move that takes a project beyond consultation.

"Mutually beneficial": Why do co-production?

The stories were full of examples of the benefits of co-production - to all parties involved. Fundamentally, there was a sense that co-production was **essential** in moving research and provision forwards, and that involving everybody makes projects stronger and improves outcomes. Many of the stories framed coproduction as the only way for their projects. One medical researcher said that it would be "impossible" to do their work "without including the family, friends and understanding the lived experience" of people living with the condition. Another person, working in co-production in housing, stressed the need to "make sure that the voice of the people that the services are designed and delivered for is included in the design and delivery of those services - because why wouldn't they be?". Many projects may be able to create change, but co-production is "necessary if we want to create the right change", stated one storyteller. There was a strong sense in the stories that co-production in almost all circumstances leads to "stronger and more valuable outcomes". Although ideas may be based on evidence, statistics and research, that is nothing like "being in someone's shoes". Storytellers felt that the end products were more likely to



meet people's aspirations and needs, and to be used by a community, than those that weren't designed together.

Some of the responses took this further and emphasised they felt that coproduction was **better value** (both monetary and in terms of contribution to society) than other projects. "Can we afford *not* to?" asked one person. Coproduction "really does help get the best value for public money that we are investing on the public's behalf", another storyteller told us. These stories resist a narrative that casts co-production as more expensive or wasteful compared to traditional research methods or standard ways of managing projects, instead suggesting that, because its outputs are so tailored and the community already have a stake in them, they are more likely to provide value for money than other ways of working.

Almost all stories emphasised the **mutual benefits** of co-production, with a particular emphasis on the **mutuality of learning**. We "all learnt a lot from the process together" said one co-producer, while another felt like the community co-producers that they work with underestimate how much the academic researchers have learnt from them and the community. One young person involved in co-production summed it up as it "makes everything better because you're using everyone's ideas".

Co-production has benefits to both those who are directly involved in the project and to wider society. Again, many of the responses stressed a two-way, mutual flow of benefits. One told us how they loved "watching people create and thrive - it's beneficial for them and it's beneficial for the people they are trying to help". Others described how involvement in co-production had built skills, confidence and opened up opportunities for people involved in all capacities. Many people also described feeling positive about the **altruism** of co-production, "the sense that you are helping other people in your community or community of interest". Co-production lets people help others, and this in turn makes them feel good about themselves.



People also spoke about the ways in which being involved in co-production "opens up". This is both in terms of personal development - "being part of a co-creation" team opens your minds to lots of different things" - and in terms of creating access to things like research and academia for more people. Opening up the process to a "diversity of voices" has benefits to the project and the way the project is done: "if you have a group with the same background, same training, you all think in the same way, you won't be creative" stated one respondent. Co-production was seen as important to open up access to institutions that are traditionally closed-off to many groups of people, but also for the positive impact that the influence of diverse voices has on the institutions and projects themselves.

Co-production allows a degree of **flexibility** that isn't always achievable in other projects. One story describes how a community researcher project was able to change what they were intending to do when COVID hit, coproducing poetry and recipe books to support wellbeing. This was very different to what the project was aiming to do initially but they were able to respond to the needs

Co-Production in Action

Here are just a few of the tangible outputs our storytellers told us about from their work:

- A dementia research website portal which matches people with dementia and their carers with researchers who are looking for participants in studies.
- Trauma-informed care training for GPs (online and face-to-face).
- A self-management tool book for patients and family members to gain insight on life after a stroke.
- A day-long workshop on co-production in mental health research.
- An organisation where people with multiple needs help other organisations to improve how they support people with multiple needs.
- A study testing the results of the impact of intensive treatment of gum disease on diabetes outcomes in the community.
- A toolkit for young autistic people to help them differentiate between autism and mental health issues.
- A parent-led drop-in group for parents of children aged 5-19.
- A report into how psychological therapies could be adapted for autistic adults.
- A Young Persons' Advisory Group to improve the research experience of young people at Moorfields Eye Hospital.

These specific examples give some idea as to the different destinations that co-produced projects can have.

of their community. This flexibility makes co-production "a much more creative way of working". Of course, these are just some of the intangible benefits of co-



production that our storytellers described to us. Co-production has real-world outcomes too such as the examples highlighted in the call-out box.

"It's just really personal": How does co-production feel?

One particularly strong story in the set highlighted the key role that **emotion** plays in co-production, and argued that it is too often overlooked and side-lined in research, perhaps because it's hard to measure, hard to articulate and undervalued in academia and society. But the storyteller felt that emotion and feelings were the key to understanding the difference between a project that makes a difference and one that doesn't. "We don't like to talk about emotions," the storyteller said, but co-production is emotional for everybody involved.

