Co-producing improvements in system-wide organisations

An evaluation to identify learning and inform improvements

June 2022

Picker

Our vision

The highest quality person centred care for all, always

Our mission

We are here to:

- **Influence** policy and practice so that health and social care systems are always centred around people's needs and preferences;
- **Inspire** the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood; and
- **Empower** those working in health and social care to improve experiences by effectively measuring and acting upon people's feedback.

Background

NHS England and NHS Improvement (NHSEI) funded 10 system-wide organisations to use a co-production approach to improve services. These covered a mix of systems including Cancer Alliances, Integrated Care Systems and Health and Social Care Partnerships [see Appendix for details]

NHSEI commissioned Picker to evaluate the co-produced improvement projects to identify learning and inform improvements.

The results presented in this report are based on:

- 11 in-depth interviews with staff and people with lived experience
- 6 survey responses from people with lived experience

Quotes from interviews and survey responses are used throughout the report to illustrate findings.

Report structure

- Summary of main findings
- Key facilitators and challenges to co-production
- Understanding co-production and the value of co-production
- Key learnings for organisations and NHSEI
- Progress against the values and behaviours in this Co-production Model:
    - Ownership, understanding and support of co-production by all
    - A culture of openness and honesty
    - A commitment to sharing power and decisions with citizens
    - Clear communication in plain English
    - A culture in which people are valued and respected

Values and behaviours for a culture of co-production

NHS England and NHS Improvement and Coalition for Personalised Care (formerly Coalition for Collaborative Care). *A Co-Production Model*. 2020

Summary of main findings

Summary of main findings (1)

- There was variation across the ten system-wide organisations on the **progress** made:
  - Eight systems had recruited people with lived or learned experience to co-produce the work and had successfully engaged with local communities; in some cases this was with groups that had seldom been reached or heard before.
  - Three systems had moved beyond the engagement stage to co-produce a solution, but had not reached the stage of measuring outcomes or impact.
- Key facilitators to implementation included: working with third sector organisations, training people on the principles of co-production, laying the foundations for co-production through engagement and relationship building, ensuring processes are set-up to aid co-production and the funding/support from NHSEI.
- Key challenges faced by systems included: resource and time constraints, recruitment of a diverse group of people with lived experience, managing expectations, a lack of understanding of co-production by some staff, and learning how to share control and work in a different way.

Summary of main findings (2)

- Overall there was good understanding of the principles of co-production. However, the extent to which the projects were being fully **co-produced** varied across systems.

- People with lived experience, who provided feedback via a short survey or interview, were generally positive about their experiences of co-producing improvements.

- The value of co-production was recognised as addressing what is important to patients and their families/carers to make meaningful improvements, as well as shaping and improving project implementation. Some noted that closing the feedback loop was important and that co-production encourages greater consideration to inclusion. Other valuable aspects of co-production were bringing different services together and providing useful insights for other work.

- Key learnings for systems include:

  - Keeping an open mind about the outcome/process of co-production, including flexibility around the need to support people with lived experience throughout the project.

  - Training staff on the principles of co-production.

  - The importance of engaging with a diverse group of people and ensuring sufficient time is given to recruiting and engaging with people with lived experience. Exploration of preferred methods of engagement and ensuring flexibility around this.

  - Building in time to reflect on the co-production process.

- Key learnings for NHSEI include: allowing teams greater time to co-produce projects, being clear on expectations, consider the timing and availability of training and providing more constructive criticism.

Key facilitators and challenges to co-production

Key facilitators

Working with third sector organisations

Some systems worked closely with local charities and third sector organisations to help them recruit people with lived experience for project steering groups and/or for wider engagement work with local communities.

Sharing the value of co-production…

…with people with lived experience. Co-production was an unknown initiative to some people with lived experience. Explaining the true value of co-production helped with recruitment, engagement and enthusiasm of people with lived experience.

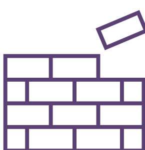
….**with staff**. Training and informing staff of the importance of co-producing improvements is key as it requires a culture change for some. Where staff have been engaged with the approach, the initiative has been embraced.

