NHS

**East of England
Clinical Networks**

NDTi

National Development Team for inclusion

Co-producing support for people with long-term health conditions: Evaluation of an NHS East of England co-production programme

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Executive summary

In 2014 the East of England Strategic Clinical Network (SCN) commissioned the National Development Team for Inclusion (NDTi) to run a programme to pilot ways of embedding and evaluating co-production and personalisation to support people with long-term conditions within the scope of the East of England SCN.

The programme was designed to develop and demonstrate a broad understanding and adoption of the principles of co-production across the East of England, whilst supporting a small number of localities to champion change and demonstrate how this can be achieved. This was done through a combination of action learning sets (ALSs) and in-depth sites. The programme ran from early 2015 to early 2016.

Action learning sets

Luton: Using co-production to develop a rare neurology disease pathway

Suffolk: Using co-production to support the Suffolk mental health strategy

Thurrock: Using co-production to improve the uptake of annual health checks for people with a learning disability

In-depth sites

Hertfordshire: Using co-production to support people with progressive neurological disease

Luton: Using co-production to identify crisis points for carers and commission practical solutions to the needs of carers of people living with dementia

South Norfolk: Asset-Based Community Development (ABCD) approach to mental health and wellbeing

This report describes the findings of an evaluation which has looked at the outcomes of this initiative based on the following three objectives from the original project brief, namely to:

a) Co-produce a personalisation approach to ensure there is an equal and balanced partnership between professionals providing services and those in receipt of them.

b) Achieve an outcome with a cohort of people who are able to say that there has been a qualitative and/or quantitative improvement in their outcomes from services as a result of co-produced service action.

c) Raise awareness, knowledge and expertise in such a way that the approaches to and implementation of co-production and personalisation can be sustained beyond the life of the project.

Overall findings

This report describes how all the localities involved in this initiative have made progress in learning about and using co-production as a working methodology. All have faced challenges and struggles in doing so, including it being more time-consuming and resource intensive than anticipated and it challenging some of the well-established power relationships and pre-conceptions. Nonetheless, there is a near unanimous view that the benefits derived from using co-production are positive and that the approach should be applied more widely. There is evidence that, in most locations, the knowledge of co-production is being embedded and will be continued and indeed spread into other areas of organisational activity.

For reasons illustrated in this report, actual service delivery change and resulting improved outcomes for individuals have not been achieved as anticipated by this point in time. There are nonetheless some clear and tangible positive outcomes from the programme, including early stages of evidence that alternative approaches to service delivery are taking shape that *should* lead to outcome and cost-effective benefits in the future and new plans and strategies being developed that have support from people who use services. In addition, we have identified:

- Notably different working practices being in place that engage people who use services, and commitments made to continue these beyond the project and into wider areas of clinical commissioning groups (CCGs) and related work

- An increased understanding between services and people who use services of perspectives and agendas

- Clear benefits described by participants from their participation, development of their skills levels, work competencies etc.

Key Learning Points

From this evaluation, we have identified 8 key learning points for the future development of co-production which can be used to inform future initiatives. While we think these will be of interest to anyone becoming involved in co-production, they are primarily aimed at people involved in developing and/or leading a co-produced initiative:

1.   You cannot co-produce a solution if you have not co-produced the identification of the problem/challenge

Co-production is not a tool that services or professionals can use to develop a (co-owned) solution to a problem that they have defined on their own without the involvement of people who use services. This, in turn, has a knock-on impact on the point below about time and expectations. Co-production means involving people from the start – and it may be necessary to go back to the start and revisit things that services and professionals believed they already had answers to.

2.   Co-production means everyone's active involvement

The clue is in the name! Co-production is not about handing over responsibility to someone else, it is about all partners retaining an active involvement in order to bring their particular knowledge and expertise to the work, along with their authority networks and connections. The disengagement of any one partner weakens the enterprise. It is particularly important that diverse groups of people, such as those who use services, are represented by those who are well connected with and understand the issues of concern to the wider community.

3.   Co-production does not work if people have pre-defined answers

Linked to the first point co-production means all participants being willing to explore different ways forward to those they might have started out with, and putting pre-determined solutions to one side. If there are genuine non-negotiables around an issue, these have to be declared at the outset and everyone be aware of them and accept them prior to engaging in co-production. Beyond that, people's favoured ways forward have to be up for negotiation – otherwise tensions will arise and co-production is unlikely to work.

4.   Leadership styles needs to be facilitative and appropriate

Leaders will be found in different places in co-production, not just in a manager or similar who is responsible to the statutory sector for delivering change. Those leaders need to be identified and appointed on the basis of their abilities to bring together a facilitative and creative approach, networking skills and a focus on delivering outcomes.

5.   Do not expect short-term service change when starting out with co-production - set realistic expectations for outcomes

It takes time to undertake effective co-production. Firstly, people need to understand the nature of co-production and how to take it forward. Secondly there needs to be trust and understanding between the different parties. The most rapid progress was made where key players understood the concepts and knew each other before this work started. Where those (and other things) are not in place, additional time is needed. Whilst there will be short-term learning and change achieved, this is more likely to be around behaviour and process (see below) than actual service change.

6.   The starting point for change is cultural and behavioural

The first thing that will be seen and observed when using co-production will be different behaviours and actions by all the partners to a co-produced change. Listening to and acting upon information that was not previously heard, operating in different ways to include people, considering different types of solutions – these are all inevitable consequences of co-production. They will therefore be the things that can be seen and evidenced before service change takes place.

7.   It is essential to evidence the outcomes of co-production

Given that co-production is time and resource intensive, and often requires people who use services to give their time up to participate, it is essential that the benefits of co-production can be evidenced. This means placing the collection of data and information about the outcomes of a co-produced initiative as an early agenda item and involving people in the work who have the skills, time and access to information.

8.   It is different everywhere

Given all the above points, and the huge variety of issues and organisational constructs within which co-production can be used, there is no template for how to do it. There are a series of questions that can be put, and issues to be considered (the points in this section being amongst them) but there is no set way to go about co-producing a service change – beyond adherence to the core principles of what it is and what it is not.

1. Introduction and overview

In 2014 the East of England Strategic Clinical Network (SCN) commissioned the National Development Team for Inclusion (NDTi) to run a programme to pilot ways of embedding and evaluating co-production and personalisation to support people with long-term conditions within the scope of the East of England SCN.

This report describes the findings of an evaluation which has looked at the outcomes of this initiative based on the three objectives described below under 'programme objectives'. It seeks to identify the learning from this NHS England funded initiative, specifically with a view to identifying how future co-production initiatives can use that learning to maximise the potential for:

(i)   action described as co-production being genuinely that, including it being a positive experience for those involved; and

(ii)   co-production resulting in improved services and outcomes for people.

While we think that the learning explored in this report will be of interest to anyone becoming involved in co-production, it is primarily aimed at people involved in developing and/or leading a coproduced initiative.

Definitions used in this report

Co-production: Organisations and local citizens working together, as equals, to design, deliver and improve opportunities, support and services that enable people to have a good life and communities to flourish.

Experts by experience: Someone who has expertise as a result of lived experience of a condition, of receiving a service or of being a carer. In this report we use this term to include patients, service users, people with long term conditions and carers.

Professionals: In this report we use the term professional to include any individual employed in a health, local authority or voluntary or community sector organisation.

