AN ENGAGEMENT REPORT WITH
RECOMMENDATIONS
CO-PRODUCED & CO-AUTHORED WITH
PEOPLE WHO USE SERVICES AND CARERS,
SURREY COALITION OF DISABLED PEOPLE,
HEALTHWATCH SURREY AND
SURREY MINORITY ETHNIC FORUM

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WHO HOLDS THE POWER? UNDERSTANDING CO-PRODUCTION AT SURREY AND BORDERS PARTNERSHIP NHS FOUNDATION TRUST

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ACKNOWLEDGEMENTS

This report, its toolkit and appendices have not only been co-produced but co-authored by people with lived experience and the three partner organisations. It is important to acknowledge this teamwork at the outset of this report as it demonstrates how people can come together, in unity and equality, to produce a shared vision and goal. Undeniably, there have been challenges to this work, but they have been outside of the project group. The group has responded with agility, interest, and a determination to succeed in spite of challenges. Our thanks to all the stakeholders who generously gave of their time, willingness to step out into ideas of the possible and reflect honestly on current practice at a time when the ‘system’ is deeply challenged.

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EXECUTIVE SUMMARY

Project purpose

Surrey and Borders Partnership NHS Foundation Trust (SaBP) commissioned a project to transform the future of co-production at the Trust, working with Surrey Coalition of Disabled People, Healthwatch Surrey and Surrey Minority Ethnic Forum.

The project partners developed the following definition of co-production, and used this throughout the project to explain co-production:

> “Co-production is a way of working that involves people who use health and care services, carers, and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development, and evaluation.
>
> Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives.”

Approach

The project engaged with SaBP staff, service users, carers and stakeholders through a wide variety of events, workshops, one to one interviews and surveys to gather as many diverse opinions as possible. This took place between November 2021 and February 2022. The contributions of over 400 people are represented in this report.

Findings

<u>Understanding and impressions of co-production</u>

The level of understanding of co-production among staff varies across the Trust, but there is considerable existing knowledge of co-production among Trust staff. Around a third spoke of having a strong knowledge, and a further half recognised the general concept. Only around 1/5 said they were unfamiliar with coproduction.

Similarly, staff experience of co-production across the Trust is varied.

- Many staff cited examples of co-production being used successfully, with the Recovery College, Managing Emotions Programme and ASD/ADHD services being singled out for praise.
- Despite these pockets of success, other staff reported no experience of witnessing co-production being practised at all.

Staff are overwhelmingly in favour of co-production – there is a strong feeling it is the 'right' thing to do, certainly at the level of individual care planning and a view that co-production ought to be the norm. There is recognition that it does happen at SaBP (or an assumption that it does) but no sense that it is embedded as a way of working in the Trust.

Few service users are familiar with the term "co-production", although given the appropriate context many can make a guess at what it might be. Whatever the term used, most do want to be involved with decisions made about their treatment.

Experience of Individual Co-production within SaBP

Co-production at the individual level appears to be a common approach for many staff, with practice ranging from simple involvement through to true co-production. Practitioners showed pride where they had been able to take this approach.

However, the impression is that individual co-production is the practitioner's choice rather than something that is embedded in the Trust. It is unmeasured in the clinical context, and is not delivered consistently.

Service users, mostly reporting through the survey rather than face to face**, reported much lower levels of experience of individual co-production**, and the majority were unhappy with the level of involvement they had experienced in decisions around their care, and also wanted to see more co-production in the development of services and strategy.

That said, service users and carers who had been **involved in what they considered to be "good" co-production found it a positive experience** – whether it was from an individual practitioner, or through a service such as In-Reach where co-production is baked in.

Service users reported a high degree of confidence in their understanding of their needs. This is driven by their insight into their own unique experience of their condition, and expertise gained through learning about their condition (e.g. in the case of carers of CYP).

Experience of Service and System Co-production at SaBP

Staff cite good examples of services where co-production has been instrumental to development and success, such as Recovery College and Managing Emotions Programme. However, these tended to be discussed at the level of individual services rather than embedded in SaBP culture or strategy overall.

Service User experience of service and system level co-production is mixed. While some have had what they consider to be 'good' experiences, others have felt their involvement to be belittled or lip-service, with little time allowed for genuine discussion or reflection.

Barriers to Co-production

While staff can point to good examples of co-production at SaBP there is still concern that **that conditions in the Trust are not favourable** to putting co-production into practice. Staff cite

- **limitations of time and workforce** – co-production is assumed to be or has been experienced as a slow, demanding way of working that does not sit well while the Trust is under significant pressure
- **systemic barriers and organisational culture** – while there are examples of excellent co-production at the service-development level, co-production is not embedded as a foundation of the SaBP approach to service development. Issues including risk appetite/blame culture, power/relationships, access to the right service users and tokenism were all raised by staff requiring focus before true co-production could be embedded.

Services users cited several barriers to involvement – some practical but many emotional. Predictably, time poverty, financial reimbursement and access were frequently cited. Possibly more important are

- the emotional burden: feeling intimidated or out of their depth, and the impact this would have on their mental health; devoting precious personal time to talk about their mental health and experiences (the danger of re-traumatisation)
- disillusionment: suspicion of tokenism, a belief that nothing would really change as a result of their input
- poor previous experiences: where the format was built around the trust (meetings, presentations, formality) and not around realistic expectations of the service user's understanding and ability to contribute

Black and minoritized communities reported feeling their needs were not catered for, with cultural and language barriers not considered, a lack of peer support, a sense of isolation, and anxiety around attending unfamiliar clinical settings. Many people said they would feel more confident being treated by a practitioner from a diverse community background.

Recommendations:

Co-production can be used across the Trust to d**rive a move away from a culture of 'power over' towards 'power with' service users and carers.**

1. Groundwork: analysis and audit

    - a. Adopt a Trust-wide definition of co-production and employ this as the basis of training for all staff
    - b. Revisit visions and policies to ensure co-production is embedded in all key strategies
    - c. Review the ways service users and carers are addressed and represented through literature and communications
    - d. Assess where individual teams are now (Audit tool can be found in the report Toolkit)
2. **Establish co-production as Business As Usual**.
    - a. Build momentum, share learnings
    - b. Use agile methodologies as the Trust establishes co-production in the organisation
    - c. Empower staff through training
3. **Create new roles** to ensure the lived experience voice is heard at all levels of every team, including
    - a. A co-production lead for each directorate
    - b. A Communities Director – a non-clinical lead with lived experience
    - c. Lived experience personnel in every team, and these to be included in the decision-making process.
4. **Enable the purposeful employment and appropriate support of staff with lived experience**, developing new policies to achieve this if necessary.
5. **Build reciprocity and parity of esteem for service users/carers**
    - a. Develop a new framework to **standardise recruiting, supporting, engaging, managing, remunerating, and supervising volunteers** with lived experience.
    - b. **Recognise and reward the expertise of service users and carers** who formally support co-production, through financial remuneration or alternatives appropriate to the individual.
    - c. **Support black and minoritised communities to engage** with co-production, through peer support, reaching out to communities and utilising the stakeholder group to improve equity of access and provision in SaBP services.
6. **Open channels of communication with a wider and more dynamic range of service users and carers**, and ensure feedback is collated and shared regularly with staff, service users, carers and other stakeholders. Reach out to service user groups and seldom-heard communities, and develop the use of social media and the Trust's own website to maximise reach.
7. **Ensure carers have clear information about their roles and rights** and provide support for carers both in terms of risk reduction and in preserving the relationship between carer and service user.
8. **Redevelop the Forum of Carers and People who Use Services (FoCUS).**
    - a. Make the meetings more accessible to a wider range of service users and carers by changing the format, reducing formality, and alternating dates and times of virtual and physical meetings.
    - b. Replace current groups with 6 local groups. These would feed into a development group which will have responsibility for raising issues with

senior leaders of the Trust, holding PALS to account, and discussing issues raised in the local groups.

9. Expand co-produced commissioned services by **developing and extending relationships with third sector care providers**, including community and voluntary organisations.

PART ONE

The Clinical Strategy at Surrey and Borders Partnership NHS Foundation Trust (SaBP) firmly establishes the service user and carer as partners in the pursuit of excellent care:

"Our core purpose is to work with people and lead communities in improving their mental and physical wellbeing for a better life; through delivering excellent and responsive prevention, diagnosis, early intervention, treatment and care."

However, a recent peer-review commissioned by the Mental Health Partnership Board found that the experience of service users was considerably poorer than staff perception of service quality, with people using services rating Surrey services as 2/10 on average compared to staff rating the quality of services as 7/10 on average.

SaBP leadership team have commissioned the Project Partnership to propose new ways to transform user engagement involvement and co-production at SaBP

PROJECT PARTNERS

healthwatch Surrey

SURREY COALITION OF DISABLED PEOPLE

One potential enabler of change in this chasmic difference may be for SaBP to work in closer partnership with people who use services, their carers and wider system. A change in the culture of the organisation may begin to happen during the process of co-production as individual clinicians and teams see the immediate benefits of working in this way.

WHAT DO WE MEAN BY CO-PRODUCTION?

Individual with Clinician and Carer: Care planning and shared decision making with patients and carers as equal partners.

Service: How people with lived experience and carers are involved in designing, improving and monitoring services, or making service changes.

System: Strategy and policy development, delivery and monitoring in partnership with people with lived experience and carers.

There is no single, universal model of co-production. A definition of co-production was developed through research and agreement in the project group and shared throughout the process as an explanation of co-production.

‘Co-production is a way of working that involves people who use health and care services, carers, and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development, and evaluation.

Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives.’

Co-production in mental health enables a change in relationship between caregivers and service users and their carers, away from ‘doing to’ to ‘doing with’. All co-production requires thinking about people, relationships and resources in ways that are different to residual paternalistic cultures. Co-production acknowledges that both those who hold professional expertise and those who hold experiential expertise are experts.

In a wider context, service users and carers bring vital knowledge about local services which can be harnessed to improve outcomes, services, and systems, making services more responsive to people’s needs.

This report, its recommendations and toolkit have been developed using the principles of co-production in partnership with people who have experience in using, working in and with Mental Health Services at Surrey and Borders Partnership NHS Foundation Trust and carers. They have brought their extensive knowledge and expertise together with their own ideas and feelings around co-production. Working this way has offered fresh perspectives and highlighted the intrinsic value of service user and carer contributions.

As in all arenas of co-production, one method of engagement does not suit all stakeholders. The project team used an extensive multi-method approach to maximise our insight opportunities. The project team:

1. Conducted desk research into co-production best practice within other Mental Health Trusts, and wider related healthcare settings (APPENDIX 1)

2. Established a project working group and steering group which included carers, people with lived experience of mental ill-health, and SaBP staff and project volunteers. The project group met (bi-weekly) to provide a space to bring insight back to, and to co-design and refine the involvement and co-production strategy and recommendations.
3. Undertook one to one interviews with as many stakeholders as possible (c.50 interviewees), predominantly SaBP staff members and system partners to gather greater insights and understanding around the co-production culture, barriers, and practices at SaBP. These were reported anonymously.
4. Conducted, through Surrey Minority Ethnic Forum, 10 engagement events with black and minoritised community groups. At these events, engaged with around 200 people; both individuals and families.
5. Conducted a series of SaBP staff workshops (c.35 attendees) to gather insight and allow for the cross-pollination of ideas for new ways of working.
6. Conducted a series of FoCUS and Stakeholder and VCFS workshops (c.90 attendees) to gather insight and allow for the cross-pollination of ideas for new ways of working.
7. Conducted two surveys to gather insight and experience from over 170 SaBP staff and service users and carers
8. Identified and utilised the significant skill sets within the co-production project group to produce the components of this report and toolkit.

LINES OF ENQUIRY

Across the varying engagement methodologies all stakeholders were given the opportunity to address four main areas of reflection, which were co-developed and agreed in the project group. Three levels of co-production were explored with respondents and attendees: individual, service and system level co-production. To make recommendations, it was important to understand if SaBP was actively co-producing exclusively in places where existing policies ‘nudge’ co-production or whether co-production happened throughout the organisation.

What is your understanding and impression of co-production?

What is your experience of co-production within SaBP? (What went well and what could have gone better?)

What are barriers to co-production?

How would you like to see co-production at SaBP in the future?

FINDINGS

During the engagement phase it became clear that our work was far from passive - that the conversations and lines of enquiry became a way to spark interest, the art of the possible and to generate change. The process and the reflective conversations became part of the project.

Staff understanding and impressions of co-production

Understanding co-production is key to revealing how staff, service users and carers feel about the way that SaBP and people co-produce or more broadly work together. With many definitions and interpretations available in the literature, unsurprisingly, 20% of staff said they were not confident in their understanding of co-production. 50% were fairly confident and 30% were very confident. These survey results were mirrored in group engagement with a vocal third firmly advocating for co-production, citing examples which reflect our agreed definition. Around half of the respondents correctly identified the hallmarks of co-production and around a third of respondents had a broad conceptual understanding:

> *"… working directly with someone, a carer or someone using services or an advocate or whoever to work together to try and make someone's life better… those things are done much better and much more effectively when we listen to each other we understand each other's perspectives and work together on a shared understanding and therefore a shared document…. if you just produce something they may or may not agree with it and they may or may not value it… if you've all got stake in it, you're more likely to have success and I suppose that principle probably holds true whether you're going from working with an individual to developing a new service for £1M. If we all come together, if we make a bad decision, at least we made it all together."*

> *"It's involving and engaging people who use services (or may need to use services in the future) but extends beyond that, shifting the balance of power to see them as equal partners in the process of creating or improving services"*

This demonstrates that SaBP already has considerable knowledge internally. There may be a need to disseminate a shared meaning and purpose more widely, but the foundations are well laid.

There is an almost universal view from staff that co-production is, in concept, a good idea. Some went so far as to say that it was the right thing to do, almost a moral obligation.

> *"It is absolutely the thing to do, especially in our field. We need to listen to our clients, even if we don't like what we hear. For us that has been almost like a Delphi-type approach, and it works really well and for our clients. We feel that the "power" lies with our clients."*

> *"…through your own professional knowledge and professional integrity, you should know when it is right to work with and involve people… my default position is that you should involve people much more often than not and that should definitely be your starting place"*

However, the impression of whether co-production is currently widespread throughout the organisation is mixed. Some assume it exists but aren't sure, some know that there is a team responsible for co-production (or at least engagement) but haven't seen evidence of their work outputs. The collective understanding is "Yes, co-production at SaBP happens, but…",

> *"My perspective on the organisation today is that there may or may not be good examples of co-production and co-design in a care and treatment plan between a clinician and a person who uses services, their carers family etc. but, I couldn't give you any assurance how comprehensive that behaviour is, but I'm clear that our policies and procedures say that it should exist"*

There is an impression that co-production is time consuming and resource heavy, but there was also recognition that, with the right systems and framework supporting co-production as business-as-usual, these processes might become an adopted way of working rather than something 'extra'.

> *"It promotes hope of recovery, values people with lived experience and captures insight and wisdom which only lived experience gives."*

> *"I think "co-production", like many other initiatives and terms, walks a fine line between becoming a buzz word for tokenism and a true commitment to cultural change. The creation of true, meaningfully co-produced services is fraught with challenges. I feel passionately, however, that just because it is difficult, does not mean it shouldn't be done"*

Service user & carer understanding and impressions of co-production

Service users and carers are mostly unfamiliar with the terminology of co-production, but many are willing to 'have a go 'at a definition, sometimes very succinctly guessing:

"*I have never heard this term. I would guess this is something where patient and provider work to agree and complete a treatment plan".*

This raises an important reminder that although as a system there is some familiarity and understanding of these concepts, they need to be communicated in a more practical way, perhaps with staff teams developing understanding alongside service users and carers as a community of inquiry.

32%

32% of service users and carers have no reported understanding of co-production

38%

38% of service users and carers have some reported understanding of co-production

30%

30% of service users and carers have good reported understanding of co-production

Most people engaged with want to be involved in decisions made about their lives and the way that they are cared for through service and system co-production. Intuitively service users and carers resist paternalistic arrangements which usurp their power and choice, and even those who choose to handover choice to the ‘experts’ are making that choice. The alternatives to this can be devastating:

> *“When I was sectioned and surviving on a ward for months on end, I felt like I was invisible. Doctors and staff spoke to my mum and not to me, they ignored my thoughts and feelings and the things that I wanted because I was a mad person. I was mad, angry mad…. I was getting better, but they didn’t ask me if I was getting better, they just looked at how many tablets I was taking and whether I had asserted myself that day as a measure of my wellness, and not in a good way. I felt like a child, and a naughty child at that, like someone had taken all the hope out of my life and I was reduced to a collection of body parts and a condition. How is that ok?”*

Staff experience of individual co-production within SaBP

It is difficult to pinpoint examples of good individual co-production, possibly because of confidentiality, but it is understood that it is common practice for many staff. Reported experiences ranged from true co-production approaches to simple involvement. There are stories which tell of an ethos of ‘working with’, even in some of the most challenging of spaces.

> *“We have got pockets where people are doing it [co-production] and are doing it naturally and I would bet if we looked at every team there will be people who are working creatively and effectively”*

Where ‘working with’ has happened staff are proud of their work and the outcomes and praised for their exceptional work but some challenge the idea that this makes co-production seem exceptional rather than the baseline of good practice.

Many staff told us how they are practicing co-production as far as possible with the service users and carers they see in the service:

> *"Peer support workers within the team - 1:1 support, group work, multi-disciplinary team discussion, care planning. People with lived experience on recruitment panels. Part of service development. Part of an assessment involves having input from everyone involved in that person's care. That is how you come to a shared decision."*
>
> *"Quite often carers/family members accompany attendees for their new patient assessments. Their information and opinions are usually really valuable"*

However, meaningful individual co-production and experience is unmeasured in the clinical context:

> *"…. Surely a team's performance should be measured on experience? Fundamentally that's got to be the most important thing, but we don't. We look at experience as an add on and not something that we are actually required to do and it's the most important thing that we should be collecting… doesn't make any sense to me"*

There is a critical awareness that often co-production is not where it could be:

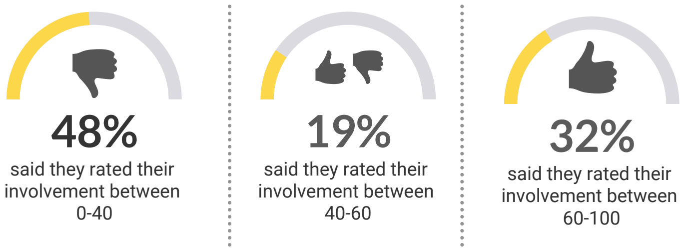
> *"Co-production in our service starts by clients having choice around their appointments, what is written in their reports. Post-diagnostically, we are not there yet, as we are currently co-producing some post-diagnostic materials"*
>
> *"I involve carers more so than service users but where I can also agree the care plan with family and individuals, but it's always within the context of the limitations of the service, which feels at odds with co-production"*

Service users and carers experience of individualised co-production

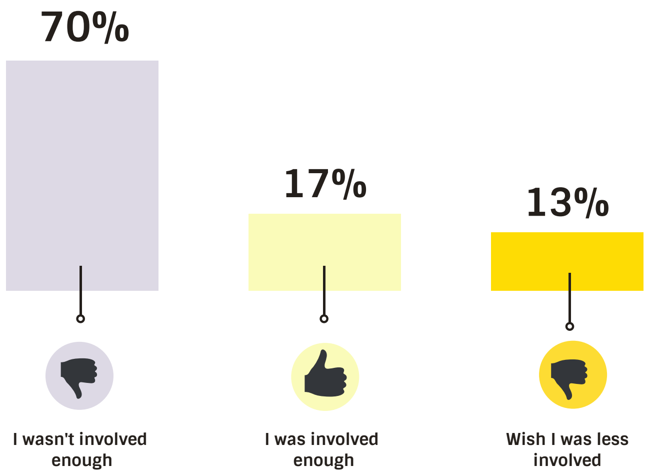
Compared to the experiences of the clinical staff, service users were much less likely to have experienced co-production, even at the level of basic involvement. As both are self- selecting surveys, there is the possibility of bias, but staff and service users may have a different perception of what constitutes real choice and involvement within the limitations of the current system design.

The majority of our survey respondents were unhappy with the level of involvement they had experienced in decisions around their care: fewer than one in five felt they had had the right level of involvement.

How involved do you feel in decisions made about the type of mental health care and treatment you receive?' (unfavourable 0 - 100 favourable)



How happy were you with the level of your involvement in your care and/or treatment?



"Staff were too robotic and didn't take time to listen. Felt like a number and not a person. Felt we were caught between different services and weren't being listened to."

"I feel I am cut out of the decision making and just get informed of 'the plan' - which people forget is the life and home of the person I care for."

Approximately 80% of complaints through PALS are centred around or have an element of people not being listened to by their service.

Many patients and carers are confident they understand their own needs. This view is grounded in:

- Their unique insight born of their first-hand experience, and in many cases their experience of different treatments
- Expertise in their condition – many are highly motivated (for example, parent carers) and invest time in reading around the subject.

"How confident are you that you know what good care and treatment for you looks like and that you understand what outcomes you're trying to achieve?"

"The medical team/recent psychiatrist have been very attentive when it comes to respecting my prior negative experiences on medication and looking for solutions that I am comfortable with. This is really important to me as some past professionals have seen my resistance as unwillingness to engage as

> *opposed to needing trauma informed care and alternate solutions to the standard 'anti-depressant' route"*

The legal framework of informed consent requires a practitioner to discuss all the treatment options available and the material risks and benefits of each so the service user (and carer) can come to a shared decision on a course of action. A lack of choice should, with due consideration to the legalities of capacity, always be explicit to service users and carers.

In-Reach is an excellent example of how the service user and their individual needs are placed at the centre of care provision and planning is effectively co-produced. Service users find this care transformative and highly value this work:

> *"The staff who referred on ward [need] to be trained on what this service offers and the benefits it brings, it is filling a big gap that the NHS does not support. The service has been invaluable in getting me out the house walking and connecting with others as well as providing activities to do during the week. The staff at RFT have been patient, considerate and proactive. The in-ward session was really good as it got me thinking about things that I hadn't thought of, having never been in this position."*

The continuity of co-planned support as clients transition from in-patient care to Home Treatment Team and then the CMHRS team, for example, provides familiarity and the feeling that someone is journeying with them. This continuity gives the service user the opportunity to reflect upon their experience, have control of the creation of an action plan, and feel supported and empowered.

Staff experience of service and system co-production

Throughout the engagement, it has been evident that the desire to hear the service user voice in service and system development is widespread. There is almost a sense of urgency and certainly the recognition that without it, endeavours are always going to be restricted in their effectiveness and value.

> *"My vision is really opening the organisation up and valuing the service user voice at every level…. The reason I want to move to that model is that it's really hard to design services that have fabulous quality outcomes if you are not a learning organisation and it's very hard to be a learning organisation if you don't hear use the service user voice feedback in the moment when is the easiest to receive"*

> *"I think it would be fair and not an exaggeration to say that if we did not have the service user voice in this project that it would be catastrophic, not only because it would be a complete betrayal of the express values of the*

> *Partnership and the Trust… not having the input would probably adversely affect the service and it wouldn't really be informed by people with mental health needs”*

There is a general perception that service and system level co-production is moderately well embedded in SaBP overall, and well embedded in some individual services:

> “*I think we’re patchy I think there are some projects where we do get it right and we do work well… there other times where frankly we ignore the views of people who use services and there are probably many other projects somewhere in the middle”*

There are also many good examples given where the service user and carer voice has been instrumental in the genesis of a project and critical to its development:

> *“I think we've got some examples where we really trying to push on co-design; safe havens were a good example, GPiHMs, to some degree the New Hospital Project “*

> *“Safe Havens are one of the real success stories, where a group of people including people who had lived experience came together and did something really impressive and if we run every project programme like that, we would be doing the right thing”*

The staff survey revealed a wide array of examples of co-production. Three services were particularly highlighted:

Recovery College:

- Staff working in equal partnership with carer/patient experts to deliver courses
- Lived experience staff write and deliver courses, support students, and engage volunteers
- All staff are encouraged to consider their own mental health and to have frequent opportunities for support
- Team decisions are shared, the direction of travel for the service is co-designed
- Co-producing and facilitating courses
- Coaching/guiding individuals to find their solution for themselves by asking open questions in the form of enquiry
- Development of the Recovery College has been co-produced since its formation

Managing Emotions Programme (MEP):

- A co-produced team where over half of the staff are people with lived experience of mental health difficulties
- Psychoeducation training that MEP delivers is co-designed and co-facilitated by people with clinical background and lived experience

ASD and ADHD Service:

- Currently co-producing a post-diagnostic workbook with four autistic clients. Their engagement provided valuable insight, expanding on the rationale for what we do, and occasionally challenging what "we thought we knew".
- ASD training sessions co-produced with a patient which was co-presented across the trust, for other services and a project for hospital staff
- Co-produced training for therapists in Working Age Adults division.

  > *"From the outset the person with lived experience had input into the content of the training materials and co-facilitated on the day. We have subsequently written up the article and jointly attended the Executive Board Meeting to share her story"*

- Devising a psychoeducational virtual group for autistic adults and in consultation with feedback from people currently using the service

In recently formed services where co-design is part of the planning (i.e., Safe Havens, GPiHMs and MiCHS, PD Pathway, Recovery College, Early Intervention in Psychosis) the service appears to evaluate well and be effective in its outputs. The Perinatal Metal Health Team, in addition to being agile and exceptionally person centred in their design and management of their pathways (including lower thresholds for women from some communities), have embedded peer support workers into their team with parity and developed their skills for supporting women and birthing people. The new Maternal Mental Health Service is also being co-produced from design.

These services build on an existing smaller culture of involvement and respect, and perhaps there are new staff who bring with them this strong ethos of involvement. Certainly, the current training of clinical psychologists puts a strong emphasis on the importance of recognising and responding to the individual and their social context. These services appear to have leaders and managers who are prepared to give their teams power to adapt services when faced with feedback from service users:

> *"If we could … have them at the meetings where we would find it the most uncomfortable and have advocacy that really lets their voices be heard … these are great concepts, but they are terrifying."*

In addition, some services such as the PD Pathway have approximately 50% of staff having lived experience. In these teams there is a positive culture and teams are prepared to 'give it a go' even if they couldn't pursue an in-depth level of co-production at first. Having built up the service, they have then adopted structures and processes to sustain co-production, such as training and evaluation committees (Safe Havens).

Service user and carer's experience of service and system co-production

Often the experiences of involvement can serve as a cautionary tale to future co-production and to others. Service users and carers report that they are often not responded to, or their concerns are left "*in the ether*" for months at a time, particularly when they have raised a complaint or have requested care which may diverge from the norm. When system level co-production presentations are brought to groups, service users and carers report that there is often little time allowed for genuine discussion and exploration of the issues at hand, that they are presented with a '*fait accompli'* sometimes by someone who may not be completely sighted on the nuance of the project and so delivered with some intransigence:

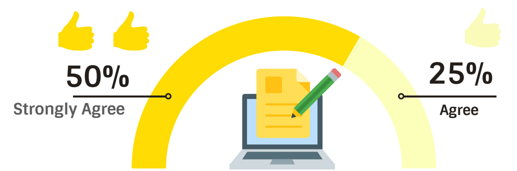
> *"The facilitator who was delegated the task was clearly out of their depth. If they had understood the importance of what I was saying they would have validated my view and agreed to take this back to the design group. Because I did not receive any validation, or any acknowledgement of my views and I was told "we need to move on with the agenda" this made me more determined to try to explain why this was an important issue.... I felt humiliated"*

Contrastingly, those who experienced what they considered to be 'good' co-production valued the experience and the opportunity to make a difference, additionally it prompted some empathy in the service users and carers, recognising the complexity of delivering mental health care:

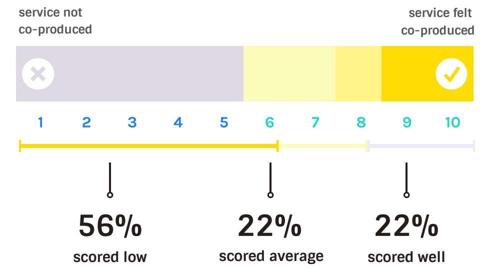
> *"Enjoy it and seeing a range of people who do a fantastic job under difficult circumstances."*

> *"Like to hear from those presentations from the different mental health professionals."*

Given the agreed definition of co-production, Service Users and Carers were asked whether they thought co-production would make a positive difference to their care:



Given the agreed definition of co-production, service users and carers were asked whether they thought their care/ service felt co-producted?



Many service users and carers felt that the benefit of more co-production in services might be more or better access to service. This may be the case for some services - for example the co-design and production of the Safe Havens delivered rapid access to crisis support it but would be unlikely to increase access to a CMHRS service. This demonstrates the need to be clear and realistic in discussions with service users and carers about what co-production can and cannot achieve.

Almost all respondents had some thoughts about how services might be improved. Many of the responses will come as no surprise to service providers:

> *"Making sure training for users and professionals and decision makers and hold them accountable for the quality of service delivered"*

> *"Hire many, many more CAMHS psychologist and psychiatrist staff to reduce waiting times"*

45% of these suggestions related to empathy, the need to offer person-centred care, listening and engagement, all important elements of co-production:

> *"People are accused of refusing to engage when actually their mental state does not allow them to. That has to be recognised."*
>
> *"I would give carers a voice and respect their insight. I wouldn't assume what care they can provide, and I'd ask what they need"*
>
> *"I would make them listen to what I think I would benefit from"*

Whilst there are service users and carers who feel that they have been sufficiently involved with decision making around their care and service, from these results it can be understood that service users feel that they and the services that they are involved with would benefit from an increase in co-production or the elements of co-production.

In addition, the needs of carers are often side-lined in a way that dismisses the responsibility that carers have for delivering the care plans

> *"Only by understanding what the lived experience is for the carer can the care planning for the person include all actions to ensure that both the independence and well-being of the person is designed, that also provides the carer with a life of their own beyond caring – if this is what the carer wants. It must be a mutually agreed contract of expectations that everyone is happy with their situation– rather than assumptions made about what a carer can or is willing to do. The caring situation also must be sustainable."*

Surrey Minority Ethnic Forum

SMEF's engagement heard that people's experience was of a 'one size fits all' approach – a lack of personalisation was apparent. As a specific example, being encouraged to join a group therapy session, rather than being offered 1:1 options, and no acknowledgement of the challenges that ethnicity, language, and culture present in terms of psychological safety. Although SaBP has an above representative BAME workforce, it was regularly felt that there was a lack of BAME representation in Trust communications, additionally, people that SMEF engaged with did feel there was a missed opportunity to be cared for by someone from their community. A common theme was the observation that people would have liked to have been treated by a practitioner from a diverse community background. There was a sense of isolation and lack of peer support, many people felt that their ethnicity made them feel more isolated and lonelier during their treatment.

People reported feeling intimidated by accessing services and support in clinical settings unknown to them. In some cases, the apprehension around this had been enough to put them off seeking support or taking up an offer of support.

When asked about the ability to influence care, most people felt that they were at a disadvantage, being in an unfamiliar setting, and often struggling with language barriers. Most people felt that they would "*go along with what the doctor said*". Almost everyone, when asked, reported that they hadn't previously had the opportunity to be involved in improving services.

The above themes align closely with the findings from the IMHN/SMEF peer research conducted during 2021, which identified a lack of representation, a lack of personalisation and a preference for community settings (over clinical) as key findings. This earlier research did not probe into feelings of power and the sharing of that power with a clinician, so the most recent SMEF insights have been useful in exposing a power imbalance which stifles co-production at an individual (care-plan) level.

System Partner Impressions

Across the system there are mixed external impressions of how SaBP are involving, engaging, and co-producing with people who use services. System partners similarly identify that there is a will but not necessarily a system which supports effective co-production with people or partners:

> *“Some voluntary staff struggle to feel valued by services like the CMHRS as they don’t reply to emails and are not willing to collaborate.”*

There is also a significant body of opinion which recognises that within SaBP and their own work as system partners there is a group of people who use services and carers who are familiar voices and who have been representing the wider service user and carer voice for many years and perhaps are not representative. This is very much seen as a barrier to effective co-production. Often the most effective co-production found at the Trust was co-production where services have sought service user and carer opinion outside the usual channels of co-production or in addition to the usual channels for co-production, involvement, and engagement.