“There are already links there with some of those organisations, so in terms of recruitment, that felt like a streamlined process.” [Staff member, Interview]

“The voluntary sector obviously have got so much experience and insight into co-production.” [Staff member, Interview]

“Put on training around co-production immediately to help everybody understand what that process is, and what the benefits are.” [Staff member, Interview]

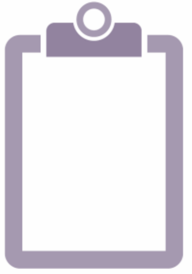
Key facilitators (continued)



Creating foundations for co-production

Allowing sufficient time for **engagement and relationship** building with people at the start of the project is important for laying the foundations for effective co-production.

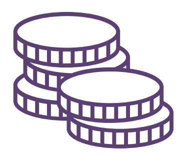
"True co-production to deliver service improvements requires trust and a relationship based on understanding each other's interests. This is more likely to happen when the engagement process has matured." [Staff member]



Planning

Some systems highlighted the importance of putting processes in place to aid co-production, such as providing support for people with lived experiences, scoping who needs to be involved and developing a code of conduct for meetings.

Funding and support from NHSEI



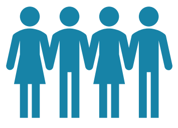
The funding and support from NHSEI was regarded a key facilitator to progressing the co-production projects by some systems. For example, the funding was used to support the recruitment of people with lived experience (including via third sector orgs), commissioning specialist support and funding particular roles.

"… because we had a decent amount of funding, we could incentivise the organisation to work with us" [Staff member]

Key challenges

Timeframe

Some systems had not progressed as far as they had hoped within the time frame for the project. Some teams spent more time on recruitment and engaging with local communities to ensure a wide range of voices were heard, which takes time to do properly. Other teams experienced delays due to Covid-19 and/or resourcing issues.



Recruitment of people with lived experiences

- Due to time constraints, some systems felt rushed or did not spend enough time recruiting people with lived experience to ensure a wide range of voices were heard.
- One system felt that stigma impacted the ease of recruiting people with lived experience; where a condition has a stigma attached, it was felt that people may not want to come forward.
- In other systems, certain conditions meant that people with lived and learned experience were time-poor and may have been less able to contribute and engage with a co-production group.
- Language barriers contributed to recruitment difficulties for some.
- Those with small steering groups felt that they were not necessarily representing the voice of the communities affected.

Onboarding experiences

A few teams needed to allow the time and space for people with lived experiences to share and ‘offload’ their previous negative experiences of care. This was not necessarily planned for but was needed to ensure people with lived experience felt heard and to enable true co-production.

Key challenges (continued)

Setting expectations

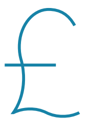
Some groups had multiple aspects of care that were voiced as needing improvement, but not all could be solved within the project time or budget. Setting the expectations was key for the people with lived experience to find a focus for service improvement. Others noted how they found it difficult to condense all that had been shared via engagement activities and to find the focus of the improvement.

Educating staff

While some groups managed to engage staff with ease, others found educating staff on what co-production is and how it differs from patient engagement or involvement was challenging.

Equality within the group

Some project leads noted how they found not being in control and not always knowing the direction or focus of the work challenging, but recognised that to ensure true co-production, they were to be equal to the rest of the group.



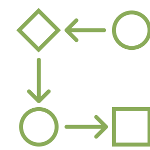
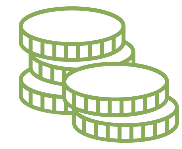
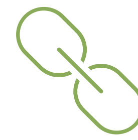
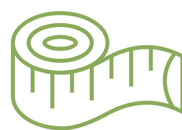
Reimbursement of people’s time

A few systems spoke of the challenge in knowing how to financially reward and recognise the contribution made by people with lived experience.

Measuring impact

While none of the project teams had reached the point of measuring outcomes, many were still considering and/or were unsure how best to measure and evidence the impact. Some noted extra guidance and support on how to measure outcome was needed.

Resources to help co-production

Help with **recruiting participants** for co-production project/steering group	 Support with **addressing relationships** between health services and people with lived experience	Training **staff and people with lived experience** about a co-production approach to quality improvement	 Funding for **recruitment, expert involvement, facilitators, translators**, and **payment to recognise** the time and effort that people put into co-production
 Supporting **links with third-sector**/voluntary organisations	**"Check and balance"** system to ensure that the voices of unrepresented communities are heard	 Support on **measuring/evidencing impact** of co-produced projects	**Training staff** with necessary skills, such as facilitation, and supporting a change in the way of working

How is co-production understood and delivered?