The core principles of co-production as described by the Social Care Institute for Excellence[1]

1. Equality – co-production starts from the idea that no one group or person is more important than any other group or person. So everyone is equal and everyone has assets to bring to the process.

2. Diversity – diversity and inclusion are important values in co-production. This can be challenging but it is important that co-production projects are pro-active about diversity.

3. Accessibility – access needs to be recognised as a fundamental principle of co-production as the process needs to be accessible if everyone is going to take part on an equal basis. Accessibility is about ensuring that everyone has the same opportunity to take part in an activity fully, in the way that suits them best.

4. Reciprocity – 'reciprocity' is a key concept in co-production. It has been defined as ensuring that people receive something back for putting something in, and building on people's desire to feel needed and valued.

1.1   Programme objectives

The objectives of the programme were to:

a)   Co-produce a personalisation approach to ensure there is an equal and balanced partnership between professionals providing services and those in receipt of them. This will represent a major shift in thinking allowing individuals to actively contribute and share in the design and delivery of services.

b)   Achieve an outcome with a cohort of people who are able to say that there has been a qualitative and/or quantitative improvement in their outcomes from services as a result of co-produced service action and that there is evidence to back this up.

c)   Raise awareness, knowledge and expertise in such a way that the approaches to and implementation of co-production and personalisation can be sustained beyond the life of the project.

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[1] Social Care Institute for Excellence (2015), Co-production in social care: What it is and how to do it, London: Social Care Institute for Excellence, www.scie.org.uk/publications/guides/guide51/files/guide51.pdf

1.2   The programme

The programme was designed to develop and demonstrate a broad understanding and adoption of the principles of co-production across the East of England, whilst supporting a small number of localities to champion change and demonstrate how this can be achieved. This was done through a combination of action learning sets (ALSs) and in-depth sites. The programme ran from early 2015 to early 2016.

Action learning sets

This element of the programme brought together three groups of local partners for personalisation within the NHS together four times over the year to share their learning and experiences. The intention was that each person should come to this with partners from their local user led organisation or other expert by experience. Each group identified a service change or issue that they wanted to address in a co-produced and personalised way. People brought real-time issues, experiences and successes to the meetings that their peers across the region could help them to solve, progress and learn from. ALS projects did not receive funding.

In-depth sites

This element of the programme involved working in-depth with three local areas to build and demonstrate the local impact of co-production for people with long-term conditions across the East of England with support provided by NDTi. This entailed:

● NHS England (East) identifying three areas where there was a commitment from (i) the senior management (including clinicians) and (ii) local commissioners, to try out a co-produced approach to addressing a service issue or challenge they are facing

● Undertaking short, focused work with those stakeholders to explore and share a common understanding of approaches to co-production

● Using co-production approaches, taking the identified issue(s) to be addressed and agreeing/designing a service change/development process

● Taking forward the proposed change process as identified – including ensuring that the co-production principles underpin how this is done and supporting people to build in evidence based change techniques.

The sites received funding from NHS England to help resource local action and were also allocated 12 days of input from NDTi to be used as agreed with them. The specific nature of NDTi's input to each local area was agreed with them on the basis of the task being addressed, the support that was needed, and the current state of expertise in each area

around co-production and personalisation. NDTi also aimed to facilitate the three sites to learn from and with each other. The aim was to build the level of knowledge and confidence in each site so that they can increasingly be autonomous in delivering this work and thus also be a resource to other localities in the east of England.

Evaluation

As part of the programme NDTi was also commissioned to evaluate the programme and produce a final report – the methods involved in the evaluation are detailed below.

1.3   The six projects

Following an application process, the following sites were selected:

Action learning sets

Luton: Using co-production to develop a rare neurology disease pathway

Suffolk: Using co-production to support the Suffolk mental health strategy

Thurrock: Using co-production to improve the uptake of annual health checks

In-depth sites

Hertfordshire: Using co-production to support people with progressive neurological disease

Luton: Using co-production to identify crisis points for carers and commission practical solutions to the needs of carers of people living with dementia

South Norfolk: Asset-Based Community Development (ABCD) approach to mental health and wellbeing

1.4   Evaluation methodology

The broad approach taken in this evaluation is based on a tried and tested methodology called 'realist evaluation', which seeks to answer not just "does it work?" but, "what works, for which people, in which set of circumstances, how and why?". This approach is well suited to programmes such as this, where changes may be long-term, complex and are likely to be influenced by a range of external variables for which it is not possible, or necessarily desirable, to control. Although traditional evaluation designs can shed light on

what is or is not effective, they are unable to answer the crucial questions of why something works, who it works for, and the circumstances in which it was made to work. Realist evaluation addresses these complexities by encouraging evaluators to map out the logic behind the project or programme that is being evaluated, and to articulate the assumptions that lie behind their programme, linking the contexts, mechanisms and outcomes; i.e. "Why do we (stakeholders) think that doing things in this way (or in this place/time) will bring about the change we want?".

In-depth sites

The in-depth sites were evaluated through a series of stakeholder interviews and the mapping of logic models for individual sites. Interviews were conducted in the in-depth sites at three stages:

- February 2015 when the projects were getting started

- September 2015 when the projects were mid-way through

- February 2016 at the end of the projects

The first set of interviews allowed us to build up an understanding of the context of the projects, explore the projects' desired outcomes and to learn about individual's knowledge, expectations and attitudes towards working in co-production. The second set of interviews focused on the activity of the co-production groups, progress towards outcomes and experiences of working in co-production. The final set of interviews allowed individuals to reflect back over the project and identify what worked, what didn't work, what has been learnt and what will change going forward.

Following the first set of interviews individual logic models for the projects were mapped out, which considered the context and rationale behind the projects, the inputs and activity of the projects and sought to identify the anticipated outputs, outcomes and long-term impact. In April 2015 all three in-depth sites met together for a workshop to give the project groups the opportunity to agree on the logic model and to identify what data could be used to measure the outcomes.

In total 59 interviews were conducted with 42 different individuals, totalling 79 interactions, including:

- Experts by experience

- CCG commissioners

- Local authority commissioners

- Public Health specialists

- Other local authority staff (including project manager, assistant director)

- Health professionals (including GP, community matron, occupational therapist)

- Voluntary sector professionals (predominantly managers)

Interviews were conducted either one to one or in small groups of two or three. Most were conducted face to face with some by telephone where the individual was not available to meet face to face. Some people were interviewed at all three stages, some were interviewed at two stages and some were only interviewed at one stage.

Action Learning Sets

Due to the level of resource available it was not possible to conduct an in-depth evaluation of the three ALS projects. The ALS were therefore evaluated with a series of four surveys: before the first ALS meeting (baseline), two through the year and one after the final ALS meeting. The surveys asked individuals to self-rate their knowledge, experience and attitude towards co-production, outline initial desired outcomes and to comment on progress towards the outcomes and challenges faced.

Anonymity

Many of the individuals interviewed were very open and honest in the interviews, and, as is explored below, some found working in co-production had its challenges, both personally and professionally. In order to respect the honesty and openness of individuals (which has been key to the evaluation) and to protect the anonymity of individuals, quotes used in this report are not attributed to individuals, and, with exception of section 3 where activity and outcomes are outlined, the experiences and challenges described have not been attributed to individual projects.