While few other people made this point explicitly in their stories, it resonated very strongly with others at the workshop. As a collection, the stories are full of emotive language about how co-production makes people feel. Most of this is **positive**: co-production has emotional benefits to individuals and it is "exciting", "inspiring", "fantastic", "satisfying", and "amazing". Co-producers have "fun" and "feel a sense of achievement". Overwhelmingly the stories suggest that co-production is an enjoyable way to work and makes people happy.

Co-production can stir up powerful emotions. Some even described the experience of taking part in co-production as "transformative". This raised the question of how we meaningfully measure the emotional impacts, especially when evaluating and accounting for the outcomes of projects.

There were also more **difficult emotions** attached to co-production. One contributor described it as "a rollercoaster", suggesting that there are low points as well as highs. People said that they found it "exhausting", "frustrating", and "challenging". However, this was one area in which responses from people who are experts by experience differed from those involved in co-production in other roles. One respondent felt that they were "damaged" by co-production (when



not done well), another felt "not listened to". As one person with lived experience summarised: "it's just really personal, it's really difficult to get involved in, especially when it really matters. It's not as easy as just join in. It's hard. You really grow and learn through it." This provides a stark reminder that however equitable we try to make participation in co-production, some people have more at stake and the **emotional burden does not fall equally**, and this needs to be carefully considered.

The other emotional aspect of co-production that emerged through the stories was one of **identity** and involvement. Several of the participants highlighted that although they were involved in co-production as part of their professional role, their journey to that place had been influenced by personal lived experience, either as a patient themselves or as seeing the experiences of a family member. One stroke survivor discussed the blurring of their identities as patient and practitioner. They had trained as a physiotherapist before having a stroke, and were able to use their knowledge to get good care, because they knew the language and what to ask for. They saw this experience in contrast to the care that others received, and wanted to use their expertise in both spheres to "bridge gaps" between patient and practitioner.

Some storytellers described damaging experiences they/their families had had with services before they became involved in co-production (sometimes this acted as a spur to get involved - immediately or later in life). One described how, as a long-term mental health patient she felt "routinely disregarded", "discredited" and "ignored", but felt a huge contrast when she got involved in co-production and felt "so validated to be involved". Others described having witnessed close family members interact with mental health services and being critical of the treatment they received. Another came to co-production when they had to drop out of university due to an anxiety disorder. They have now worked in numerous roles in co-production in universities, the voluntary sector and local authorities. They describe themselves as "a walking, talking example

¹ "Bridging gaps" was a phrase that came up in other interviews, and is even the name of one of the co-production projects.

of how taking part in a co-production opportunity can be transformative". Co-production practitioners often have a personal history that has drawn them to the field or sparked their desire to create change. Understanding the emotional ties and the personal experiences of co-producers can help us understand what motivates people to become involved in co-production. These switches or merging of roles and realities also tie into the ideals mentioned above about the sharing of knowledge. The personal histories of people doing co-production give further evidence to back up the assertion that "we all have more than one type of knowledge".

"I'm not a method, I'm not a framework": The problems with careless co-production

The emotional impacts of co-production outlined make it necessary, one person said, for researchers to "examine their motives" before they start. They plead with researchers not to do it "because it's the thing to do or a box-ticking exercise", because that can "do harm to people". The next section of this report examines what happens when co-production is done without due care and equality of involvement.

A repeated theme in the stories was rejecting co-production or engagement experiences that felt like a "box ticking exercise", with this exact phrase being used in several of the accounts. One storyteller outlined a frustrating and disempowering co-production experience and said that their colleagues feel "it's just a tick box exercise from the council. They want to hear from us but not actually improve the services that we use". Co-production projects can feel "tokenistic" if people are "involved too late to have a meaningful impact", agreed another storyteller. Similarly, if people approach co-production "with an agenda, knowing what they want" then co-production again becomes a "tickbox exercise", when it should be "a blank canvas". Co-producers were dismissive of and disheartened by these "faux-production" efforts that they felt did not properly attempt to engage, change and share power.



However, one of the stories did say that on occasions when they have felt they have been "brought in as a tick box exercise", they have then managed to convince the other people in the project where their value is. What they find more frustrating is when a project isn't involving service users at all, "when you can't even get a foot in the door".

As the emotional impacts outlined above suggest, co-production done badly can be **emotionally damaging**. One storyteller spoke candidly about their heavy emotional investment in projects: "I am involved because my life depends on it". As someone living with a condition, they want and need the research to succeed. There are some imbalances and inequalities that are impossible to adjust for in co-production. They have found it hard to walk away from projects "even though I know that there's situations that have been damaging to me". Sometimes, they reflect, "the only power we have is the power to walk away". This was echoed by another person who'd had a negative experience, feeling "fobbed off" by the co-production group they are involved in. They were considering joining together with colleagues and refusing to attend the group, protesting outside instead. Again, this suggests that for some people the only way to take power out of an uneven co-production relationship is to remove themselves from it. Stories like these raise issues around how we safeguard each other from harm as we become involved in co-production.