Understanding co-production

In general there was a good understanding by systems of the key aspects of co-production. Those interviewed recognised that co-production requires:

- the involvement of people with lived experience at every stage of the process
- taking engagement one step further
- sharing control, responsibility and power so there is an equal partnership.

An "open conversation" - "it's equal partnership and from the beginning to the end".

However, some teams noted that an understanding of co-production and how this differs to patient engagement and experience can be lacking amongst wider staff. Despite the increase in co-production, it was felt there is a need to still educate people.

"…some people, kind of, feel that the engagement is co-production, and that's not my understanding."

Even within the project team there could be different understandings of what co-production means, and one system suggested NHSEI could provide further guidance on this (see slide 26)

When discussing the importance of feeding back on progress, one system referred to *"You said, we did"* rather than *"We said, we did"* showing a need for some staff to move from an engagement to co-production position

Extent projects co-produced

The extent to which projects had, so far, been co-produced varied across the systems:

In some teams, people with lived experience had been involved in all stages of the project, including presenting the work at the NHSEI shared learning event. Some teams described how people with lived experience had leadership roles, shaped the focus for the work, had chaired meetings, co-produced meeting agendas, recruitment materials and reports.

Of the 6 people with lived experience who completed a survey, all said they were a ‘member of the project team’ and/or ‘participated in project meetings with staff’. Five said their views were taken into account by staff ‘a great deal’ and one said this was the case ‘to some extent’.

[However, responses were not received from people with lived experience in all teams; those who responded to the survey may have been more engaged.]

The extent of co-production was less far-reaching in other systems.

While engagement with people with lived experience was undertaken, there appeared to be less of an equal partnership between staff and people with lived experience in shaping the project and identifying solutions.

Only four people with lived experience, who responded to the survey, said they were involved in making decisions about improvement changes and just one reported being involved in additional activities (such as joining the NHSEI coaching calls and writing reports).

The value of co-production

Views of co-production for **people with lived experience**: positive findings

- Although systems are still implementing their projects, some teams already identified the value of co-production for people with lived experience. One person with lived experience noted that co-production had increased her confidence which had subsequently meant she was able to get a new job.

- People with lived experience shared **positive views** of co-producing the projects, including:

  - feeling like equal partners with healthcare staff
  - having their views listened to / being heard
  - enjoying working with staff and other people with lived experience to improve care for others
  - being made aware of services beneficial to them

- Of the six people with lived experience who responded to a short survey, all ‘definitely’ felt their involvement was equal to that of members of staff working in the group

Positive views of co-production by people with lived experience

"The staff have been really open to ideas and very patient at listening to peoples experiences"
[Survey]

"I have enjoyed working with the team and having my views listened to."
[Survey]

"[I] definitely feel equal. I could say something that [staff member] probably isn't sure of, never heard of, or didn't come across in his mind and I could explain it because I know it. That's not being big-headed about it, I've lived for nearly 50 years with [condition] so I want to believe that I know what I'm speaking about."
[Interview]

"First time I've felt heard in a long time"
[Survey]

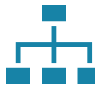
"I think my views and experience are always really taken into account. I think that's absolutely fine and I always feel heard"
[Interview]

"To meet other cancer sufferers and be able to help other patients […] going forward. Also the staff have made me aware of services I was unaware of."
[Survey]

"We're an integral part of the project team"
[Interview]

Views of co-production for **people with lived experience**: areas for improvement

Of the six people with lived experience who completed the survey, three suggested how their experience of co-production could have been improved:



"Clearer governance structures"

"More direct topics, discussing individually"

"Clearer about what the members need to contribute and what they don't so it doesn't end up in a general moan. Perhaps more directive and the staff feel able to focus members more readily."

Two survey respondents said they had received some, but not enough support from staff when working with them.

In the interviews, a few people with lived experience highlighted the challenge of staff sharing control with people with lived experience and the difficulties that can exist when overcoming disagreements or differences of opinions.