1.5   About this report

The purpose of this report is to explore the findings of the evaluation of the co-production programme. The findings are reported in three sections which link to the initial aims of the programme:

1.   **Co-producing an approach to the design or delivery of services**: This section reports on how the projects worked in co-production, the challenges they faced in doing so, the lessons they learned and the outcomes achieved around working in co-production.

2. **Achieving an improved service outcome for people**: This section reports on the activity undertaken by the projects and the progress towards achieving outcomes towards the service change or issue being addressed.

3. **Sustaining co-production**: This section reports on the wider impact of the projects in local areas going forward.

As is clear in the sections below, the exact experiences of the six projects varied for a range of reasons including: the condition or need being focused on; the particular issue or change being addressed; and the local, national, historical and organisational contexts. However, it has also become clear through the evaluation that there were common experiences across all or most of the projects, and that where experiences differed, this has been drawn on to highlight what has worked and what has not worked. The emphasis in this report therefore, is to focus on overall experiences, learning and lessons. It should be highlighted that this programme was designed and implemented as a pilot project to learn about using co-production as an approach to addressing service needs or issues and in order to develop and embed co-production more widely. As such the emphasis in this report is as much on learning from the challenges the projects faced, as well as celebrating the successes.

2. Co-producing an approach to the design or delivery of services

> **Co-produce this personalisation approach** to ensure there is an equal and balanced partnership between professionals providing services and those in receipt of them. This will represent a major shift in thinking allowing individuals to actively contribute and share in the design and delivery of services.

2.1 Understanding co-production?

For most of the people involved in the six projects, co-production was a new way of working. To varying degrees people were aware of co-production, were interested in the concept of co-production and various people had been involved in engagement and consultation, but few had been actively involved in using co-production as an approach to addressing a service issue, problem or challenge. A minority of people initially had little understanding and/or saw co-production as no different to past 'user involvement' initiatives.

Perhaps unsurprisingly since most of the people on board at the early stages had been involved with the application and had actively sought out the opportunity to work in co-production, there was a general overall enthusiasm about co-production. One of the ALS survey questions asked participants to rate their overall attitude towards co-production with 0 being "I am sceptical about co-production" and 10 being "I am enthusiastic about co-production". In the first survey, before the first ALS meeting individuals gave a rating of between 6 and 10, with an average of 8.6.

There were also differing levels of understanding about co-production at the outset. A handful of people understood the concept and wanted to promote it, whilst others did not grasp its content or significance – thus highlighting the importance of early work to promote a shared understanding of meaning and the systemic and cultural changes involved. For example:

"It's not really different to what we've been doing for many years – just a new name" In-depth site professional (Health)

"It means having a steering group so we listen to people more" In-depth site professional (VCS)

Amongst those people who did broadly understand the concept, there was evidence of an element of apprehension:

"It excites me, we're doing something different… but it scares me a little" In-depth site, professional (CCG)

"I'd never heard of co-production, it's new to me. No-one's ever asked my opinion, it's like a breath of fresh air – I'm cautiously optimistic" In-depth site, expert by experience

"We've done loads of consultation it's in the blood – but co-production is completely new" In-depth site, professional

In this section we explore and reflect on some of the key challenges these "cautiously optimistic" people experienced as they embarked on this new approach, and some of the lessons learnt.

2.2   How do we *do* co-production?

Following the general enthusiasm about the concept, there was evidence of some uncertainty about how to actually *do* co-production. Although the groups had introductory workshops on co-production and were provided with support, there was a lack of confidence in how to get started. In addition, people who became involved at later stages of the projects did not get to benefit from these sessions. People commented that although they understood the principles of co-production they were apprehensive about actually doing it.

This was particularly challenging for some of the professionals, particularly some of those who had been involved in applying for the project. These professionals were used to being the ones with knowledge about service delivery and design and felt that they should be able to guide or support the experts by experience - but co-production was new to them and they were learning it alongside the experts by experience. Although this change in the dynamics of the relationship initially felt uncomfortable for some professionals, when they reflected back on the project they identified that learning together side by side was important in contributing to the building of trust between the group members.

There was some evidence of an ongoing checking or self-reflection about whether what they were doing was co-production through the project, for example one professional commented mid-way through the project:

"We have been trying to do it – but we're constantly reflecting and checking back. Everyone tells us we're doing it – but are we actually?" In-depth site, professional (LA)

Another group chose to formally self-evaluate their experiences as part their project, reflecting on and writing up their experiences in a report.

This self-reflection proved important as without it there were risks to the process of co-production – for example, that co-production might be understood as handing complete

power and authority over to one or both of the voluntary sector or people who used services. The continuing and ongoing involvement of the statutory sector, bringing knowledge and expertise as well as decision making authority, was not always understood as part of co-production.

"They're doing such great work, we've just let them get on with it" In-depth site, professional (Public Health)

For one group the self-reflection enabled them to identify and address a problem at an early stage. A particularly vocal VCS group member was behaving as if they were the voice of people with lived experience and as such dominated the group and inhibited experts by experience from speaking up. Recognising that this was hindering co-production, this individual was asked to step down from the project.

As the projects progressed and by the end of the programme, as they reflected on what they had learnt about co-production, many people came to realise that to understand co-production you have to do it.

"I think you have to do it to get it, rather than talk in the abstract." ALS participant, professional

Although at times it was a challenge to get on and do it, it was clear that the learning came from the doing and reflecting.

A particular issue arose where co-production was taking place in relation to people whose health conditions meant they were either one of a very small number of people in a locality and/or they had life-limiting conditions. Co-production to date has largely been developed around those who were part of a significant, relatively identified group of people - people with mental health problems, older people, etc. and where time is a relative luxury. This initiative identified that different approaches to co-production are needed when co-producing with people who may have different labels or time constraints – though the scale of this project meant that it has been possible to do little more than scratch the surface of learning about this.

Lessons learnt:

You have to do co-production to understand it

There is a need for an ongoing process of reflection and learning

Further work is needed to develop and understand co-production with people outside and beyond the usual main health and social care 'client groups'

2.3   Co-production is demanding

While it was recognised by the project groups that working in co-production would require more in terms of time, resource and effort than other ways of producing service change, an almost universal experience across the groups was that the demands of working co-productively exceeded their expectations. People involved in the groups invariably talked about it being "hard work". Unpicking this, it seems that this was in part to do with the time it took

> *"It is really time consuming" In-depth site, professional (VCS)*

> *"I'd never ever understood the resource needed – the time!" In-depth site, professional (LA)*

This was a particular problem for the professionals in the ALS groups who had not received funding and so were doing it in addition to their usual responsibilities i.e. engagement in co-production had not been legitimised by their managers as a priority for use of their time:

> *"The added work load to our project manager and the team were quite unmanageable at times" ALS, professional (VCS)*

However, it should also be noted that despite these time demands, all of the people involved in the ALS made the choice to find and keep finding the time.

As well as taking up a lot of time, it also took a longer time period than anticipated for the projects to get going:

> *"Co-production can feel quite frustrating, it's felt like progress is not quick. The ethos and principles are correct but it's slow and frustrating." In-depth site, professional (CCG)*

> *"Progress is slow; it takes longer to deliver to be as inclusive as possible" ALS, professional (health)*

As this health professional highlights, being inclusive, involving a range of experts by experience and stakeholders takes both a longer time period and a greater amount of time than working in other ways.