"It's going to be messy": What are the challenges of co-production?

When asked what the challenges of co-production were, **time** was an extremely popular answer among our storytellers. "Recruiting and supporting people to co-produce is a big job" reflected one storyteller. There is a mismatch between the way the timescale of co-production appears on paper (perhaps as "a couple of workshops"), and the way it is experienced in reality. This also clashes with the timescales of the institutions involved, for example the time needed for preparatory work for a grant application exceeds the time available. Availability or perhaps suitability of **funding** was another big interlinked concern of many of



the contributors. Co-production "doesn't cost a lot of money, but it does require resource", reasoned one participant.

Some storytellers felt that it wasn't even that co-production takes more time and money compared to other ways of working, but the ways in which co-production **rubs up against standard established working patterns and practices in institutions** such as healthcare, funding bodies and universities, which often have quite rigid ways of working. For example, one researcher described their attempt to apply for funding for a project working with special autism schools in London: "The project was the idea of the headteachers, we designed it together and they wanted to collaboratively apply for funding, but the application had to be through an academic institution, so the power automatically goes to the institution, even though the point of co-production is about sharing power". This shows the need to influence funding bodies into changing the way their grant and award schemes work to better support co-production.

Another researcher describes the radical alteration that their research, funded by the Centre, has had from their intended timescale. Their initial proposal was that "in the first meeting, we'll work out how we're going to work together, make our agreements and then we'll get on and start designing the project. In reality, it's taken a year to work out how we're going to work together". Everything that they hoped that they would do has taken a lot longer than they imagined, because of the need to work together and build trust. These examples show that co-production does not necessarily fit the structures of the institutions that want to use it as a method, nor is it predictable in the same way. They demonstrate the need for flexibility, adaptability, not just from the people involved but from the institutional structures that govern the way "work" is done in these spaces.

Practical suggestions that emerged from the stories are:

 improve institutional systems for paying people for involvement - remove "red tape"



 "better funding is needed to allow for pilot work, so you are in a better position to apply for grants".

Overall, the challenges described back up one storyteller's idea that "people are under so much pressure, particularly in university settings, workload is an issue, time, money" that it is a challenge to "step out of this and work differently". However, most conceded that the outcomes were worth the extra time and effort involved "because at the end of it all a better project comes out of it".

The other challenge that emerged throughout the interviews was that coproduction can be "messy" and can sometimes fail or not go as well as you'd hoped. "You hear 'no' a lot", said one storyteller, "and you have to be okay with that". Other storytellers emphasised the importance of "listening to people, even if they are criticising, they will often have a really valid point". The crucial thing, people told us, was that in co-production you learn from your mistakes and missteps. "Don't do it if you're not prepared to listen and you're not prepared to change things as a result", said one co-producer. The stories suggest that co-production is not always a smooth and linear process, but there is learning to be gained along the way if you are open to it. One story stressed the need to see failure as "a worthwhile outcome", a sentiment echoed by another who urged "let's celebrate what we got wrong". Co-producers want to take a positive attitude to failure and they want this to be reflected in the funding, evaluation and support structures for co-production.

Another advocated for the importance of **building trust** at the start of the coproduction process as a way to help people navigate the messiness of what comes later in the journey, which "can be challenging for some people...you have to ride with it, run with it, know that it's going to be messy. But if you all understand each other and have that relationship then it's only going to be the stronger for it...work through that conflict". This suggests that all people in the co-production process need to be adequately prepared for the hard and often emotional work that comes ahead, again reflecting the need for support for



people involved. There is real labour involved in forming the relationships and trust necessary for co-production projects to succeed.

The COVID-19 lockdown has presented some challenges for co-producers. Not being able to meet face-to-face highlights issues of digital exclusion, and, returning to the point about emotion, some felt it's harder to "make sense of what everyone's feeling" over Zoom. However, for others COVID has presented new opportunities: one co-producer was pleased that their research can now involve people from all over Europe at much lower cost than face-to-face. The full impact of COVID on co-production, and how co-production helps provide solutions to some of the issues that COVID has presented, remains to be seen.

"We are desperate for you to support us in a holistic way": What are the barriers to co-production?

For co-production to be at its most effective, and to live up to the values of equality, power-sharing and mutual benefit, we need to remove the **barriers** that make it hard for people to get involved. A big - but perhaps easily avoided - barrier that several stories highlighted was the use of **language and jargon** that can exclude people and prevents clear communication. Jargon and language can make it "difficult" and "intimidating" to get involved, says one storyteller, urging co-producers to "cut through that and get people to share their experiences from the heart". Once again, the language of personal experience and emotion may make for a more effective way to communicate. Another contributor noted that there are often many different services and institutions interacting in co-production - healthcare, social care, local authority, community groups - and all use different terminology which "creates barriers".