Views of co-production for **people with lived experience**: areas for improvement

“I think it was challenging throughout. I think it's really hard. My perception is that it's really hard for paid members of staff to be challenged by patients. I think it's very, very hard for paid members of staff to feel on the back foot, because the patient might know more than they do, and I think that has to be accepted within co-production, if we move on.”

[Person with lived experience, Interview]

“…you've still got staff in senior positions who will talk the talk about co-production but actually I know that they have no understanding of what co-production actually means […] It's a massive culture change. I know that social care staff didn't trust us, and then we didn't trust them, and there are still massive issues around trust.”

[Person with lived experience, Interview]

Value of co-production for staff and systems

Most systems have yet to be complete their projects, but the value of co-production as an approach to quality improvement was recognised in the following areas:

	Value	Quote from staff interviewed
	Addressing the right area for improvement	*"If this project was done with a room full of suits just presupposing what the issue is, we would be nowhere near where we are right now"*
	Improving project implementation	*"They* [people with lived experience] *were fantastic at telling us that our flyers were rubbish. The colours were awful, and the language wasn't good, and they really, really helped us redesign them right from the beginning."*
	Responsibility to action findings	*"When you have co-production at its core, you have a responsibility to feedback to people and say well actually, 'I've involved you all in this, here's what we found out, now what are you going to do?' It feels like a bit of social enterprise almost."*
	More consideration given to inclusion	*"How [a projected project will be] impacting people, how you can mitigate against exclusion, and how you're involving the community or the affected demographic's voice".*

Value of co-production for staff and systems

	Value	Quote from staff interviewed
	Greater insight into **inequalities** in access to healthcare information and services: often the only resources in other languages are online. A lack of adequate attention is paid to differences in language.	*"I went to my local GP and I was quite surprised that there was quite a lack of information on the shelves, with regards to diabetes…Are these leaflets in different languages? Actually, there weren't. I remember looking at various websites and there's a logo that's used so that you can listen to the website in different languages. Again, that's not readily available either."*
	Bringing services together	*"There was a lot of silo working in terms of the services that support [cohort], and what this project has done is really brought people together from across the system."*
	Supporting other co-production work	*"When this is complete, you think about what could have gone better, and I want to use those findings to then help other co-production projects, if that makes sense?"*
	Provide useful insight for other work streams / services	*"…us being present doing those workshops, helped to identify some [issues] which I've been able to feed back as part of the mental health collaborative, and the Foundations for our Future work that we're doing […] and the local transformation plans, so the insight has really helped to shape some thinking around what is actually happening on the ground."*

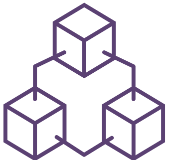
Key learnings for system-wide organisations

Key learnings: project set-up

Expectations of project direction. Some staff had an idea of what the focus of the improvement would be, but following co-production with people with lived experience, the direction of the project changed. This highlights the importance of co-production for ensuring improvements are meaningful to patients, service users and their families/carers. Groups must keep an open mind about the outcome/process of co-production and allow people with lived experience to share their views before considering next steps.

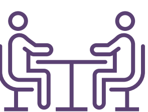
Staff training / awareness of co-production. Ensuring staff understood the purpose and process of co-production, and were onboard with this way of working, was important.

Time for recruitment. Working/partnering with third sector organisations, such as local charities and Healthwatch, helped some teams with recruiting people with lived experiences. These organisations have already built up the trust with the community which can streamline the process. One system noted the need to be flexible and engage with organisations at a time and approach suitable to them.

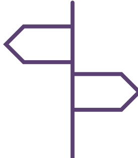


Building relationships. To ensure people with lived experience feel confident that their time will be valued, systems noted the importance of building relationships and rapport and to be realistic as to how long this can take.

Key learnings: implementation



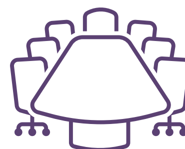
Reflection and receptiveness. Allowing time for reflection can be important for ensuring that everyone in the project team is equal and that people with lived experience feel that co-production is working to meet their needs. Additionally, a key learning for some was being open to ongoing feedback about how to make improvements to the process of co-production.