An important lesson however, was that this time and energy, though more demanding than expected, was often key to making it work. One group reported that while things had felt very slow, time consuming and frustrating at the beginning, with lots of meetings where it felt like they didn't get anywhere, as they looked back they could see that the time spent together was what had made the group and the project so strong.

"I think with co-production you need to travel that journey together" In-depth site, professional (VCS)

Getting to know each other, learning together, and coming to shared decisions allowed them to build confidence and trust in each other. They were able to recognise that the time and energy involved was not wasted time and energy but was key to making co-production work.

In addition to a greater demand on time than expected, people have also found the projects more emotionally demanding than anticipated. While several people talked about their real passion for the work and for the projects, they also recognised that this can be quite emotionally draining as a result.

"I have never had such a rollercoaster of a ride… it's a constant up and down." In-depth site, professional (LA)

While some of the groups had identified the need for practical support for experts by experience – for example funding for support for people with long term conditions when carers were involved – the need for emotional support was underestimated. Because of the range of conditions covered among the groups, there were instances of people whom the groups had been talking to significantly deteriorating in health and even dying. Through involvement with the projects some people met or heard from people at a more advanced stage of the condition then themselves or the person they cared for and got an insight into what the future may hold which caused distress.

"We were discussing pathways, end of life – with people who don't have long to live. Where is the support structure? Who do I talk to? Where do I go?" In-depth site, expert by experience

Some professionals found that they had an unplanned role in providing emotional support to experts by experience. Furthermore, some of the professionals also found the issues that were being dealt with and the conversations they were having with people distressing themselves. None of the projects had considered the support structures required for professionals.

Lessons learnt:

Don't underestimate the time and energy needed when planning a project (physical, mental, emotional)

The time and energy is not wasted – it can be the key to making it work

Think about support structures – for people with lived experience, carers and for professionals

2.4   Achieving an equal partnership

Although as noted above, there was a widespread commitment to the ideas, theory and principles behind working together as equals, the groups found that in practice this could be challenging in a number of ways.

2.4.1   People come to co-production at different starting points

Firstly, the people involved in the co-production groups were at different stages in their knowledge and experience in delivering service change, co-production and the subjects in question. Some of the professionals in the groups (probably through having identified the issue and having been involved in the bid process) were keen to get going and were frustrated by some of the initial meetings, which tended towards being dominated by experts by experience talking about their experiences.

"Practically equality is hard. It's easy to understand on paper, but doing it is a different kettle of fish. Some people have needed encouragement, we've had to give [experts by experience] time and space to step off the hamster wheel and think about what would help" In-depth site, professional (health)

"It takes time for everyone to get to the same page" In-depth site, professional (CCG)

This is one of the factors that contributes to explaining the point raised above – that co-production takes more time than other approaches. Allowing time to get to the same page was important in developing equal and respectful relationships within the group, which was in turn key to realising and enabling each member's individual contribution.

2.4.2 The biggest challenges to co-production arise when equal partnership is threatened

The importance of having an equal partnership was emphasised strongly through the key finding that the biggest challenges arose when shared or equal partnership was threatened. This was evidenced in two particular challenges, both of which were experienced in more than one of the groups.

The first was through key people stepping out or stepping back from their involvement in the co-production projects. Although who this was varied across the projects, three of the projects experienced problems with health commissioners not engaging at all or dropping out after some initial involvement. In some of the projects voluntary and community sector (VCS) organisations who had been part of the initial bid dropped out of the projects. Other groups identified people or roles who in hindsight it would have been useful to have been involved, or whom they had tried to involve but had not taken up the offer. In another case, limited commissioner involvement allowed the focus of the work to drift away from the original intention, and this had to be corrected part-way through.

The second was through key people remaining in the groups but being unwilling to move from set agendas. This was a particularly difficult challenge for the groups to deal with. Several professionals acknowledged they had preconceived ideas of what they thought (or hoped) would come out of the co-production projects. Some of these expressed this in terms of being up front and acknowledging it – they recognised that it was difficult in practice to be truly open and not influenced by past experiences but they were genuinely committed to co-production and were prepared to be moved from these agendas. Others had clear agendas and the difficulty arose when people were not prepared to shift on these agendas. For one individual it was clear from the initial interview that he was hoping to "use" co-production to get the solution his organisation wanted:

"I see in co-production an opportunity to use our voice and say we have evidence to say […] is the solution" In-depth site, professional (VCS)

When people with set agendas remained involved in the co-production project but did not move in line with the project as a whole, this caused significant difficulties within the groups. It undermined the relationships that had been building and created conflict between individuals. Ultimately it challenged some individuals' experiences of co-production and threatened the continued existence of the co-production group.

"It's overshadowed the really good work we've been doing" In-depth site, professional (LA)

Interestingly, in contrast to what was perhaps anticipated, the problem in achieving equal partnerships within the co-production groups did not lie between professionals and experts by experience, but between different groups of professionals – e.g. between people in the statutory sector and the voluntary and community sector, or between CCGs and local authorities. Indeed, we did not come across any expert by experience who had felt that they hadn't been treated as an equal partner:

"It feels equal – I've really felt I can say stuff, especially as the meetings go on… It's a committee's decision rather than one professional making a decision." In-depth site, expert by experience

"It feels genuine, not tokenistic. I feel part of the team. My biggest concern was putting forward my view, them saying thanks and doing the opposite – but it feels different." In-depth site, expert by experience

"I can confidently say everyone who has been involved has experienced inclusivity" In depth site, CCG

As one professional observes, she doesn't think this was what experts by experience expected:

"[Experts by experience] expected a fight, now they're coming into contact with enthusiasm from professionals – it's good for them to see" In-depth site, professional (LA)

The fact that professionals have been keen to work in partnership with experts by experience and have been shown to be willing to move from their own agendas has had an important impact on the trust that experts by experience have in the process.

2.4.3 Negotiating power and equality with roles and responsibilities

Although not overt, there were some interesting dynamics within the groups in trying to negotiate equality within the different roles they had acquired or been given.
In most of the projects there were a range of people with some kind of leadership responsibility, most projects having variations of: an individual who had driven the project and led the application process, an appointed project manager and a chair of a project or steering group. Some of these had been given the task of managing the project as part of their day job, others had applied for a position, others were nominated and others self-appointed. Some people were involved on a voluntary basis (usually having their costs covered in the in-depth sites, but not for the ALSs), some people were involved through their paid employment so were involved during employed hours, others were employed by the projects to take on a particular role. Though this didn't create overt tensions in any of the projects, it did create a level of inequality in that some of the people in paid roles took on, or felt a greater sense of responsibility - both for the outcomes of project and a responsibility to protect some of the experts by experience either from the challenges experienced or from feeling burdened by the project.

Some of the professionals faced particular challenges in negotiating the appropriate power balance within project groups. Many professionals are used to working behind closed doors and presenting a solution to service users, but co-production is open and exposes the nitty gritty messiness of the way organisations work and the way decisions are made. Professionals had to let down their professional boundaries, open the doors and let experts by experience in.