> *“I've been around for quite a few years now, and have had various different interactions over the years, I think they probably want to [work in a co-produced way], and try to, but just don't have the understanding and where-with-all about how to… I don't think that as an organisation, they work with people in that kind of equal way, with people having a voice and they don't have the right mechanisms to enable that. At the moment.”*

This idea of the ‘system’ interrupting the flow of co-production with system partners is a theme which has arisen in most conversations with outside support agencies, organisations, and statutory bodies, one example being:

> *“The biggest challenge over these projects is actually getting referrals from the ward staff and the information we need and getting referrals from staff, especially the Single Point of Access because they're so busy and don't have time to do referrals, we’ve come in to relieve pressure, but they don't have time to fill in the referral so that we can help them…. so yes, we've had previously low referral numbers, they are definitely going up now but we expected to have a lot more and so I think there's been just some work to do around communicating with them and them getting to understand our surveys and what we can do, and I think that is working better now…. having access to computer systems would streamline these activities, it can be frustrating”*

Other partners feel that there is mostly beneficial and effective co-production both with partners and service users. The Surrey High Intensity Partnership Programme for example, appears to be a good example of where external agencies and SaBP come together with a shared objective and understanding, which is then tailored to the needs of the service user, uses a trauma informed approach and is effective. That being said, there are also simple but practical barriers that get in the way of working well together, for example, emergency services and GP practices have reported that they struggle to know the basics of where to call and which number is operational.

> *"co-production with partners starts with communication, how can I as a GP work with service users to support their mental well-being if I can't even find out where I need to refer them? If I as a GP and someone who has previously worked at Surrey and Borders am unable to navigate the system, how on earth is a person in crisis going to do the same? It's confusing…"*

Staff perception of barriers to co-production

There is a perception that there are barriers to co-production on multiple levels. In some cases this felt completely overwhelming, perhaps best demonstrated by one respondent whose only response to all the survey questions was a variation of :

> *"I would love to do this, but…. We don't have the time and critically the staff to do this, we'd love to…. But we just can't"*

Most of the barriers staff told us about were systemic or external, requiring practical and cultural changes at Trust level. They were not barriers that could be removed by the staff member alone, or through training.

SaBP Culture - Service Facilitation Vs Patient Management

> *"The Trust is not embedded with a collaborative, compassionate leadership model which is essential for co-design."*

Staff were offered 1:1 interviews as well as sharing thoughts and feelings through the survey, three staff workshops were held and a Clinical Cabinet meeting was observed. Across these experiences it became clear that organisational culture was a forceful driver in whether co-production was a dominant and likely to be an effective feature in SaBP.

In the Clinical Cabinet meeting, when asked: "*Why do we exist as a Trust*?" most responses placed the services and Trust in partnership with the service users and carers, seeing the trust as helper, enabler, supporter, and facilitator.

> *"To offer evidence based, personalised care and support for people in Surrey, when they need us."*

> *"To enable a person to live to their optimum level of independence regardless of setting"*

> *“To promote strong user and carer voice in the design and delivery of services in a culture of continuous improvement”*

However, a subtle difference in tone towards a ‘management’ role was noticed in some responses:

> “*To use our knowledge, expertise and resources to improve mental health outcomes for people in Surrey”*
>
> *“To deliver and improve mental health outcomes for people”*
>
> *“To be the custodian of Improvement across Mental Health, Well-being and Learning Disabilities, using our specialist knowledge and experiences to improve outcomes and life for the people of Surrey and its borders”*

Positive intention is clear and there is an alignment with the Trust values which support co-production. However, there remains a small but critical voice which could perpetuate paternalistic thinking and practices.

In addition, whilst there are processes in place to support co-production and co-design, in practice care planning co-production may be diluted down to engagement. For example, whilst the service user and carer are listened to, care and treatment decisions are made in MDT meetings that the patient does not attend - the patient is informed of decisions made. They may be given the option to adapt the plan, but they are not placed at the centre and decisions are not made in the knowledge that the service user may know best what is right for them.

SaBP Culture - Risk appetite and fear of blame

One barrier that came up repeatedly in our engagement was a culture of fear, as in a ‘fear of speaking up and out’, a ‘fear of taking risks’, a ‘fear of trusting the service-user’, for *‘fear of the consequences’.* There is a recognition that sometimes handing over power and control to the service user may introduce an element of fear, unacceptable risk, or loss of control. This is a marginal but considered view, mostly held by clinicians who question whether there is support for positive risk taking.

> *“There is a real challenge for us, we are used to managing risk, containing risk and if things go wrong, that does shape people's mindset and their practice… I would really like to take some time to understand what the real barriers are, what’s likely to happen, what's imagined and how we can support working in a way that is comfortable with positive risk”*

Some staff question whether they will be supported if there is an undesired outcome:

> *"The moment something goes wrong now, we don't support, we blame… basically what happens is something goes wrong somewhere and suddenly it is the focus of masses of attention … these people, who are very senior, are coming in to say "what did you do wrong?", "what should you have done differently?, that doesn't feel supportive – supportive would have been listening [to staff concerns about safety] … a year before."*

SaBP need to enable staff to have a voice and influence their organisation in the context of working in a fair and just culture which is more focused on learning then blame and autonomy than directorship. SaBP staff reflect that they need to feel part of a team and feel cared for, as part of an organisation where they feel valued and respective and supported.

Tokenism

Throughout the engagement there was a strong sense from participants that they considered the absence of co-production to be better than tokenistic or half-hearted co-production which itself could be damaging. There is also a balance to be found between doing something and using potential tokenism as a reason not to do something. The suggestion from group sessions was to focus on a small idea and do it well - learn the lessons and apply those later treading cautiously on the way. This theme was identified most strongly in the areas of learning disability:

> *"Not having the right support for people with a learning disability to enable them to understand the task and engage fully so as not to be tokenistic."*
>
> *"To give you an example of what happens if you don't put support in place… we had a person who has mild LD and a local hospital wanted to have some people to come and look at their processes and we thought she'd be a great advocate. So going in, she had to find her own way there, they paid for taxi but then booking it was just left to her, she didn't get any support when she got there, and she didn't know what she was doing…. this person's mental health suffered for few weeks after that, they needed a lot more support, all because we thought that she would be a good advocate… so if you're going to do it, do it properly, for the right reasons and actually embed it."*

Disconnect between will and execution

In response to the question around barriers to co-production, around a third of staff talked about the 'will of the system':

> *"…. cross-divisional work is tricky due to differing cultures in the various divisions and yet this is where co-production could really increase understanding and compassion "*

There is a perception that there is a directive ‘from the top’ which encourages and supports the ideas and ideals of co-production, and at service level a workforce who are keen to work in a way that is co-produced. But, in the middle, there is a disconnect between ‘will’ to ‘facilitation’ to ‘execution’.
In conversation with staff, one member’s perception of co-production at SaBP was that there has not yet been the shift required to view co-production as something which makes life easier:

> *“Most people’s experience of working with the people who use our services is managing concerns, problems, complaint and challenging needs and so there's this kind of default mentality about it being a variable that has to be contained and controlled rather than the inevitable evolution into co-production”*

And another who would welcome a team member with lived experience, with the right support:

> *“As middle managers, if you want to call us that, we are working at a time when it’s incredibly difficult to look up. There may be top-down directives and maybe even two up from me directives, but where I sit, this is added to our workload with very little consideration of the reality of managing teams – is balancing the needs of staff with lived experience going to make my role easier or more challenging? I don’t know, but I do know at the moment, there wouldn’t be the appropriate support for me, my team or that person.”*

Perhaps more hopefully, there is a dominant view that “we are all in this together”

> *“People who are going to be using the service that we're trying to develop, and change are the best group of people to give us insight… does that mean that we should devalue professional qualifications, professional opinion and people who run the numbers? No, of course it doesn't, but things generally are much better when you try and develop them together”*

There are commissioned services which function within SaBP which are highly regarded by staff and service users alike that are driven by co-production, both on an individual and service design level.

There are, however, system blocks which prevent partners being fully embedded and integrated within the systems and spaces. For example, the well documented System One challenges around access to records and a lack of understanding from clinical teams around the purpose and scope of In-Reach teams. There was a reported confusion over their scope, where their roles allowed for disclosure of confidential information which had the potential to contribute towards an unwelcome environment for the In-Reach workers. In addition, a lack of communication around the discharge date of some clients meant that the provisions were sometimes rushed and insufficient.

Time and workforce pressure

44% of respondents to the staff survey identified that the limited workforce restricted the capacity to dedicate to innovation and re-design and that the pressures on service, being very stretched and short staffed at present were contributing factors. There is an understanding that co-production, done well takes some grit and determination and a commitment not only in the short term but to long term co-production and evaluation of a service.

> *"…doing it [co-production] needs a lot of prep and a lot of time before hand often and actually people getting the right type of questions that you can get the right kind of information back because what we often do is that we go in there with the wrong questions and therefore you getting the wrong debate … you have to go into it with preparation on both sides and it's an important thing to engage but don't estimate that is going to be an easy thing if you do it properly"*

This is balanced with the long-held narrative that the NHS is cash-strapped and overburdened so teams feel a split in their loyalties of not wanting to suggest new and potential costly ways of enhancing services and working with people, whilst on the other hand, balancing the demands of the service and wondering about whether spending 'the money' on engagement, denies 'the money' being used to provide clinical services. In this quandary, there is no assumption that co-production has the capacity to save time or money in the long term. This is perhaps a symptom of over-reliance on short term fixes to solve long term problems which is reportedly familiar in mental health services generally.

> *"Clients tend to be offered the cheapest service available in the hope that this will stop them needing more expensive treatments."*

There is also a strong opinion that time can usually be found for matters which are considered to be of vital importance and that the agility demonstrated during the recent coronavirus pandemic was evidence of such. There is also a sense of stoicism and determination:

> *"You could always find a reason not to do something so, if you believe it's important you can probably find some time somewhere somehow… if we really looked at the time people spend in doing other things, probably there will be time that we can carve out everywhere… we might need multiple opportunities to make it work but if we plan in that way there will be an opportunity"*

> *"Of course, we want to do co-production well and properly but equally that shouldn't be a barrier…to start somewhere is better than not doing anything*

> *and progressing something leads to growth and success if you stick with it and things kind of develop from there…"*

Getting it right for service users, and getting the right service users

42% of survey respondents talked about service user challenges as barriers to co-production.

There are various repeated themes around the practical barriers to service user involvement in co-production (especially service or system co-production) such as perceptions around the cost and time involved, implications for people's welfare benefits, time, and resources as well as more philosophical questions around how staff can be really honest about what can be delivered and what can't. Some respondents were not certain how to access service users for co-production:

> *"Access to service users who may wish to be involved in co-production is not clear to secondary care. Do we have access to service user volunteers or paid experts by experience?"*

> *"Not enough links with lived experience organisations (e.g., Mind, Alzheimer's Society) and not a lot of understanding of community resources."*

Time and time again we heard from staff (and system partners) that there was a sense that they were not hearing from the 'right' service user

> *"It feels like the current voices that we hear from are the same everywhere, in every meeting. Whilst it's good to hear their point of view, I wonder what would happen and who would step forward if they stepped back? Sometimes we have [to] make space for new things and new people and be curious about their experience in a way that gives them priority over stories and people we have hear from for many years."*

> *"Finding people with the relevant lived experience who are able to communicate with us about the issues in question- we cannot assume that someone with a mild LD and better communication can represent the views of people with more severe learning disabilities and different life experiences"*

We also heard that those who consistently represent the service user voice are not necessarily representative of the wider service user and carer base. Certainly, the current training of clinical psychologists puts a strong emphasis on the importance of recognising and responding to the individual and their social context.

In these cases, there was often a lack of service user engagement and involvement and very minimal co-production in that service. In services where teams had recognised the challenges of relating with the existing 'voice space' and in the absence of any known or effective Trust mechanisms for involving people, found an effective work-around and consequently meaningful improvements were made to the service. This was however, perhaps more to do with the fact that they asked people who specifically used their services rather than avoiding existing voice spaces.

One additional theme to consider which staff mentioned is whether service users trust services to hear, hold and value their contributions:

> *"I also wonder if there may be reluctance for service users and their carers to be involved as they may not believe their contribution will be as valued"*

Diversity and Representation of Service Users

Another repetitive barrier to co-production cited was a lack of diversity and representation in the current service user voice base. There was a perception that the 'frequently engaged with' were an active barrier to hearing from the 'seldom heard from' groups. There was an understanding that the current engagement arenas were or had the potential to be a hostile environment for new voices especially if those voices were in any way marginalised within the external Surrey and Northeast Hampshire communities. Throughout the engagement there was only one reported structure which supported the outreach and engagement of an ethnic minority community.

It was also understood that it was common for there to be some selection bias by teams looking for service users and carers to be involved and the people selected were more likely to be compliant, have had a positive experience and that they held relatable characteristics:

> *"If I am asking a group of people to take part in a project but I only have limited hours to pull some form of co-production together, I am naturally going to choose the people who I think will be able to show up, who will probably give me some valuable insight and will be responsive if and when I need any kind of follow-up. By limiting the amount of time and giving me the responsibility to administrate the co-production I am already skewing the responses to my questions"*

Cognitive Dissonance – the complexity of autonomy in mental healthcare

Whilst there is the will to co-produce, some practitioners navigate the line between facilitator of choice and remover of choice, such is the complexity of autonomy in mental healthcare. This complexity is uncomfortable and rightly weighs heavily on the caring practitioner's mind. There are ethical barriers to co-production of obligation over choice:

> *"…There is this tension that's part of my job which is trying to work like that [in a co-produced way] and the other part of my job is a bit like "I'm sectioning you" or "if you don't have this injection you will probably end up in hospital soon" so there's a coercive aspect… living with that paradox can be quite difficult at times … you're a bit of an agent of social control where you have a duty of care which, depending on your viewpoint, might be seen as paternalistic or coercive"*

What can be challenging however, is if, as reported, there are those practitioners who choose to remain in a place of control and management of service users as 'risks', even when that is not legally necessary:

> *"There is a danger that some clinicians are set in their ways and the idea of service users on panels for example would be a really strange concept and not part of everyday business… some people might think, you know, I am the professional… and the dynamic needs to shift maybe that's through training but we need to have a closer look at what the barriers are to change whether that's re-education and training."*
>
> *"Sometimes, people do lack capacity, but that's a very small cohort of people and not all the time… So why do we view everyone in mental health services as lacking the ability to lead their own journey to recovery or management of their own mental health? The only reason I can think of is because we prefer the familiarity and safety of being the expert to the alternative, which is less control."*

Service user and carer's perceived barriers to co-production

After reading the explanation, 59 survey respondents described some of the reasons why they might not get involved, citing both practical and emotional barriers.

As seen above, "co-production" is an unfamiliar concept to most service users and carers in our survey. Many perceive that there is insufficient support for people with lived experience to be involved; *"you can be in a constant state of anxiety with the job you do and there is not much in place to deal with this."*

27% of respondents cited the emotional burden of co-producing, not wishing to use precious personal time to exclusively talk about mental health when that is their everyday life experience.

20% of service users and carers were somewhat disillusioned and suspicious of tokenism

> *"At present they like to ask people to get involved but it appears to be lip service as they have already made the important decisions"*

> *"If they were prepared to change their minds and there was more money put into the service"*

12% of service users and carers felt their own health and wellbeing was a barrier to co-production:

> *"Anxiety about attending meetings with strangers. Feeling too intimidated to share my opinions with 'experts'".*
>
> *"I was not in the right frame of mind to be able to do this because of my illness with mental health"*
>
> *"confidence"*

41% cited time poverty:

> *"Time - both the amount required and when I work, what might be required as I have a full-time job"*
>
> *"I work full time and I care full time outside of my working hours. I would have to stop doing one of those"*

This expression of 'time poverty' highlights the risk of only hearing from a narrow demographic if groups are scheduled during the working day, for example. This may exclude those who work or have day-time responsibilities, perhaps giving weight to the suggestion of a range of ways and times that service users and carers can feedback.

A further 22% needed practical help, requiring meetings or discussions to have as much notice and flexibility as possible and 17% needed financial compensation asking for consideration through "*vouchers for time taken*" or covering childcare costs so that they weren't disadvantaged by the process of co-production.

Disturbingly, we did hear stories of co-production where the service user experience had been poor – where their needs had not been considered and their potential contribution wasted. This kind of experience destroys trust.

> *"I wanted to get involved but after about half an hour of one meeting, mentally, I just switched off. I couldn't understand the context of the improvements and when the staff spoke to me, I felt like I was being patronised for asking questions. What would have been more useful is if they had sent me some information ahead of the meeting and then distilled down what they needed from me. I could have responded in the meeting then rather than worrying that I wasn't saying the right thing."*

HOW WOULD YOU LIKE TO SEE CO-PRODUCTION IN THE FUTURE?

How staff would like to see co-production at SaBP in the future

The staff at SaBP mostly had a clear vision and determination for what the future of co-production at SaBP might look like and a willingness to share these thoughts. There is a will for co-production to be genuine and meaningful:

> *“A culture that promotes working relationships in a genuine way with the people who use our services and their families - rather than one which focuses on speedy interventions, promotes or relies on promoting independence - resource issues as well.”*
>
> *“Talk more openly and frankly about lived experience of staff especially thinking equality and diversity (reverse mentoring as example)”*
>
> *“…having worked with people directly in a department where they've embedded the service user voice … you have to offer them support, you need to bring them with carers and an understanding so you can guide them and ask the right questions to get the right answers. They’re not necessarily always going to have the empathy or be able to think about this stuff because that may not be how they are wired up, especially people with autism for example who may be very good representing their own views and their experience of life but they don't necessarily see it from somebody else's because it sometimes it's a core deficit in their condition and they don't recover… their views are still important you should still hear them.”*

There is also an ambition to have the service user voice in and at every level within the organisation so that the service user voice is in all spaces where decision making happens:

> *“I've had a long-held ambition that everything that the trust does has a user-led design element to it, so it is a really collaborative partnership between people who use services their carers and families and the people who deliver those services so that it is true working together to deliver the improvements “*

And, to ensure that that space is safe for people who use services and carers, so that the engagement is appropriate for them and their circumstance but also so that the Trust begins to place the service user and carer at the centre of all of its functions, for example the way policies and papers are written and shared in public spaces:

> *“Can we commit to say, “when we say something will write it in a way that everyone can understand everything”, “that we’ll write exec papers… everything should be so anybody that has an education or not can read it and know what it says in the plainest of English” … Our real communication is*

> *buried in the complex… there should be a distilled version and then those people have a look at it give their comments in a way that suits them…. you can get people to participate if you try, but you have to try."*

The ambition isn't limited to service delivery level or middle management, but rather to embed lived experience in the leadership spaces and structures within SaBP. In conversational engagement the idea of targeted employment of people with lived experience of services in the executive spaces and leadership roles was prevalent, and excitedly imagined, the idea of genuine and authentic leadership which was advocating for services shaped around the local population and service users seemed to reignite possibilities and overcome previously stated barriers.

Late in the survey, 62 staff respondents shared ideas for the future which were a rich range of ideas and suggestions:

#1

Cultural buy-in

- "That co-production should be central to the Trust Strategy "
- "Buy in from commissioners"
- “If we were 10 times braver, I would hope we could co-lead this organisation with people with lived experience”
- Resource people with lived experience in leadership roles with management functions with equal decision making
- “We could work in equal partnership with people who uses services.”

#2

Paid roles for service users/carers

- Employment of people with a learning disability within the division so that they can be valued for their contribution.
- “my vision is really opening the organisation up and valuing the service user voice at every level....”
- "true parity will come when we have a shadow chief executive who is a person with lived experience, and we pay them properly"

#3

Fresh approaches to accessing service user input

- List of ready made advocacy or focus groups that might be consulted in partner organisations
- I think that there should be a selected panel of people keen to co-produce and use their experience
- Make giving feedback really really easy. A text like GPs do that asks no more than five questions that people can give feedback directly to, either on a scale, so they just text a number back or written text.

#4

Investment in resources and processes

- Ensure additional time to allow for effective meaningful co-production work.
- Employ specialists in co-production with an interest in mental health or even better, lived experience
- Include co-production in work plans
- Develop Trust-wide policies for finding and supporting people with lived experience

#5

Commitment to training

- Training for both clinicians, services users and carers on how to do this well
- People who have lived experience leading training alongside practitioners.
- Supporting people with lived experience with training to participate
- MDT Training across directorates

#6

Wider reach/cross-fertilisation of ideas

- Increased opportunities for frontline clinicians to engage with service user forums and people who use services *outside* of the scope of their daily practice
- Opportunities for people who use services to meet with service managers in mutual spaces
- Opportunities for service leads and people with lived experience to work on pipeline projects together ready for funding surges

How service users and carers would like to see co-production at SaBP in the future

As we have seen above a majority of service users are unhappy with the level of involvement they have in decisions about their care, with 70% wishing they had more involvement. Only 17% are happy, and only 13% would have liked less involvement:

> *“They will suggest things and I can kinda say yes or no. I feel like they could listen to the suggestions I have a bit more”*
>
> *“I could not make the time of the sessions and rather than offer an alternative time I was discharged. I felt lost, cast adrift and discarded. I would have preferred to discuss what options, but the decision was advised to me once made.”*

Perhaps unsurprisingly, 71% of service users and carers are confident they know what good care/treatment for them looks like:

> *“I know what good care/treatment looks like as I've experienced really negative prior experiences and learnt my way around the system and how to advocate for myself.”*
>
> *“This is my daughter and I totally understand her condition.”*

What is clear from the responses is that whilst service users and carers may not currently understand the term ‘co-production’, they welcome the concept and notice where systems and services are not designed with them in mind.

Service users and carers tell us that they would like to be offered a range of ways to engage, feedback or get involved, at a timescale which suits them and their needs, with a single point of contact, in ways that they can understand.

56%

56% of service users and carers feel their service was not designed with user input

73%

73% of service users feel co-production would make a positive difference to their service

72%

72% of service users and carers said they would be interested in service redesign

There is an understanding that co-production and working in a way that always involves people brings hope, an opportunity to steer one’s own ship, to take back control and power which may feel lost and to be useful. Co-production on all levels can be part of mental healthcare, not only a way of making improvements to a system and service which is crying out for change.

> *"It is the best way to be truly person centred."*

PART TWO

SaBP should use co-production as a critical driver, facilitator, and performance indicator for cultural change within the organisation. Co-production has the power to move SaBP from a culture of 'you said, we did (or are going to)' to *'we said, we did it together'*.

Successful co-production will require a sustained commitment from leadership at all levels, as well as a willingness to inspire, to share the stories of where it has gone well and the honest lessons from where there have been challenges. SaBP needs to take positive steps towards an 'assets-based' approach to service users and carers; changing perceptions so that people are no longer seen as the passive recipients of care and services, but as equal partners in designing and delivering their own care journey and the services they use:

> *"I would assert that co-production is about collaboration in equal partnership, and that the general population is not interested in power and control. Instead, we want to have partnership rights in the process for how we are referred and assessed, then how a treatment plan is formed, how this is reviewed, and what happens regarding other services such as onward referral and further support."*

This report acknowledges that it will take time to fully embed and reflect the principles of co-production in SaBP services but sets out an ambitious mandate and outlines the key steps required for the adoption and implementation of co-production principles.

There is some wisdom in just starting somewhere and building momentum as progression is made, as staff share wins with those around them and people who use services and carers report successes – as co-production in organisations grows, so the culture within it changes and new ways of working become embedded into the everyday. Working in a way that adopts appreciative enquiry and use an agile methodology whilst reflecting in-action has an increased chance of embedding co-production at SaBP which will, in turn, enable the culture change to keep pace with the changes to ways of working:

> *"I think if we could show them how easy it can be and show them some successes and keep a really positive narrative going about co-production, those are the key ingredients."*

(In addition to these recommendations, recommendations formed from the narrative review can be found in APPENDIX 1.)

Recommendation 1: Preparing SaBP for a future where co-production is embedded at every level

There is some groundwork which could be considered before setting up the formal structures and recommendations of this report.

1.1 Address visions and policies to underpin your co-production goals for the future:
Co-production should be an intrinsic component in all key strategies and drivers under development in SaBP, not merely in a reference to a co-production strategy but instead embedded within each document with practical applications. This may mean the creation of new policies which support the purposeful employment of staff with lived experience, provide flexible working structures which do not penalise the employee for periods of mental ill health, and provide robust support for supervision and reflection.

1.2 Address how communications messages share information and portray service users and carers:
Where possible, literature, both patient facing and otherwise, should be written in a way that places the service user and carer at the centre of the document, using minimal jargon and co-produced to ensure that supportive language is used. A full communications review is recommended and a subsequent developing of policies which supports information sharing which promotes equity, autonomy and choice. Perhaps first, look at the way you communicate on a public level with service users, are your communications part of an active conversation? Who are the board papers on the website published for?

1.3 Assess where individual teams are now:
Our engagement and surveys revealed that services differ in terms of where they are currently. To identify services with greatest potential benefit and to reveal service-specific barriers it would be helpful to audit each service. A SaBP specific audit tool can be found in the toolkit of this report (Toolkit 1). Each team should audit themselves, in partnership with their CP Lead annually and then that summary should be ratified by service-users with an opportunity to work together in co-production on a GAP analysis and action plan for service adjustments.

Recommendation 2: Set up co-production as business as usual

James Clear, the well-known author and change thinker, discusses the idea that organisations do not rise to their potential so much as they are likely to fall to the level of their systems. SaBP should consider whether systems and processes currently get in the way of people becoming ‘co-producers’ and what the solutions may be to embed co-production as ‘business as usual’, from ‘design to delivery’.

2.1 Standardise co-production structures:

If SaBP would like to maximise the lived experience (service user and carer) voice across the organisation, it should develop a framework of standard operating procedures for recruiting, supporting, engaging, managing, remunerating, and supervising those people with lived experience who choose to become both employees and involved on a voluntary basis. These may need adjustments for each service/directorate.

Recommendation 3: Empower staff through training

Co-production must sit aside organisational culture change which liberates staff to co-produce effectively. This requires the examination of power structures within the organisation which may need to move away from 'power over' towards 'power with'. A sense of powerlessness can prevent people from getting involved or wanting to get involved, therefore an educational offer is indicated.

All groups consulted highlighted the need for a more consistent understanding of co-production. There should be a Trust-wide definition of what co-production could look like, and this could form the basis of mandatory training for new employees and continuing professional development training for all staff.

3.1 Co-designed and Co-delivered Training

MEP, SUN and PICT are shining examples of how, when training is co-designed and led jointly between clinical teams and lived experience staff what follows is comprehensive training which considers projects and services in the round. Co-production training for SaBP should involve genuine partnerships between patients, service users, care partners, and clinicians as the foundation for future co-designing and implementing reliable care processes that hold promise for transforming care experiences.

Recommendation 4: New employment structure

It is recommended that SaBP adopt a bold employment structure which enables co-production to be the river that runs through SaBP. The staff engagement revealed a desire to work in a way that is co-produced all the time but there are barriers to its current success which are unlikely to resolve themselves without a significant restructuring of services. Rather than overburdening clinical teams with additional roles and responsibilities it is recommended that these co-production aims be met through new roles and co-production pathways.

4.1 Lived Experience Personnel in every decision-making arena

This report recommends that there be lived experience personnel (either people who hold expertise through using services or caring for someone who has used services) in every arena where decisions around service design, funding, training, provision, evaluation and reflection are made. In this way service user voice is a natural and obvious consideration in decisions, clinical or otherwise in parity with enquiries like "is there budget for this?", "do we have the staff to enact this decision?".

Genuine co-production would mean a culture shift in services; if people with lived experience are to be equal partners and peer employees working together in the commissioning, design, and evaluation of services, they would also, in some form, need to share in the responsibility and accountability for those services.

To measure progress against this recommendation, SaBP should first benchmark the percentage of the workforce with lived experience of mental ill-health, caring responsibility, and other equalities demographics (such as disability, ethnicity, and age). This anonymized information should be published every year as part of an annual co-production review, SaBP then would lead the system in terms of integration of people with lived experience into the workforce and transparency around this.

The aim of this model is to ensure that the lived-experience voice is an integral permanent member of every team throughout the organisation, clinical teams being the priority; this might be in the form of peer support workers, administrative support, clinical members, or leadership with the aim of there being permanent teams which hold maximum expertise which cannot be found in clinically led teams alone, this approach has been embedded in the Perinatal Mental Health Team, for example.

EMBEDDING CO-PRODUCTION THROUGHOUT SURREY AND BORDERS

COUNCIL OF GOVERNORS

COUNCIL OF GOVERNORS

A council of governors who are actively engaged with current service users and carers across services and places, who regularly attend community forums and track co-production within the Trust.

LIVED EXPERIENCE LEADERSHIP

LIVED EXPERIENCE LEADERSHIP

Trust leadership which holds significant personnel with lived experience at the most senior levels.

TRUST COMMUNITIES DEVELOPMENT GROUP

TRUST COMMUNITIES DEVELOPMENT GROUP

Trust community forums feedback through this exec-level development group which offers strategic support, raises thematic concerns, monitors involvement and co-production.

LIVED EXPERIENCE & COMMUNITIES DIRECTOR

LIVED EXPERIENCE DIRECTOR

Director with lived experience to over see the co-production within the Trust. To be responsible for embedding the co-production leads in services and for the processes and policies which support future co-production

CO-PRODUCTION LEADS

SERVICE SPECIFIC CO-PRODUCTION LEADS

A co-production lead with lived experience for each service, the first point of contact for co-prod. within each service, employed by or seconded to arms length organisation to maintain a 'critical friendship'. CP Leads will link between place based forums and services.

TRUST COMMUNITY FORUMS

PLACE BASED COMMUNITY FORUMS

Community forums which have a triple purpose: a place for informal and formal peer support, a space to feedback and receive information and a place for service and system co-production

LXP TEAM MEMBERS

LIVED EXPERIENCE TEAM MEMBERS

Proactively recruit team members with lived experience to any post within the team, clinical, allied, peer and administrative so the team is appropriately balanced with lived experience personnel.

4.2 New Roles

As well as ensuring that there are lived experience employees within each team, SaBP should work rapidly towards the appointment of three new roles:

4.2.1 Co-production Leads

A Co-Production Lead (CP Lead) appointed into each of the Trust's directorates. Within this model Service Managers would work as peers with CP Leads to embed co-production throughout service management and delivery. CP Leads would be place-based but may 'specialise' in one favoured or familiar area of service (directorate).

CP Leads would be the first port of call for any projects, feedback gathering, changes in policy and communication (for example). They would work directly with Service Managers, Directors, and Associate Directors to embed and organise co-production within their 'specialist' service'.

CP Leads would undertake to build up a clear quarterly picture of feedback narratives from PALS, FFT data and Community Forums and other community assets to maximise the range of feedback analysis brought, with representatives to the Trust Communities Development Group. To maintain their role as a critical friend, CP Leads may be independently employed by a funded arm's-reach organisation.

4.2.2 Communities' Director

Employing a non-clinical director with lived experience would demonstrate to the wider organisation that people with lived experience should share in the accountability and responsibility for delivery of clinical services and be an equal partner in setting strategic objectives and ensuring that these are achieved in partnership with people and families.

4.2.3 'Guardian of Service Users and Carers':

There should be some consideration given to how lived experience can be given real parity at executive level, not just in fora but in a way that has an equal voice and whose role is principally being a 'Guardian of Service Users and Carers' in a similar appointment to a Freedom to Speak Up Guardian, with similar executive level parity and access.

4.2.4 Leadership at all levels:

A consistent and prominent commitment to co-production is needed, by all leaders, at all levels, who should be seen and heard supporting working in partnership with service users and carers, even when it is challenging as an organisational default.