Supporting people with lived experience. It was noted that people with lived experience may need support not only in terms of co-producing the project work, but may have ongoing queries for staff and/or require signposting to services/support; this staff time needs to be built in. Some teams liaised with charities or other third sector organisations to provide support at engagement events with local communities.

Exploring preferred methodologies. A few systems noted the importance of exploring the preferred approach(es) to engagement for people with lived experiences, rather than an approach favoured by staff. For instance, one system learnt that people with lived experience are more comfortable to talk in focus groups, but this was the least used method to engage with people with lived experience by healthcare professionals.

Active listening. One system noted the benefits of active listening, rather than making notes or paraphrasing, when engaging with people with lived experiences. It was felt active listening allows for a richer understanding of the views and experiences shared.



Diverse engagement. Some groups noted the importance of ensuring that engagement of people with lived experience is diverse, such as groups who are socially or visually deprived, or time poor. Ensuring they were diversifying the methods of engagement and being flexible around others existing commitments, helped them to engage with groups that they may not otherwise have reached.

Key learnings for NHSEI

NHSEI support: positive findings

Responsiveness
Several systems commented positively on NHSEI's quick response via telephone and email.

Freedom and flexibility
Recognising the impact of Covid-19 and the uniqueness of every co-production project meant that systems felt free to engage in co-production in the best way for them.

Engagement and interest
One system commented that NHSEI "almost take on your objective as if it's their own", and another described NHSEI as "so engaged".

Knowledge and guidance
NHSEI were described as "so resourceful", with one system praising that "they gave us guidance and connections and its not just cold emails".

Connections and networking
Systems appreciated opportunities to share learnings between themselves, praising the FutureNHS Collaboration platform and the Co-Production Forum Event, as well as catch-up calls. There were some suggestions to increase resources uploaded to the FutureNHS platform, to ensure it could be used as an ongoing resource.

"When I've emailed them, they've **rang me straight away**."

"The most support I've received from anyone has been through NHS England and NHS Improvement […] **They gave us freedom to actually develop the project. They gave us guidance and connections and it's not just cold emails** […] they almost take on your objective as if it's their own. That's all of them, everyone I've met with and it's from some quite senior people as well, they've been super helpful. **In fact, I can't speak highly enough of them**. They've done the most heavy lifting out of any third party involved in this project".

"What I also found really helpful was a session that they facilitated around actually **evidencing the improvement later on**, so actually walked through the differences and with sort of balance measures, process measures, what it means within the context"

NHSEI support: areas for improvement

Allow more time Most systems had not progressed as far as hoped with many yet to co-produce an improvement. Some noted that engagement with people with lived experience takes time and needs to mature before effective co-production can commence.
Be clear on expectations One system thought greater clarity is needed as to what would be expected of systems when the bid is launched
Availability and timing of training Some stage-specific (video editing/shooting (mobile phone)) training offered too early in the process – difficult to recall content. Some systems would have liked more training on measurement and/or theory of change management.
Communication of connections One system suggested that it would be useful to know if there are other teams within NHSEI that systems could connect with for wider support/information or influence.
Critique: guidance can be encouraging but too uncritical – one system stated they would like more constructive criticism.
Frequency of coaching calls One system felt that once a month may be too frequent: *"every other month would have been okay. You know, things haven't changed that much for the month".*

"sometimes when you're unsure **it can be really helpful to have some constructive criticism and feedback**, and whilst the encouragement is fantastic actually when it is an area that you're not familiar with actually some, 'Have you thought about doing it this way?', which is really helpful, could also be, 'I'm not sure this is the best way of doing it'."

"It would be good to have, as part of when these bids come out, is actually what's really expected, because there wasn't any of that in terms of that, if you were successful in this bid, there would be this, this and this, and I think also **managing the expectations** of what they were expecting back."

"I think next time the national team should do this programme but they should run in parallel some kind of training on the **theory of change**. So, you know, each project has a theory of change associated with it that they help and they mentor the programme to put in place that is a document theory of change. A, that would really help learning because you can implement theory of changes in so many different ways. And B, then it would help with evaluation as well."