On the other hand, at certain stages, in some of the projects professionals were being so careful not to dominate or assert their views, there was a concern that the balance of the power was going too far towards the experts by experience with professionals holding back from expressing their views. As well as not necessarily being an equal space for everyone this has the danger of losing professional involvement:

"We're potentially losing the co-production element – there is a see saw of professionals and service user involvement – there is a danger of going too far the other way, that we're not keeping the professionals involved" In-depth site, professional (CCG)

These points highlight the delicately balanced nature of power in the relationships within the co-production groups and the potential impact his can have on co-production.

2.4.4 The Importance of Leadership

Within each initiative, leadership was located in a different way and in a different place or location. Whilst in most cases this was formally through some form of steering group, in reality the leadership was coming from one or more individuals who were driving the work forward. The leadership style adopted by those people equally varied – some being facilitative, others being more directive, some very much taking personal ownership of the outcomes, others seeing this as a work task to be delivered. Co-production requires a different culture and behaviour from leaders to that which is, arguably, traditionally found in either the statutory sector or many service delivery focused VCS organisations. It has to start from belief systems such as accepting that knowledge and wisdom lies in the room rather than in the leader, that the end point of the 'journey' will be unknown at the outset as people's views are listened to, and that, whilst the leader has to support outcomes to be achieved, different types of authority and decision making are in place. Some of the difficulties and challenges we observed within different projects arose from the application of traditional leadership behaviour in a co-production environment where different approaches may have been more productive.

2.4.5 Difficulties engaging people with lived experience

In order to achieve equal ownership there needs to be the right level of engagement from experts by experience. Although this was recognised by the projects from the outset and they were all very committed to this, in practice it proved difficult to engage and retain experts by experience for some of the projects for a range of reasons. In particular, some of the ALS groups who had less time and resource to dedicate to this found it particularly challenging. Furthermore, the nature of some of the conditions posed additional challenges – some people were facing quite rapid deterioration and some became too ill to stay involved. Some of the groups who quite successfully engaged a keen cohort of experts by experience recognised that they did not reflect the full range of experiences – for example they did not reflect the ethnicity of the local population, or they did not reflect the range of conditions that the project focused on.

Lessons learnt:

Co-production does not work if people have pre-defined answers

Everyone will have an agenda – acknowledge and be open about these from the start

It can take time for everyone to get to the same place

Leadership styles need to be facilitative and appropriate

Co-production means everyone's active involvement

2.5   Fitting co-production into existing culture and structures

A final set of challenges the groups experienced in their projects were the challenges which arose from trying to fit a co-production approach into the existing structures and culture of NHS settings or processes.

Most groups experienced tensions between working in a co-productive way and the need to comply with the demands of an NHS funded programme. The nature of co-production means it must start with an open and relatively unstructured agenda to allow for genuine co-production to happen. As one person commented:

"Sometimes it really is just 'trust the process' and be prepared to have your outcomes adjusted as you learn more from the experts by experience." ALS, professional (VCS)

However, on the other hand the projects received public funding and the NHS has a need to be accountable for this by demonstrating clear outputs or outcomes, value for money and to fit with reporting timetables. Both the demand to demonstrate clear outcomes (see next section) and the need to deliver within a year caused challenges (as discussed in the sections above around time demands).

At the heart of this is the notion that effective co-production involves different partners learning about and from each other – and crucially adapting normative behaviour in order to operate in ways that could be understood by, and acceptable to, co-production partners. One site conceptualised this in terms of Squares (the statutory sector and service focused voluntary sector) and Blobs (experts by experience). The Squares needed to become more blobbish and the Blobs more squarish. One aspect that was identified as particularly crucial to this was that of the language used and the communication methods applied. For example:

"I can see small ways in which they've changed how they behave (examples given) – but that is really important" In-depth site, professional

"When the CCG talked about outputs, we didn't always know what they meant" In-depth site, professional (VCS)

"We used pictures and graphics, they are a common language" In-depth site, expert by experience

It became clear that for co-production to be effective, one key was genuine wider organisational buy-in. Although all of the projects had sign off from senior NHS staff, there was a difference between whether there was genuine buy-in throughout the organisations or whether it as nominal support for the general concept. Some groups reported buy-in at the very top, but more difficulties with the layers and structures in between. There was limited benefit if there wasn't real wider organisational support for co-production as good work would not produce change.

In addition there were difficulties in fitting the co-production into specific organisational structures. Responding to a question around challenges, some ALS participants responded:

"Progress depends upon development work and commissioning timetables" ALS, professional (LA)

"staff changes, organisational structure, processes being very bureaucratic", ALS, professional (CCG)

Again, the open and relatively unstructured nature of co-production does not necessarily fit neatly into existing structures and processes.

> Lessons learnt:
>
> There needs to be genuine wider organisational support
>
> Although cultural change happens sooner than service change (see below), it needs to be a recognised that cultural change takes time

2.6   Outcomes around co-production

Despite the challenge described above, the projects all achieved significant outcomes in the areas of working in co-production, ensuring an equal and balanced partnership, achieving a major shift in thinking and sharing in the design and delivery of services.

2.6.1 Understanding about co-production

There is strong evidence to show that people's understanding of what co-production is and how to work in co-production has increased.

"In my head I thought it was patient engagement wrapped up in a different name – it's not. The badges and roles have gone… everyone brings their own skill set." In-depth site, professional (VCS)

"In the beginning professionals thought it was just another word for consultation, we "knew" what the outcomes were going to be… then actually everyone has evolved, the preconceptions have gone out of the window, our eyes have been opened to a new way of working." In-depth site, professional (LA)

"With co-production the issues are on the table, the group takes ownership." In-depth site, professional (VCS)

The ALS survey which asked respondents to self-rate their knowledge and understanding of co-production showed that the average rating increased at each survey, from 6.1 in the first survey to 9.3 in the final survey.

2.6.2 Different actions arising from co-production

There is also a recognition of the impact of co-production on the outcomes of the projects with projects recognising that co-production has produced different outcomes:

"The findings are definitely different than if it had been done by professionals" In-depth site, expert by experience

"The results are not what I expected – I thought it would be big things like [new services or more care] – the things we're getting from [experts by experience] are very different, it's processes, like they want people to get back to them when they say they will, they want peer support" In-depth site, professional (LA)

"It's a committee's decision rather than one professional making a decision. I think the outcomes will be very different." In-depth site, expert by experience

"The results are better and validated and it has made a difference to the findings" In-depth site, professional (CCG)

In the final ALS survey people were asked what impact they felt working in co-production had on achieving the outcomes of their project – 50% thought it definitely helped, 33% said it helped to some extent and 17% thought it didn't have an impact.

2.6.3 A sense of progress with the issues

Whilst, as noted below, measurable change in services cannot be identified, with a number of projects there was clearly a sense and belief that this co-production project had resulted in progress being made across a range of issues.

"Everything we've got back is applicable and usable" In depth site, professional (CCG)

"Relationships have developed – it's broken down walls and got people talking together about different concepts" In depth site, professional (CCG/LA)

"We have learnt to ask questions in a different way – thinking community and prevention rather than services all the time" In-depth site, professional (CCG)

2.6.4 Embedding co-production

As a result of increased understanding of co-production and recognising the different outcomes it produces, most of the individuals involved in the projects are committed to co-production going forward.