Leadership in clinical teams, especially, it is understood, can still work under the old ideas of hierarchy, which may perpetuate a more prescriptive, traditional approach to the care of service users and their carers. It is therefore our recommendation that teams which naturally or otherwise work in this way, that these teams be the early adopters of increased lived experience voices in their teams. In teams where organisational structures are a significant barrier to co-production, service leads and directors should consider how they can increase local management autonomy to maximise service agility to meet the needs of service users and carers.

Recommendation 5: Reciprocity and parity of esteem

Move towards understanding, acknowledging, and valuing the expertise held by service users or carers and within an improvement framework, offering people a range of benefits to working in reciprocal relationships with professionals to improve services, where there are openly agreed mutual responsibilities and expectations. The ask and the benefits of co-production would need to be explained so that service users can make an informed choice about contributing to co-production.

5.1 Support people financially

Provide financial remuneration or flexible alternatives for service user/carer who formally support co-production. People, working in co-production with SaBP staff should be recognised for their contribution to the development of services. This recognition helps to support the inclusion of people who might not otherwise be able to get involved, whether for financial or other reasons relating to access. Consequently, it widens the potential pool of people who might influence service development. It is considered good practice for organisations to pay for peoples' involvement, and the NHS supports the remuneration of patient participation voices across services.

5.2. Allow flexibility to personalise the reward

Receiving payment of a fee for involvement is often likely to have some implication if the person is receiving a salary or state financial support and so some attention should be directed towards developing a Trust-wide framework for remunerating co-production work. You should seek to understand what is valuable to the individual, for example, would experience, training and a qualification be of more benefit to that individual than an Amazon gift card? An over-arching framework should primarily be developed and then later, a simple tool to support staff in these conversations on an individual level be co-produced.

Recommendation 6: Black and minoritised communities

From the SMEF engagement conducted, it is clear there is still work to be done around equity of access and provision in mental health services and embedding co-production will be key to achieving this.

6.1 Outreach

SaBP should commit to regular targeted outreach to establish equity in access to care, experience of care and the ability to feedback and co-produce on all levels. The community infrastructure is in place for this targeted outreach, and the CP

Leads model will allow SABP to have the staff capacity to ‘get out’ into communities and build trust.

6.2 Consider Peer Supporter approaches

To embed co-production effectively, black and minoritised communities may need to be supported to ‘seize the power’ in the relationship they have with their clinician. Peer support was raised repeatedly throughout the engagement sessions, with some groups suggesting that peer-buddying approaches may be effective. Consider piloting a peer-support scheme with faith and community leaders.

6.3 Lower Thresholds

It is understood that people from minoritised communities seek support much later in mental ill health than other demographics, they are also less likely to pursue support if it not forthcoming or if they are met with a barrier (bias, accessibility, IT, interpersonal or structural) and so adopting lower thresholds for these communities to access care is vital in striving for equitable practice (SaBP example: Perinatal Mental Health).

6.4 Stakeholder Groups

SaBP should utilise the stakeholder group for people from black and minoritised communities, through sustained work with this group to build relationships and trust - it would be an ideal forum for future co-production work.

Recommendation 7: Feedback channels and loops

In order to understand Trust-wide and service-specific challenges, develop a more rigorous network of gathering service user and carer feedback, and aim to have this collated regularly with thematic analysis within services and across the Trust.

7.1 Reach Out to Gather In

Professionals should reach out and visit service user groups more often rather than expecting service users to go to professionals’ meetings. Pro-active outreach methods should be used for communities which are seldom heard from in order to understand the experiences of service users from these communities. Some efforts could also be made to follow up on the experiences of those discharged from services in order to gather insights into the overall effectiveness of services and systems which support service users and carers after discharge.

7.2 Social Media

Consider using social media to gather feedback, stories and start conversations, particularly when communicating ‘wins’, service improvements and new services which might support a wider population. Develop the confidence of engagement and communications staff in utilising new and innovative social media platforms. As a specific example, using TikTok as a communications tool. Shelter, the national charity, have shared their sector-leading approach to engagement through TikTok : Using TikTok to tackle the housing crisis

7.3 Micro-Site

Consider a micro-site on the SaBP website which offers the opportunity to feedback around services, vote for improvement initiatives and share progress of current projects. Be transparent about the challenges and the timelines of projects, in a 'you said, we did' style, adopt a 'you said, and we are doing' moving towards 'we said, we are doing' approach to feeding back to service users and carers to manage expectations and increase understanding as well as closing feedback loops whilst maintaining the clear communication of joint enterprise.

Recommendation 8 : Distinguishing between the needs of users and carers

8.1 Identifying Carers

There is currently a confusion caused by the misunderstanding of the term carer. Both staff and families need support and explanations to understand how the term carer is defined and how that understanding can open up ways of increased involvement, support and benefits.

8.2 Understanding the rights of carers

There is not a common understanding of the rights of carers, as such it is recommended that staff are informed of these rights in order to avoid confusion and missed opportunities, this should form part of the staff induction process and teams should have an annual refresher. (APPENDIX 2).

8.3 Think Family

Fully adopt the 'whole family approach', to support all members of a family both as individuals and as a family unit, particularly in the case of young carers. Make a trust wide commitment to making policies and strategies all-age, to embed a whole-family approach. When strategic teams are formed and roles are assigned, a named member of the team should take responsibility of being the 'whole family' champion.

8.4 The Service User/Carer Relationship

The relationship between the carer and the person isn't always good or healthy. We recommend that SABP develop a function to offer supportive mediation during and following recovery, helping carers to understand how they can best support the person; and understand the benefits of the therapies they are having.

Recommendation 9: Expand co-produced commissioned services

Trusted partner organisations can act as a second 'shadow' workforce providing the vital areas of the service which may have become squeezed out through staffing levels, volume of caseloads and service acuity but with the ability to move in lockstep with service delivery teams.

9.1 Third Sector Relationships

Increase and expand relationships with organisations within the third sector, such as Community Connections and others. Build a co-production measure/commitment into trust procurement process; SaBP should expect all providers to demonstrate how they will co-produce the service for which they are being commissioned. This should form part of the contract review process.

PART THREE

The Project Partnership was tasked with reviewing the structure and function of FoCUS (Forum of Carers and People who Use Services).

FoCUS is currently part of the SaBP governance structure. It comprises of local area groups for carers and people who use SaBP services, and an over-arching ‘FoCUS committee’ with the Trust leadership. Its purpose is to:

- Empower and enable people who use services and carers to **provide feedback to the trust**, and gain responses to their feedback, without accessing a more formal mechanism.
- Give people the opportunity to ‘**share the power’** with SaBP by providing spaces for equal and respectful conversations between trust staff, people using services, carers and other professionals across the system.
- Give SaBP services and departments a forum they can access to run **co-design workshops and/or hold big conversations** about a particular topic or theme.

In addition to the service user and care survey, FoCUS area groups were attended and co-production workshops facilitated. When feedback had been gathered and collated, a further workshop was held with members of FoCUS and its facilitators to shape future plans.

What Service Users and Carers say about FoCUS

Our main service user survey received 10 responses from FoCUS members. 25% of the remaining survey sample had heard of FoCUS but weren't members, and 59% of respondents had never heard of FoCUS.

Feedback from the workshops identified that the FoCUS representatives mostly understand the function and purpose of FoCUS, especially the FoCUS committee meeting:

> *“Opportunity for discussion between services and people who use that service and their carers, share information and raise concerns or identify good practice.”*

Non-members are generally uncertain what FoCUS is or does; however they recognise that it is important to be involved and to hear information. Service users and carers like to hear from different mental health professionals and hear what is going on in the Trust which in some way maintains their sense of connection to the Trust. There may be a therapeutic value to the very informal peer support and contact with the Trust that FoCUS offers and a sense of purpose for those volunteering as FoCUS representatives.

It was also noticed that FoCUS fulfils a function for SaBP staff:

> *"Some professionals say they find out more from FoCUS about development or changes happening within the Trust than they do from internal communications - it shouldn't be like this. This is positive also as carers and people using services know what is happening in the Trust."*

> *"It is good for staff to hear first-hand experiences for carers and people who use services."*

Ideas around trust have emerged - the idea that FoCUS as a body may not trust SaBP to listen, make improvements, follow through, or respond in a timely way. There is a question over whether the SaBP trusts FoCUS to want to do anything else other than score points. Does FoCUS work from a shared purpose of improvement, or is it more concerned with holding SaBP to account? These views, in some measure, were heard from multiple respondents.

> *"…going to FoCUS feels like turning up to the headmaster's office…there's no sense of joint enterprise or a potential for resolving issues it just feels like where you go to kind of take the beating" (SaBP staff member)*

What SaBP Staff say about FoCUS

There is a sense that the FoCUS committee and groups have achieved some historical successes, but less so recently, this could be in part due to the shift to online groups and meetings as well as the capacity for change within the pandemic timeframe. Progress in making changes to FoCUS appears to have been stifled by the tight service specification it is being delivered to, partly dictated by FoCUS being part of the formal governance structure of the Trust.

Some staff reported a lack of clarity over the role and purpose of FoCUS; some thought it was a complaints vehicle, others a peer support group, some conflated it with IMHN, and others had a clear understanding of its remit and purpose in committee but not the community and vice versa.

Staff who attend FoCUS regularly share that they value hearing from people who use services and carers and engaging with them.

> *"I have some fantastic conversations with individuals in FoCUS about what's really going on in our services what we should focus on, and what we need to change which I didn't really get in FoCUS the meeting… we don't get a chance to really explore ideas properly…. I want really creative area to go*

> *where we can talk about this kind of stuff … FoCUS tends be about briefings and that’s fine but is that different to what we need?”*

“Its [FoCUS area groups] good for professionals to get feedback, almost instantly.”

However, there is recogniton that there can be tension around the role and responsibilities of FoCUS members:

> *“It can be an issue … [the people with lived experience], when they interact with us are quite focussed on their own experience and find it difficult effectively represent all people who use services well and they are going to be very focussed on their own experiences and I think, actually it’s a bit unfair, that sometimes people have been told that they shouldn’t talk about their own experience , and I accept that sometimes they do it a bit much and they get very focused in a way that's not helpful but, having said that, we need to hear those voices somehow or how else are we going to learn from it?”*

There was a recognition that FoCUS was not for just one purpose but instead could serve to function as a space for feedback, raise concerns, raise up best practice and congratulations, share transformative care stories, peer support, general communication, and education:

> *“It is not just a space to share ideas and thoughts, it is about improvement and change and the Trust listening and actively acting upon what we are saying, and that is missing from these statements”.*

“It is a forum/educative place where people can get information back from the Trust.”

Challenges around FoCUS

Attendees of the workshops, who were both SaBP staff and FoCUS members, were asked to share what they felt were the challenges around FoCUS:

- **Formality**: There are barriers to attendance including papers, agendas and the formal running of a meeting. These formalities present a structure which serves as a barrier to new attendees or attendees who have been away for a while and deters people from participating. This formality is dictated as part in the formal Trust governance structure.

- **Digital inclusivity**: Challenges were raised around the use of Zoom during the pandemic and whilst this allowed for some to access meetings more frequently than they had previously been able to, it also acted as a barrier to others left unable to access digital platforms. The FoCUS team have issued equipment and data to those who needed it to access, but some people prefer in person interactions. Equally, there is concern from those who prefer online access, that they may be ‘left behind’ if FoCUS were to return to exclusively face to face delivery in the future.

- **Representation**: It was recognised that FoCUS was not currently representative of the population of Surrey and Northeast Hampshire, nor the spread of services available at SaBP.

- **Diversity**: There is a lack of diversity and inclusion in the membership of FoCUS and particularly those who attend meetings (versus those who contribute asynchronously).

- **Static membership**: Same people, few fresh faces. People have developed trusting relationships with FoCUS and gain some peer support and structure from it, so they tend to attend for a long time. This can put new people off returning and actively contributing.

  “FoCUS is usually about half a dozen of the same people each of the different focus groups that are there all the time and they dictate terms, and I don’t think it’s particularly high functioning.”

- **Challenging behaviour**: Some challenging behaviours such as late arrivals, criticism of contributions, blunt language, interruptions, speaking over people, use of acronyms and other ways of implying expertise, ‘showboating’ about committee experiences, repeating unhelpful comments multiple times and focussing too much on single/personal issues. Some experiences of challenging behaviours that were considered disruptive, offensive and in some cases inexcusable. These feelings are palpable but have perhaps become more myth and legend than indicative of recent experience. There is also a recognition that working with groups of people who are often in distress, or facing difficult circumstances, means that an element of support and understanding is crucial, it is therefore unrealistic to expect forums involving predominantly people who use services and their carers to hold the function and form of a professional meeting.

- **SaBP Responsiveness**: It was identified that the Trust is currently often minimally responsive to the issues raised within FoCUS and it is suggested that they must dedicate time and resource for managing any future contract for FoCUS; that they must work with the support team giving timely responses to queries or questions and ensuring a schedule of topics to be covered at meetings that are of benefit to all to have value.
  “*FoCUS feels like a transactional meeting*.”

- **SaBP staff commitment:** Some frustration was expressed with staff commitment.

> *"CMHRS Managers or other staff presenting who give their apologies and don't attend the meeting which is disappointing for those who may have travelled or given up their time to attend. The Trust must tell staff that the meetings are important and if they make a commitment to attend, they must do so."*

Succinctly, it was identified that *"FoCUS must not be meeting a need as there are few service users and carers that attend. Something is not working."*

Even so, FoCUS gives people an opportunity to feedback what service users and carers are experiencing at the current time; it is regular and accessible to many and can fulfil a valuable function:

> *"It offers a space to process and to give feedback without going through a complaints procedure"*

A vision for the future

Through the extensive engagement with FoCUS local groups, the service user and carer survey, 1:1 conversation, and a FoCUS Workshop, a vision for the future of SaBP community engagement emerged which opens up FoCUS to build and support communities, for the cross fertilisation of ideas and a space for co-production and productive positive engagement as well as the freedom to share concerns and challenges.

It was broadly felt that the new overarching principles might be:

- Being **accessible** to people using services and carers – e.g., physically accessible but also accessible in format (e.g., shorter sessions that people can dip in and out of), as little paperwork as possible, so people can join having never read anything about it.

- Having opportunities to be involved in-person, virtually or asynchronously.

- Having a mix of times and dates (to include an evening offer) for participation in the group.

- As **informal** as possible e.g., is being a 'member' important? Much more accessible for people to register (for communications) without having to consider 'membership' when they are unwell or in recovery.

- Having a good **mix of people using services** (all of the services) and carers as well as inclusion and representation of others to ensure quality and equality i.e., LGBTQ+ groups.

- Providing staff with a **safe space** to run co-design workshops, with the support of the FoCUS support team.

- The FoCUS coordinator being able to **out-reach into other services** (e.g., In-Reach service) as well as wider community services, to ensure they are advertising the community forums to a diverse range of people.

The new model should be a collegiate space where service users, carers and Trust staff work in concert to achieve effective communication and co-production goals:

> *"FoCUS is there to ensure people's voices are heard and it's better to do this in partnership rather than an aggressive style".*

New Format 1: Trust Community Forums

The suggestion is a new style of 'SaBP Community Forum' (name to be decided upon in a co-produced way, perhaps as a first joint endeavour) which would be six place-based local groups replacing the current area groups. These would feed into the committee meeting, which will be rebranded as the 'Trust Communities Development Group'. These groups would be co-facilitated by the Co-Production Leads (CP Leads) and a FoCUS coordinator.

These groups would have a drop-in feel rather than a formal meeting one, dropping formality in the local forums and keeping papers and agendas limited to the Development Group only. These forums would rotate in format, some online and some in person to allow for increased engagement. The forums would also have a significant shift in the structure of the meetings to meet the needs of the community groups for example:

Community forums – online format
Part 1 - Co-design workshop/trust update – 45 mins
Break - 10/15 mins
Part 2 - CMHRS local feedback and problem solving – 45 mins

Community forums – in person format
Part 1 - Co-design workshop/trust update – 45 mins
Social time – 30 mins
Part 2 - CMHRS local feedback and problem solving- 45 mins

In the second part of each community forum, points raised could be recorded on an over-arching feedback 'Trello board' – which is then typed up and shared with the Trust each month, so they can see if an issue is being raised by a number of people, for example, and get early sight of issues being raised in certain areas which gives advance insight of challenges and themes emerging to discuss at the Trust Development Group.

Trust Community Forums should be frequently attended by governors as part of their agreed duties to ensure that they are fully sighted and more importantly, representative in their spaces of wider feedback. Community Forums should also have pop-up PALS clinics at the end of them, offering advice and liaison. As well as CMHRS having a regular attendance, GPiHMs and MHICS regularly attend in - person meetings to offer signposting.

Each Trust Community Forum should diversify its co-production methodologies regularly to address different learning and feedback styles to operate fully as a community of enquiry and production. This could, for example use arts as a medium, perhaps feeding into a larger trust wide arts project, ensuring that people's voices are, literally, part of the fabric of the buildings.

New Format 2: Trust Communities Development Group_

The Development Group would:

- facilitate representatives speaking to senior leaders of the Trust about themes they have been hearing
- hold PALS to account – what are they hearing and what actions have been taken (themes rather than specifics)
- have one or two 'big conversations' with the Trust about relevant topics.

The Development Group will become a space where the Co-production Leads, together with existing experience leaders, can triangulate feedback from across the Trust (service feedback, PALS, complaints, Friends and Family data) to present a wider picture of emerging themes for strategising.

In addition, the Development Group could discuss the most voted for areas of concern on the 'Trello Board' chosen at Community Forums.

The Development Group will maintain its status as a formal style meeting with papers, terms of reference and governance structure. These papers should be published on the Trust web (micro) site and available to Community Forum attendees who prefer to receive this information with the formality of minutes. More general themes and any answers/ progress from Development Group should be shared in a quarterly newsletter, co-produced with the representatives. This newsletter and its contributors should be appropriately resourced.

New Format 3: Logistics

Community Forum schedule

Quarterly rounds - 24 meetings a year (5 area forums and 1 evening) and make the meetings longer to allow for peer-to-peer support and 'free range' engagement before the meeting.

- **Month 1** – community forums (early in the month) - all 5 areas and an evening. (6 total)
- **Month 2** – collating info/putting it together and going to trust. Committee meeting (end of month 2)
- **Month 3** – comms month – focus roundup newsletter out. Newsletter – advertises dates and arrangements for the next 2 sets of forums.

Split between in-person and virtual forums

- **Round 1**
  Virtual - Surrey wide (evening), East Surrey, Northwest Surrey.
  In-person - Surrey Downs, Guildford & Waverley and, Farnham and Northeast Hants.
- **Round 2**
  Virtual - Surrey wide (evening), Surrey Downs and Guildford & Waverley.
  In person - NW Surrey, East Surrey, and Farnham and Northeast Hants

- **Round 3**
  Virtual - Surrey wide (evening), Farnham and Northeast Hants, East Surrey.
  In person - Northwest Surrey, Surrey Downs, Guildford & Waverley
- **Round 4**
  Virtual - Surrey wide (evening), Northwest Surrey and Surrey Downs.
  In person - Guildford & Waverley, Farnham & Northeast Hants, East Surrey.

SaBP dependencies

- That SaBP agree a response time for the 'Trello board' tickets– so responses can go into the news round up before the next Community Forum.
- Adequate funding and resourcing of the staff attending and a contract sufficient to enable all elements described to be facilitated and planned well.
- Considerable increase in SaBP Communications interactions, particularly for the micro-site i.e., sharing publishing rights with an appointed officer.

Locations for in-person

- Wi-Fi
- Disabled access
- Hearing loops
- Different room layouts, perhaps not so formal.
- Reimbursement of travel – via BACS (taxi provision as it is now for those who need it to their local area group or for the area group they choose for that round).

TOOLKIT

This is, by no means, a step-by-step manual about how to ‘do’ co-production in mental health services. There are already several guides, frameworks, and toolkits available:

-The New Economics Foundation (NEF) (www.neweconomics.org)
- 4Pi Standards - The National Survivor User Network (NSUN) (www.nsun.org.uk)
-Think Local Act Personal (TLAP) (www.thinklocalactpersonal.org.uk)
-Rethink (www.rethink.org)
-National Development Team for Inclusion (NDTi) (**Error! Hyperlink reference not valid.**)

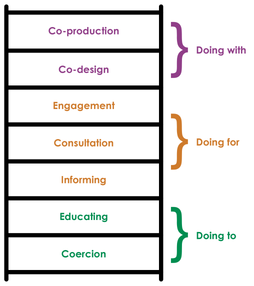
These ‘tools’ are in response to requests made by stakeholders throughout the project lifespan, they are not definitive guides.

TOOLKIT CONTENTS

1	Self/service evaluation
2	How to guide: Social-media for co-production
3	Community Asset Mapping
4	Think Carers
5	Think Young Carers
6	How to guide: Survey
7	How to guide: Creating a safe space for co-production sessions
8	How to guide: Running a creative feedback session (example session)
9	Glossary of terms

TOOLKIT 1

SaBP Co-Production Evaluation Tool



This co-production self-assessment scoring matrix has been developed to help Surrey and Borders Partnership NHS Foundation Trust teams that are implementing co-production to review their own practice. The tool was originally developed by Colette Lane (SaBP) and has been adapted by the co-production project partnership. It should be used in partnership with the ladder of co-production.

Team:/ Department ____

Please use the scoring grid to give a score from 0-3 for each question.
Question 1. Incorporating peoples' skills and experiences into the design of services

0	1	2	3
No input from people with lived experience in the design of the service	*People are encouraged to volunteer informally.*	*Unpaid/ voluntary 'Expert by experience' roles exist for people within the service.*	*Paid 'Expert by experience' roles exist for people within the service.*

Do you have people with lived experience	**Score**
As part of your working group on service design?	
Asked for their ideas about the design of your service e.g. at a workshop/focus group?	
Average Score	

Please use the scoring grid to give a score from 0-3 for each question.
Question 2. Incorporating Peoples skills and experiences into the delivery of services

0	1	2	3
No input from people with lived experience in the design of the service	*People are encouraged to volunteer informally.*	*Unpaid/ voluntary 'Expert by experience' roles exist for people within the service.*	*Paid 'Expert by experience' roles exist for people within the service.*

Do you have people with lived experience: -	**Score**
On interview panels?	
Involved in staff induction?	
Involved in staff training?	
Involved in presentations?	
Helping in the production of comms/ leaflets?	
As part of a working group on improvements, outcomes, and evaluation?	
Providing regular feedback?	

Please use the scoring grid to give a score from 0-3 for each question.
Question 3. Enabling people to find ways to support one another

0	1	2	3
A support system is not in place to support people with lived experience working with us.	*People are supported by a staff member.*	*Informal mentoring or buddying takes place.*	*A peer network exists that enables the transfer of knowledge and skills.*

Do people with lived experience have: -	**Score**
A support system in place to support them?	
An allocated staff member to support them?	
An informal mentoring or buddying system in place?	
A peer network available to them that enables the transfer of knowledge and skills?	
Average score	

Please use the scoring grid to give a score from 0-3 for each question.
Question 4. Recognising and celebrating peoples' contribution

0	1	2	3
People are not routinely asked for their views about the service.	*People are asked for their views and these ideas help to shape the way that services are run.*	*People know that when they get involved that it will be celebrated/ rewarded.*	*Peoples' contributions are systematically recorded and celebrated/ rewarded*

Do people with lived experience: -	**Score**
Get asked for their views about the service?	
Get asked for their views and these ideas help to shape the way that services are run?	
Get celebrated/ rewarded for their involvement?	
Have their contributions systematically recorded and celebrated/ rewarded?	
Average score	

Use this space to consider co-production in your service area, perhaps complete the statements?

Our service would be truly co-produced if.....

Our service would be more person-centred if ....

We would do more co-production if....

TOOLKIT 2

9 social media features to boost co-production

01

Poll

Instagram Stories, Facebook, LinkedIn, and Twitter

Set 2-4 closed options to choose from. 24 hour window on Instagram stories. Quick fire responses.

Example: *What job title do you prefer for peer-support workers? Option A or Option B.*

02

Q&A

Instagram Stories

Set a topic for viewers to input answers and thoughts. Answers can be shared within 24 hours of the original story to generate more discussion and engagement.

Example: *What does 'mental health' mean to you?*

03

Comments

All platforms.

Can be used to generate discussion and for people to informally voice their opinions. Interaction between users can build a community atmosphere.

Example: *'What will happen with the info?'*

04

Tags

All platforms

Direct users to the other organisation to learn more Makes other organisations aware of the posts.

Example: *@MaryFrancesTrust are looking for...*

05

Hashtags

Twitter, TikTok, LinkedIn, Instagram

Categorises and can get trending hashtags for larger reach. People can follow hashtags which will inform what they see on their feeds.

Example: *#LivedExperience #HiddenDisabilities*

06

Share

All platforms

Helps promote other projects and existing posts/information, useful for organisations who may not have a strong media presence.

Example: *SaBP shares a post from Catalyst.*

07

Collaboration Posts

Instagram

This allows for the same post to show up on multiple Instagram accounts. Helpful for joint/collaborative projects as the same information goes to different demographics.

Example: *A project with more than one organisation.*

08

TikTok Q&A

TikTok

Similar to question box but doesn't disappear after 24 hours. People can always access this feature unless it is turned off.

Example: *How can I get involved with projects?*

09

Video Replies

TikTok

Creates dialogue between comment section and the feed. Allows to continue discussion better than TikTok comment section as there is a character limit. ***Example:*** *Engage with comments that need a longer reply that the character limit allows.*

TOOLKIT 3

TO FOLLOW

TOOLKIT 4

THINK CARER

I am identified as a carer at an early stage; my needs assessed within the context of my whole family and I have choice and control in my caring role.

I am encouraged to recognise my role and rights as a carer; the rights of the person/s I care for, and our rights championed and protected.

I am included and supported safely when the person I care for is discharged from inpatient care; and I know who to contact if I or the person I care for has an emergency, including a mental health crisis.

I have access to high quality information, including financial and welfare benefits advice, that is personalised.

I am able to stay healthy and live well myself, able to be socially connected, not isolated and have breaks to support me and maintain my own wellbeing.

I have my own needs and wishes as an individual recognised and supported, and I am supported to remain in work, training and/or education.

I have access to support and training that will enable me to feel confident in my caring role, and I am informed, respected, included and supported as an expert partner in care.

I have meaningful opportunities to have my voice heard and be empowered to share my lived experience which will influence learning and change.

TOOLKIT 5

THINK YOUNG CARER

The condition of the person we care for is not the full story – they're a person too; their condition affects their mental health and the rest of their life, and it affects us in lots of ways. We need recognition and support too.

We need more long-term solutions and support for us and the people we care for. Six weeks isn't enough. Refer the person we care for to activities, support groups and days out, to decrease their isolation. This helps decrease our isolation and caring roles too.

Having a consistent, supportive adult who we trust can really help. We shouldn't have to tell our story over and over. We want and deserve to feel like we're a priority and know which services are supporting our family

Treatment needs to be more accessible and flexible to allow us to support the person we care for.

We need more detailed information from doctors from a younger age about medicines- knowing what it's for, what it's supposed to do and any side effects,

If we're telling you about our situation, it's because we need comfort and support. Training for professionals is essential so you understand what we have to deal with, how this affects us and how you can support us in ways that work.

Workers need to be clear about what they can or can't do in their roles, so we are clear on expectations.

Better communication between GPs, pharmacists and us would make life easier for the people we care for. Fewer errors and confusion with prescriptions, would help them and us a lot.

Checking in on a patient regularly can help head off a crisis, with crisis and discharge plans that are written in language we can understand, so we know what to do before a crisis happens.

We need quicker crisis responses when it is known that the patient is cared for by a young carer – we shouldn't have to cope on our own and we need to know what to do when things go wrong.

TOOLKIT 6

Co-Producing a Feedback Survey

1. **Define the objective of the survey**
   Be clear about exactly what you are hoping to learn, and why
2. **Identify the target audience for the survey**
   Who will have insights into this subject?
3. **Form a working group with members of that target audience, and representatives of different organisations and stakeholders**
   Aim for a cross section who can provide diverse perspectives
4. **Discuss what you are hoping to learn**
   Use this information to develop questions
5. **Gather question and theme suggestions from all members of the group**
   This can help you refine the survey
6. **Use the working group suggestions to create questions in Plain English**
   Use simple language to make the survey as accessible as possible
7. **Consult with group about interpretation of the questions**
   Rephrase questions accordingly
8. **Bring survey back to the group for review and make any necessary adjustments**
   Invite feedback from the group at all stages
9. **Review final draft with members of target audience who were not involved in its creation**
   Gaining a fresh perspective mean you confirm the questions are interpreted as you would expect
10. **Promote survey through a variety of organisations connected to target audience**
    Follow up with reminders so the survey doesn’t get overlooked

TOOLKIT 8

Running a Creative Feedback Workshop

Objective

Allow service users to:

1. feel heard
2. express their emotions
3. start conversations about the service user experience
4. have their say about their care.

Creative workshops can help bring autonomy to service users and find ways to help increase co-production discussions between service users, clinicians, and carers.

Resources

For each participant

1. Cut out card circles
2. People cut outs x 3
3. Flashcards in red, orange, and green.

Other

1. A whiteboard with pens.
2. Decorating materials such as glue sticks, scissors, pens, pencils, felt, sequins, coloured paper etc.

1

Ice breaker

This will help bring the group together and become more comfortable in the space.

EXAMPLES What would be your superhero power? What colour would your superhero suit be?

2

Introduce aims

Provide an overview of the workshop and break down the activity into steps. Opportunity for participants to ask questions.

EXAMPLE 'Today we are exploring how you feel about the care you receive through a creative activity.'

3

Resources

1. Three cut-out people to decorate (provide examples for the participants)
2. A circle
3. Give each person three flashcards: Red, Orange, and Green.

4

Explain resources

Explain how each colour represents a different emotion, and no emotion is wrong. The colours could mean:

Red = anger, sadness, frustration.
Amber = I am unsure how I feel.
Green = I'm content, I feel good.

The cut-outs represent:
A doctor, a carer, themselves.

Allow time for participants to decorate cut-outs.

5

Apply

Ask the participants to place themselves in the circle relative to how involved their feel in decisions made about their care.

The closer to the middle of the circle = the more say that cut-out (doctor, carer, themselves) has about their care.

EXAMPLE Doctor in the middle = doctor has all the say.

They may place themselves outside the circle.

Have an example of the ideal: 3 cut outs standing side by side.

6

Questions

Ask the participants situational questions to further discussion and see if the positions of the cut-outs move closer or further the centre.

EXAMPLE:

1. Do you feel you have a say in your care?
2. Do you understand what medication you are on and why?
3. Does the doctor speak to you or your carer when in a meeting with them?

You could also use the questions from the survey.

7

Close discussion

Be sure to thank participants
Remind them the aims of the project and how they have helped
Let them know how you will let them be involved with the project as it continues and how you will feed back at the end of the project.

TOOLKIT 9

Glossary of terms:

This document shows common terms associated with co-production.

A

Access
The opportunity to use, get or benefit from something. If you have a disability, you may need changes to be made to enable you to have full access to everything in your community, including services, facilities, and information.

Accountability
When a person or organisation is responsible for ensuring that things happen and is expected to explain what happened and why.

Acronym
An abbreviation consisting of the first letters of each word in the name of something, pronounced as a word.

Active listening
A way of listening that enables you to be fully heard, especially if you have dementia or difficulties with communication. Someone who is actively listening to you will be giving you their full attention, not interrupting, not doing other things, and checking with you that they understand what you are saying.

Active participation
When you are included in decisions about your care and support and have a say in how you live your life and how you want to spend your time.

Assets
Things you have that may be valuable in money terms (such as a house), or useful in other ways (such as particular skills, knowledge, or relationships).

Asset-mapping
Working with individuals and communities to look at the positive things that people and communities have, and at what they can do rather than what they lack. These positive things - assets - include people's knowledge and skills, local community organisations and the connections that exist between people.

Autonomy
Having control and choice over your life and the freedom to decide what happens to you. Even when you need a lot of care and support, you should still be able to make your own choices and should be treated with dignity.