The stories also demonstrate the need for recognition that co-producers with lived experience may be **experiencing multiple barriers and disadvantages in their everyday lives**, as well as their involvement in the research. One storyteller



co-producing with African-American communities described their stakeholder group's "justifiable reasons not to want to be involved in research" when they come from communities who "have not been treated as well as we would like in the past when involved in research". While co-production often seeks to open up access and involvement, this may first mean confronting social relationships that have been damaged by past harm and wider structural inequalities.

Another story tells powerfully how racism, disability discrimination, the stigma of a mental health diagnosis, language barriers and caring responsibilities can intersect to make the life of the storyteller and the lives of the people they advocate for extremely difficult. The person tells us how they have challenged their council's co-production forum for the institutional racism that they have experienced. They feel discriminated against and failed by their co-production experience: "everything is being decided by abled people for disabled people and nobody's listening to us...and that's not how co-production is meant to be". In this story, social disadvantage and disability rub up against bureaucratic structures that frustrate the storyteller's attempts to achieve change through co-production.

Some of the stories also show how small **adjustments** can make it easier for disabled people to take part in co-production. When these adjustments are overlooked, it can make life difficult, but when they are remembered and implemented they can open up research and be transformative in people's lives. One storyteller describes a time when they were brought along as an interpreter to support a colleague, "you see that people can make the changes, people can adapt and make reasonable adjustments", which contrasted to their other experiences where people's needs were ignored. Another storyteller described how their co-production group was a place where "autistic identity was positively embraced and explored", because the psychologist was familiar with facilitating groups with people with autism and made allowances for individual preferences, for example using interaction badges so people could indicate the level of participation that they wanted in that session. These stories show that a small amount of time and effort spent listening to a disabled





person's needs and implementing adjustments can have a huge impact on their ability to participate in co-production.

Failure to make adjustments to allow disabled people to participate can be a barrier, but co-production can also provide the solutions to this. One story tells of how a pan-disability network co-created some cooking classes for their visually impaired members. As the storyteller notes: "lived experience will tell you what the seemingly little things are that are actually major barriers", and knowing about them enables us to change things and involve more people.

Another barrier to effective co-production is **economic and employment structures**. Power sharing is difficult to manage in any circumstances, but often co-production situations involve a mixture of people attending as part of their job, who are working and getting paid to be there, and people with lived experience, who are not being paid, or being paid with food or vouchers. The storyteller who raised this said that they look to pay people where possible, but this can also create problems as it can interfere with people's benefits. This raises a question for co-producers as to how we achieve financial equity within our teams.

One of the barriers identified by many storytellers was the idea of getting "bogged down" in the theory of what co-production is or sidelined by trying to achieve some vision of pure, true co-production. Contributors cautioned against this: "Don't get too caught up in what co-production is or isn't, this can detract from the actual job of doing – just start it with an open mind" advised one. "I think we need to move away from having one model of what good co-production is" said another, stressing that there is value in anything that involves people in research. Another said they had abandoned the word co-production altogether. Instead they say "working together to create positive change". To the storytellers, it is the intent and practices of co-production that are more important than any strict criteria or rules.



"This is the way we need to move forward": What about the future of co-production?

All of our storytellers were **hopeful** about the future of co-production. Co-production is "vital" and there is "real value" in it, they told us. One storyteller stated emphatically that "it needs to be the way we progress in many fields, not just health research". Storytellers wanted to see **more support and**encouragement for working together in this way, and in particular for co-production organisers "to think more about the support needed for people who are involved in co-production", which might be support to stay engaged, to deal with emotion or the challenges of a diagnosis or a condition.

Some storytellers commented on the role that they foresaw for the Co-Production Collective. The Co-Production Collective is important in "providing help and support to community participants", and one participant hoped that it will help to build "a sustainable community of co-producers". Another asked for a shared learning group for co-production because "we all need to learn from each other". A forum where best practice could be shared would also provide a way to take forward learnings from mistakes and failures that have been highlighted by these stories as being so important. Another storyteller hoped that the Co-Production Collective will be able to effect the kinds of institutional change that have been highlighted in this report, "streamlining" the process of co-production and making it "the norm rather than the exception" by "supporting researchers", training junior researchers in co-production methods and "pushing for structural change".

Particularly poignant was one storyteller who urged the Co-Production

Collective to "keep creating a space for people to coproduce together, because we can make the world a better place". This highlights that underpinning every co-production experience - positive or negative, neat or messy, successful or failed - are individual people trying to make things better for society and for



each other.

You can listen to a set of extracts from the stories we gathered here:

https://cutt.ly/GgcyVDd