"I can't imagine ever trying to do another service change without involving members of the public ever again – to do so would be a nonsense… It must be used to make changes." In-depth site, professional (health)

"Would I work in this way again? I'd jump at it a million times over" In-depth site, expert by experience

Several of the experts by experience have already become involved in other work being co-produced including work on personal health budgets. Several are continuing their involvement with the groups that have been set up for this project beyond the 'official' lifetime of the project. Some of the professionals, from both voluntary and statutory sector talked about taking what they've learnt about working in co-production into their respective organisations.

Despite widespread support for working in co-production as a result of their experiences through this project, there was also some cautiousness about whether it is always the right approach to use, or whether it was practical to use co-production for every service change.

"I think it's probably the right way to go but to do this with every project would take a long time" In-depth site, professional (CCG)

"I know co-production is the way forward but it should not be used for everything – it needs to be specific and realistic" In-depth site, professional (LA)

There was also some hesitancy among some experts by experience who felt that they needed to see what changes arose from the projects before they could decide:

"I'm not sure whether co-production is the best way… the concern is what happens next" In-depth site, expert by experience

"The proof will be in the pudding… Overall the idea is good, the idea of the project is good, I hope something comes out of it if not… well" In-depth site, expert by experience

2.6.5 Benefits to the people involved

Although this cannot be a justification in itself for investing resources in an initiative such as this, we were also struck by the frequency with which it was described how the people directly involved in this work had benefited. Notwithstanding the earlier comment about how, in some cases, the work had been stressful for some, there were examples of how the experts by experience involved in the work had developed their repertoire of skills and knowledge, been able to use that for life benefits beyond the project and taken the benefits into other areas of life. One person described this work as "possibly the best thing they have ever done". This benefit extended to some people from the statutory sector, who were able to identify how they had 'grown' personally as a result of involvement in the project.

3. Achieving an improved service outcome for people

Achieve an outcome with a cohort of people who are able to say that there has been a qualitative and/or quantitative improvement in their outcomes from services as a result of co-produced service action and that there is evidence to back this up.

While clear outcomes have been achieved in the aim of people experiencing and learning about working in co-production, the programme has been funded because of an underlying assumption that working in co-production to address a service need or issue will ultimately produce better service outcomes for people. This section provides an overview of the activity undertaken and outcomes achieved by the six projects, and then considers some challenges the project faced in producing measurable improved outcomes from services for individuals and what can be learnt from these challenges.

3.1   Projects and outcomes

Luton: Using co-production to identify crisis points for carers and commission practical solutions to the needs of carers of people living with dementia

Aim: To give carers an opportunity to identify difficulties and worries that contribute to stresses and breakdown in their caring role and to further identify what would support them – the things that would 'make a difference'.

Desired outcomes:
* Stronger relationships and partnerships are established across the dementia environment in Luton

* Service redesign delivered through a co-productive process

* Carers of people living with dementia are engaged in service development and redesign

* Longer-term – reduction in causes of carer stress and carer breakdown

* Longer-term – more people living with dementia will be able to stay in their own homes longer, with effective support for them and their carer

Activity and outputs:
* Set up Project Implementation Board group Chaired by expert by experience

* Training for carers to carry out peer supportive interviews

* Recruitment of carers to conduct interviews

* Conducted around 80 carer to carer interviews and two focus groups asking: 1) What are the things that you find most difficult? What do you worry about? And 2) What are the one or two things that would support you in your caring role?

What is the one thing that you think – if only I had that, it would make so much difference?

- Collated and analysed results

- Identified key themes for change to take forward

- Implementation of quick changes (low cost/high impact) e.g. virtual dementia tour

- Production of graphic representations of findings in format of 'support tree' and 'stress tree' and support and stress venn diagrams

- Self-evaluation and report of the group's experiences of working in co-production

- Final report of findings from carer to carer interviews

Next steps:
- Develop an on-going pathway/inform Luton's joint dementia strategy

- Commission dementia services based on local needs, as evidenced through carer to carer interviews

Hertfordshire: Using co-production to support people with progressive neurological disease

Aims: To use co-production to scope the width, efficiency and effectiveness of support currently available for people with progressive neurological conditions; to identify common issues and concerns and to co-produce recommendations for future neurological support; and to develop co-produced information for people who use neurological services.

Desired outcomes:
- Improved experience for services users

- Improved choice and control

- Improved potential for independence

- Improved quality of life

- Standardised and integrated care

- Care closer to home

- Access to accurate and timely appropriate services

- Improved self-management

Activity and outputs:

- Project group established with experts by experience, carers and professionals

- Expert by experience employed as Chair

- 11 service user listening events

- 80 people spoken to

- Information from listening events collated

- Service scoping

- Patient pathway developed using information gathered

- 'Map of medicine' for GPs improved

- Production of an 'information wheel'

- Production of 'information on prescription' for GPs

- Information fed into equipment and wheelchair service reviews

- Work with local information phone line to signpost people to services

- Work with CCG and council boards on co-production

Next steps:

- Feed information gathered feeding into business case with recommendations

- Business case to go through commissioning process

South Norfolk: Using co-production to develop community based supports for people living with mental health conditions

Aims: To use coproduction in tandem with an asset based community development (ABCD) approach in order to develop and access mainstream community resources that people with mental health conditions can link into as alternatives to, and as prevention to avoid, use of secondary mental health provision.

Desired outcomes:

- Mapping and understanding support available in the community

- Creation of a sustainable resource that people would use into the future to access available support

- People with mental health conditions are aware of alternatives to traditional support, feel better connected to their communities and use this as part of their recovery

- Building the confidence and strengths of people engaged in the project

- Commissioners and other professionals have a greater understanding of the potential contribution to recovery of community options

- Commissioning patterns change as a result with resources moving from secondary to community/preventative supports

- Learning about both co-production and ABCD will be transferred to and used by other parts of the health and social care system

Activity and outputs:
- A Project Steering Group established and operative with wide stakeholder engagement

- Project lead with ABCD expertise appointed, support by project team of experts by experience

- A substantial use of graphics and other communication tools to facilitate wide usage of the information being gathered

- Engagement with a wide range of community organisations including a particular early focus on one geographical area

- Connections brokered between a number of community groups that have left to shared activity and engagement

- A map of community resources across the area developed and shared

- Engagement with the Council's community directory as a way of maintaining and sharing the resource into the future

- 8 'WE Can' awards made to support community resources develop engagement with people

- Festival organised to share wellbeing opportunities – over 70 groups present, more than 500 people attended and good local media coverage.

Next Steps
- A 'legacy plan' has been devised that involves continuation of elements of the work

- Commissioning have stated they are starting to incorporate the learning into commissioning discussions/decisions

- Other parts of the CCG/Council are looking to apply the learning.

Suffolk: Co-producing a joint mental health commissioning strategy for adults in Suffolk

Aim: To deliver open dialogue between commissioners, local organisations, service users and carers about what is working well in local mental health care, identifying needs and priorities for the strategy.

Activity & Outputs:
- 10 big conversations with 470 people

- A 'stepping forward' event

- Conducting surveys

- Widespread engagement and a recognition of the positive role of co-production including a county wide agreement on the definition of co-production, a draft charter for improving services together and a commitment to roll out co-production.

Next steps:
- Identifying and following up further opportunities for co-production

- Embedding the improving services together charter

Luton: Co-production of a rare neurological diseases pathway for Luton

Aim: To establish, through a scoping exercise, the need for a service, to identify what service is needed and to plan its delivery.