B

Benchmark
A way of comparing the same type of service in different places. The level of quality that every service should provide is set as a 'benchmark', and each service is measured against it and compared. 'Benchmarking' in this way should help services to work out how they can do things better and where they are doing well.

C

Capacity
The ability to make your own choices and decisions. To do this, you need to be able to understand and remember information and communicate clearly - whether verbally or non-verbally - what you have decided. A person may lack capacity because of a mental health problem, dementia or learning disability.

Care Act 2014
A law passed in England in 2014 that sets out what care and support you are entitled to and what local councils must do. According to the law, councils must consider your wellbeing, assess your needs, and help you get independent financial advice on paying for care and support.

Carer
A person who provides unpaid support to a partner, family member, friend or neighbour who is ill, struggling or disabled and could not manage without this help. This is distinct from a care worker, who is paid to support people.

Clinical Commissioning Group (CCG)
A group of GP practices in a particular area that work together to plan and design health services in that area. Each CCG is given a budget from NHS England to spend on a wide range of services that include hospital care, rehabilitation and community based. Your local CCG should work with the council and local community groups to ensure that the needs of local people are being met.

Clinical governance
A way for health care organisations to continuously improve the quality and safety of care they provide, and to explain how they are doing this.

Co-commissioning
Joint working between commissioning authorities, such as NHS England and local groups of GPs, to make sure that particular health services are available.

Co-design
When you are involved in designing and planning services, based on your experiences and ideas. You may be invited to work with professionals to design how a new service could work, or to share your experiences to help a service improve.

Cognitive dissonance
When there is a difference between what you believe is true and your experiences or behaviour.

Collaboration
Two or more people or organisations working together to create or achieve something.
Commissioner
A person or organisation that plans the services needed by the people who live in the area that organisation covers and ensures services are available. Sometimes the commissioner will pay for services, but not always. In many areas health and social care commissioners' work together to make sure that the right services are in place for the local population.

Continuity of care
There are two meanings to the phrase 'continuity of care': seeing the same doctor or other care professional every time you have an appointment or having your care well-coordinated by several different professionals who communicate well with each other and with you. It is particularly important if you have a long-term condition or complex needs.

Coordinated care
A way of joining up all the care and support offered to someone with complex needs by getting people and processes to work together. It means considering what you need as a whole person, not just treating each type of symptoms separately.

Co-production
Acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. It is a way of working that involves people who use health and care services, carers, and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development, and evaluation.

Culture
The attitudes, customs, and social behaviour of a particular people or society.

D

Diversity
Recognising and respecting people's differences in race, gender, sexual orientation, age, physical abilities, religious beliefs, and other things. Valuing and including people from different backgrounds and helping everyone contribute to the community.

E

Early intervention
Action that is taken at an early stage to prevent problems worsening at a later stage. It may apply to children and young people, or to help that is offered to older people or people with disabilities to enable them to stay well and remain independent.

Engagement method
A range of interactions from simple information giving through to supporting community activity to hold people’s attention and promote involvement in the wider

discussion. Before choosing an engagement method, it is helpful to think about purpose and people.

F

Facilitator
Someone who makes a process easier, or helps people reach a solution or agreement, without getting directly involved in the process, discussion, etc.

Forum
A situation or meeting in which people can talk about a problem or matter.

I

Inclusion
Meeting the needs of everyone in a community by taking action to create an environment where everyone feels comfortable, respected, and able to achieve their potential. It means treating people as equals and removing barriers that may stop them participating in an event or activity.

Integrated Care
Joined up, coordinated health and social care that is planned and organised around the needs and preferences of the individual, their carer, and family. This may also involve integration with other services e.g., housing.

J

Jargon
Words and phrases used by particular groups of people, especially in their work, that are not generally understood by other people.

L

Lived experience
The knowledge and understanding you gain when you have lived through something or experienced it for yourself.

M

Mapping
Part of the process of planning services in a particular area and looking at what already exists, what is needed, and where.

O

Outcomes
In social care, an 'outcome' refers to an aim or objective you would like to achieve or need to happen - for example, continuing to live in your own home, or being able to go out and about. You should be able to say which outcomes are the most important to you and receive support to achieve them.

Outputs
The things that an individual or organisation produces because of the work they do. Outputs are not the same as outcomes, which refer to the things you hope to achieve. For example, the output of a care agency is the number of hours they

spend providing you with a care service. The outcome for you is that you remain in your own home.

P

Panel
A group of people with different backgrounds and areas of expertise who jointly make decisions - or agree decisions made by others - about services and funding.

Participation
Taking part in decisions about things that affect you and other people. This may be about your own day-to-day life, such as what to eat or how to spend your time, or about how a service or organisation is run. It is more than consultation: you should not just be asked your view but should be able to have an influence over the final decision.

Peer support
The practical and emotional help and support that people who have personal experience of a particular health condition or disability can give each other, based on their shared experience. People support each other as equals, one-to-one or in groups, either face-to-face, online or on the telephone.

People who use services
Anyone who uses care services, whether you are in your own home, in residential care or in hospital. The NHS is likely to describe you as a 'patient', while the council and other care providers may also describe you as a 'client' or '**service user**'. You may also be described as a 'cared-for person', in relation to your carer.

Performance indicators
Ways of checking that an organisation is doing what it is supposed to be doing, by measuring progress towards particular goals. An example of a performance indicator might be how long people wait after requesting an assessment.

Person-centred care
An approach that puts the person receiving care and support at the centre of the way care is planned and delivered. It is based around you and your own needs, preferences, and priorities. It treats you as an equal partner and puts into practice the principle of 'no decision about me without me'.

Practitioner
A person who works in a skilled job such as social work, nursing, or medicine, providing care or support directly to people.

S

Service user
A person who receives services from a care and support provider. Not everyone likes this term and may prefer to be described simply as a '**person who uses services**' rather than a 'service user.'

Stakeholders
People or groups who have an interest in what an organisation does, and who are affected by its decisions and actions. When an organisation such as your local council or NHS trust is planning to make changes to the way it works or the services it offers, it may hold a **consultation** with stakeholders, to find out what you think and what your experiences are.
Statutory guidance
Information from the Government explaining how specific laws such as the Care Act 2014 should be put into practice and what they mean for people.

T

Tokenism
Doing something only to show that you are following rules or doing what is expected or seen to be fair, and not because you really believe it is the right thing to do. This can be giving a member of that group an important or public position; however, this act doesn't contribute to any beneficial or long-lasting changes.

Triangle of care
A way of making sure that carers are involved in planning the services that the person they care for needs. The 'triangle' should be a partnership between the person who uses services, the carer and the main professional involved.

U

User involvement
The involvement of people who use services to inform how those services are designed, delivered, and run. It may be an opportunity to use your experiences to make a particular service work better, and to be involved in decisions about things that affect you. User involvement takes different forms in different organisations, from voicing your opinion to getting actively involved in the way a service is run.

V

Voluntary sector
Organisations that are independent of the Government and local councils. Their job is to benefit the people they serve, not to make a profit. The people who work for voluntary organisations are not necessarily volunteers - many will be paid for the work they do. Social care services are often provided by local voluntary organisations, by arrangement with the council or with you as an individual. Some are user-led organisations, which means they are run by and for the people the organisation is designed to benefit - e.g., disabled people.

W

Workshops
A meeting in which people learn about a subject by discussing it or doing activities related to it.

Y

Young carer
A young person aged 18 or under who looks after, or helps look after, a family member or friend who has an illness, disability or drug or alcohol problem. They may be responsible for cooking, cleaning, shopping, personal care, or emotional support.

APPENDICES

1	A narrative review of co-production
2	Carers : A guide to what SaBP Staff should know
3	What We Did : Co-Produced Staff Survey Report
4	What We Did : Co-Produced Service User and Carer Survey and Social Media Report
5	What We Did : A Co-Producted Poster
6	Creative Workshop Guide

APPENDIX 1

Co-Production Success - A Narrative Review

Contents

Executive Summary

The findings of this narrative review are persuasive enough to say that efforts towards public engagement and co-production will be rewarded beyond their cost, given some provisions about how best to engage. National and regional policies and strategies require it to be implemented. Many local and national services have made it their policy and put that into practice.

It is essential to improve how engagement and co-production are enabled, especially to address health and social inequalities which have increased for many reasons including the disproportionate effects of cuts on areas of most deprivation. Co-production will add value, whether one is attempting to develop policy or strategy, conduct research, make system improvement, develop service delivery, or improve outcomes and impact. Co-production is about learning that produces effective change.
Value will include staff morale and sustainability as well as improved client care experiences, wellbeing, and outcomes, which extend to families and wider community.

The findings make a compelling case for following models and examples into local practice because they have resulted in sustainable and enduring achievements. However, some systematic developments are needed to create the right environment for success. These include wider cultural improvement, leadership and

Quality Improvement skills, data and digital infrastructure, the framework for multi-agency and multi-disciplinary collaboration. In turn these can only happen if reflective practice, teamwork, and wider communities of practice are nurtured. This is not resource free but will pay off eventually.

I think any development in this field should be from the starting point to engage as early as possible, and to ensure that a wide segment is reached. I infer that there are “no wrong people” but we need to think more clearly about the distinct roles of “engagers” and the support needed to benefit effectively from the experiences of people engaged in co-production. We also need to think about how to reach people. The community providers in our localities have established a powerful reputation for person-centred care and a demonstrable capability to cultivate engagement and co-production that is sustainable and effective. Our higher education institutions and our major businesses and industries may be under-utilised in connecting mental health service research, policy, and practice with patients and public and communities.

Who are the people who need mental health services and where do we find them? We find them at work, in our education and other social institutions, at home and collected within the places and services to which people with such problems are referred, and we find that people with some characteristics in common have a higher prevalence of such problems; people who are in a minority of one kind or another, whether or not their characteristics are protected; people who have suffered trauma, adversity, prejudice; discrimination, persecution; people who did not get what they needed, when they needed it; criminal justice services; homelessness services; welfare services; disability and social care and support services; people finding it hard to fit in to education, training or employment; wider health services;

Therefore, while I have not ignored examples from mental health trusts, I think the contribution of ideas from other organisations can significantly improve how these trusts can implement co-production to realise its benefits. The biggest lesson is to ensure that clinical services collaborate with community organisations and individuals to balance clinical and social value.
There is an extensive body of work from NHS Improvement and many other sources available for anyone searching for approaches to engage people in co-production.

Co-production is part of cultural change towards person-centred care, invoking the core values of the NHS, recognising social value as well as clinical standards in improving wellbeing. The value of person-centred care cannot be realised without recognition that individuals may need support to exercise a strengths-based approach, and this in turn demands that systems are accessible, produce effective assessments and care plans that inform care coordination and integration and deliver social as well as clinical value. Overcoming systematic obstacles is essential to release the potential that co-production offers, and that must include how staff are supported. The biggest challenge is in adapting services to respond to individual needs, rather than towards performance indicators that are service-centred or politically driven.

Currently, NHS is under intense scrutiny to improve how it delivers services for minorities suffering health inequality. Service outcomes for some minorities are poorer compared to the average outcomes of the general population. Some outcomes are determined by the quality of NHS services, but wider determinants may have an even greater effect. It is therefore essential in my view that the measures used to evaluate and improve services are themselves subject to improvement and co-production. This is especially true for mental health services, because unless there is wider social change, NHS will continue to be the backstop for the failures of other institutions to provide effective care to prevent or mitigate social harms. For example, there is a higher incidence of mental health problems among people brought up in care, people suffering adverse childhood events, people with other conditions that affect development and wellbeing, people suffering prejudice and discrimination because of minority social identities. In turn, many such people become subjects of the criminal justice system, homelessness services, domestic abuse, addiction services and others.

We also need to involve the private sector more effectively in prevention and early treatment. Occupational Health standards vary enormously and improvement in how we engage employers of all kinds will have social value and clinical value. Instead of asking whether we should engage in co-production, and whether we can afford it, we should be asking how we can engage in co-production more effectively because we cannot afford not to do so. We can then avail ourselves of the sources referred to in the findings to follow some practical advice about how to do so successfully.

Co-production in NHS – policy and definition

There has been an evolving NHS policy to engage in co-production. NHS England in collaboration with many organisations has put personalised care at the heart of the co-production approach. Refer to the Coalition for Collaborative Care (C4CC), now merged with the Coalition for Personalised Care (C4PC) This collaboration has produced guidance resources and a model for co-production.

This collaboration has produced the following description of co-production:

> *"Co-production is a way of working that involves people who use health and care services, carers, and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation. Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives".*

Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective. It is important to note that the whole branch of work that produced the model and guidance from NHS England is set within the NHS Improvement framework. That itself is a main branch of effort to achieve the aims of NHS transformation.

NHS Improvement itself provides extensive source material from more than a decade of improvement effort and is worthy of detailed search and study. However, not all the resources use co-production methods. Some extensive resources do not even mention it. In my view, they are focused within a clinical model that seeks to improve the "work of care" rather than the "relationships of care." While experiences of care vary in all clinical fields, it is of central importance to improve the relationships of care in mental health services. The reader will find it helpful also to review the NHS England "CORE20 plus5 – an approach to reducing health inequalities" strategy and resources. This addresses health inequality in terms of wider determinants, under which category we find many people with mental health conditions and other problems.

Definition for this review

I will define Co-production loosely for the purposes of this review as the meaningful engagement of people as service users and/or carers as an integral part of work that has produced some recognisable work products that have at least some measurable outcomes and preferably some impact that contributes or is likely to influence "improvement", which in this review refers to mental health services. In a sense, if we have experienced mental health services or support as a primary client including as a carer, then we may be said to have "co-produced" our assessment, care plan and treatment, to the extent that we have been involved in the process and its direction. That type of experience is not included in this review unless it is part of engagement in co-production of systematic improvement as above.

Other definitions are available: notably from "Working Well Together"

> *"Co-production is an ongoing partnership between people who design, deliver and commission services, people who use the services and people who need them."*

It is worth quoting their more extensive definition, as a set of guiding principles:

> *"Co-production should flatten hierarchies and promote respect, while acknowledging and making the most of the experiences and skills of people with mental health problems, and of their families, friends, and carers.*
>
> *Everyone should have an equal opportunity to contribute value to decision-making throughout the co-production process. Positive outcomes in co-production need a culture change in which people no longer perceive each other as 'us and them,' but as us together.*
>
> *Everyone involved should have the same level of control and choice, throughout the process, where appropriate and required.*

> *Co-production should be a continuous journey over which the successes and mistakes of individuals and the whole group lead to learning.*
>
> *Co-production needs to take a flexible approach when engaging people and working together as a team.*
>
> *Everyone involved in the co-production project should continue to be involved in its evaluation. Ongoing improvements and adaptations can then be made based on the feedback. All the people involved should have access to support, training, resources, and recognition and reward."* RCPsych

Success in my review means outcomes or impact that produce Improvement. Impact examples could improve the following activities among others:

- Access
- Engagement
- Increase in positive outcomes or decrease in negative outcomes
- Increased patient or staff safety or satisfaction
- Enhanced sustainability, value, increased resources for treatment
- Enhanced treatment and support standards, methods, or options
- Reduction of the "health gap" and "health inequalities" for people with mental health problems compared to the general population

An example of success in co-production of research can be found here.

Outcomes could include the development of new evidence leading to growth, scaling up or to engagement, influence such as new policy or legislation, or a change in practice, new training that enhances practitioner skills. These criteria are not agreed standards. They allow some areas that could be flexible. They are debatable. One may use judgement as in the example in Annex 6 which describes an interesting research experiment exploring the border between professional and personal experience and identifies a local "success": the development and delivery of Trauma Informed Care Training that is likely to lead eventually to some of the impacts listed above.

Public policy and Deprivation

It is necessary to recognise the disproportionate adverse effects of cuts in resources on the most deprived communities within the population. On average this means that cuts affect people within areas of deprivation 50% more than those in least deprived areas. This average disguises some even worse adverse impacts even for issues where policy dictates that efforts should be focused. For example, the percentage reduction in resources for delivering the national child measurement programme was 4% in the least deprived areas and 79% in the most deprived areas. This is blind and unconscionable given the policy to address problems upstream.

The implications for opportunities for engagement in co-production are obvious. Policy is to engage but opportunity is reduced. Then we are called "hard to reach."

Also refer to extensive work by CIPFA: compare the performance trackers between 2019 (pre-COVID) and 2021. These trackers indicate the increased demand and the increased performance in terms of overall workload of all our health systems and show some alarming trends. We cannot ignore for example the rise in demand from the working age population for social care support. In turn, this has implications for how we support employment, both in general and for carers and people experiencing mental health problems.

In general, clinical staff levels have increased though not as fast as demand so vacancies have increased and there have been increased turnover problems, but in social care the increase in vacancies and turnover have been proportionately greater. The increase in demand to address children’s needs has never been greater for local authorities, which suggests that we are building mental health demands for the future. The ongoing fall in enrolment for teacher training also presents a grim picture.

After years of cuts the criminal justice services are also under pressure. There are many other causes of concern in the CIPFA data. Against this background it is a credit to Surrey, and in particular its police service, that a cultural change in how services engage with each other has taken place over the past few years, with the strategic boards engaging with the IMHN, efforts towards integration of mental health with social care, a strong effort to develop strengths based and trauma informed care training and communities of practice and improvements in how improvements are evidence-driven with some data transparency, though it is frequently observed that for some issues the role of unpaid carers is often less well covered.

RECOMMENDATIONS

Commission a more detailed formal review to extract learning from the most successful examples of coproduction in mental health services. Make sure it is collaborative between sectors and is co-produced. Commissioning should check that resources are allocated for multi-disciplinary working and reflective practice to be effective generally but also in engaging in co-production, with corresponding development of training for providers and engagers and suitable models, ensuring that they are co-facilitated. Professionals and engagers “need time out to think and time in to understand.”

Cultivate Engagement leadership. Allocate responsibility for an organisation within our localities to lead co-production and develop definitions, policy, and strategy for co-production to become a main workstream or cross-cutting theme for all commissioned services for mental health and social care, including co-production in its methods and collaboration with all other relevant agencies.

Nurture relationships between levels of organisation, disciplines and encourage leadership and quality improvement to emerge from any level. This needs some resources.

Work more closely with Education and Research institutions There are funding opportunities for research that would benefit services and provide engagement opportunities.

Extend engagement to potential sources for collaboration in co-production especially with higher education, industry, and local services.

Some benchmarking measures for local services need to be established to evaluate co-production and reflect transformation.

Creating a safe space to discuss mental health concerns. The Safe Havens spaces are an important and successful example of one method, but I recommend a much wider access point that could be implemented digitally or by a series of small local events, [responding to “granularity” of needs or “granularity” of performance issues], integrated with other community activities, not in a “ghetto”.

Create an engagement and development hub
The NIHR has introduced a regular feature to keep engagers up to date, providing feedback on the projects in which they have participated and offering further opportunities. This is achievable locally within existing resources, especially if we look at examples of skills and knowledge exchange, such as Hexitime. This hub might also be used to develop ideas for community interest initiatives to develop, as a starting point to cultivate a niche market for local services that can support quality of life and wellbeing.

Use feedback more astutely to drive improvement
Avoid engagement becoming a complaints forum by improving the mechanisms to address concerns and provide more timely responses to feedback indicating a problem. Make engagement a positive driver and use benchmarking to create brief engagements that provide some immediate results, using the Folkslab approach.

Do not settle for “average” – change the culture
The Public Health performance data for Surrey seem to indicate that “amber” performance hovering around “average” for England does not drive improvement. Attention is given to “red” performance data where outcomes are significantly below average. In many cases, the England average is vastly below what can be achieved at best, with the same resources. Understanding and addressing the causes of these variations may also help to improve the wide variation in care experiences.

Balance and integrate clinical and social aspects of services
Recognition of the difference between the “work of care” and the “relationship of care” is important in improving quality and experience of care. This is especially

important in the interface between services, especially with the development of "Discharge to Assess" (D2A). Discharge within mental health acute services is often seen as a problematic area for service users including carers, who often suggest as a remedy what has variously been called "throughcare" or "hot transfer." This should ensure that onward care is coordinated and integrated and can develop in a direction that contributes to wellbeing and supports strengths-based work, facilitating the client's potential. A clinical care plan which does not recognise the social context of its beneficiaries can produce some intense conflicts. Co-production in this area might also invoke the value of peer support. The pathways need to recognise that recovery does not always follow a linear plan, so that onward referral needs to be supported by the reassurance that there is a path back if the onward referral does not produce the desired results. We must allow for people to start where they left off, not from the beginning.

Start engagement and continue in the direction it indicates. For example, starting a service user peer group and then providing some training may enable peers to conduct research into diversity needs that are not readily apparent from formal staff assessment. Do not make it all about complaints.

Be practical

- Plan for engagement at the earliest stages; include people in forming a purpose; make the purpose clear.
- Make sure that access is provided to engage; address accessibility needs.
- Make practical arrangements.
- Listen and respond.
- Make engagement meaningful; ensure that products and outcomes and their impact are reflected in feedback to the people who were engaged.
- If personal stories are used make sure that how, where and when they are used are transparent; be trustworthy.
- Make sure resources are available and allocated to support engagement; and make reimbursement where commitment of time and skills is over and above voluntary patient or carer experience.
- There are no "wrong people" for engagement, just find the "right roles"; consider creating a skills and experience library to make sure that the right roles are found for engagers.
- Solve problems to remove obstacles and provide suitable venues or environment.
- Give time to think, attending to access needs and neurodiversity.
- In the cycle from preparation through action to conclusion, try to make each cycle short rather than long.
- Cultivate options first then refine them towards priority solutions.
- Record process and work products accurately.
- Define measures and report on outcomes.
- Understand impact.

Example: 10 times better

In one example I was involved with in homeless services, the peer group itself developed a model called “ten times better” in which participants were asked to form a simple goal and progress towards it in 10 sessions or steps. The entire project was facilitated and delivered by trained peer facilitators and became self-sustaining when they cultivated their own successors as they moved on.

Example: prisoner motivation

In another example, prisoners showing some aspirations towards recovery were provided with some motivational training and facilitated to deliver groupwork to young people excluded from school due to behavioural issues, to break the cycle of exclusion leading to offending behaviour. Whatever the benefits to the young people, the prisoners valued the experience, it measurably supported their motivation and progress towards more formal rehabilitation programmes.

Services need to recognise the social context and identities of those they serve

Projects regarding social context are one of the focal points for the Clinical Psychology training programme at Surrey University, in which service users and carers are engaged. However, in practice, commissioning and service delivery systems may not fully support this and may even work against this recognition, unless its importance is included as one of the fundamental drivers.

Focus on locality for engagement and improvements including feedback and measures of success

The origins of integrated care models are beyond scope of this review but involved multi-agency effort focused on localities where health inequality was most evident.

Follow “Inclusion” principles -Try to overcome barriers to engagement and inclusion

Give some thought to methods for engagement, whether the meetings are in a room or online. What are the invitations like? What information is provided? Are there forms to complete to participate? Many people with experience of mental health problems, treatment, coping and recovery have contended with a lifetime of exclusion, based on cultural or other minority identities, practices that fit the majority, communications methods that are service centred rather than person-centred. If presentations are not paced for easy comprehension, are filled with jargon, or if events do not have facilitation that promotes clear communications and allows participation, this will negate their value.

Give some thought to the subject matter, particularly to experiences likely to be evoked and to “triggering” and be prepared to deal with the turbulence that this is likely to cause as people remember difficulties regarding services and the problems that had adverse impact for them.

Overcome stigma

According to the NEF study mentioned in findings, participation in co-production has many benefits including improving self-esteem and prevention of deeper problems for clients with mental health problems, but also had a wider effect in improving staff attitudes and reducing stigma, which had a wider impact when extended to co-production and co-delivery of projects and training for community groups.

Set some milestones and celebrate success

The journey towards transformation and improvement may be long. It is important to identify some real goals and stages, some measures for achievement and celebrate their completion. Consider what rewards may be appropriate for engagement as volunteers and ensure that policy is followed to provide material rewards appropriate to the level of commitment and expertise that is deployed by engagers.

Use practical methods for empowerment including direct payments

For integrated care to be successful, collaboration between the various agencies involved is essential, and must include collaboration in co-production. The developing vision for integrated care included how the direct payment system could contribute to wellbeing and become sustainable by cultivating local wellbeing services. This so-called "market conditioning" depended on how well local authorities within integrated care systems adapted their systems to ensure that resources would be nurtured to match needs.

Findings

Prior to this review, participation in the Independent Mental Health Network (IMHN) has provided opportunities for local co-production throughout its activities. Local stakeholders and service providers have established their approaches using co-production. Mary Frances Trust, Richmond Fellowship and Catalyst all have established policies and current practice which produces ongoing developments. Similarly, national organisations relevant to the field of mental health and multiple needs, in which I have been involved, such as MEAM, take co-production to be fundamental to their approach. In my search, the first case study example I found of successful co-production that met most of my criteria was cited in the Skills for Health guide on co-production in mental health referred to in Annex 1.

Sheffield Flourish

A mental health commissioner in Sheffield wanted to invite tenders for a web-based guide to mental health services with telephone service for broad support, advice and information, adding a requirement that the provider must include people with lived experience in the development of the service. The result was that a local mental health charity won the tender and delivered a "successful" service. Their core values supported client-centred work, the produced service has several "**work products**" including measures that indicate some positive "**outcomes**" and has had an enduring **impact**; I have checked that they still provide telephone advice and have since developed a range of further activities. This is important because it illustrates that not all mental health service improvements are from mental health foundations trusts. I suggest that the emerging "communities of practice" concept and the development of active support for reflective practice and multi-disciplinary collaboration will support facets for transformation, including as in this case, improving access to care, improving care experience (in this case by being person-centred) and it is foreseeable that this would improve how teams perform and their sustainability.

Dorset CCG

The guide then cites an example set in Dorset. It describes a complex set of system improvements involving statutory and non-statutory services in collaboration, involving elements of co-producing a new mental health acute pathway.
Reviewing this example, the CCG role has been pivotal in working in partnership alongside the Mental Health Provider Trust and community organisations and individuals to instigate improvements in response to consultation and involvement, including independent investigation of care episodes. Like Surrey, they have formed a successful crisis concordat, itself informed by engagers.
There is a documented trail of policy statements, evidence, and outcomes.
This leads on to a distinct theme of "peer support" which I have separated into Annex 8.

Sandwell Mental Health People's Parliament

I can do no better than to extract a statement from the report:

> *"Co-production within Sandwell Mental Health Parliament works in a variety of ways, to hold services to account, to embed Quality of Life Mental Health Standards (developed by local people with current/lived experience of mental health conditions) and use them to co-design services and measure how effective they are at enabling ordinary life outcomes, and to co-design services. The partners working together on Sandwell Mental Health Partnership take their lead from people with lived experience. "Rather than professionals sitting in a darkened room, we start with people who use services. With the crisis concordat work, we said what does crisis mean for you?"*

This has now developed into the current "State of Sandwell" who produced a report in 2021 regarding the impact of COVID19 and related measures on ethnic minorities.

The purposes of this review are supported by citing all the main points of their summary report, and I commend the full report.

- All communities in Sandwell should be enabled to talk about and normalise mental health
- Existing mental health services in Sandwell should be planned and run with an awareness of how cultural differences affect a person's experience of mental health and wellbeing
- There should be more representation in mental health professions of people with lived experience of mental health difficulties and/or people from a range of minority ethnicity communities

- Mental health should be threaded through all the practical day-to-day support offered to Sandwell residents
- Sandwell needs more spaces for communities to meet, not with a particular mental health focus
- Sandwell residents should have greater access to knowledge about existing mental health resources and the rights they have relating to their mental health
- There should be more money and support for people, groups, and small organisations in Sandwell to set up their own solutions
  Statutory services in Sandwell should work with community groups to create connections with Sandwell residents from minority ethnicity and new migrant communities
- Statutory organisations in Sandwell should work with community groups to ensure good quality information is available in a range of languages
- Sandwell should do more to support therapists with community languages

These are fresh and vibrant principles that I see echoed in my current networks. We should remember that not all citizens will present to mental health services of any kind. However, they may have strong concerns of various kinds that need to be discussed. All kinds of people may have a socio-cultural identity that is in a minority that needs its social space in some form or another. Other examples of community led developments that embody co-production are emerging, usually supported by local charities that have strong values including person-centredness.

Changing Our Lives is a rights-based organisation working with people with disabilities and mental health difficulties. It nurtures workstreams, and hosts the strategic body led by MPs known as the Mental Health People's Parliament. Changing Our Lives adopts a social model and a recovery approach. These are principles that have been repeatedly affirmed in various focus groups as being valuable and appreciated by patients and carers.

The Mental Health Parliament example illustrates an important point about the people involved in co-production; it should not be all about complaints, but if issues are identified that need to be addressed there should be clear mechanisms, as in this example, to take action and determine if it solves the problem.

I would contrast this example with experiences often shared in the Independent Mental Health Network for Surrey and NE Hampshire (IMHN) that an important example or incident does not lead to anything like immediate action, feedback is often not provided about action and repeated attempts get submerged under further incidents or concerns.

Collaboration in peer co-facilitation

Professional services can incorporate lived experience. In Surrey, the collaboration between the statutory provider SABP and community providers Catalyst and Mary Frances Trust involved elements of co-production in the development and recruitment of peer worker roles in the personality disorder service. This flags-up the importance of inter-organisational collaboration.

Royal College of Psychiatry and UCL collaboration- National Collaboration Centre for Mental Health

Working Well Together (2019) – Evidence and Tools to enable co-production in mental health commissioning

This is a major piece of work and if the reader does nothing else with this review, please click the link and review the key principles of Co-production and the benefits it offers. The paper cites examples and links to other resources. It refers to the Five Year Forward View for Mental Health, which promotes numerous recommendations for leadership in which co-production is embedded on principle. Equalities, Diversity, and Inclusion are seen as intrinsic to improvement and the role of co-production.

Example: Perinatal Mental Health

Among many recommendations in **Working Well Together**, of relevance to Surrey is the recommendation regarding perinatal mental health. Surrey for many years had a strategic objective to improve the attention given to perinatal mental health, and not much progress starting from a low base until it progressed with integrated care. It then developed a coordinated system that included a helpline staffed by people with the right expertise to respond to emerging needs throughout pregnancy. Many of the concerns were about wider health issues, not just mental health. The model of care was to provide a first response and access via onward referral to the right care. This improved client experience of care, reduced ambulance call outs and A&E visits and improved outcomes. This service was based at Epsom and was subject to an equalities review including patients and public as part of the Epsom St Helier equalities policy. The review was favourable. The evidence used for the review appears to support holistic approaches to overall health and wellbeing. Perinatal mental health can be improved by providing access to services supporting overall health as well as responding to mental health concerns.

Healthy London Partnership (HLP)

HLP's starting point was the review by the London Health Commission led by Lord Darzi to form a London health strategy. In my view, how the health needs data is set out in that report puts mental health in the correct wider context as an element of overall health and wellbeing. The recommendations regarding mental health include attention by commissioners to provide digital access to services, strengthening the role of GPs to address mental health concerns, adoption of a multi-agency approach to crisis and an integrated approach to the needs of homeless people and rough sleepers.

The report was far-reaching in its vision and HLP have run with many of the original themes to seek improvements that have tangible impact on wellbeing, including continued effort regarding support for Children and Young People's mental health, which the data indicated was a prominent need, Perinatal mental health, early intervention for psychosis, addressing physical health inequalities for people with serious mental health problems, and a multi-agency approach including training in mental health crisis care. See also Healthy Lives project. Surrey has its own data and needs, but many of the themes in London are also applicable in Surrey, which have been vigorously pursued through the Primary Care Network, GPiMHs and MHICS developments linked with Social Prescribing and Crisis Concordat work, Community Connexions, Safe Havens and enhancing the roles of community providers and engagement with the community via network groups.

Co-Production example – development of awareness training in Surrey to address health gap for people with serious mental illness

Led by a Darzi fellowship, this work included forming a focus group of service users and carers and then using feedback to develop information leaflets and co-develop and co-deliver a training module for nurses to deliver health checks for people with serious mental illness. The training was subsequently adapted for a wider awareness session for the annual primary care seminar.