"I think it would have been good to actually do a piece which is maybe a little bit more analytical on **what they mean by true co-production**. Because there are a number of models […] NICE have got guidelines around co-production. And I, you know, I don't know how other projects have got on, but I think we, in our project, have had **different understandings of what co-production means**."

Progress against the Model's values and behaviours for a culture of co-production

Ownership, understanding and support of co-production by all

How was this achieved?	Acknowledged needs/ challenges
Engagement from the service-wide organisation to help spread the word about the project, which in turn can help with recruitment and allow different services to learn from one another.	**Education on what co-production is.** Some staff have less of an understanding and there can be confusion between patient involvement/engagement and co-production.
Educating and training staff/organisations about co-production and identifying clear distinction between co-production and patient involvement. A few systems are working towards an educational 'toolkit' on co-production.	**Staff engagement.** There was a perception that clinical staff are only engaged to a limit, due to clinical workload and time constraints.
Co-production coming from the top down. Support from Senior Executives, such as Directors, was seen as having a positive impact on the success of the co-production approach to quality improvement	**Diverse engagement.** Some systems were aware that due to small numbers of people with lived experience within their steering/project groups, they were not necessarily representing the voice of the communities affected the most, that they were less diverse and there was reduced representation from communities affected the most.
Staff having protected time, to dedicate to the co-production quality improvement project.	**Covid has caused some disruption** to how co-produced improvements would have run ordinarily. Groups having to change to remote ways of working, has meant that the visibility of the project within care settings has reduced, so engagement of staff has been more challenging.
Individuals' enthusiasm for co-production.	

“We **can’t just assume that everyone knows what co-production is**. It’s going to take workforce development, it’s going to take a really good plan to make sure that people do understand what we mean, if we’re saying co-production, that there’s a common understanding of what that is.”

“The issues I've had with co-production is sometimes if you have a **small steering group**, you do not quite feel like you're representing the voice of the communities most affected.”

“…and this is potentially a very large cultural change that we are trying to do here, and […] what I thought was going to be a big challenge actually hasn't been, because people have been really **ready to think about things differently**.”

“…**trying to educate them about what co-production is, again that was a real challenge**, so I think that for me is the biggest challenge, is trying to get that word out there, and change […] people’s, or encourage people to see things from a different perspective, and particularly those people that are in a position to be able to help co-production and encourage and develop it, and help it grow in that local community”

“There are still some challenges. We know that particularly we've got some really strong support from directors, and we've got some directors that have **never done co-production**, don't know what it is and use the term incorrectly. So we've still got a lot of **education** we need to do with them.”

“So it’s [co-production] almost like a two steps forward, one step back, process that we’ve been going on, which is why it’s **taken longer**.”

A culture of openness and honesty

How was this achieved?	Acknowledged needs/ challenges
Overcoming difficulties with recruitment; utilising knowledge of group members with lived experience in design of recruitment materials	Some groups found that **working remotely**, made it more difficult to build rapport within the group.
Allowing people the time and space to share negative experiences. Some people with lived experience joined co-production project groups with negative experiences of patient care. Resolving tension of those with lived experience by listening to their story, and in some cases signposting to support services, allowed the focus to then move on to the improvement.	
Those with lived experience need to be heard and feel empowered to speak up. Facilitators ensured equal speaking opportunities, and conversations weren't dominated by bigger characters	
Setting funding expectations early on so the group were aware of what could realistically be achieved.	

“They were completely different from the week before, they said what they needed to say and we listened. A lot of people still were quite distressed and had a lot of anger with the NHS and the system and what has happened and no one has ever listened to them. **What's been lovely over that week and the week after when we met them was we managed to resolve a lot of stuff for them that wasn't resolved for over 5 years** so we got more engagement from them because they were like, 'You've actually listened to us’.”

“It set expectation a little bit as well, I think they think I've got half a million pounds for this. It set expectation that I can't do that in this, but when it comes to shared learning events and stuff you can talk about it so the people who are going to be listening can hear your thoughts and ideas. **There's only so much that we can do in this**.”

“Although the online approach certainly has its benefits and it does enable people to engage who perhaps otherwise wouldn't because of geography, some of just the nuts and bolts of moving this forward, it just made it **so much better when we were sitting in a room together**.”