Activity & Outputs:
- Bringing together people from voluntary and statutory agencies to work together with a high level of voluntary sector leadership

- As a very significant piece of learning the project sought to co-produce with people with rare neurological conditions who were often hard to identify and few in number - by the nature of their conditions possible participants had little time to become engaged in the project

- Successfully identified need for and developed a service plan despite very considerable challenges caused by the capacity of partner organisations and changing roles/responsibilities

Next steps:
- Maintain and grow the partnership to deliver the strategy

Thurrock: Using co-production to improve the uptake of annual health checks for people with a learning disability

Aim: To address the lack of annual health checks for people with learning disabilities - lead by people with learning disabilities from an established self-advocacy and service provider organisation.

Activity & Outputs:

- Engaging with people with learning disabilities, families, services and a range of health and social care providers to raise and discuss concerns about the impact of health checks not being completed

- Co-productively designed 'passport to health' day for people with a learning disability - over 200 people attended

- Surveyed over 200 people with a learning disability to see what the barriers to obtaining a check were

- Frustrated by the lack of local action, the project met with The Secretary of State for Health to discuss their concerns

- The project sought for health checks to be delivered by local GP's and other health service - this was not achieved so the team have chosen to establish a mechanism for delivering the health checks themselves.

Next steps:
- Delivery of health checks for people with learning disabilities

These summaries illustrate that the projects made some really admirable achievements and undertook a great deal of activity. However, it is clear that they had not, by the end of the project, achieved the level of change that they had envisaged at the start and there was limited evidence of changes which had yet started to have a direct impact on the lives of individuals. Below we have outlined some of the reasons identified by the evaluation for this being the case.

3.2 Clarity over project aims

On reflection some of the projects recognised that the initial scope or aims of the project had been unrealistic or overambitious. This was for a number of reasons. Firstly, some were very broad in their scope. One of the projects which had tried to cover a number of conditions, on reflection felt they would have made more progress if they had focused on a single condition. Secondly, some of the projects were very ambitious in what they could achieve in a 12 month project - for example, one project had 12 outcomes listed in their

application including reducing costs, enabling people to remain in their home and reshaping commissioning practices. As projects progressed, the project groups acknowledged that achieving all of these in a short-term project with a relatively small budget was not realistic. Thirdly, some of the initial aims or desired outcomes were not specific, for example "Improved experience". Non-specific aims such as these are difficult to measure and it is difficult to know when they have been achieved.

Fourthly, a very specific issue arose with two of the projects which is an issue for co-production work more widely. In these projects the initial application to the programme was initiated by a professional or a small group of professionals who had identified what the broad problem, issue or service change needed was, and proposed to address this using co-production. Although the application process asked for some confirmation that there was 'service user' buy-in to this issue, the depth of that buy-in turned out to be questionable. Put another way, because the identification of the exact nature of the problem or issue had not been co-produced, it proved necessary to take several steps backwards and co-produce agreement on what the *real* issues were. Thus, much of the activity of the projects was focused on gathering information widely from people with lived experience – they co-productively identified the priorities for change. Although the plan was for the projects to then use the findings and information from this to inform service change, because of the time taken for the initial information gathering activity, the projects had not progressed as far as they had hoped with implementing the changes. Essentially the projects were aiming to both co-produce the priorities for change and co-produce the change/action itself in a short project – which was not feasible.

As well as learning for sites, these points highlight additional learning for organisations selecting and supporting co-production projects. It has become evident through the programme that tighter selection criteria, or more guidance for projects at the selection stage around setting realistic aims and objectives would have mitigated some of these issues. An alternative approach might have been to support sites to initially co-produce an agreement to an issue to be addressed and then provide further support to implement change where there was clear, multi-stakeholder buy-in to the question in hand.

The projects also seemed to experience an additional challenge, specific to the nature of this programme. They were trying to address a service issue or need *at the same time* as learning a new way of working. At times, through the evaluation, it was clear that this led to some confusion for them: which was more important – learning to work in co-production or making change? At times there was so much focus on working in co-production – from NDTi, from NHS East, from their own organisations and from external interested parties – that the focus on what the projects were delivering in terms of service change received less attention than if the projects had been funded solely to deliver the change. However, as noted earlier, there was consensus that the only way to really understand co-production is to do it around an issue – so this is an unavoidable tension.

The conclusion is perhaps that one should not set unrealistically high expectations from the first project/initiative that is co-produced by people.

3.3   External forces

As with all initiatives, there were things beyond the influence of the projects which had an impact on the progress towards achieving service outcomes. For example, projects mentioned the following: the commissioning timetable restricting progress, contracting systems within CCGs delaying actions, staff in key positions leaving or changing role, existing and long-term issues with CCG commissioning, relationships between professionals and funding. As someone reflecting on these sorts of external challenges stated:

> *"So it wasn't a failure on co-production's part." ALS, professional (VCS)*

It wasn't working co-productively that stalled the service change in some cases, but factors beyond the control of the projects.

3.4   Evidencing outcomes and impact

The intention for the evaluation of this project from the outset, due to the resources available for the evaluation, was that the in-depth projects would be responsible for collecting their own data to evidence their progress towards identified outcomes. Despite highlighting this at the initial evaluation interviews, running a session exploring different types of data as part of the workshop developing the logic model, and providing a template to assist projects in identifying what data could be used to indicate progress towards outcomes, none of the projects systematically collected data to do this. This was in part due to the stage the projects had got to in terms of being ready to make changes – as described above, two of the projects that focused on identifying the problem had not yet implemented the actions which would lead to change. There was also a clear lack of confidence within the projects around collecting data and evidence. This highlights that evidencing change may be something that is missing in the whole culture of services and needs additional support over and above that which was provided through this programme.

While there is very clear evidence described above to show that people are working in new ways, individuals have learnt a great deal about working in co-production and that this is having reach beyond the six projects, ultimately the rationale behind working in co-production is not because it feels like a positive way to work and the right way to work – but that it leads to better outcomes, better experiences and better quality of life for people with long term conditions. As one of the experts by experience quoted above says "the proof will be in the pudding". Moving forward, the projects who have made such a positive start in addressing problems or issues, need to monitor and evidence what they are very confident about – that it will result in better lives for people. Co-producing

something *does* take more time than working in other ways and *does* take more resources. However positive it feels to work in this way, and however confident individuals involved in it are that it will lead to good outcomes, if the evidence is not available to back up that it leads to better outcomes it will inevitably be vulnerable to less resource intensive ways of doing things.

Lessons learnt:

The starting point for change is cultural and behavioural

You cannot co-produce a solution if you have not co-produced the identification of the problem/challenge

Do not expect short-term service change when starting out with co-production

Set realistic expectations for outcomes

It is essential to evidence the outcomes of co-production

4.   Sustaining co-production

Raise awareness, knowledge and expertise in such a way that the approaches to, and implementation of, co-production and personalisation can be **sustained beyond the life of the project**.

There are very clear signs that the awareness and knowledge gained through the projects and the new expertise of the people involved in the project will be sustained beyond the life of the project.

4.1   Project groups continuing

In at least two of the projects there is a clear intention from all involved that the existing co-production group will continue to work on the project once the funding has stopped. One project plans to continue and although it is likely to meet less often, all involved, experts by experience and professionals, want to remain involved to see what has been started through.