NEF literature review – impact and value, social networks, and inclusion

This review was commissioned by MIND to evaluate the impact of co-production and its value.

If you are looking to develop evidence of impact or how to evaluate co-production this is essential reading. Please also check the reference to the Holy Cross Centre Trust, which provides guidance for engaging volunteers.

Rethink mental Illness

It is well worth exploring many of the themes that Rethink has developed on its website. One area that particularly drew my attention is the co-production work to improve the national development of secure services for people with mental health problems. This is a subject that is often missed, and importantly they include families and carers in the work.

NDTI

This link is for a position paper which poses the question whether mainstream mental health services offer the right conditions for transformative co-production, and what issues might need to be addressed. It attempts to build on the NEF literature review for MIND, mentioned above.

Ignoring the revolutionary hype and dramatic soundbites, the paper usefully identifies some important factors to address if co-production is to be successful, including how direct payments are used to empower clients, and also how the creation of a forum space separate from the workplace may overcome obstacles to engagement of clients with practitioners. In that context we see that among other forums, the Independent Mental Health Network and FoCUS membership groups have created spaces where commissioners, service providers and community agencies can interact with people with experience of local services including carers on a facilitated basis to discuss developments.

4Pi national involvement standards

Note these standards were used as a starting point for the development of the process and governance for IMHN. Note also that HLP draws attention in a related section regarding care planning and self-management to the value of peer support and holistic approaches to wellbeing.

National Coordination Centre for Public Engagement regarding Public Engagement in the Knowledge Exchange Framework (KEF) in higher education.

This is a substantial review running to over 100 pages and contains some detailed evidence.

Briefly, locality provides a strong focus in public and community engagement within higher education institutions. Health and social care are one of the main policy drivers, alongside equality, diversity and inclusion.

Surrey Example – service user and carer advisory group, psychology department Surrey University

One of the most successful examples of co-production I would cite from my personal experience is as a participant in Surrey University's service user and carer advisory group for the Psychology department. This has a robust structure, supported by a coordinator and is influential in delivery of training to clinical psychologists and other professionals. We participate in co-production of lectures, providing feedback to trainees, recruitment of each new intake, feedback to trainees on their work, including research projects and responding to their questions about practice. We also participate in the overall University's development, such as their Equality, Diversity, and Inclusion (EDI) initiatives. We sometimes co-train with learners, for example in their recruitment approach for new intake.

The outcomes from our group have included higher quality ratings from inspection, the development of lectures, feedback from a variety of perspectives responding to learners' questions, co-produced recruitment practice and our participation has influenced how clinical psychology is led and practised, including the direction of research and programme development. The impact of the latter is open-ended as the learners go into practice and progress through their careers and conduct research into their fields of interest.

The connection between universities and research to inform the evidence base for health research and health education could not be more profound. The executive summary from the KEF review identifies some important themes for engagement and co-production, echoing other findings, which I have translated into my terms within the framework for this review (please refer to the original for a more detailed understanding):

- The lens of civic responsibility to inform the public is not enough on its own to engage sufficiently to realise the value of lived experience, but some value emerges from specific efforts towards minorities, especially people suffering from exclusion and inequality.

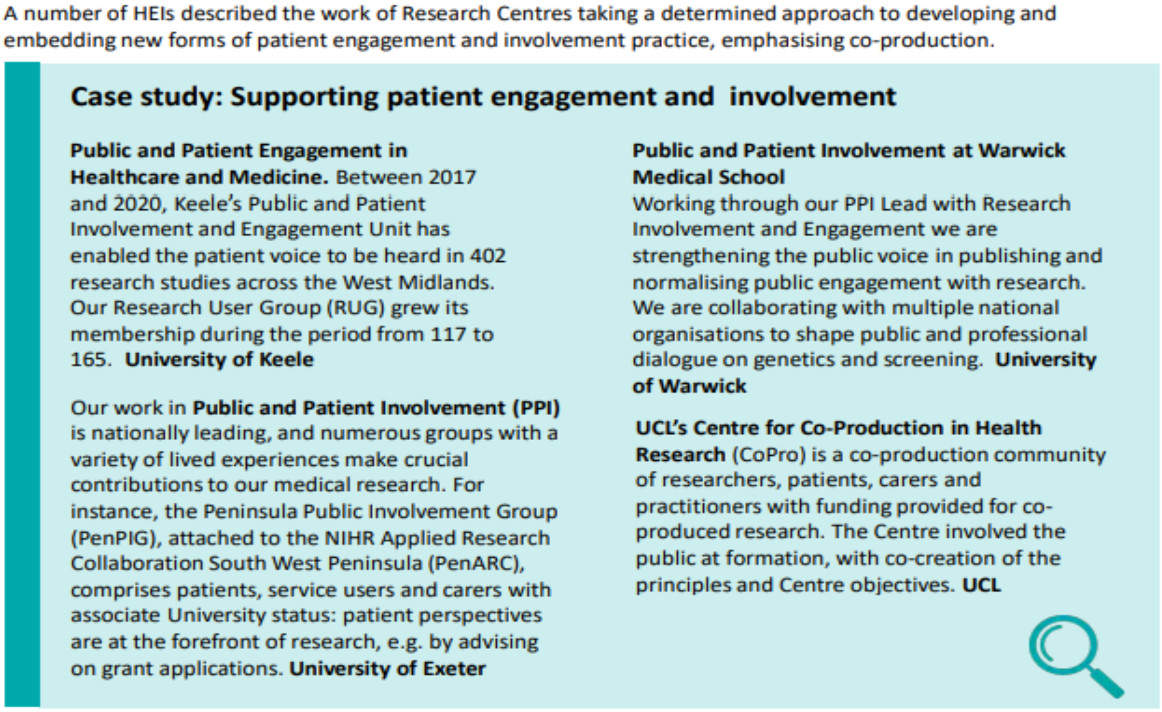
- Dedicated resources supporting patient and community involvement and engagement (PCIE) may embed it in the wider organisation, not just the department where it is based.
- Recognition and reward are important, in turn invoking ways to evaluate and review participation.
- Monitoring and evaluating engagement and co-production may support strategic objectives or project impact, but in practice mere evidence of engagement does not provide enough connection between events and outcomes or impact, so design and practice for monitoring and evaluation are important and could also be co-produced.
- The benefits of co-production seem to spread across main workstreams or themes and so treating co-production holistically as an integral main theme is recommended to achieve social impact.
- A starting point should include forming a vision for the objectives of the engagement.
- One ought not to be too prescriptive in defining the PCIE role, allowing it to develop along the lines that local engagement produces, so that public participants and wider community collaboration and engagement are seen as complementary.
-

I noticed that what is distinctly different in HEI focus from HSC focus is the priority the former give to working with business and industry. In my view this would be a promising area of development for mental health care because occupational health could be the springboard for prevention and early intervention and could also enhance the availability of resources and the outcomes and impact for individuals.

The use of digital methods for engagement is a strong theme, of perhaps paramount importance in improving sustainability, environmental impact as well as patient access, care coordination and integration and service experience.

Locally, we can see that SaBP include public members in their governance process, as do local community providers who have established advisory groups from the client base. Commissioners have increasingly recognised the need to engage across communities

Many other areas of the KEF review will reward attention, including how to drive engagement, such as by providing community access, inclusion governance and by offering staff training in how to engage. They cite case examples from Brighton and East London universities. Please refer to lens 1.5 in the report for a specific focus on patient and public engagement, from which section of the report the following image



A number of HEIs described the work of Research Centres taking a determined approach to developing and embedding new forms of patient engagement and involvement practice, emphasising co-production.

Case study: Supporting patient engagement and involvement

Public and Patient Engagement in Healthcare and Medicine. Between 2017 and 2020, Keele's Public and Patient Involvement and Engagement Unit has enabled the patient voice to be heard in 402 research studies across the West Midlands. Our Research User Group (RUG) grew its membership during the period from 117 to 165. **University of Keele**

Our work in **Public and Patient Involvement (PPI)** is nationally leading, and numerous groups with a variety of lived experiences make crucial contributions to our medical research. For instance, the Peninsula Public Involvement Group (PenPIG), attached to the NIHR Applied Research Collaboration South West Peninsula (PenARC), comprises patients, service users and carers with associate University status: patient perspectives are at the forefront of research, e.g. by advising on grant applications. **University of Exeter**

Public and Patient Involvement at Warwick Medical School
Working through our PPI Lead with Research Involvement and Engagement we are strengthening the public voice in publishing and normalising public engagement with research. We are collaborating with multiple national organisations to shape public and professional dialogue on genetics and screening. **University of Warwick**

UCL's Centre for Co-Production in Health Research (CoPro) is a co-production community of researchers, patients, carers and practitioners with funding provided for co-produced research. The Centre involved the public at formation, with co-creation of the principles and Centre objectives. **UCL**

is copied:

It is also important to draw to attention how the Higher Education Institutions define their impact.

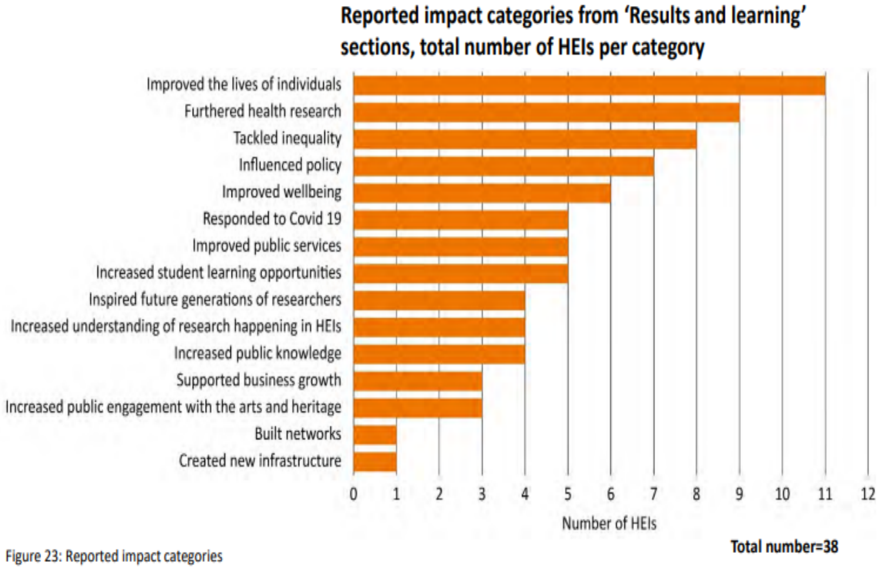
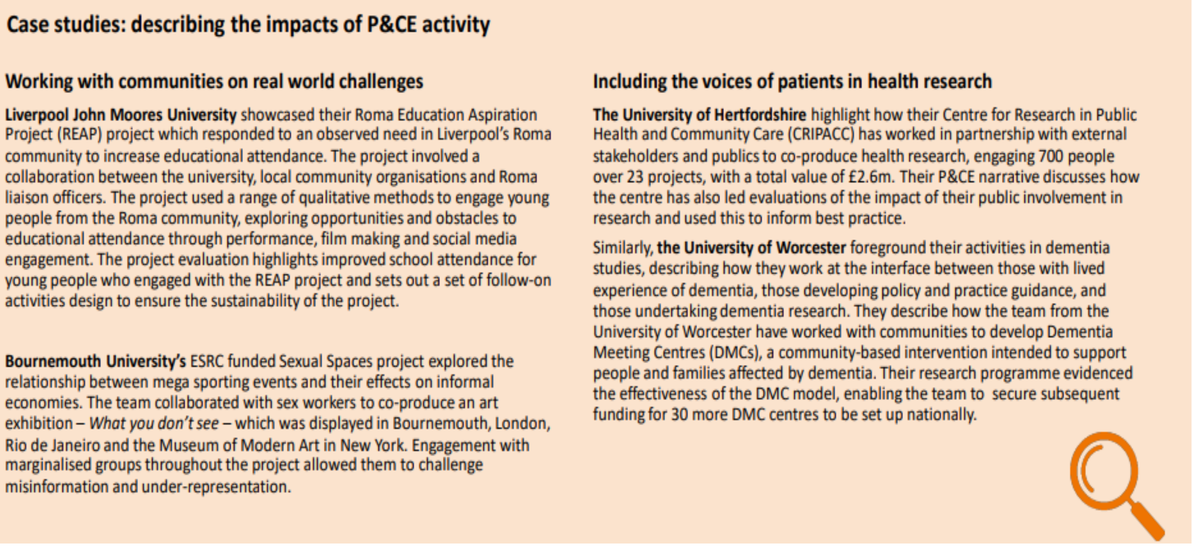


Figure 23: Reported impact categories

The case studies related to impact include the following:



Case studies: describing the impacts of P&CE activity

Working with communities on real world challenges

Liverpool John Moores University showcased their Roma Education Aspiration Project (REAP) project which responded to an observed need in Liverpool's Roma community to increase educational attendance. The project involved a collaboration between the university, local community organisations and Roma liaison officers. The project used a range of qualitative methods to engage young people from the Roma community, exploring opportunities and obstacles to educational attendance through performance, film making and social media engagement. The project evaluation highlights improved school attendance for young people who engaged with the REAP project and sets out a set of follow-on activities design to ensure the sustainability of the project.

Bournemouth University's ESRC funded Sexual Spaces project explored the relationship between mega sporting events and their effects on informal economies. The team collaborated with sex workers to co-produce an art exhibition – *What you don't see* – which was displayed in Bournemouth, London, Rio de Janeiro and the Museum of Modern Art in New York. Engagement with marginalised groups throughout the project allowed them to challenge misinformation and under-representation.

Including the voices of patients in health research

The University of Hertfordshire highlight how their Centre for Research in Public Health and Community Care (CRIPACC) has worked in partnership with external stakeholders and publics to co-produce health research, engaging 700 people over 23 projects, with a total value of £2.6m. Their P&CE narrative discusses how the centre has also led evaluations of the impact of their public involvement in research and used this to inform best practice.

Similarly, **the University of Worcester** foreground their activities in dementia studies, describing how they work at the interface between those with lived experience of dementia, those developing policy and practice guidance, and those undertaking dementia research. They describe how the team from the University of Worcester have worked with communities to develop Dementia Meeting Centres (DMCs), a community-based intervention intended to support people and families affected by dementia. Their research programme evidenced the effectiveness of the DMC model, enabling the team to secure subsequent funding for 30 more DMC centres to be set up nationally.

These offer a major recommendation for Mental Health Foundation Trusts to consider how they work with Higher Education in general to broaden and deepen patient engagement from which co-production base could extend.

Annex 1

Some main policy documents

The underlying influences for recent NHS transformation can be considered to emerge from concepts of integrated care resulting in
The Triple Aim:
better population health; better care experience; better value
This aim was formed from ideas emerging from efforts in the US to address health inequalities by integrating care across relevant agencies and focusing on localities where high prevalence and poor health outcomes were prominent
The NHS' "Call to Action" in 2013 proposed NHS transformation along these lines
Some main themes emerge such as improving access, improving care coordination and integration, especially with social care

Parity of mental health soon emerged as a major policy statement

The strategic five year forward view for mental health (FYFV MH) then followed, included policy for co-production to be adopted at every stage of commissioning

The 4th aim – The Americans soon realised that the triple aim could not work without supporting providers and their staff in their roles, which NHS adopted as the aim to promote team wellbeing, cultivating methods such as reflective practice and supporting a collaborative approach

Skills for Health produced a guideline in 2018 called **"Coproduction in mental health: not just another guideline".** It has many good recommendations although there are some statements that are questionable. It cites the FYFV MH and defines co-production and what has come to be known as the ladder of engagement. Also see "CORE20 plus5 – an approach to reducing health inequalities" strategy and resources. This addresses health inequality in terms of wider determinants, under which category we find many people with mental health conditions and other problems.

Annex 2

Research paper:

Service user involvement in the coproduction of a mental health nursing metric: The Therapeutic Engagement Questionnaire (2017)

This project set out to engage service users with experience of inpatient treatment in the improvement of how therapeutic engagement is assessed. I regard it as important in this review because it set out with the simple premise that it was necessary to involve service users in professional effort to improve the quality of assessing service user engagement in treatment. It was regarded as a success because after an initial phase of improving the tool for how engagement was assessed, a second phase used the improved co-produced tool in a wider study, with favourable responses from service users and staff. It distinguished responses for care delivery and care interactions.

A strong statement emerged, regarding the value of including service users:
… including a small group of service users in research can generate change. Service user perspective brought benefit … provided insight into what they felt was important with regard to their relationships with nursing staff. … ensured that it is relevant to the needs of those who will be completing the tool in the future… provided useful feedback which enabled their “voice” to be heard and their opinion on what they believe is good practice and/or what concerns them to be counted. … service users can help to develop ways of working that improve service quality. The active involvement of service users in research enables them to develop a sense of empowerment and provides opportunity to share and allow others to benefit from their unique experience …. If health and social care research is to be of real benefit to service users, then we must strive to involve them more in setting the questions to which we are seeking answers; time and time again evidence has demonstrated that service user involvement results in outcomes that are more relevant and useful to the practice that is delivered. Strength of this project derives from the collaboration with service users at each stage of the development of the tool.

The author was not blind to the limitations of their approach, recognising the weaknesses in “self-reporting”, the lack of access to patient notes and the absence of service users as members of the research team itself. (See annex 6 for a research experiment which involved researchers who also had lived experience of mental health services) This is an important example of the need for service user engagement in co-production to start at the beginning. Engagement in co-produced research is therefore a big step forwards in service transformation. An even bigger step is in deciding the direction and funding for future research. Examples of this in NIHR at national level, and its regional developments are provided later.

Annex 3

Forensic services - Client engagement and co-production in secure settings

Also see: Rethink mental Illness

Using the search term “forensic mental health client engagement” produced some interesting links to recent work in Canada (J.D. Livingston) and Sweden (Selvin and more recently Nyman) as well as work in the nineties in UK (Keys to Engagement; Centre for Mental Health) regarding how to engage clients within secure mental health services.

In general, providing choice and valuing lived experience is a matter of policy and should be followed within the limits imposed by the context. They found it practical to create peer support, patient advisory groups and patient-led research. The Canadian research ran over 19 months and seemed to indicate limited effect on outcomes, positive from peer support.
Selvin especially identified prerequisites including good communications practice, and mutuality within it, in which professionals took responsibility to adapt the principles to the settings and assess the patients’ capabilities to be actively engaged.

I commend Nyman’s paper “You Should Just Keep Your Mouth Shut and Do As We say: Inpatient Experiences of Risk Assessment” This is outside my present scope for the review. Limiting the search to the UK immediately produced authoritative work from the Royal College of Psychiatry (RCPsych) in the form of their Standards for Forensic Mental Health Services (2019) which cover client engagement throughout the low to medium secure estate system.

Briefly, this establishes engagement as a standard, from admission and transfer through care planning and review, related activities, feedback, inpatient community, PCIE strategy and leadership, peer support, carers engagement, facilities, training and governance, through to subsequent care upon discharge.

Anna Aboaja et al published a paper: Involving service users to identify research priorities in a UK forensic mental health service (Cambridge University Press) in which service users identified physical health, future plans and moving on, and causes of illness and crimes as their top 3 of 8 priorities. This seems to echo references cited by RCPsych from CQC and Public Health England about health gaps and wider determinants for patients in forensic mental health services, for example concerns about higher prevalence of obesity. The IMHN co-produced some training for health checks for people with Severe Mental Illness and currently (March 2022) engagement is being actively sought for a new round of training development.

This work also points out the overlap between secure mental health services and prison services to support mental health. Further work is needed to explore the best methods for engagement and the extent to which the priorities of service professionals overlap the views of service users and carers.

The Totalising Nature of Secure and Forensic Mental Health Services in England and Wales - an "evidence-based opinion piece" – Sarah Markham
This contrasts policy with practice, the latter placing "an overriding emphasis on physical and procedural security" to the detriment of therapeutic value and even safety, being counter-productive to the extent of increasing risk of harm. According to the author, this unbalanced emphasis causes some "non-thinking" responses.

There are examples to be found across services for people "sectioned". One such example in Surrey involved a window left open in a ward, which a patient used to complete suicide by hanging using a ligature suspended from the window bar. The immediate response was to nail the window shut, which is a "non-thinking" response. A similar response to an untoward incident at Epsom hospital resulted in locking up access doors to a garden area within the hospital. This brings into question the whole concept of how risk is assessed and managed. I have seen cases where risk is assessed as a snapshot and then frozen for a decade or more, regardless of changing risk factors.

In another incident, a "voluntary" patient within an inpatient service was at high risk to herself, but the protocols to protect her safety were much different to those for people whose treatment was mandated by sections of the Mental Health Act. This resulted in failures to communicate with other agencies such as the police services, despite bystanders expressing concerns. She lost her life. The coroner expressed serious concerns but two years after the coroner's report and four years after the incident, the only action by the service had been to draft a revised protocol. This opinion piece presents a stark contrast between the forces influencing practice and the thrust of policy and strategy.

There appears to be no intrinsic reason regarding safety, security and the management of risk why forensic services should not pursue the recommendations for good communications and professional responsibility to create mutuality in treatment, and the pursuit of the recommended and mandatory standards for engagement.

Annex 4

Author details and reflection - Pause for thought

My name is Eleanor Levy. I was born in the 50's. My childhood is full of adverse events, including poverty and abuse. I had significant hearing loss that grew to become profound later. My expressions of gender identity and sexual orientation were stigmatised. I had disfiguring skin conditions. I was vulnerable to abuse. My education was full of difficulties, though I was selected for A stream grammar school. I entered higher education but by that time my drug addiction was intense, and I left. There were periods of homelessness and street sex work. Despite addiction, I found a successful career in quality management and price negotiation for international engineering projects, moving into high technology commercial management. After a crisis involving my arrest, my employer arranged addiction treatment and I have been in recovery since 1986.

I retrained as a counsellor and in 1999 took up a post working in prison. In 2000 I accomplished transition from male to female while working in that role, possibly the first person to do that. From 2002, I worked in Surrey probation Services while sustaining care responsibilities for my parents. I met my current partner in 2004, which has involved some care from time to time, regarding physical and mental health issues. I worked from 2008 to 2014 as a senior manager of multi-disciplinary health and social care in homelessness and mental health services. During that time, I had further care responsibilities for my brother. I completed additional training in teaching and in health and social care.

I have been involved with patient and public engagement since 2013, which coincided with being unable to sustain employment due to mental health problems. I participated and chaired the PPV advisory group for the London Clinical Senate. I used this experience and the training they provided to lead the development of the Independent Mental Health Network (IMHN), which I chaired or co-chaired or represented from 2015 onwards. I have since undertaken further training as part of Surrey Heartlands Leader 500 programme, completing regional leadership and Quality Improvement training and Mary Seacole facilitation training. I am a Chartered Manager eligible by examination centred on a project to develop the governance process for the PPV group. To support my participation on behalf of the IMHN I also undertook training in Suicide First Aid and the London PPV also provided us with Mental Health First Aid training. I am currently a Public Advisor for the board of the Applied Research Collaboration for Kent Surrey and Sussex.

Throughout my professional and patient and public roles, my training and experience has confirmed that to achieve enduring improvement and change, we need multi-disciplinary involvement from every level of an organisation and to include its stakeholders, being receptive to feedback about what works and what problems need to be addressed. Based on that experience, I have conducted research to make the case for change, using and transforming data systems and developing models of service that respond to needs and produce improved outcomes that are valued by stakeholders and are more conducive to staff and client satisfaction. I have developed training and practice including group work and reflective practice. All these efforts have been informed and improved by the engagement of clients and stakeholders.

My own journey towards recovery from mental health problems has been problematic but eventually I gained access to services that produced assessments and treatments that recognise and respond to my social context and my personal conditions. Why have I bothered to provide these personal details? It is because my ethos as a professional person-centred counsellor was strongly reinforced by my prior experience of recovery from addiction within “mutual support groups in the community” who are self-organised, with strong traditions of equality, diversity and inclusion; we have a common mission, a vision that focuses our efforts together to produce support that adapts itself to circumstances. Earlier than that, my experiences in developing services and systems to respond to new demands indicated to me that we should inform developments with practical experiences of stakeholders. As a health and social care practitioner and manager, as a patient and carer, I have met with considerable difficulty in obtaining responses from services that meet the needs of my clients, my colleagues and the people I cared for personally, and my own needs throughout my life but especially during mental illness. My experience is that what works best comes from engagement, adding value and improving outcomes that matter to the beneficiaries of service and are socially productive.

My personal experience is that assessment and treatment planning did not necessarily involve me in any meaningful way. I was not even notified of some assessment products, or indeed if any were produced. In one instance, an assessment report mixed up my details with someone else entirely (probably based on one report being used as a template for another), as well as inconsistencies mentioning both correct and incorrect details and was sent to my GP without checking with me. The report was so deeply flawed my GP requested another assessment and treatment plan. The resulting complaint took over a year to resolve. Meanwhile, in contrast, a process was being conducted with my full engagement, leading to some excellent work together. Even then, systemic issues caused the resulting gains to dissipate. In my view the brunt of these systemic failures fell on the individual practitioner to exert extra effort, rather than for management attention to rectify faults in the system.

This included extra effort when the pandemic mov ed our interaction online. There have been numerous problems in my experience with the adoption by NHS of MS Teams as the main platform for online engagement, with a lack of appreciation for its deficiencies regarding interaction with people who are not within the NHS team and IT structure, especially regarding accessibility features.

In contrast with these experiences, opportunities to engage in other levels of NHS such as in research and in tertiary education have provided strong positive experiences where the theme of co-production is embedded systematically in organisational structures and methods of working, supported by leadership and by roles dedicated to the task of coordinating participation by service users and carers. This is not a check box exercise. The criteria for evaluating funding proposals includes scrutiny of how public and community involvement and engagement will be resourced and implemented. A lack of credibility in this arena leads either to deficiencies being rectified, with strong support, if necessary, from the funding body, or the proposal does not proceed.

The brief

I was requested to "Give attention to co-production successes (you can decide on what success looks like!) in NHS MH Trusts."

Search strategy and methods

I used preliminary search terms for "coproduction and engagement in mental health services" and "NHS Improvement mental health coproduction". After defining my search terms, what I mean by coproduction and success, I created Annex 1 to explain the NHS context. I quickly reached the proposition that any NHS organisation should follow NHS policy and strategy for engagement and co-production. The search, using Google, produced about 550,000 results, beginning with academic reference papers. I selected the studies cited in Annex 2 regarding assessing therapeutic engagement; and in Annex 6 regarding the combination of professional and lived experience. The search page refers to NDTI; then the report from Skills for Care, which in turn points to the good examples from Sheffield, Dorset and Sandwell. These few references produced 12 pages of review comment. The rest of the first page in my google search provided reference to the Royal College of Psychiatry, the PARTNERS2 writing collective, MIND, Nursing Times, Middlesex University Centre for Coproduction in Mental Health and Social Care (already referred to as providing a good definition), the New Economic Foundation (NEF) who produced a literature review of Coproduction in Mental Health, commissioned by MIND in 2013 and a resource page from Healthy London Partnership which itself involved extensive engagement.

That seemed enough for me to make the first recommendations: if commissioners want to make the most of existing knowledge, skills and understanding about how to use and optimise co-production, a systematic review needs to be resourced. Meanwhile, I can conclude from my review so far that these are successful examples that have produced enduring outcomes. I therefore decided to explore the rest of the sources identified in page 1 in more detail, and pursue lateral connections, rather than pursuing page after page of google hits. Google itself recommends a selection of other search terms in what is a colossal field of policy, strategy, research and practice.

Annex 5 The borderline between professional and personal experience

Outside the scope of this review because it originated in 2008 is an interesting research paper
"Staying native": coproduction in mental health services research

The abstract starts with a statement regarding the purpose of the research:

> *"The purpose of this paper is to describe a recent experiment in research coproduction in an evaluation of service planning at a London Mental Health NHS Trust. The paper aims to consider whether members of the research team who have themselves been users of mental health services are able to contribute to the research process as "experts by experience", or if their experiential knowledge is "colonized" within the academic research team."*

This identifies an important issue regarding whether professional practice is beneficially informed by personal lived experience. Does the experience get "colonised" by the overlay of professional culture or is professional research unduly biased by personal experience? Or is there, as the paper suggests, a balance achieved between the two that produces added value?

This reminded me of the development and delivery of Trauma Informed Care training that was funded in Surrey for staff delivering Crisis Concordat Services. There were elements of co-production, in the sense that mental health network representatives were included in developing the framework and principles for the training design and delivery. We were also admitted to one of the training sessions for observation. The training delivery included facilitation by professionally qualified and trained people who also had lived experience. It also emerged that many of the trainees, who were frontline staff from the various Crisis Concordat organisations, including clinicians, paramedics, police and responders from community organisations, also had lived experience as service users and carers.
I believe that this leavening of personal experience within the field of mental health and social care research, policy and practice is a vital area that needs more recognition and voice, and some structured commissioning support, along with recognition by providers to ensure that their education, training and development includes the cultivation of professional development combined with lived experience.

We need to recognise the adverse conditions that people with lived experience have overcome, our strengths and resilience but also the specific support needs regarding how professionals manage the intersection of personal and professional agendas in dealing with their organisation and the systems in which it operates and the clients and stakeholders with whom they interact

Annex 6

More than just green shoots; recent developments

Searching for a better definition of co-production, one finds this:

Co-production is **an approach to research, policy and practice in mental health and social care** based on the principle that people who use services have valuable knowledge and expertise.
This is from the Centre for Coproduction in Mental Health and Social Care in Middlesex University,
Co-production is a central part of current NHS policy, but its practice is at different stages within various groups. The National Institute of Health Research itself has increased opportunities for engagement and co-production. It is an embedded theme in regional Applied Research Collaboration (ARC) organisations.

Locally, I am aware of some recent examples of engagement and co-production in research funded by our regional ARC which is ARC Kent Surrey and Sussex (ARC KSS)

Care Leavers

Care Leavers as a group experience a higher level of health and social problems, including higher prevalence of mental health problems and are "over-represented" in services such as criminal justice and homelessness support.

During the first COVID 19 lockdown a rapid research project was launched, known as the "Beyond Lockdown" project to engage care leavers to improve services. It involved 88 Local Authorities and 79 Leaving Care Teams, some national events and wide engagement of care leavers. The results of the project were published in January 2021 and were followed by further action to check that "pledges" from services to make changes have been pursued.

Work products were created as resources, including video messages from participants. The outcomes include authorities undertaking to make improvements based on the evidence, checked by follow up, and messages to Parliament. An immediate impact has been to induce service change. It is not yet possible to measure this fully. It will become measurable over time, depending on whether care leavers in the region have improved mental health and wellbeing and reduced morbidity and mortality. However, the process is likely to influence policy and practice

Dementia Support

Following research into Remote Memory Assessment, the RMAS toolkit was launched to support clinicians to assess and diagnose patients with dementia. Co-designed and co-produced by clinicians, researchers, and people with lived experience of dementia, including carers, and funded by the University of Sussex

Higher Education Innovation Fund, the resources include: a remote memory assessment toolkit, a patient video, and an information leaflet.

So, the outcomes of the research work products were to create a toolkit. The impact has been that 38 of 54 participants agreed to follow up with further review of outcomes and impact. Meanwhile, it is likely that impact will continue to develop as the tool is deployed, initial experiences being that the increased awareness of clinicians about how to engage clients in the assessment process will be productive of better experience and improved efficiency in assessment and diagnosis. Again, ongoing impact is likely to develop over time.

Guidelines for Online mental health services for children and families

The "Zoom or Room" project

Published on 1st February 2022, the guidance followed research involving clients, practitioners and employers and produced guidelines, video and leaflet resources. So, there are work products, the outcomes so far are favourable in that practitioners have produced positive feedback about the guidelines, and again, if they are followed and practice spreads, the resulting improvements are very likely to have measurable impact over time.

Shaping our Lives

In February 2022 the report on Service User Involvement was featured in the Kings Fund Health management and Policy alert. Please also refer to Healthwatch England's report regarding accessibility in health.