A commitment to sharing power and decisions with citizens

How was this achieved?	Acknowledged needs/ challenges
Remote working can increase accessibility While for some groups remote working proved to be more challenging, for others, remote working meant that it was more accessible and easier for people with lived experience to participate and meant meetings could be held at much shorter notice.	**Balancing members' diverse views.** With multiple people with lived experience working on co-production groups, some found it challenging to come to a consensus on decisions. When there were lots of aspects to consider groups were conscious that they did not want to lose important, valuable information and input from others, but that there needed to be focus.
Building on existing knowledge and experience. Some systems already had connections with the community/people with lived experience via local charities or third sector organisations. This built on learnings, strengthened existing relationships and meant people are comfortable in making their voices heard.	**Working remotely.** Some groups felt it was difficult to co-produce and progress the improvement as a group when they could not meet in the same room. Groups felt it ended up being delegated to one person, then sharing for feedback.
Addressing potential power imbalance. One system tried to address the potential hierarchy between staff and people with lived experience by requesting members of team do not mention their role or who they worked for.	Some staff mentioned that it felt very different being led by people with lived experience, **some found it difficult not knowing the plan or outcome.**
Allowing time. Some systems noted the importance of allowing sufficient time to engage with people with lived experience before progressing on to co-producing an improvement.	**Time required.** It can be difficult for some people with lived experience to commit to the time required to progress the project
Differences between visions of staff and people with lived experience. Some staff highlighted having a different vision for the project to the people with lived experience and acknowledged that this was the importance of co-production and making meaningful improvements.	

“We’ve been kind of nail-biting, like we’ve not progressed fast enough in the time/space we were given, but actually it’s been **really important that we did spend that time** [engaging with a wider group of people], and **not jump ahead too early**, because otherwise we would have just gone down another engagement route.”

“I don't want there to be this **hierarchy**. From our first meeting, I think I mentioned that I didn't want people to mention their names, not necessarily their roles, who they worked for, what their status was in terms of health.”

“I'm a control freak so **it has been led by them and I've really struggled with that** because I like to know the end outcome”

“One of the issues of co-production I've found is time […] A lot of people who are affected cannot make the time and so we need to think a bit more flexibly around how we incorporate the ideas of others who are the most affected group”

“Sometimes you have many voices speaking and you want to get a **consensus** but you recognise that lone person who's speaking of lived experience is also right”

“My perception is that **it's really hard for paid members of staff to be challenged by patients**. I think it's very, very hard for paid members of staff to feel on the back foot, because the patient might know more than they do, and I think that has to be accepted within co-production, if we move on.”

“Our approach of **going through an organisation that has a direct relationship with the community** has paid dividends […] we wouldn't have known where to start [cohort] are a minority within a minority, so, getting direct access to them, would have been very, very difficult.”

Communication in plain English

How was this achieved?	Acknowledged needs/ challenges
Use of interpreters/translators. Some groups were working with people whose first language wasn't English, but it was important that everyone still had an equal opportunity to voice their opinions and experiences. To overcome language barriers, some groups had the opportunity to have the involvement of interpreters/ translators.	**Some groups experienced language barriers recruiting and when implementing activities.** One-to-one meetings were manageable, but in larger meeting situations, this was more difficult. For this group, translators were not accessible due to lack of funding.
Using consistent terminology. One system explained that to help people's understanding of co-production they have a very clear definition which they're consistently using in information that's produced	**Language barriers for implementation.** Some groups acknowledged that their survey had low accessibility and inclusivity, as they were unable to get it translated, due to lack of time and funding. Therefore, potentially missing a large proportion of the target population that they would have ideally heard from otherwise.
Active listening. One system noted the value from actively listening to people with lived experience, such as paying attention to the conversation and observing non-verbal communication. It was felt active listening allows for a richer understanding of the views and experiences shared.	
Easy-read materials Some systems ensured that questionnaires or other materials used to engage with, or gather feedback from, people with lived experience were easy to read and used plain English	

“I think that's another thing we could have done, given time we could have actually **had the survey in different languages**”

“One key thing that I’ve learnt from this work […] is actually **actively listening** […] to what people with lived and learned experience have to say, because […] there’s really rich feedback within that […] and within the corporate work, there is an innate desire maybe to sanitise it down, and paraphrase it, but actually learning to actively listen and to **actually note down exactly what they’ve said**, how they said it, because it is really emotive language, when they’re talking about their care.”