"We'll still carry on, we'll still exist as a group. People will want an outcome so we'll follow it through." In-depth site, professional (health)

"It can't stop – there's too much life and enthusiasm in the group." In-depth site, professional (LA)

A second project has developed a 'legacy plan' that includes actions such as spreading the initiative to another part of the county and applying co-production to a different commissioning initiative.

There are also examples of the existing groups being consulted on either in order for their specific knowledge they have gained through the activity – for example feeding in the information gained through finding out the needs of experts by experience to a service review, or for expertise on co-production – being asked to give advice on co-production to another commissioner who wants to co-produce a service review. One of the professionals involved in one group is hoping to use the existing group to develop a new strategy.

4.2   Experts by experience being involved in further projects

As referred to above, some of the experts by experience within the groups have been asked to join new groups addressing other issues - including a personal health budget group and a condition awareness project. In addition specific opportunities have arisen for individual experts by experience – for example two experts by experience were asked to speak at a meeting for GPs in the CCG which was extremely well received.

4.3 Professionals taking their experience back to their organisations

Some of the professionals talked about using what they have learnt through the project to change things in their own organisations:

"I'm going to be using co-production in [my organisation]. I want to run a session on co-production with the staff" In-depth site, professional (VCS)

"I'll look at involving carers and patients in things like service redesign." In-depth site, professional (health)

4.4 A source of expertise about co-production

There is clearly a lot of interest in co-production, as one professional described it "co-production is the buzzword, everyone is interested" and project groups and individuals have been approached as a source of expertise from others wanting to co-produce.

"Professionals have approached us about different work streams – they've snapped my hand off." In-depth site, professional (LA)

"What's happening which is nice, is that lots of people have heard about it, people have been asking for advice and support about co-production" In-depth site, professional (LA)

"People in the CCG have come and asked what's worked well, what hasn't" In-depth site, professional (CCG)

Similarly to the experts by experience, some of the professionals have had the opportunity to share their experiences to wide audiences, for example running a workshop on co-production at a CCG annual general meeting.

4.5 Spreading the co-production culture

Perhaps most importantly, in some of the areas there was evidence that the concept of co-production was taking root beyond these initial projects, as the benefits from it were being seen by people in the wider organisation. These examples ranged from co-production being used to design a different commissioning initiative and senior Public Health officials seeking out information about how it had operated.

4.6 Building blocks for change

Although, for reasons described above, actual service change which has had a measurable impact on individuals has not been evidenced in the time available, there are a number of developments that should form the building blocks for service change and

better outcomes for people in the future. These include (i) strengthened and increased activity by a range of non-statutory community resources that people will be able to access (ii) networks and relationships being developed between those community resources that should enable people to make greater use of preventative 'services' (iii) staff in provider agencies having access to knowledge that will enable them to offer non-traditional support options to people in the future (iv) county wide information resources having grown the breadth of community supports they are aware of and which people can therefore access. Whilst evidencing the impact of these things in quantitative terms will prove challenging, this challenge is, by nature, inherent in evidencing the benefit of preventative activity.

5. Summary

This report has described how all the localities involved in this initiative have made progress in learning about and using co-production as a working methodology. All have faced challenges and struggles in doing so, including it being more time-consuming and resource intensive than anticipated and it challenging some of the well-established power relationships and pre-conceptions. Nonetheless, there is a near unanimous view that the benefits derived from using co-production are positive and that the approach should be applied more widely. There is evidence that, in most locations, the knowledge of co-production is being embedded and will be continued and indeed spread into other areas of organisational activity.

For reasons illustrated in this report, actual service delivery change and resulting improved outcomes for individuals have not been achieved as anticipated by this point in time. There are nonetheless some clear and tangible positive outcomes from the programme, including early stages of evidence that alternative approaches to service delivery are taking shape that *should* lead to outcome and cost-effective benefits in the future and new plans and strategies being developed that have support from people who use services. In addition, we have identified:

- Notably different working practices being in place that engage people who use services, and commitments made to continue these beyond the project and into wider areas of clinical commissioning groups (CCGs) and related work

- An increased understanding between services and people who use services of perspectives and agendas

- Clear benefits described by participants from their participation, development of their skills levels, work competencies etc.

Key Learning Points

From this evaluation, we have identified 8 key learning points for the future development of co-production. These can be used to inform future initiatives. The evidence to support these points is contained in this report:

1. You cannot co-produce a solution if you have not co-produced the identification of the problem/challenge

Co-production is not a tool that services or professionals can use to develop a (co-owned) solution to a problem that they have defined on their own without the involvement of people who use services. This, in turn, has a knock-on impact on the point below about time and expectations. Co-production means involving people from the start – and

it may be necessary to go back to the start and revisit things that services and professionals believed they already had answers to.

2. Co-production means everyone's active involvement

The clue is in the name! Co-production is not about handing over responsibility to someone else, it is about all partners retaining an active involvement in order to bring their particular knowledge and expertise to the work, along with their authority networks and connections. The disengagement of any one partner weakens the enterprise. It is particularly important that diverse groups of people, such as those who use services, are represented by those who are well connected with and understand the issues of concern to the wider community.

3. Co-production does not work if people have pre-defined answers

Linked to the first point co-production means all participants being willing to explore different ways forward to those they might have started out with, and putting pre-determined solutions to one side. If there are genuine non-negotiables around an issue, these have to be declared at the outset and everyone be aware of them and accept them prior to engaging in co-production. Beyond that, people's favoured ways forward have to be up for negotiation – otherwise tensions will arise and co-production is unlikely to work.

4. Leadership styles needs to be facilitative and appropriate

Leaders will be found in different places in co-production, not just in a manager or similar who is responsible to the statutory sector for delivering change. Those leaders need to be identified and appointed on the basis of their abilities to bring together a facilitative and creative approach, networking skills and a focus on delivering outcomes.

5. Do not expect short-term service change when starting out with co-production - set realistic expectations for outcomes

It takes time to undertake effective co-production. Firstly, people need to understand the nature of co-production and how to take it forward. Secondly there needs to be trust and understanding between the different parties. The most rapid progress was made where key players understood the concepts and knew each other before this work started. Where those (and other things) are not in place, additional time is needed. Whilst there will be short-term learning and change achieved, this is more likely to be around behaviour and process (see below) than actual service change.

6. The starting point for change is cultural and behavioural

The first thing that will be seen and observed when using co-production will be different behaviours and actions by all the partners to a co-produced change. Listening to and acting upon information that was not previously heard, operating in different ways to

include people, considering different types of solutions – these are all inevitable consequences of co-production. They will therefore be the things that can be seen and evidenced before service change takes place.

7. It is essential to evidence the outcomes of co-production

Given that co-production is time and resource intensive, and often requires people who use services to give their time up to participate, it is essential that the benefits of co-production can be evidenced. This means placing the collection of data and information about the outcomes of a co-produced initiative as an early agenda item and involving people in the work who have the skills, time and access to information.

8. It is different everywhere

Given all the above points, and the huge variety of issues and organisational constructs within which co-production can be used, there is no template for how to do it. There are a series of questions that can be put, and issues to be considered (the points in this section being amongst them) but there is no set way to go about co-producing a service change – beyond adherence to the core principles of what it is and what it is not.