Communications

I have just received the report of a survey in which I participated, regarding the training needs of people communicating within health research. Unsurprisingly the responses ranked their training needs for infographics and data visualisation highest, followed closely by communicating with policy makers, planning and strategy and then writing news, features, blogs etc, followed closely by Co-production and then the rest of the 20 needs. This implies a strong appetite and a high importance on engaging more effectively with co-production. To what extent are our wider health-related communications co-produced? My impression is that this is not seen as important to a similar degree.

In general, my experience is that researchers engage with PCIE groups to produce their invitations and the briefings for the public to participate, including plain English summaries. These are often very good. So, if they think they need more training to communicate and engage us effectively, what does this say for the mainstream of health communications?

When we have been provided with opportunities, such as the Health Checks leaflets and training, or the video to support strengths-based training, or the awareness presentation to promote support for Carers, the product has been well-received. On the other hand, where there has been no engagement in the initial phases of developing communications, this has often resulted in grave omissions from policy or even strong adverse reactions towards the subject matter from the wider public.

Multi-disciplinary working

There are some features within the NHS Improvement Infrastructure and individual Trust intranets to provide and nurture networking and Continuous Professional development (CPD) including commercial applications and tools to which organisations can subscribe.

"Shaping our Lives: tick boxes and tokenism?"

Looking at current developments and ideas, I came across the report "Shaping our Lives: tick boxes and tokenism?" which is a report about "service user involvement" that provides abundant practical advice about how to make engagement work.

Consistent with Quality Improvement principles as practised in NHS, the "Plan, Do, Study, Act" (PDSA) the cycle should include engagement and coproduction from the beginning, starting with how policy is developed to respond to changing needs, how research funding is directed, how services are evaluated and developed, how change is introduced and evaluated and subsequent iterations of the cycle to ensure that actions are evidence-based and support the goals of transformation.
Engagement and coproduction in training is useful and productive towards the overall goals of transformation, when supported by other developments including the means to develop and evaluate evidence, support and resources for professional development including reflective practice and supervision processes that have access to data, systems that eliminate obstacles and promote inter-operability

Annex 7

Peer support in mental health

Centre for mental health care

One of the papers cited in Dorset Vision to support their development approach is a report originally published in June 2013 from the Centre of Mental Health which explored the value for money of peer support workers. This theme has had substantial attention from a variety of sources. I have chosen just one report reflecting some of the sub-themes, noting that it is important to have a clear basis regarding how peer support is conceived, developed, and delivered, and supported. There is a distinction between peer-led and system-led peer support and another between paid peer workers in a system role and peer supporters who are voluntary or receive ad hoc rewards.

A good example of inter-agency collaboration and co-production in Surrey was the recruitment of peer support workers for group work supporting people with personality disorder. The collaboration involved the main clinical provider, and two community providers and co-production was invited via a community provider's service user advisory group. We participated in how the process would identify and evaluate the characteristics of candidates to fulfil the roles, how the interviews would be conducted and how selection took place. Bravely, despite the pressures of circumstances, not all the roles were filled in the first round and another round of recruitment was made. Our participation also influenced the wider HR process for recruitment for the organisations involved.

Contrast this with the recent invitation from the main mental health provider through the IMHN to participate in recruitment of its CEO, less than two weeks before the interview date. It was proposed to include us in discussion of a topic, the subject not being disclosed. The job role and selection criteria were not provided. Asking for these and to clarify the reimbursement policy produced negative reactions up to the day before the interviews and produced no eventual response other than exclusion.

APPENDIX 2

CARERS AND CO-PRODUCTION:

Introduction

Surrey and Borders Partnership NHS Foundation Trust (SaBP) has a vision to make sure that carers' issues are firmly embedded throughout the organisation: in the strategic thinking; policies; business plans and quality indicators. It wants families, carers and loved ones of the people who use services to feel connected, to the care and treatment it delivers, in a way that is positive and wholesome. The Trust has pledged to achieve its vision by having a plan for strengthening its insight into people's experience, carer involvement in service development as well as care, and the opportunities and ability for carers to help improvement in the quality of care it delivers. In this pledge it has stated

"Our vision is to make carers integral to all that we do and so we want to make it easy to work with carers at every level"

The Trust will do this by strengthening carer involvement to be enabled through a range of ways.

1. *A review of policies will be undertaken as well as a review of how we involve carers in our policy development*

2. *Standard Operating Procedures within our Inpatient, Community and Liaison Services will be strengthened in order that our practitioners and administrators will Think Family and involve families at every appropriate opportunity.*

3. *Carers alongside users will be involved in transformation.*

4. *Methods of making experts by carer experience will have parity with experts by profession or education will be explored, including, but not limited to, remuneration and recognition of value.*

5. *Statutory changes to the way care and treatment are planned, reviewed, and explored will be used to improve carer involvement. The changes to the Care Programme Approach gives scope and opportunity for more meaningful co-production and would build on our objectives to give all carers and families the opportunity to be involved in a person's care.*

6. *We will also train a strong cadre of carers in quality improvement methodology, in order to have robust challenge of the QI projects across the Trust, as well as give carers the opportunity to co-lead QI projects.*

Previously, key carers and service users devised five aims they would like to see delivered, and this is relevant today:

- *Improving our support and advice to carers*
- *Improvement and involvement in Care planning*
- *Improve our carer training to our staff*

- *Support young adult carers and young carers*
- *Support our staff who are carers.*

There is real opportunity for co-production, and a workstream of the Surrey Heartlands Mental Health Summit Improvement Plan is for SaBP to work with the Surrey Heartlands Mental Health Coalition and Surrey Healthwatch to improve the experience and participation of users and carers across Surrey. This project has a Senior Responsible Officers triumvirate, representing all participating agencies, demonstrating true collaboration from transformational change.

We are reviewing our processes, structures, leadership, and capability in the organisation to improve the experience and participation of carers in the treatment and care, in order that we deliver the vision. We will design a Leadership Framework for Carers' Experience and Participation.

The Trust's refreshed Carer's Strategy was in development when the Covid pandemic resulted in the strategy not being ratified. Our aspirations as an organisation, to inform and raise awareness for our work with and for carers, remain ever relevant and even intensified post-covid.

Until the Carers Strategy is finalised and ratified, the source for the following section has been extracted from the Joint Surrey Carers Strategy 2021-2024.

Who are carers?
A carer is someone who provides unpaid help and support to a family member, partner, friend, or neighbour. Carers include adults, parents or children and young people. They might be adults looking after other adults, parent carers looking after children with a disability, and young carers under 18 years of age.

Carers may provide emotional and physical support, including care for those with mental ill health concerns and addictions. Without the care they give, those benefiting from their help would find difficulty managing or may be unable to cope, yet on average for 25% of carers it takes five years to recognise themselves as a carer. Many carers combine caring with other responsibilities, for example, combining work or education with caring; looking after their children and older or disabled relatives.

As such carers are distinguished from care workers who provide paid care.

People may become carers at any time in their life and may move in and out of a caring role as the needs and circumstances of people around them change. The needs of carers and those they care for will vary through time, including at key stages of life such as transition to adulthood or reaching older age. Many people view their caring as an extension of their family role, such as husband, wife, son, daughter, friend, or good neighbour, and not as a carer. Although this is their choice, they still have a right to support.

Carers are more likely than the rest of the population to be affected by health problems such as depression, stress related illness or back pain caused by moving or lifting the person they care for. They may also have a disability, or a condition or illness, themselves.

Carers and the people they support are also more likely to be on a low income.

Many carers combine working with caring, although it is often a struggle to balance, with some caring for more than 50 hours on top of working full time: while others may give up work or reduce their hours because of their caring responsibilities. These carers may then struggle with financial difficulties. Many carers work within our health and care services, juggling their roles with caring in their personal lives.

So that the circumstances for carers, including their own health and wellbeing, can be improved it is essential that carers are supported to have a voice through co-production to make sure that policies, practice, and services meet their needs as well as those of the people they support.

From the 2011 Census and subsequent population projection figures, there are an estimated 115,216 carers of all ages who live in Surrey including 31,850 people caring for more than 20 hours a week, while 68,943 juggle work with caring.

There are an estimated 18,870 carers from ethnic minority communities and there are also an estimated 14,700 young carers under the age of 18. However, research shows much higher numbers of young carers than identified in the Census.

New data will be provided by the 2021 Census. This should be seen in context of the GP Patient survey which estimates the real caring population is nearer 17%. For Surrey this would mean our caring population is closer to 200,000 carers of all ages.

Valuing carers
The value of care provided by unpaid carers can be viewed in two ways:

- *The monetary value of the support they provide,*
- *The skilled personalised approach and high levels of expertise carers bring to the people they care for.*

Carers are the largest source of care and support in the UK. As an example of what this means to our community, the University of Leeds estimated that carers in the UK provide care to the value of £132 billion per annum. In Surrey they save the nation some £1.8 billion a year which would otherwise be spent on admission to hospital care, long term home placements or expensive home support packages. This value in monetary terms rose significantly during the Covid pandemic when many more carers took on the role. (Carers UK research found that carer numbers rose by 28% during Covid 19 and estimates of £193 billion per annum is the revised value of carers contribution).

The total value of the joint budget for carers in Surrey was £5.8 million per year, prior to Covid 19, while the pre-Covid 19 total value of the contribution delivered by carers across Surrey was approximately £1.8 billion per year (£19,336 per carer). In financial terms it pays to provide funded support to carers. It has been calculated that on the pre Covid value:

- *Every £1 spent on carers saves the NHS £4 (Royal College of General Practitioner/Baker Tilly 2014)*

- *Every £1 spent on preventative support for carers saves Surrey County Council £2.97 in replacement care costs (Department of Health/ADASS 2015).*
- *Every £1 invested in supporting young carers saves children's social care £3 (Ecorys 2019).*

As well as help to carry out their caring role, carers should expect to be supported to have a life outside of caring. Apart from the economic benefits to the health and care sectors of supporting carers, there is a moral case and a legal duty to support them to have a life outside of caring; to be able to enjoy a family life and relationships; have good health and wellbeing; participate in work, leisure activities, as well as education and training.

This is why carers must be involved in discussions about the support of the person they care for and be able to comment on how services are developed to support carers; and their families -including their children, in a whole family approach.

The legal and best practice drivers for co-production with carers and young carers.

The Health and Social Care Act (2012) places a duty on NHS Commissioning Boards and clinical commissioning groups to promote involvement of patients and carers in decisions about their care. This is strengthened in the Health and Care Bill 2021, that is currently moving through the parliamentary processes, at the time of writing, and will be a duty of the Integrated Care Boards once the Bill is enacted as law.

Traditional service-led approaches to meeting needs in care has meant that carers have not always received the right help for the right issues in the right way, or at the right time.

This is addressed in the Surrey Carers Strategy 2021-2024 which aims to strengthen the carer voice by committing to ensure that all carers should have regular and meaningful opportunities to have their voices heard, share their experiences, and contribute to developing, evaluating, and improving services and support in Surrey. The commissioners of services are committed to inclusivity and to recognise the diversity of communities across Surrey. Carers will have the opportunity to be involved as much as they want to be by

- *a trusted route for carers to feed back in their own words on their lived experience of caring in Surrey.*
- *delivery of the commitment to co-design and co-production.*
- *developing and maintaining effective reach across and into communities in Surrey, recognising diversity and individuality; and*
- *a strategic, co-ordinated approach so that carers feel empowered to voice their views and share their experiences, without being overwhelmed by different and/or multiple asks.*

The Carers Strategy also states how important it is to ensure equitable and accessible routes to sharing feedback and experience.

The Care Act 2014

This was ground-breaking in that it placed on Local Authorities, and partner statutory organisations such as the NHS, “a duty of parity of esteem”. For the first time unpaid carers were to be seen as equal in status to the person/ people they care for or support.

The Care Act 2014 provides for a “duty of co-operation and integration” this makes integration, co-operation, and partnership a legal requirement on local authorities and on all agencies involved in public care, including the NHS. Duties of wellbeing, information, prevention, assessment, and eligible service provision apply equally to people who use services and carers, along with the whole family approach.

The Care Act 2014 makes provision to ensure that carers have maximum control over how their needs are met. This is done through a whole family approach to assessment and support planning, and the right to request a direct payment.

A guiding principle of the Government’s approach to designing a reformed care and support system is that *‘Carers are recognised for their contribution to society, as vital partners in care, and are supported to reach their full potential and lead the lives they want’.*

“*Carers make an enormous contribution to our society and to the lives of the individuals they care for – whether they are family, friends, or neighbours. However, carers’ needs, and the impact on carers of any changes made to the care and support system, can sometimes be overlooked. If personalisation and community-based support is to work well, it needs to work well for everyone, including carers. Personalisation means that all services and support available to carers should be tailored to their specific needs as far as possible: for example, that advice and information should be inclusive of all, including disabled carers, young and older carers, inter-generational carers and carers from ethnic minority groups, and that universally available services should be flexible in their approaches in order to respond to the variety of ways in which those with caring responsibilities can be supported.”*

As well as the legislation that requires involvement of carers at a personal level relating to their own care and support, as well as the person they care for, there is a need for carers to be included in overall service and system changes and developments as well as in the monitoring and evaluating of services. It is becoming more common to find carers involved in interviews for staff members as well as highly regarded members of training teams, bringing their lived experience to the partnerships.

Children and Families Act 2014, Children Act 1989, The Carers (Recognition and Services) Act 1995, and The Care Act 2014

Parent Carers, Young Carers and non-parent carers of disabled children are supported through a range of legislation. Young carers are children under 18 with caring responsibilities. A parent carer is someone over 18 who provides care to a disabled child for whom they have parental responsibility. A non-parent carer of a disabled child is someone over 18 who provides care to a disabled child for whom they do not have parental responsibility (such as a grandparent).

Young carers

Young carers are children under 18 with caring responsibilities, and their rights to be assessed come mostly from the Children Act 1989 and the Children and Families Act 2014.

They can be sibling carers, helping to provide support to their disabled siblings or caring for an adult. If there is an adult being looked after by the young carer, then the local council has a duty to consider whether there are any children involved in providing care, and if so, what the impact is on that child.

The local council has a duty to assess ‘on the appearance of need’ (i.e., without a ‘request’ having to be made). They also have a more general duty to ‘take reasonable steps’ to identify young carers in their area.

The local council must involve the child with caring responsibilities, their parents, and any other person the young carer requests in the assessment process. The assessment itself must look at whether or not the young carer wishes to continue caring, and whether it is appropriate for them to continue caring. When doing this they have to consider any education, training, work, or recreational activities the young carer wishes to participate in.

Where a young carer’s eligible needs are identified as requiring support, local councils will have to:

- *provide support directly to the young carer or*
- *demonstrate that the ‘cared for person’s’ assessment has provided adequate care and support to prevent inappropriate care being required from the young carer.*

This is re-enforced through the Care Act 2014 where a Whole Family Approach is used to assess and support young carers caring for an adult.
The Care and Support Guidance to the Care Act 2014 states the following: -
“*Local authorities must also consider whether any of the caring tasks the child is undertaking are inappropriate. They should consider how supporting the adult with needs for care and support can prevent the young carer from undertaking excessive or inappropriate care and support responsibilities. A young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing or their prospects in education and life. This might include:*

- *preventing the young carer from accessing education, for example because the adult’s needs for care and support result in the young carer’s regular absence from school or impacts upon their learning*
- *preventing the young carer from building relationships and friendships*
- *impacting upon any other aspect of the young carer’s wellbeing*

Inappropriate caring responsibilities should be considered as anything which is likely to have an impact on the child’s health, wellbeing, or education, or which can be considered unsuitable in light of the child’s circumstances and may include:

- *personal care such as bathing and toileting*
- *carrying out strenuous physical tasks such as lifting*
- *administering medication*
- *maintaining the family budget*
- *emotional support to the adult*

When a local authority is determining whether the tasks a child carries out are inappropriate, it should also take into account the child’s own view wherever appropriate. “

Services should be provided to the adult who is being supported, so that children and young people are able to participate in education, socialise and maintain their wellbeing – enjoy their childhoods.

Parent carers of disabled children
A parent carer is someone over 18 who provides care to a disabled child for whom they have parental responsibility.

The Children and Families Act 2014 amends the Children Act 1989 requiring local councils to assess parent carers on the appearance of need or where an assessment is requested by the parent. This is called a parent carer needs assessment. This assessment can be combined with one for the disabled child and could be carried out by the same person at the same time.

The local council must also be satisfied that the child and their family come within the scope of the Children's Act, i.e., that the child is a child in need (see below).

The local council must then assess:

- *whether a parent carer has needs for support and what those needs are*
- *whether it is appropriate for the parent to provide, or continue to provide, care for the disabled child, in the light of the parent's needs for support, other needs and wishes*

Parent carers' needs assessment must also consider:

- *the wellbeing of the parent carer*
- *the need to safeguard and promote the welfare of the child cared for, and any other child for whom the parent carer has parental responsibility*
- *Wellbeing has the same meaning as applies to adult carers of adults.*

Non-parent carers of disabled children
A non-parent carer of a disabled child is someone over 18 who provides care to a disabled child for whom they do not have parental responsibility (such as a grandparent). Such carers do not have the same right to an assessment as parent carers.

The Government has said it will preserve the right to an assessment for this group of carers by not repealing the relevant parts of the Carers (Recognition and Services) Act 1995.
However, this means that such carers will still have to request a carer's assessment and will have to show they are providing, or intend to provide, regular and substantial care.

Disabled children
Assessments for disabled children will be carried out under the Children's Act 1989. Local councils have a duty to assess a 'child in need' under the age of 18 for any services that they or their family may need.

A 'child in need' is defined as one of the following:

- *a child who is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services by a local council*

- *a child whose health or development is likely to be significantly impaired, or further impaired, without the provision of services*
- *a child who is disabled*

Note: The Children Act considers a child disabled if the child is blind, deaf, non-verbal, suffering from a mental disorder of any kind, substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed.
The assessment considers all the help that the disabled child needs, the needs of any other children in the family and the help that you may need to care for the disabled child.

Transition to adulthood
When a child is moving into adulthood: -

Parent carers will want to be as well informed as possible about what their child's options are, especially as they move into adulthood.

When young carers and disabled children are approaching 18 there are different provisions in place.

Young carers become entitled to a Young Carer's assessment 'in transition'.
Disabled children become entitled to a Child's Needs Assessments 'in transition'.
Carers of disabled children (either with or without parental responsibility) become entitled to a Child's Carer's Assessment 'in transition'.

These assessments must be carried out by the local council where it considers that the young carer, disabled child, or carer of a disabled child is likely to have care and support needs after the child becomes 18 and there is 'significant benefit' to the young carer, disabled child, or adult carer if an assessment is carried out.

The duty to involve parent carers, young carers, non-parent carers and disabled children in having a voice. applies equally as with all carers and people who use services.

The Whole Family Approach
The Care Act 2014 introduced a number of reforms to the way that care and support for adults with care needs are met. It requires local authorities to adopt a whole system, whole council, whole-family approach, coordinating services and support around the person and their family and considering the impact of the care needs of an adult on their family, including children. With the transformation of care services and the introduction of integrated care systems in 2022, there is a need to make sure that the NHS plays its part in adopting the whole family approach with its partners, to promote the wellbeing of our communities.
Surrey and Borders Partnership NHS Foundation Trust already uses the Think Carer approach and there is already a considerable focus on whole-family approaches across public services. For example, The Department of Work and Pensions introduced The Family Test which describes the importance of supporting families.

> “*Strong and stable families, in all their forms, play an important role in our society. Families have a major impact on life chances of individuals and*

> *strong family relationships are recognised as an important component of individual, community, and national wellbeing*."

The variety of relationships that constitute a family is not limited to marriage, civil partnerships, cohabitation, or children, siblings, grandparents, and other extended family members. It includes whoever the person who needs care and support identifies as their family members – such as friends, neighbours, or other support networks. The interdependencies and interconnections between family members mean that what happens to one affects everyone else. Caring is a universal activity and an important part of family relationships. Much caring activity is seen in families as simply an integral part of the day-to-day lives and for some people they do not require or desire any additional support to be able to continue with that activity outside of their own support networks.

However, circumstances can arise which might impact on the ability to continue, in the short or longer term, to provide such support. The extent of the care and support may become excessive or, particularly in the case of children and young people, inappropriate. Roles within a family can fluctuate and evolve. For example, the role of carer is only one aspect of a person's family relationships. An individual may be partner and carer, person in need of support and carer, daughter or son and carer, parent and carer or sibling and carer. As a child or young person being both a carer and child is particularly challenging.

Many older couples find that each has their own needs for care and support, but they also provide care and support to the other. This mutual caring is also quite commonly found with older families of someone with a learning disability, where the balance of the caring relationship between the long-term family carer (often a parent) and the person with learning disabilities (normally an adult son or daughter) has changed. Often, without each other's support, neither person would be able to remain living independently within their local community.

People who provide care for both an older person and a child (sometimes referred to as 'sandwich carers') find they have conflicting demands on their time and many different roles to fulfil. Not all carers live in the same household, and some will provide care and support from a distance.

A whole-family approach is about more than simply considering the caring roles within a family. For example, in a family where a father has developed multiple sclerosis, the responsibility of practical and emotional support may fall upon his wife. However, his son may not know how to cope with the fact that his father is ill, and his mother has much less time for him than previously. While the son would not be defined as a young carer, his father's needs for care and support have nevertheless had a major impact on him and he may require other forms of support.

Recognising the complexity of these relationships is important to respond to supporting these multiple and coexisting family roles. Many people value their role in providing care and support to an individual but there is ample evidence of the negative impact caring can have on their health and wellbeing if their needs are not addressed and support provided at an early stage.

Taking a whole-family approach from the outset means local authorities and health services, in an integrated system, stand the best chance of identifying everyone's needs including those with caring responsibilities and supporting people to achieve

the outcomes that are important to them whilst maintaining a strong supportive family unit.
Working together with families 'Think family' means being alert to considering the impact of any event on other family members and alert to engaging with the person's circle of support. It involves coordinating services and support so that they work around the family. This means breaking down professional barriers and achieving changes in culture that mean practitioners work across organisations and service providers to achieve the best outcomes for the whole family. This will help support and maintain strong families and contribute to actively promoting wellbeing and independence, preventing, or delaying people reaching a point where they would need ongoing care and support.

NHS Constitution – Handbook updated 27th January 2022.
Pledge:

> *'The NHS pledges to work in partnership with you, your family, carers and representatives.'*
> *"Working in partnership with you as an individual patient is at the heart of the NHS ………… Another way you can be more involved in the care you receive is through personalisation and working in partnership with your family, carers, and representatives"*

The NHS also prioritises working with your family, carers, and representatives wherever this is appropriate. For example, 'Recognised, valued and supported: next steps for the carers strategy' (2010) includes a number of key commitments on involving carers in care and discharge planning and on ensuring their own needs are met. It identifies 4 priority areas:

- *supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages*
- *enabling those with caring responsibilities to fulfil their educational and employment potential*
- *personalised support both for carers and those they support, enabling them to have a family and community life*
- *supporting carers to remain mentally and physically well*

Pledge: 'The NHS pledges to encourage and welcome feedback on your healthcare and care experiences and use this to improve services.'

> *"Only by listening and responding to your views and experiences, and those of your family and carers, will the NHS know that it is delivering high quality care in the eyes of patients and the public. There are a variety of different methods that the NHS uses to capture your feedback. The feedback is then used by the NHS to improve in areas that patients say matter most to them, or to celebrate where things are going well, so do please be honest and open about your experiences when providing feedback."*

The Triangle of Care

Services such as Surrey and Borders Partnership NHS Foundation Trust use a set of standards that measures how mental health services respond to carers. This is called the Triangle of Care. This is a monitoring programme used by many mental health trusts across the UK and was developed by The Carers Trust and the Royal College of Psychiatrists.

The philosophy behind the Triangle of Care is that a working collaboration, or "therapeutic alliance" between the service user, professional and carer, promotes safety, supports recovery, and sustains well-being.

The Triangle of Care was initially developed to improve mental health acute services by adopting six principles. It is widely accepted that these key principles can be applied to all service areas.

What are the standards?
The six principles are:

- *Carers and the essential role they play should be identified at first contact with services or as soon as possible thereafter.*
- *Staff should be aware of carers and trained to engage with carers more effectively.*
- *Policies and protocols should be in place to ensure confidentiality and improve information sharing with carers.*
- *Defined roles (Carer link workers), responsible for carers should be in place.*
- *Carers should be "introduced" to the service and provided with a range of information.*
- *A range of carer support services should be available to offer or signpost carers*

It was designed to recognise carers as partners in care and to ensure that carers are fully included and supported in mental health services – which benefits staff, carers and people who use services alike – the triangle of care. At a personal level these standards are a model to guide all teams and ward staff in their responsibility for making sure that carers are recognised, listened to, and supported and are to be used to achieve better collaboration and partnership with carers during their journey through services and that of the person who uses services. It was designed to recognise carers as partners in care and to ensure that carers are fully included and supported in mental health services – which benefits staff, carers and people who use services alike – the triangle of care.
In more detail the standards are as follows: -

1. Carers and the essential role they play should be identified at first contact with services or as soon as possible thereafter.

- *Carers must be given a choice about caring if they are willing or able to provide this support to the person.*
- *They must be listened to so that their views and knowledge are heard throughout the assessment and treatment process of the person.*
- *Consent to involve the carer is regularly obtained from the person and recorded.*
- *Treatments and medication management are explained to the carer.*
- *The carer has access to advocacy and carer support information.*

2. Staff should be aware of carers and trained to engage with carers more effectively.

- *All staff will have received carer awareness training with enhanced training for front line staff in awareness of care needs; carers assessment pathways, treatment, and support; dealing with carer queries and concerns; referral processes to carer support and other sources of help; advising on treatments and medicines management; how to involve with carers and the person they care for.*
- *Training is delivered by carer trainers or carers are part of the training team.*

3. Policies and protocols should be in place to ensure confidentiality and improve information sharing with carers.

- *Consent by the person is sought to share confidential information with the carer.*
- *Agreement is reached about what information can be shared with the carer.*
- *If the person wishes no disclosure staff will regularly revisit this decision with the person.*
- *The carer is offered support, general information, referral to social care for a carers assessment when the person wishes no disclosure.*
- *The Carer is encouraged to share information with the team about the person to inform the assessment and treatment.*
- *Carers notes, care plan and letters are kept in a separate section of the person's notes on the electronic records system.*
- *Advanced statements or directives are routinely used.*
- *A recovery plan is in place.*
- *The leaflet re Carers and Confidentiality is provided to the Carer.*

4. Defined roles responsible for carers should be in place.

- *A carer contact person is identified in the team.*
- *All staff members are responsible for identifying and supporting carers.*
- *Carers are referred to the local carers support organisations.*

5. Carers should be “introduced” to the service and provided with a range of information.

- *On first contact the carer is given an introductory letter that explains the service and points of contact (e.g., nurses, psychiatrist, mental health professional).*
- *An early formal appointment is offered to the carer to hear their story, history, and address carer concerns.*
- *At first contact the team has meeting and greeting protocols in place to reduce carer distress and address concerns.*
- *Carers are routinely given an information leaflet covering immediate practical matters upon referral to the ward or team.*
- *A carers information pack is provided to new carers at their first meeting.*
- *The cultural and language needs of carers have been addressed in the carer's information pack.*
- *The format of the information pack is flexible and regularly updated.*
- *A member of the ward or team is responsible for commissioning and issuing the packs.*
- *Staff from the ward or team offer carers the opportunity to have a conversation and provide support.*
- *The carer is involved in discharge planning from inpatient care or transfer from community services.*
- *The carer is asked for feedback about the service as part of service monitoring or improvement.*

6. A range of carer support services should be available to offer or signpost carers.

- *A carers support service is in place locally with dedicated carers support workers in post.*
- *Carer has access to local advocacy services.*
- *Carer has access to one-to-one support if needed.*
- *A new carer is automatically referred to social care for carers assessment and support plan*
- *The carer’s needs and plans are regularly re-assessed.*
- *Family therapy or talking therapies are offered to carers and family if required.*

The Care Programme Approach Transformation

The CPA was first introduced in England in 1991 to provide a framework for effective mental health care. The approach was subsequently revised following the introduction of the Department of Health (UK) document ‘Refocussing the Care Programme Approach: Policy and Positive Practice Guidance (2008)’.

CPA Transformation 2021
A number of concerns were raised by a range of stakeholders in recent years that the continued way in which the CPA is used in community mental health services represents a major barrier to providing the higher quality, more flexible and personalised care that the Community Mental Health Framework for Adults and Older Adults 2019 envisaged and that service users need. The Community Mental Health Framework makes clear that one of its purposes is to enable services to shift away from an inequitable, rigid, and arbitrary CPA classification and bring up the standard of care towards a minimum universal standard of high-quality care for everyone in need of community mental healthcare.

In 2021 the Care Programme Approach – Position Statement was published by NHSE to clarify that the level of planning and co-ordination of care can be tailored and amended, depending on:

- *the complexity of an individual's needs and circumstances at any given time*
- *what matters to them and the choices they make*
- *the views of carers and family members*
- *professional judgment*

The Position Statement makes clear that the shift does not mean taking away any positive aspects of care that someone currently on the CPA is experiencing, and local services need to be equally clear about this in their communications with service users and carers.

The new approach is based on the following five broad principles, some of which are further outlined below:

- *A shift from generic care co-ordination to meaningful intervention-based care and delivery of high-quality, safe, and meaningful care which helps people to recover and stay well, with documentation and processes that are proportionate and enable the delivery of high-quality care.*

- *A named key worker for all service users with a clearer multidisciplinary team (MDT) approach to both assess and meet the needs of service users, to reduce the reliance on care co-ordinators and to increase resilience in systems of care, allowing all staff to make the best use of their skills and qualifications, and drawing on new roles including lived experience roles. (Peer support)*

- *High-quality co-produced, holistic, personalised care and support planning for people with severe mental health problems living in the community: a live and dynamic process facilitated by the use of digital shared care records and integration with other relevant care planning processes (e.g., section 117 Mental Health Act); with service users actively co-producing brief and relevant care plans with staff, and with active input from non-NHS partners where appropriate including social care.*

- *Better support for and involvement of carers as a means to provide safer and more effective care. This includes improved communication, services proactively seeking carers' and family members' contributions to care and* *support planning, and organisational and system commitments to supporting carers in line with national best practice.*

- *A much more accessible, responsive, and flexible system in which approaches are tailored to the health, care and life needs, and circumstances of an individual, their carer(s) and family members, services' abilities, and approaches to engaging an individual, and the complexity and severity of the individual's condition(s), which may fluctuate over time*.

Better support for and involvement of carers as a means to provide safer and more effective care.
This includes improved communication, services proactively seeking carers' and family members' contributions to care and support planning, and organisational and system commitments to supporting carers in line with national best practice.

Support for and involvement of carers.

Carers often play a vital role in supporting people with severe mental health problems in the community. While past national CPA guidance laudably set clear expectations around carer involvement – and much of the content in Standard 6 of the National Service Framework for Mental Health regarding carers remains helpful if not outdated – there continues to be variation reported in the extent to which services and statutory organisations understand and act on their legal duties (including promoting the right to a carer's assessment for carers of people with mental health problems), as well as best practice.

Carers often face specific inequalities and are protected from discrimination under the Equality Act. NHS England and NHS Improvement's development of a Patient and Carer Race Equality Framework for use in mental health services is a response to the need to address racial disparities and is part of a wider Advancing Mental Health Equalities Strategy.

For this reason, NHS England and NHS Improvement has asked all ICSs preparing to use new Long Term Plan funding to transform their community mental health services from April 2021 to develop and implement plans for a specific strategy to involve and improve the lives of carers of people with severe mental health problems.