“We have quite a **clear definition** that we work to. We are trying to make sure that that is repeated and reflected in any kind of information that's produced, whether that's taken to the board or taken to even just our sponsors, just to make sure that we're very much […] continually using the **right terminology** to build up people's getting used to the terms.”

“She also **provided the volunteers who acted as translators during the events**. Also translated into, in some cases, into their own languages, the publicity and other material.”

“What I’ve done through the questionnaire is sort of, created an **easy read**. It was a really brief questionnaire”

A culture in which people are valued and respected

How was this achieved?	Acknowledged needs/ challenges
Giving the people with lived experience a platform to share their experiences and views not only allowed teams to explore the focus of the quality improvement, but also enabled the staff to signpost individuals to support that is already available. This benefits individuals that have engaged in the work, as well as contributing to the overall improvement focus.	**Reimbursement**. A few systems spoke of the challenge in knowing how to financially reward and recognise the contribution made by people with lived experience
Some groups were able to offer incentives and had funding for meeting rooms, refreshments etc, which they felt made it more appealing for people with lived experience to share their time and showed their time was valued.	**Recruitment was difficult** when services or staff were not active in the local community or where people had felt let down by local health services. Recruitment of people with lived experience was challenging where groups were focused on **conditions with stigma**, i.e. Diabetes.
Having connections with other organisations that have used a co-production approach people with lived experience know how to make themselves heard now and are familiar with the approach	In one case, a person with lived experience said it **requires confidence to make your voice heard** and that it can be **difficult to resolve an issue** if you have a different opinion to staff. The person has since disengaged with the group, in part because they felt they've made their point and they don't want to 'battle' anymore.
Flexibility in approaches to engagement A few systems noted the need to be flexible in methods of engagement. For instance, in one system children and young people were less comfortable joining meetings so were involved in different ways, such as contributing via WhatsApp.	There was difficulty in some groups around **integrating people with lived experience and certain staff groups**, in order to highlight the importance of the improvement. Other groups had **concerns about staff feeling criticised**, and had anxieties around sharing the findings from engagement work

"I think the other thing that I underestimated was the pain of people in that community…that sense of pain for the community that they are rejected, isolated, not included, it's not for them, and how **we needed to give them the time and the space and the opportunity to rant**, because they'd have to rant, in the nicest possible way, but we had to give them that space to be able to do that."

"One of the areas that's been more challenging than I thought it might be, […] is **reimbursement**. It's an area that everyone's grappling with. In terms of our system, nobody thinks that we shouldn't do reimbursement. At the working group it generated a lot of debate."

"The people with lived experience themselves that are coming into this forum now, and they've been in forums for a long time, they've been in groups for a long time. They understand how things work, how they can make their voice best heard, and I think that's the stuff that you can't get overnight. So, we are benefiting from that, people being quite **comfortable and confident in what they've got to say** as well, and able to share that, so we're **not starting from scratch**, which would take a longer time to get people in that space. I think we're definitely benefiting from that."

"The other reason I'm not quite as involved is because I feel that we've made our point and **I'm not going to battle if it doesn't go my way**, because it's splitting hairs. I'm not prepared to battle any more. I've made the points I wanted to make and **it'll be what it will be**, and that's fine now".

"They wanted to be involved, they just didn't want to come to meetings […] It's about our **flexibility**, that we learnt about. It's not about what we want them to do, it's about what they want to do."

Appendix: Systems in the cohort

Picker would like to thank the following systems for participating and for the time taken to share their experiences of co-producing a project in the NHSEI programme:

- Cambridgeshire and Peterborough Integrated Care System
- Central London Community Healthcare
- East of England Cancer Alliances
- Hampshire & Isle of Wight ICS and Dorset ICS / Wessex Cancer Alliance
- Lincolnshire Clinical Commissioning Group
- Nottingham and Nottinghamshire Integrated Care System
- Sunderland Clinical Commissioning Group
- Sussex Health & Care Partnership
- Wirral Clinical Commissioning Group (Living with and beyond cancer)
- Wirral Clinical Commissioning Group (End of life care)