Resources to help services and ICSs do so include:

- The Carers Trust's Triangle of Care The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England - Resources - Carers Trust

- NHS England and NHS Improvement's carers toolkit www.england.nhs.uk/commitment-to-carers/carers-toolkit/

- NHS England and NHS Improvement's Supporting carers in general practice: a framework of quality markers www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/

- NICE guideline NG150 on Supporting adult carers Overview | Supporting adult carers | Guidance | NICE

- Information on the use of Family Intervention approaches www.nice.org.uk/guidance/qs80/chapter/quality-statement-3-family-intervention

Specific resources for supporting young carers. www.childrenssociety.org.uk/information/professionals/young-carers/resources-for-people-working-with-young-carers

Legislation, policy and practice that might impact on carers involvement.

There can be a minefield of policies and practice guidance that carers might have to negotiate so that they can be assured of being involved in the planning of care for the person they provide unpaid care to. These include the following: -

Confidentiality and the Caldicott Principles (Gov. UK)

Good information sharing is essential for providing safe and effective care. There are also important uses of information for purposes other than individual care, which contribute to the overall delivery of health and social care or serve wider public interests.

These principles apply to the use of confidential information within health and social care organisations and when such information is shared with other organisations and between individuals, both for individual care and for other purposes. The principles are intended to apply to all data collected for the provision of health and social care services where patients and service users can be identified and would expect that it will be kept private. This may include for instance, details about symptoms, diagnosis, treatment, names, and addresses. In some instances, the principles should also be applied to the processing of staff information.

They are primarily intended to guide organisations and their staff, but it should be remembered that patients, service users and/or their representatives should be included as active partners in the use of confidential information.

There are 8 Caldicott Principles

Principle 1: Justify the purpose(s) for using confidential information. Every proposed use or transfer of confidential information should be clearly defined, scrutinised, and documented, with continuing uses regularly reviewed by an appropriate guardian.

Principle 2: Use confidential information only when it is necessary. Confidential information should not be included unless it is necessary for the specified purpose(s) for which the information is used or accessed. The need to identify individuals should be considered at each stage of satisfying the purpose(s) and alternatives used where possible.

Principle 3: Use the minimum necessary confidential information. Where use of confidential information is considered to be necessary, each item of information must be justified so that only the minimum amount of confidential information is included as necessary for a given function.

Principle 4: Access to confidential information should be on a strict need-to-know basis. Only those who need access to confidential information should have *access to it, and then only to the items that they need to see. This may mean introducing access controls or splitting information flows where one flow is used for several purposes.*

Principle 5: Everyone with access to confidential information should be aware of their responsibilities. Action should be taken to ensure that all those handling confidential information understand their responsibilities and obligations to respect the confidentiality of patient and service users.

Principle 6: Comply with the law. Every use of confidential information must be lawful. All those handling confidential information are responsible for ensuring that their use of and access to that information complies with legal requirements set out in statute and under the common law.

Principle 7: The duty to share information for individual care is as important as the duty to protect patient confidentiality. Health and social care professionals should have the confidence to share confidential information in the best interests of patients and service users within the framework set out by these principles. They should be supported by the policies of their employers, regulators, and professional bodies.

Principle 8: Inform patients and service users about how their confidential information is used. A range of steps should be taken to ensure no surprises for patients and service users, so they can have clear expectations about how and why their confidential information is used, and what choices they have about this. These steps will vary depending on the use: as a minimum, this should include providing accessible, relevant, and appropriate information - in some cases, greater engagement will be required.

(Published December 2020)

Confidentiality and Information Sharing

In their personal relationships with mental health services, carers often face huge problems when consent is not given by the person who uses services for certain information to be shared such as the prognosis of their illness; medicines management; the skills needed by the carer to provide safe and sustainable care or support. Carers should not face barriers in co-production caused by issues of confidentiality if clear guidance is co-designed and followed, using the guidance of the Caldicott Principles.

No confidential information should be required to be shared during co-production activities, and the guidance for group work should address confidentiality with group members who will co-design their own ground rules. There are times when people, including carers, might want to share with their peers, their stories to illustrate how changes could improve their experiences and in these circumstances group members might need to agree to keep this shared information private to the group. Any notes taken should not include any identifying information nor should any feedback from the group. It is the issue under discussion that is important to share, agreed by the group members, not the personal details of the group members. There are also times when people, including carers might be asked to do a presentation to illustrate their lived experience.

Legal considerations when sharing information

Personal information may be shared legally in one of three ways:

- with the consent of the individual concerned (providing that individual has mental capacity)
- when it is required by law (e.g., The Children's Act 1989 requires information to be shared in safeguarding cases)
- when it is in the public interest

When information sharing is legally permitted, the Caldicott Guardian may need to decide how much information it is appropriate to share, in line with the third Caldicott Principle. An organisation may hold a great deal of sensitive information, and any decision to share information must be proportional and relevant.

Caldicott Guardians may on occasions be asked to advise on disclosures that may be in the public interest, for example to protect individuals or society from risks of serious harm, such as serious communicable diseases or serious crime, or to enable medical research, education or other secondary uses of information that may ultimately benefit society. Personal information may be disclosed in the public interest, without consent—and in exceptional cases where consent has been withheld— if the benefits to an individual or to society of the disclosure outweigh both the public and the patient's interest in keeping the information confidential.

There may be occasions when information sharing is legally permitted but not required. In these circumstances there must still be a justifiable legal basis for breaching confidentiality such as consent, benefit to someone without capacity to consent, or in the public interest.

There may also be circumstances where although it is legally permissible to share information, the Caldicott Guardian may decide that it should not be shared. There may also be occasions when there is no clear legal basis, or the legal basis is disputed, when the Caldicott Guardian may nevertheless agree that information may be shared. The circumstances should always be considered in each case, as factors present in one may be absent in another. In all cases, the Caldicott Guardian should be able to justify their decision and provide evidence of their considerations in making the decision.

Keeping a record of decisions made

Caldicott Guardians should take care to document any advice offered, judgements or decisions made and the reasoning behind them in the interests of transparency and accountability. For example, often emails and written communications are preferable to verbal conversations as they provide Caldicott Guardians with a clear, documented history including details of the request received, how the Caldicott Principles have been considered, advice given, and how much information has been shared and with whom. Some organisations may also use a decision log as a way of monitoring and evidencing their role and impact.

Surrey and Borders Partnership NHS Foundation Trust, through the Carers Action Group, authorised the leaflet below that can be found on the SaBP website. (The Carers Action group is a planning group of unpaid carers and professionals from SaBP services, social care, and the third sector who come together to monitor the Trust's response to carers by the Triangle of Care and to consider other areas of support to carers.)

Confidentiality and Information Sharing Leaflet – Surrey & Borders Partnership NHS Foundation Trust

This section has been taken from the ‘Carers and Confidentiality’ leaflet produced by The Royal College of Psychiatrists and The Princes Royal Trust for Carers.

> *‘The sharing of information is crucial to the ongoing wellbeing of both people who receive services and their carers. If carers are excluded from important discussions and decision making involving the person this can have serious practical, financial and personal consequences for both the carer and the person receiving services.*
>
> *Not being involved increases a feeling of isolation, grief and loss which are common to many carers. The relationship between the professional and the person using the service is based on having confidence or trust that what is said will not be disclosed without their agreement.*
> *We are required by law not to share information without getting consent from the person using our service. When we get consent, we will be ensuring that the person using services understands what it is they are consenting to, and the purpose of sharing it.*
>
> *There might be risk to the carer if certain information is not shared with them. We understand that these situations may happen, and it may be difficult for carers, and we will listen to your views and any concerns you may have about the person that you feel you need to share with us. We try to find a way of offering support and information without jeopardising the confidentiality of the person.*
>
> *We will ensure we are confident that the person has the capacity to make this decision.*
> *As a carer you are likely to have known the person before they became unwell. We acknowledge that you may have key information relevant to how we provide effective care for them. You will likely be aware of what may influence their wellness. We will encourage you to share this information because it will help us to provide the best support for the person you care for, as well as giving you a positive role and confidence in what we are doing.*
> *There may also be times when a carer shares personal information with us about themselves that they do not wish the person to know. We have the same obligation to not share this personal information without your consent. This includes information you may share with us about how you are feeling or coping in your caring role.*
> *We aim even when the patient continues to withhold consent, to ensure that carers are given sufficient knowledge to enable them to provide effective care. That they are also given the opportunity to discuss any difficulties they are experiencing in their caring role and help to try and resolve these. The provision of general information about mental illness, emotional and practical support for carers does not breach confidentiality.*
>
> *There might be circumstances where not sharing essential information might place the carer and other family members at significant risk. If there is a situation that puts other people at risk or the person themselves then acting immediately and in the interests of the person needs to be progressed.*
>
> *Where possible carers are given general factual information, both verbal and written about:*

- *The diagnosis*
- *What behaviour is likely to occur and how to manage it*
- *Medication, benefits, and possible side-effects*
- *Contact details of the care coordinator*
- *Local inpatient and community services*
- *The Care Programme Approach (CPA)*

Carers are helped to understand:

- *The present situation*
- *Any confidentiality restrictions requested by the person*
- *The person's treatment plan and its aims*
- *Any written care plan, crisis plan or recovery program*
- *The role of each professional involved in the person's care*
- *How to access help, including out-of-hours services*
- *What an advanced statement is*

Carers are given:

- *The opportunity to see a professional on their own*
- *The right to their own confidentiality when talking to a professional*
- *Encouragement to feel a valued member of the team*
- *Confidence to voice their own views and any concerns they may have*
- *Emotional and practical support*
- *An assessment in their own right*
- *A referral to carer support services*

If you feel the person you care for needs more support, then there are different ways you can help them to get this.
Your GP surgery (who can also register you as a carer)
Your local council, see information section for contact number and for more information
The organisations listed in the directory.
Regular support for mental health If the person you are caring for is already receiving support from mental health, learning disability, or specialist services then the first point of contact should be their care coordinator.
How to go about getting support for the person you care for.

Frequently asked questions about confidentiality, information sharing, and understanding the care we provide

If the person I care for withdraws consent, can I still get support from you? *Yes.*
Whilst there may be certain pieces of information, we are prevented from sharing with you, you are still entitled to your rights as a carer to a carer's assessment and we can continue to support you as the carer and signpost you to additional support.
Even if we cannot give you certain pieces of information it is very important to us that you keep in contact with us and continue to feedback to us any concerns you may have about the person you care for.

What can I do if I feel that the service is not involving me appropriately in the care that is being provided?

> *It is important that any concerns you have are raised with the care coordinator or CMHRS in the first instance. If you are still dissatisfied, you can get additional advice from the Patient Advice and Liaison Service (PALS). contact details can be found at the end of this handbook."*

The Care Act 2014 makes clear that carers are still entitled to be listened to about their lived experience of caring/or supporting the person, and any problems they or their family face, regardless of the consent of the person who uses services. They have very important information about their caring situation and the personal preferences of the person they support that can be helpful to the recovery of the person who uses services, and to their own wellbeing.

> "*Carers and young carers are entitled to a carers assessment and support in their own right. Lack of consent by the person they care for, or support cannot limit a carer's rights to assessment, support or to welfare benefits that they may be eligible for."*

What is always protected is the person's private and confidential information, unless it would be in everyone's best interests to share this information, in the way that the leaflet describes.
It is better for everyone if the person who uses services does give consent to information that will help their recovery and how the carers can best support them. Carers do not need to know any personal information or choices that do not relate to the caring situation. Consent helps carers and their families to be involved in care planning. This is especially important where support to the person they care for can be designed to support the carer and family members in their caring role, and in their lives outside of caring. This is called a Whole Family Approach.

Advanced Statements are also used to establish what the person who uses services chooses to share. An advance statement is a statement, often written when the person is well, that sets down their preferences, wishes, beliefs and values regarding their future care and who they want their information to be shared with.
The aim is to provide a guide to anyone who might have to make decisions in the person's best interest if they have lost the ability to make or communicate decisions.

Decision making and Mental Capacity

What is mental capacity?

Mental capacity is the ability to decide, whether it is an everyday decision such as what to wear, or a more important decision such as where to live. Everyday millions of acts of support are done to and for people who lack capacity either to care for themselves or to consent to someone else caring for them. This might include actions such as helping an individual to wash, dress, eat or attend to their personal hygiene, taking them to see the doctor or dentist, or helping them buy food or have gas and electricity supplied to their home.

The Mental Capacity Act (MCA) which was originally introduced in 2005 applies to everyone who works in health and social care and is involved in the care, treatment, or support of people over 16 years living in England and Wales, who are unable to make all or some decisions for themselves. This also applies to family members/unpaid carers who provide the majority of care and support to those they care for. The Mental Capacity Act 2005 provides the legal framework for making

decisions on behalf of people who lack the mental capacity to make decisions themselves
The Mental Capacity Act 2005 sets out five ‘statutory principles’:

- *a person must be assumed to have capacity unless it is established that they lack capacity*
- *a person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success*
- *a person is not to be treated as unable to make a decision merely because they make an unwise decision*
- *an act done, or decision made, under the Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests*
- *before the act is done, or the decisions is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action*

There is a Mental Capacity Act Code of Practice which explains the Mental Capacity Act 2005 in detail.

How is mental capacity assessed?
At the time of writing, there is a two-stage test to work out if someone lacks mental capacity.

Stage one: Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain? This could be caused by: -

- *a stroke or brain injury*
- *a mental health problem*
- *dementia*
- *a learning disability*
- *confusion, drowsiness or unconsciousness because of an illness or the treatment for it*
- *substance misuse.*

This could include dementia, learning disabilities, mental illness, brain damage.

Stage two: Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to? A person is unable to make a decision if they cannot:

- *understand information about the decision to be made*
- *retain that information in their mind*
- *use or weigh that information as part of the decision-making process*
- *communicate their decisions*

New case law suggests the two-stage test should be amended. This is subject to the Mental Capacity Act (MCA) /Liberty Protection Safeguards (LPS) draft consultation currently underway (March 2022).
LPS, formerly Deprivation of Liberty Safeguards (DoLS), is rooted firmly within the Mental Capacity Act 2005 (MCA) and all the key principles of the MCA fully apply.

LPS will be about: -

- safeguarding the rights of people who are under high levels of care and supervision but lack the mental capacity to consent to those arrangements for their care.

- will apply to people in care homes, hospitals, supported accommodation, Shared Lives accommodation and their own homes.
- will apply to everyone from the age of 16 years.
- will need to be authorised in advance where possible by what will be termed ‘the Responsible Body’.
- where a person is deprived of their liberty before an authorisation has been given, the MCA has been amended to provide the authority to continue to care for the person.

Who assesses mental capacity?
Normally, the person who is involved with the particular decision which needs to be made is the one who would assess mental capacity.

If the decision is a complex one then a professional opinion might be necessary, for example the opinion of a psychiatrist, psychologist, social worker i.e., a professional working in health or social care.

What happens if there is a disagreement with a mental capacity assessment decision?
If someone disagrees with a mental capacity assessment decision, for example if the person they look after is assessed as lacking mental capacity when it is thought that they have mental capacity, there are various ways that can be tried to resolve this.

The matter can be raised with the person who carried out the assessment and they can be asked to give reasons why they believe the person lacks mental capacity to make the decision, and they can be asked to provide objective evidence to support that belief.

A second opinion can be sought from an independent professional.

If the disagreement cannot be resolved, then an application to the Court of Protection can be made. It can make a decision as to whether a person has mental capacity.

What happens if the person is assessed as lacking mental capacity?

No one else can give consent on behalf of an adult who lacks capacity unless they are authorised under a Lasting Power of Attorney or have the authority to make treatment decisions as a court appointed deputy. It is good practice to involve the person’s carer, relative or an advocate in a decision.

If the person is assessed as lacking mental capacity, then any decision made on their behalf should be done in their ‘best interests’. This is the case whether the person making the decision on behalf of the person lacking capacity is a carer, a lasting power of attorney, a court appointed deputy, or a professional.

Who should actually make the best interest decision will depend on the decision in question and on whether there is anyone with the legal right to make the decision. If the decision is an everyday decision, then the person most directly involved with the person should be the decision maker. For example, if a family member/unpaid carer helps them to get dressed, they will make the decision as to what they wear.

If the decision is about their health and wellbeing and the family member/unpaid carer has lasting power of attorney for health and welfare or are the court appointed deputy, they should be the decision maker.

If the decision is about property or financial affairs and the family member/unpaid carer has lasting power of attorney for property and financial affairs or are the court appointed deputy for property and financial affairs, they should be the decision maker.

If there is no lasting power of attorney or court appointed deputy in place, the professional involved should be the decision maker.

When making the best interest decision, if it is practical and appropriate to do so, the decision maker should consult any lasting power of attorney or court appointed deputy (if the power of attorney or court appointed deputy does not have the relevant authority to be the decision maker themselves – i.e. a power of attorney for property and financial affairs should still be consulted about a decision relating to health and welfare), anyone who is caring for the person, any close relatives and friends, and anyone else who is interested in the welfare of the person.

When making the best interest decision, the decision maker should also take into account the past and present wishes and feelings of the person.

At the time of writing, there have been changes to the MCA to update the Deprivation of Liberty Safeguards (DOLS) and Liberty Protections Safeguards (LPS) through the Mental Capacity (Amendment) Act (LPS) 2019. The Codes of Practice are still awaited, and, in the meanwhile, the status quo remains.

Discharge from Hospital - Discharge to Assess.

In 2020/21, hospitals in the UK faced unprecedented volumes of inpatient numbers due to the impact of Covid 19. This also included mental health inpatient care when more people who were known to mental health services, as well as those not identified previously, suffered mental health crises that required inpatient care. The Department of Health and Social Care published new guidance called Discharge to Assess, so that discharges from hospital care could be speeded up. There were unfortunately negative impacts on unpaid carers who were not always involved in the discharge planning. Assumptions were made about an unpaid carer’s willingness and ability to care. In the UK there is no obligation to care and where caring takes place it is usually within a close relationship of family, friends, or neighbours. It takes place mostly out of love and friendship, and also in the spirit of reciprocity i.e., that offspring cared for by parents from childhood to adulthood, in turn provide care to their elders when they need help.

Healthwatch Surrey recently worked in partnership with Action for Carers (Surrey) to research Carers’ Experiences of Hospital Discharge. The outcomes of this research demonstrated that the experience of carers at this time is often negative and full of risk to both patients and carers.

Carers need to be assured that as well as being medically fit for discharge from hospital, the person they care for should also be safe to leave the care of professional staff especially where they are going home to the care of family/unpaid carers.

The new discharge process (from acute inpatient care to home) known as Discharge to Assess, recognises people have different needs once they no longer need care in an acute hospital. Staying longer than necessary is not good for a person's recovery or wellbeing.
Staff are asked to arrange discharge on the day the doctor agrees they no longer need hospital care. The person cannot stay in hospital if they choose not to accept the care offered to them. This can be a time of anxiety for unpaid carers and the person they care for. Action for Carers (Surrey) has published a very important and useful leaflet to help unpaid carers understand what they can expect at this time.

This process identifies four types of patients. Those who:

- need minimal help on discharge
- would benefit from short term support to recover further at home, before assessing their long-term care needs
- would benefit from short term support to recover further in a residential setting, before assessing their long-term needs
- are unlikely to benefit from short term support and need ongoing nursing care, most probably in a nursing home.

To explain these 4 different routes from discharge: -

1. Minimal support on discharge
Ward staff manage discharge of patients needing only minimal help, for example with transport home or someone to switch on heating. They can provide information on organisations who can help, for a few weeks, with tasks such as shopping.

2. Support to recover further at home or in a residential setting
The person cared for may have potential for further recovery when their need for hospital care finishes. They may benefit from support to maximise their recovery before staff assess their long-term needs. If so, staff will discuss with the unpaid carer and the person cared for what this might mean and appoint a case manager. The case manager arranges to discharge them to a more suitable location, any settle-in support they need, and for a health professional to visit them and the carer– either on the same or following day – to agree and arrange a short-term recovery and support plan.

3. If the person's needs are too great to return to their own home, they may be discharged to a residential setting such as a community hospital or care home. Support, over and above what they were receiving prior to their hospital stay, is free of charge for up to four weeks. Staff are expected to assess their longer-term care needs within this time.

4. If the person is unlikely to benefit from further support Ward staff will discuss their long-term needs with the person and the unpaid carer and any other family as appropriate. If there is need for a higher level of care, then a care manager will be appointed to arrange discharge to a care home and a full needs assessment, so that the person can review all the options and move to a long-term care home as soon as possible.
For more information:
https://www.nhs.uk/NHSEngland/keoghreview/Documents/quick-guides/Quick-Guide-discharge-to-access.pdf

If the person needing care lacks capacity to make decisions about treatment and care and has registered a Lasting Power of Attorney (LPA) for Health and Wellbeing, (or in some circumstances the LPA for Property and Financial Affairs) and the unpaid carer is an attorney, then staff should fully involve the unpaid carer, so they can make decisions on the person's behalf. If the carer is not the registered attorney, staff must make a 'best interests' decision on the person's behalf and should consult with the unpaid carer before doing this. Staff should give the unpaid carer information at every step of this process. An assessment on the ward should be carried out to see if the person cared for is medically fit to be discharged from hospital. A discharge assessment should be carried out to see if they need support once discharged from hospital. This may require a visit from the occupational therapist to the person's home.
The unpaid carer should be asked by one of the clinical team or the discharge team if they are willing and able to carry on caring for this person. If they are not able to do so, then they need to be listened to and the discharge plan should be adjusted with both the person and unpaid carer's agreement and consent. This is in line with the Care Act 2014.

A Carer's Assessment should be carried out by the social worker either from the hospital or a social worker from your local authority team, to see whether a carer needs support once the person they care for is discharged to their final place of care.
A written care and support plan (called a 'Care Plan') should be given to the person cared for, which outlines the support required and how this will be provided.

Any extra help is arranged. For example, a visit from the district nurse or paid home help.

An Occupational Therapist will carry out a home visit or talk about any equipment or adaptations needed.

Any equipment is fitted and delivered. For example, a raised toilet seat, chair raisers, hospital bed. Home adaptions are also made. For example, grab rails in the bathroom and/or on any stairs.
(Source Action for Carers Hospital Discharge Guide – www.actionforcarerssurrey.org.uk)

The guide includes some useful questions an unpaid carer might ask before the person they care for has been discharged from hospital.
"Questions you might wish to ask. As a carer, have you:

- *Been asked if you are able and willing to continue caring?*
- *Been offered a Carer's Assessment?*
- *Been involved in a discharge meeting?*
- *Received a care plan?*
- *Know all medication they are now receiving and side effects?*
- *Spoken to a member of the discharge team?*
- *Know which referrals have been made for post discharge treatment or support and who the contact person is for each referral?*
- *Has a date for any equipment to be installed?*
- *Have received training for using any equipment?*
- *Received a detailed discharge letter*

Although the guidance for Discharge to Assess appears to be inclusive of carers who need support at this time, many representatives of carers are concerned that too many patients are being considered in the “minimal support on discharge” category when in fact the carers does have needs at this time.
It has been recognised that more work needs to be done to support carers at the point of discharge and especially in mental health services, where there are higher risks for the wellbeing for the person leaving hospital and for their unpaid carers. It is essential that this work is developed through co-production with carers.

On the 7th of March 2022 Carers UK (a national campaigning organisation for carers rights) strongly welcomed the fact that Peers had successfully won an amendment against the Government’s attempt to revoke the Community Care (Delayed Discharges etc) Act 2003 in the Health and Care Bill during its report stage in the Lords. The Bill, unamended, would have taken away unpaid carers’ vital rights at the point of hospital discharge.

The amendment, which was led by Baroness Pitkeathley, had cross-party support from Lord Young, Baroness Hollins, and Baroness Meacher. This was an important and decisive “win” for carers, showing that Peers understood and recognised the value of unpaid carers’ support. The vote of 205 to 155 against the Government’s proposals sends a very clear message to Government that they should protect carers’ rights as the Bill progresses.
The amendment safeguards carers’ rights by ensuring hospitals consult with unpaid carers at the point of discharge, builds in checks that the carer is willing and able to care and would ensure joint working to make sure that the carers are supported.
Importantly, the amendment means that the rights would apply to adults providing unpaid care to other adults who are disabled or chronically ill, parent carers of disabled children and young carers who are so often overlooked.
Carers UK’s research and in-depth evidence from carers showed that, by not consulting, involving, or supporting the unpaid carer, the health of the patient, as well as the carer, was being put at risk. This included patients being readmitted to hospital where carers said this could have been avoided.

Co-production and carers

What is Co-production?

The following section is taken from Think Local Act Personal as referenced in the Health and Social Care Act.

> *“The term co-production refers to a way of working, whereby everybody works together on an equal basis to create a service or come to a decision which works for them all. It is built on the principle that those who use a service are best placed to help design it.”*

What is important for co-production? - 10 Top Tips

- *Co-production must start as an idea that blossoms with everybody involved having an equal voice.*
- *Come to the table with a blank agenda and build it with people who use your service, their carers, and families.*

- *Involve people who use services, carers, and their families in all aspects of a service – the planning, development, and delivery.*
- *To achieve meaningful, positive outcomes, everybody involved must have the same vision, from front line staff to management/board members.*
- *Start small and build up to bigger projects, letting people lead, not professionals.*
- *Acknowledge that a range of skills are needed for co-production.*
- *Recruit the right people that support co-production.*
- *People who use services, carers and families should be clear about what their expectations are and be fully engaged in the process.*
- *People who use services and their carers know what works, so you can't get it right without them.*
- *Don’t take responsibility for solving every problem—allow the group to find collective solutions.*

How can you support co-production?

- *Ensure appropriate and adequate resources are available to support co-production (participation fees, expenses, easy read documents, and access needs).*
- *Ensure frontline staff have everything they need to for co-production, including time and flexibility.*
- *Ensure no one group or person is more important than anyone else. Everyone can contribute given the right support.*
- *It is important to have good facilitation and listening skills, and to reflect and act upon what is heard.*
- *Acknowledge and respect what people who use services, their carers and families say. Ensure everything in the co-production process is accessible to everyone taking part. Before you start the work, decide together how you are going to work and what will make it successful, then stick to it.*
- *Accept that sharing power means taking risks. Take a chance!*
- *Learn to share power. Doing things differently means we can work across a whole range of issues that confront us.*
- *Work with the group to support a clear set of identified values with a collective sense of direction.*
- *Don’t use jargon or acronyms, plain English is better for everybody.*
- *Create the expectation that people who use services, carers and families will be involved in every aspect of service planning, design/development, and delivery at every level.*

What is great about co-production?

- *Everybody is equal.*
- *The outcomes are meaningful and positive.*
- *People who use your services, carers and families are seen and recognised as valuable partners.*
- *Services will improve.*
- *It is a fun and productive way of working together.*
- *People have the opportunity to see different perspectives that may differ from your own.*

Making Coproduction Real for Carers

The Surrey Carers Strategy sets out the vision for working with and supporting carers across health and social care services. The following making it real statements of what is important to carers have been translated from the strategy values.

I am identified as a carer as early as possible, and my needs are assessed within the context of my whole family

I know who to contact if I or the person I care for has an emergency including a mental health crisis.

I am included when the person I care for is discharged from inpatient care and I am supported to care safely throughout my caring experience.

I am encouraged to recognise my role and rights as a carer.

I have my rights and those of the person/s I care for championed and protected.

I have access to high quality information, advice and support that is personalised and which I can trust.

I have choice and control in my caring role.

I am informed, respected and included as an expert partner in care.

I am able to stay healthy and live well myself, including having breaks to support me to maintain my own wellbeing.

I have my own needs and wishes as an individual recognised and supported.

I am supported to remain in work, training and/or education.
I am supported in getting financial advice, including welfare and benefits.

I have access to support and training that will enable me to feel confident in my caring role.

I have meaningful opportunities to have my voice heard and be empowered to share my lived experience which will influence learning and change.

I am socially connected and not isolated.

Making co-production as accessible as possible is a key principle but many people continue to experience barriers to participation. Some of the issues that will help carers to participate will also be identified as helpful for people who use services. Issues to be considered are:

- Greater understanding the role of carers and the part they play in the health and social care system
- Respect carers' needs and rights for involvement – understand what the legislation and best practice guidance requires in terms of involvement
- Understand the impact of the misuse of the term “carer”
- Give carers parity of esteem with people who use services

- Accessibility for carers – as well as issues of accessibility in terms of the language and jargon and technical terms used, the formats used for involvement must be accessible (using IT and all the issues relating to this and the need for ongoing support)
- The speed at which many co-production activities take place is often too fast this can make it difficult to understand things and get involved.

Other things to consider.

- Are carers free to participate? Replacement care might need to be provided even when they are at home caring. Caring can cause distractions so regardless of the setting, carers might need replacement care

- They might have difficulties getting to meetings and events

- The timing of meetings and events to allow time for childcare responsibilities such as the school run and school holidays

- Allow timing for morning caring responsibilities and so on but most importantly to discuss with individual carers what timing is best for them.

- Expenses arrangements to pre-pay for travel costs or payment on the day for example – again to be discussed with carers.

- Are refreshments provided? Dietary needs catered for? Carers spend a great deal of time supporting others and it is very much welcomed when someone thinks about them and gives them a simple treat such as a tasty snack or meal.

- Where people need to be open and honest about how they feel, it is wise to allow them to have privacy – either as a discreet group of people who use services, or a group of carers with shared experiences of being supported or of providing support or provide one to one conversations.

- What is said during the group discussions must be bound by a pledge of confidentiality and when reporting issues back, they should be anonymised and reported in a way that no-one can be identified.

- It is sometimes difficult for people who use services and carers to speak openly and honestly in front of people who provide services for fear of losing them.

- People who use services and carers can be involved with services at times when they are facing personal challenges or when they are ill or are having a crisis. People in these situations may need support to be involved in co-production, such as a peer support, or a carers support worker.

- Confidentiality can sometimes be used to restrict open and honest conversations about their lived experience. This should not be allowed to be a barrier to hearing peoples voices.

Young Carers and Co-Production

A young carer is someone aged 25 and under who cares for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support. Older young carers are also known as young adult carers, and they may have different support needs to younger carers.
During the co-production survey we heard from both adult and young carers. The experience of working with and supporting young carers in Surrey is to be found in the Action for Carers (Surrey) Surrey Young Carers service.

Surrey young carers are members of the National Young Carers Voices Network and through this medium have stated the following: -

Young Carers Top tips for mental health professionals - Made by Young Carers National Young Carers Voice Network – Louder Together

1. *The condition of the person we care for is not the full story – they're a person too; their condition affects their mental health and the rest of their life, and it affects us in lots of ways. We need recognition and support too.*

2. *We need more long-term solutions and support for us and the people we care for. Six weeks isn't enough.*

3. *Having a consistent, supportive adult who we know, and trust can really help. We shouldn't have to tell our story over and over.*

4. *Checking in on a patient regularly can help head off a crisis that otherwise we then have to deal with.*

5. *Treatment needs to be more accessible and flexible to allow us to support the person we care for.*

6. *We need more detailed information from doctors from a younger age about:*

7. *If we're telling you about our situation, it's because we need comfort and support. This means specific young carer training is needed for health professionals so that you:*
    - *understand all the different types of caring responsibilities we have to deal with and the different ways these might impact on us.*
    - *know how to offer us support in ways that actually have an impact.*
    - *This training needs to be mandatory and meaningful.*
    - *We want and deserve to feel like we're a priority. which services are supporting our family their treatment/medication (e.g., what it's supposed to do, any side effects etc) what to do when things go wrong (like when our family members have seizures or mental health crises).*

8. *Workers need to be clear about what they can or can't do in their roles, so we are clear on expectations.*

9. *Better communication between GPs and pharmacists would make life easier for the people we care for. Fewer errors and confusions with prescriptions would help them and us a lot.*

10. We need quicker responses to crisis situations when it is known that the patient is cared for by a young carer – we shouldn't have to cope with crises on our own.

11. We need crisis and discharge plans that are written in accessible language we can understand, so we know what to do before a crisis happens.

12. Please make referrals to activities, support groups and days out for the people we care for to decrease their isolation. Doing this helps decrease our isolation and caring roles too.

Thank you Be the change! Implement these top tips today

The following statements about young carers were made in response to the SaBP Coproduction project: -

"Not listened to, especially young carers.

Young carers must be identified as they are hidden. Often, they are too frightened to ask for support. They have feelings and do need more help and support

Young carers don't want to be seen as different – they are kids with different lives

Young carers need time away from their caring responsibilities and mental health workers should not underestimate the value of these interventions

Young carers feel it is important to have one consistent point of contact; they often have a lot of professionals in their lives, and they often change and then they are not sure who is their next point of contact and families stop engaging with services.

Mental health workers must be equipped to offer practical solutions, grounding techniques, a telephone number to call in need, and they need training in how to listen to and treat young carers as individuals.

Young carers need to build rapport with mental health professionals and recognise the need for them to have this with all family members

Have open conversations with young carers but make sure they are in a safe space for them to consider how you will engage with them – after school, in a café or park or at the weekend.

Not collaborating with young carers impacts them as they feel isolated, alone, frightened and if left unsupported their own mental health suffers. They need to know there is a support network around them.

If working with young carers make meetings fun and interactive – maybe offer a voucher or pizza as an incentive.

Young carers need choices."

APPENDIX 3

The process of creating the SaBP staff survey

The project needed to learn the views of everyone involved in the process of co-production. This would include people who use services, their carers, and the professionals providing those services for Surrey and Borders Partnership NHS Foundation Trust. Those groups would need to be asked different questions to ensure their experiences were accurately understood.

It was initially hoped that the majority of staff views could be captured during meetings and face to face conversations. This would be accompanied by a survey for people who were unable to attend those sessions to have their say. It soon became apparent that the ongoing safety measures around Coronavirus and the new Omicron variant would prevent visits to NHS sites from taking place. The survey then became the main way to engage with people, alongside a smaller number of online workshops.

The process of creating the questions began during a meeting of the project group. This included people representing Surrey and Borders Partnership NHS Foundation Trust, Surrey Coalition of Disabled People, Healthwatch Surrey, and Surrey Minority Ethnic Forum. It was important to learn how staff currently use co-production and how that could be developed in the future, so the questions needed to be carefully phrased to gather that information.

A Jamboard was used to capture people's suggestions anonymously during the meeting and for a period of time afterwards. There were a few common themes amongst the submissions, including:
- Checking people's understanding of the term "co-production"
- How clinicians share power with patients and carers
- The pros and cons of involving service users and carers fully
- What barriers there are to co-production, such as time, people and money
- What support staff might need
- Good examples of using co-production, and what enabled it to work well

It was recognised that making the surveys and feedback from workshops anonymous would enable participants to speak freely without worrying about repercussions.
After a few days, the list of questions was reviewed and discussed with someone who has extensive experience creating surveys involving the medical profession. This was valuable in formatting the questions in a way that would focus people's answers on the areas we were interested in, and in phrasing the questions in terminology that is used by staff at the Trust.

Once the survey was drawn up, it was presented to another meeting of the project group for review. A number of changes were made as a result of their responses. Options to recognise volunteers and people with lived experience working for Trust were included, and the order of some of the questions was rearranged to improve the flow.

After the survey had been updated with these changes, it was reviewed again by someone who had not been involved in the process of creating it. A few uses of jargon and initialisms that could be misunderstood were identified and clarified to avoid confusion. A balance was struck between using terminology that is widely used within the trust, while ensuring the language was accessible to staff without a medical background.

To gain the maximum amount of feedback, the survey needed to reach as many members of staff at the Trust as possible, so that the views of people working in all areas, and at all levels could be considered. The survey was launched with an article in the weekly newsletter, which is emailed to all staff and volunteers, coinciding with an email asking the chief operating officer and the divisional directors to share the article with all of their team managers to forward to their teams. A poster we had created to promote the survey was included in these messages, with a request to print and display it on staff notice boards in the Trust’s buildings. After two weeks, a follow up email was sent to the team managers and admins asking them to complete the survey themselves and encourage their staff to engage with it. The Trust’s communications department was asked for help in raising awareness of the survey, and it was emailed to all the volunteers who work for the trust.

It was noted that people are busy and might not be keen to spend their time on a survey, so an incentive was added by offering anyone completing it the chance to win one of 2 restaurant vouchers as a thank you.

APPENDIX 4

The process of creating the service user and carer survey

Background

In my role as Project Officer, I was tasked with utilising social media to promote the *Your Mental Health Services – Who Holds the Power?* survey to gather lived experience from service users and carers accessing Surrey's mental health services. This report covers

- Development of the surveys we used to gather insight into coproduction at SABP
- The use of social media and digital to increase engagement through our surveys

This report covers: the different types of surveys; the timeline of survey creation; why the survey became the sole feedback source; why email was chosen as the communication method; what role social media was meant to play; engagement impressions across social media accounts from the organisations contacted; and recommendations for Surrey and Borders Partnership NHS Foundation Trust (SaBP) on how social media can be used to increase and promote co-production within Surrey's mental health services.

The Project Partnership

Surrey Coalition, Healthwatch Surrey, and Surrey Minority Ethnic Forum (SMEF) worked together with Surrey and Northeast Hampshire's Mental Health Trust, Surrey and Borders Partnership NHS Foundation Trust (SaBP) to conduct an extensive engagement and co-design process into the future of co-production within the Trust. The project looked to extensively engage with people with lived experience, carers, and professionals to inform the decisions being made.

Co-production

Co-production is a way of working that involves people who use health and care services, carers, and communities in equal partnership; and which engages groups of people at the earliest stage of service design, development, and evaluation.

Within the transformation of SaBP this relates the involvement of service users and carers in planning care plans and working together to develop systems for the future and service.
Co-production acknowledges that people with 'lived experience' of a particular condition are often best (better) placed to advise on what support and services will make a positive difference to their lives.

Conclusions

- Delay with Surrey and Borders NHS Partnership Trust communications resulted in no social media posts being created or shared about the survey from their verified and well-connected social media accounts.
- As the Project Partnership didn't have a central social media presence, there was again a strong reliance on Healthwatch Surrey, Surrey Coalition, SMEF, and SaBP to lead the way.

- The Project Partnership did not have control over what the organisations did in their outreach aside from sending follow-up emails and the relevant graphics/information. The outreach was largely out of the project's hands.
- Email responses were exclusively from those sent out with a named contact and therefore future emails for survey would avoid generic inboxes.
- Organizations struggled to utilise the social media content in the formats we provided. There was a strong reliance on organisations to have an existing social media presence with a structure already in place.

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Recommendations

Dedicated central accounts/forums

Serves as the key driver for shareable content for outreach and engagement with co-production work. This will enable strategies to be built for a curated audience and result in higher quality outreach.

Adaptable brief template to help voluntary organisations outreach to their communities. This can be made accessible on a central website for organisations to download the file, removing the need to send large email attachments.

The document should include:

- Imagery and copy information tailored to various social media platforms.
- Explanation on how to upload content to each social media platform.
- Links to shareable posts from the central account if an organisation does not have the resources to create social media posts themselves and/or do not have dedicated social media accounts fit for purpose.

A consistent social media presence dedicated to co-production and engagement in order to gather continuous insight from the community and curate an audience that interacts with surveys, feedback, and other co-production content.

Lived Experience

Appoint a lived experience team member in Surrey and Borders Partnership NHS Foundation Trust Communications team if not already to support equitable and person-centred language and content. Perhaps if there was lived experience within the team there may have been further efforts to support timely communications from SaBP. Involve carers in equal measure alongside service user experience when gathering feedback and input.

Survey Development

Two main surveys were commissioned by Surrey and Borders Partnership NHS Foundation Trust (SaBP) to gather feedback about co-production in Surrey's mental health services. Each survey focused on a different demographic: SaBP Staff; Service Users and Carers; and Voluntary, Community & Commissioned Services.

Your Mental Health Services – Who Holds the Power?

The anonymous survey was designed to gather service user feedback around how mental health services in Surrey currently share power and decision-making with service users and carers.

When promoting the survey to service users and carers, it was important to highlight care plans and/or ability to access services would not be affected by completing the survey.

Timeline

In the early Project Group meetings, *Your Mental Health Services – Who Holds the Power?* was sorted out quickly because it was clearer what needed to be asked whilst the staff survey had more guidelines to sort through. The three organisations involved in the Project Partnership met with SaBP staff. Laura asked questions about what they wanted to find out. The group did a couple of jam boards to work out the general themes. Laura worked out some questions from that feedback and took the general structure back to the project group to check through it. Working with Healthwatch, who have designated survey design staff, the survey was refined with drafts going back and forth to the project group to check each stage. SaBP staff members who are also experts by experience helped inform the survey. The Project Partnership recognised an extra initiative was needed to motivate respondents to complete the 15 to 20-minute survey. It was decided to offer two chances to win a £50 Amazon voucher at the end of the survey.

All mentions of the *Your Mental Health Services – Who Holds the Power?* survey and engagement efforts with service users and carers during Project Group meetings can be found in Annex 1.

Other Data Collection

COVID-19 restricted the ability to host in-person sessions forcing the survey to become the main feedback source for service users and carers.

Social Media's Role

The social media posts promoting the survey were planned to become springboards for discussions in the comment sections, unfortunately SaBP communications could not facilitate scheduled posts or a continued conversation. These discussions would have highlighted individuals the Project Partnership could then contact to attend engagement sessions for further feedback and insight. Unfortunately, no discussions took place.

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Outreach

Targeted existing email lists curated by the relevant organisations to contact service users and carers about the *Your Mental Health Services – Who Holds the Power?* survey

Demonstrating the importance and value to networking, the contact list was informed by Janice, Lucy, and Wendy. This helped to make sure the outreach covered carers, VCFS, and service users.

Thirty-four emails were sent with the majority addressed to a named point of contact. This list included six NHS specific emails.

Timeline

31st January 2022
Long form email (ANNEX 1) sent out to the contact list explaining the project and the survey with social media graphics, a poster pdf, and a service user and carer blurb attached.

A ‘What is this? Who is it for? What can you do? Where can you find it? When will it close?’ structure was used to create the service user and carer blurb for easy understanding and accessibility.

3rd February 2022
Long form emails sent to NHS specific contact points.

Early February 2022
Laura spoke to directly to SaBP communications and shared Healthwatch Surrey posts into local community groups.

14th February 2022
Email sent to SMEF via Salem to place the survey information in their email bulletin.

15th February 2022
Shorter email (ANNEX 2) sent out to the contact list as a follow-up. This included Healthwatch Surrey’s social media posts across Facebook, Twitter, and Instagram (4.3.1 Healthwatch Surrey) as examples/options to share, as well as social media graphics with a social media blurb to attach for creating own posts.

21st February 2022
Survey had 69 responses.

24th February 2022
Megan utilised personal LinkedIn and TikTok accounts to talk about the survey.

28th February 2022
Survey closed with 74 responses.

Attachments
The following were attached to the initial outreach email for the organisations to utilise in their outreach efforts. Video and Images (Annex 4) were attached to follow-up emails.

- Instagram Grid Post
- Instagram Vertical Video
- Landscape Image for Facebook and email newsletters
- Landscape Video

- Service User and Carer Survey Poster
- Service User and Carer Survey Information
- ¶

Engagement Impressions (Email)

Action for Carers and Surrey Coalition responded to the first batch of emails. They both replied with their communication leads copied in. Richmond Fellowship responded to the follow-up email to inform us the information had been sent out into the following community groups: East Surrey Community Connections page, the Safe Haven page, Queen’s Park, and another page a lot of their community access. Wendy networked with the Recovery College to have the survey sent out to all students registered with them.

Engagement Impressions (social media)

- Healthwatch Surrey

08/02/2022 Healthwatch Surrey Twitter
Engagement: 4 likes and 3 retweets include the Alzheimer's Society – Southeast England
Have you accessed mental health services through Surrey & Borders NHS Partnership?
Do you want a say in the shape of services in the future?
The anonymous survey gives you the chance to win one of two £50 Amazon vouchers
Access the survey here: https://www.surveymonkey.co.uk/r/SaBPsuc

08/02/2022 Healthwatch Surrey Instagram
Engagement: 7 likes and 5 comments
Note: Healthwatch Surrey also linked the service user and carer survey in their Instagram bio.
Have you accessed mental health services through Surrey & Borders NHS Partnership?
Did you feel involved in the big decisions around your care?
Do you want a say in the shape of services in the future?
Do you have some time to share your thoughts and experiences?
The anonymous survey gives you a chance to win one of two £50 Amazon vouchers.
Access the survey in our bio.
The survey closes 28th February 2022
#healthwatchsurrey #surrey #mentalhealth

10/02/2022 Healthwatch Surrey Facebook
Engagement: 5 likes and 11 shares including Caterham Residents and Businesses Join Together 16/02/2022, Farnham Community Board. 16/02/2022, Alzheimer's Society - Southeast England 18/02/2022, The Loop – Surrey 21/02/2022
*Have you or someone you care for accessed **mental health services** through Surrey & Borders NHS Partnership?*
*Did you feel **involved** in the **big decisions** around your care?*
*Do you **want a say** in the shape of services in the future?*
*Do you have some time to share your **thoughts and experiences**?*
The anonymous survey gives you the chance to win one of two £50 Amazon vouchers.
Access the survey here https://www.surveymonkey.co.uk/r/SaBPsuc
#healthwatchsurrey #surrey #mentalhealth #whoholdsthepower
@Mind @Richmond Fellowship @Surrey and Borders Partnership NHS Foundation Trust @Surrey Heartlands Integrated Care System @Focus Surrey & NE Hants @Surrey Coalition of Disabled People @Mary Frances Trust @Surrey Minority Ethnic Forum

Post shared to:

- Caterham Residents and Businesses Join Together. 16/02/2022
- Farnham Community Board. 16/02/2022
- Alzheimer's Society - Southeast England 18/02/2022

21/02/2022 The Loop – Surrey Facebook
Engagement: 1 like
Your Mental Health Services in Surrey - Who Holds the Power?
#HaveYourSay 📢
This is an important survey for people currently or recently receiving care or treatment for their mental health
OR
people who are carers and care workers of people currently receiving care or treatment for their mental health.
The aim of this survey is to understand how involved people are in the decisions made about their care ⬇
https://www.surveymonkey.co.uk/r/SaBPsuc
#MentalHealth #Surrey¶
4.3.2 Surrey Coalition

07/02/2022 Surrey Coalition Weekly Update (website)
Service user and carer survey on mental health services – Please fill out the survey below if you are currently or recently receiving care or treatment for their mental health OR who are carers of people currently receiving care or treatment for their mental health within Surrey and North East Hampshire – The surveys have been created to gather lived experience to understand how involved people are in the decisions made about their care and how their attitudes to being involved in the design of new services. These are completed anonymously.

The survey takes around 15 minutes to complete with a chance to enter a draw to win one of the two £50 Amazon vouchers.

The anonymous responses will be fed back to the organisations responsible for mental health care and treatment services to help inform future service design, without your identity being shared and in no way would affect any ongoing or future treatment.

The survey closes on 28th February and the link is here: The survey 'Your Mental Health Services – Who Holds the Power?' can be found here.

15/02/2022 Surrey Coalition Twitter
Engagement: 1 like and 6 retweets including Debbie Hustings – Unpaid Carers Lead (London) @NHSEngland; Tandridge Access Group; Edmund O'Leary – Love Me Love My Mind, Epsom Trustee; IMHN Surrey
Have you accessed mental health services through Surrey & Borders NHS Partnership? Do you have some time to share your thoughts and experiences? The

anonymous survey gives you the chance to win one of two £50 Amazon vouchers. (Survey linked into post)

15/02/2022 Surrey Coalition Facebook
Engagement: 1 share from Surrey and NE Hampshire Independent Mental Health Network (16/02/2022)
Have you accessed mental health services through Surrey & Borders NHS Partnership? Do you have some time to share your thoughts and experiences? The anonymous survey gives you the chance to win one of two £50 Amazon vouchers. (Survey linked into post)

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SMEF
No social media activity on Twitter, Instagram, Facebook (Public Group or Facebook page)

SaBP
No social media activity on Twitter, Instagram, Facebook (Public Group or Facebook page)

¶
Action for Carers
18/02/2022 Action for Carers Twitter
Engagement: 1 like
'Who holds the power' is the title of an important survey into Surrey's provision of mental health services, especially how decisions are made. If you care for someone because of their MH, PLEASE take 15 minutes to complete it. Closes 28 February. https://surveymonkey.co.uk/r/SaBPsuc

20/02/2022 Action for Carers Facebook
Engagement: 2 likes including The Loop-Surrey and 3 private shares
Note: Used a stock image of a person laying on a bed hugging a dog for comfort.
'Who holds the power' is the title of an important survey into Surrey's provision of mental health services, especially how decisions are made. Surrey NHS want both people using services, AND carers to respond.
If you care for someone because of their mental health, PLEASE take 15 minutes to complete it. You can choose to be entered into a prize draw. This survey closes 28 February.
It's here: https://www.surveymonkey.co.uk/r/SaBPsuc #MentalHealth #UnpaidCarers #Surrey

25/02/2022 Action for Carers Facebook
Engagement: 1 like
Note: Used a stock image of a person laying on a bed hugging a dog for comfort.

'Who holds the power' is the title of an important survey into Surrey's provision of mental health services, especially how decisions are made. Surrey NHS want both people using services, AND carers to respond.
If you care for someone because of their mental health, PLEASE take 15 minutes to complete it. You can choose to be entered into a prize draw. This survey closes in a few days, on 28 February.
It's here: https://www.surveymonkey.co.uk/r/SaBPsuc
#MentalHealth #UnpaidCarers #Surrey

26/02/2022 Action for Carers Twitter
Engagement: 1 like
'Who holds the power' is the title of an important survey into Surrey's provision of mental health services, especially how decisions are made. If you care for someone because of their MH, PLEASE take 15 minutes to complete it. Closes v soon – 28 Feb. https://surveymonkey.co.uk/r/SaBPsuc
¶
Surrey and NE Hampshire Independent Mental Health Network
02/02/2022 Surrey and NE Hampshire Independent Mental Health Network Facebook
Engagement: 1 share
You have a real chance to shape the future of how you are involved in your care.
The anonymous survey below is looking to understand how involved people are in the decisions made about their care and how they feel about being involved in the design of new services.
The Service User and Carer survey is for:
People currently or recently receiving care or treatment for their mental health with Surrey and Borders Partnership NHS Foundation Trust
Carers of people currently receiving care or treatment for their mental health with the Trust.
Complete the survey here: https://www.surveymonkey.co.uk/r/SaBPsuc

02/02/2022 IMHN Surrey Twitter
Engagement: 2 likes
Are you currently or recently receiving care or treatment for your #mentalhealth with? @SaBPNHS
or a carer of someone who is? You have a chance to shape the future of how you are involved in your care - complete the anonymous survey below.

16/02/2022 Surrey and NE Hampshire Independent Mental Health Network Facebook
No engagement.
Survey link only
¶
National Autistic Society Surrey Branch
15/02/2022 National Autistic Society Surrey Branch Facebook
Engagement: 2 likes 1 love from Surrey Coalition of Disabled People

Note: Posted with the landscape video
Autism is not a mental health condition, but many autistic people also have mental health conditions.
This survey request for service users and carers has been received from Surrey Coalition of Disabled People.
https://www.surveymonkey.co.uk/r/SaBPsuc

Family Voice Surrey
24/02/2022 Family Voice Surrey Facebook
Engagement: 1 like, 6 shares
Posted the landscape video. No text.
¶
Organisations contacted via the email outreach

Organisation	Facebook	Instagram	Twitter	Note
Action for Carers	🟩	🟥	🟩	
Aldershot Military Museum	🟥	🟥	🟥	In hindsight, this wasn't the best place to contact for military service users and carers and where SaBP could have filled the gap.
Aldershot Safe Haven	No individual social media presence			Frimley CCG and Andover Mind, SaBP, and many other organisations sharing info about the safe haven.
Andover Mind	🟥	🟥	🟥	No blog or website activity either.
Catalyst	🟥	🟥	🟥	Retweeting/sharing posts from Oakleaf Support, Time to Change Surrey, University of Surrey, Woking Safe Haven.
Creative Response in Farnham	🟥	🟥	🟥	No named point of contact
Family Voice	🟩	🟥	🟥	No named point of contact Retweeting/sharing posts from User Voice and Participation Team.
Frimley CCG	🟥	🟥	🟥	Frimley Health and Care Integrated Care System Facebook page posted a Healthwatch Windsor, Ascot & Maidenhead survey about South Asian Carers 24/02/2022
Surrey and Northeast Hampshire	🟩	N/A	🟩	Shared Facebook and Twitter posts from Surrey Coalition 15/02/2022.

Independent Mental Health Network	🟩		🟩	Information sent out to IMHN reps/mailing list. See 4.3.5 for social media activity.
Mary Frances Trust	🟥	🟥	🟥	Retweeting/sharing posts from Love Me Love My Mind Epsom, SaBP, User Voice and Participation Team, Time to Change Surrey, The Loop- Surrey (shared a post about Surrey Coalition Tech Angels), Surrey Coalition.
Matrix the MH Advocacy service	No social media presence			
Oakleaf Support	🟥	🟥	🟥	Retweeting/sharing posts from with Surrey University and Catalyst
Outline Surrey	🟥	🟥	🟥	Social media accounts not up to date.
Pride in Surrey	🟥	🟥	🟥	
Recovery College	No social media presence, connected with SaBP.			
Richmond Fellowship	🟩	N/A	🟥	East Surrey Community Connections page, the Safe Haven page, Queen's Park, and another page that has a lot of the community they support within it.
Surrey and Borders Partnership NHS Trust	🟥	🟥	🟥	Verified social media account. No website activity under News No LinkedIn activity. This would have been useful for networking into the veteran demographic especially. Also useful for networking into the Drug & Alcohol Team, Surrey Heartlands Integrated Care System, NHS Addictions Provider Alliance, Mind Matters Surrey
Surrey Disabled People's Partnership	🟥	N/A	🟥	Retweeting/sharing posts from with Surrey Young Carers, Oakleaf Enterprise, Catalyst, Drugs and Alcohol Team, Surrey and Borders,
Surrey Community Action GRT	🟥	N/A	🟥	Mary Frances Trust,
Surrey Faith Links	🟥	N/A	N/A	Last Facebook post Nov 2021. Not included in February newsletter on their website.

Surrey Heartlands CCG	🟥	🟥	🟥	Facebook page had various post about co-production groups for service improvement.
Surrey National Autistic Society	🟩	N/A	N/A	
Surrey Young Carers	Part of Action for Carers			
The Alzheimer's Society	🟩	N/A	🟩	Shared Facebook and Twitter posts from Healthwatch Surrey
The Rushmoor and Hart Wellbeing Centre	No social media presence, connected to Andover Mind			
The Vine Centre in Aldershot	🟥	🟥	🟥	
Time 2 Change Surrey	🟥	🟥	🟥	Email bounced back. In partnership with Catalyst and Mary Frances Trust.
United Communities	No social media presence			
Woking Mind	🟥	N/A	🟥	

Annex 1: Outreach Email

Dear (named point of contact)

I'm writing on behalf of The Project Partnership (Surrey Coalition of Disabled People, Healthwatch Surrey, and Surrey Minority Ethnic Forum). Surrey and Borders Partnership NHS Foundation Trust (SaBP) have invited us to work on a re-design project looking at the future of co-production in the mental health services within Surrey and Northeast Hampshire.
Surveys have been created to gather lived experience to understand how involved people are in the decisions made about their care and their attitudes to being involved in the design of new services. These are completed anonymously.
The Service User and Carer survey is for people **currently or recently receiving care or treatment for their mental health** OR who are **carers of people currently receiving care or treatment for their mental health** within Surrey and Northeast Hampshire.
The survey takes around 15-20 minutes to complete with a chance to enter a draw to win one of the two £50 Amazon vouchers.
The anonymous responses will be fed back to the organisations responsible for mental health care and treatment services to help inform future service design, without your identity being shared and in no way would affect any ongoing or future treatment.

We think your organisation, (named organisation), will be a good fit for sourcing participants. I have attached social media graphics and a small blurb that can be used for email newsletters addressed to service users and carers to share this survey with your community.

The survey 'Your Mental Health Services – Who Holds the Power?' can be found here.

The survey closes 28th February 2022. We would therefore be grateful if you could give this your best priority.

Please let me know if you need any more additional information or imagery to share the survey to your service user and carer community.

Best wishes
Megan

Annex 2: Follow-up email

Dear (named person)

I hope this email finds you well.
Thank you so much for your help and support with rolling out our service user and carer survey. This SABP commissioned survey is designed to gather a huge body of service user feedback around how mental health services in Surrey currently share power and decision-making with service users.
The survey will close in two weeks! Please could we ask that you either share the Healthwatch Surrey social media posts on Facebook, Instagram, Twitter or create a post of your own. I've attached copy that can be used for social media posts below and the images to this email:

Have you accessed mental health services through Surrey & Borders NHS Partnership?
Did you feel involved in the big decisions around you care?
Do you want a say in the shape of services in the future?
Do you have some time to share your thoughts and experiences?
The anonymous survey gives you the chance to win one of two £50 Amazon vouchers
Access the survey here: Your Mental Health Services - Who Holds the Power? Survey
The survey closes 28th February 2022.

Please don't hesitate to reach out with any questions or queries about the survey.
Best wishes,
Megan

Annex 3: SMEF Email Bulletin email

INTRO BLURB:
This SaBP commissioned survey is designed to gather a huge body of service user feedback around how mental health services in Surrey currently share power and decision-making with service users.

SOCIAL MEDIA BLURB:
Have you accessed mental health services through Surrey & Borders NHS Partnership?
Did you feel involved in the big decisions around you care?
Do you want a say in the shape of services in the future?
Do you have some time to share your thoughts and experiences?
The anonymous survey gives you the chance to win one of two £50 Amazon vouchers

Access the survey here: Your Mental Health Services - Who Holds the Power? Survey
The survey closes 28th February 2022.

Annex 4: Social Media Graphics

healthwatch Surrey

Surrey Coalition of Disabled People

NHS Surrey and Borders Partnership NHS Foundation Trust

WE HAVE A ONCE IN A GENERATION CHANCE TO SHAPE THE FUTURE OF HOW YOU ARE INVOLVED IN YOUR CARE

WHO HOLDS THE POWER?
WORKING TOGETHER IN YOUR MENTAL HEALTH SERVICES

scan the QR code using your phone camera or go to imhnsurrey.com/survey

healthwatch Surrey

Surrey Coalition of Disabled People

NHS Surrey and Borders Partnership NHS Foundation Trust

WE HAVE A ONCE IN A GENERATION CHANCE TO SHAPE THE FUTURE OF HOW YOU ARE INVOLVED IN YOUR CARE

WHO HOLDS THE POWER?
WORKING TOGETHER IN YOUR MENTAL HEALTH SERVICES

scan the QR code using your phone camera or go to imhnsurrey.com/survey

We are looking forward to raising up your voices to work towards a more collaborative approach to mental health services in Surrey and North Hampshire

visit imhnsurrey.com/survey

We are looking forward to raising up your voices to work towards a more collaborative approach to mental health services in Surrey and North Hampshire.

visit imhnsurrey.com/survey

Annex 5: Service User and Carer Survey Poster (pdf)

healthwatch Surrey

SURREY COALITION OF DISABLED PEOPLE

NHS Surrey and Borders Partnership NHS Foundation Trust

WE HAVE A ONCE IN A GENERATION CHANCE TO SHAPE THE FUTURE OF HOW YOU ARE INVOLVED IN YOUR CARE

WHO HOLDS THE POWER?

WORKING TOGETHER IN YOUR MENTAL HEALTH SERVICES

scan the QR code using your phone camera
or go to imhnsurrey.com/survey

Annex 6: Service User and Carer Survey Information

Service User and Carer Survey

Who is this survey for?

This anonymous survey is looking to understand how involved people are in the decisions made about their care and how they feel about being involved in the design of new services.

The Service User and Carer survey is for:

- People currently or recently receiving care or treatment for their mental health with Surrey and Borders Partnership NHS Trust (SaBP).
- Carers of people currently receiving care or treatment for their mental health with SaBP.

What is it all about?

SaBP have asked The Project Partnership (Surrey Coalition of Disabled People, Healthwatch Surrey, and Surrey Minority Ethnic Forum) to look at the way that they currently involve service users and carers in all aspects of mental health services within Surrey and Northeast Hampshire.

What are the next steps?

Please click on the link below and complete the survey Your Mental Health Services - Who Holds the Power?

The anonymous answers from this survey will be fed back to the organisations responsible for mental health care and treatment services to help inform future service design without your identity being shared and in no way would affect any ongoing or future treatment.

The anonymous survey takes **15-20 minutes to complete** with a chance to **enter a draw to win one of the two £50 Amazon vouchers** at the end.

The survey closes 28th February 2022.

APPENDIX 5

Creation of co-produced poster for SABP staff survey:

To help promote the Surrey and Borders Partnership NHS Foundation Trust (SaBP) staff survey and encourage engagement, a poster was created. It needed to be eye-catching with a concise message that could attract attention at a glance. The design process considered a range of factors to increase impact and make the poster more accessible. It needed to be visually clear and simple to ensure it could be easily understood by anyone, including individuals with a visual impairment or learning disability. A clean design was created, with a minimalist colour scheme of black, white and yellow and a bold font.

The wording was carefully chosen to capture the essence of what the survey was about and generate interest with a short slogan avoiding jargon or complex terminology. The phrase “have your say today about the way you offer mental health care” was included to encourage people to make their opinions heard. The sentence “We’ve a once in a generation chance to shape the future of how you co-produce care & services” outlined the purpose of the project, and the significance of the opportunity.

For ease of access, a QR code was added to the poster which people could scan with their mobile phones to link directly to the survey. The logos of all organisations involved in the project were added, to make it clear it is a group coalition including Surrey and Borders Partnership NHS Foundation Trust, Surrey Coalition of Disabled People, Healthwatch Surrey and Surrey Minority Ethnic Forum.

Once the first draft of the poster had been drawn up, it was presented to a meeting of the project group for their consideration. Feedback from that meeting led to the message being redesigned to make it clearer and more impactful. Consideration was given to the theme of the message and how to frame it. Options included referencing the balance of power between those providing services and those using them and their carers, or about how the process is shared between them. The resulting text incorporated both of those ideas: “Who holds the power? Have your say in the way you share decision making with people and carers”.

Once those adjustments were made, the finished poster was presented to another meeting of the group. At this point it was noted that some people might not be able to use the QR code, so the decision was made to add a weblink to maximise the chances of people engaging with the survey.
The poster was used in the SaBP staff eBulletin newsletter to illustrate an accompanying article about the survey and was distributed with the survey in emails to divisional directors, managers and team leads for them to print and display on noticeboards.

APPENDIX 6

Creative workshop guide_

Topic ' Who holds the power? '

Aims and objectives

- For service users to feel heard, in terms of having a say in their care.
- Expressing their emotions through a creative workshop, which will start conversations of their experiences.
- Exploring how clinicians and carers could adapt to have co-productive discussions with their patients, bringing autonomy for service users.

Setting up a good venue

- There could be choices of the centres that are used to hold the workshop if the service users are not on a ward. This reinforces that the service user has a say in all aspects of the workshop.
- Giving options for times would make it easier for service users to attend. Currently, workshops are often set up without consultation and the service user then has to work their schedule around the clinicians.
- Consider physical accessibility, such as wheelchair ramps, and loops for people with hearing impairment. Choose a venue close to a bus or train station. Provide healthy snacks and water.

Creating a safe environment

- A service user could co-lead the session, having been given appropriate support and preparation.
- Begin the workshop by setting some ground rules.
- Allow people to finish speaking before moving on to the next person.
- Agree to disagree respectfully and without judgement.
- Be clear that no answer is wrong. No emotion is wrong. No one will get into trouble for having an opinion.
- Explain the aims and objectives, so it's clear this is about being heard.
- Workshop participants should know they can be honest and open. But they are also free not to speak if they prefer just to listen.
- Carers and doctors could attend the workshop. These would not be the service user’s carers or doctors. This would help people feel comfortable to speak, and would allow doctors to listen in real life, rather than read up on data collected afterwards.

- Whoever runs the workshop needs to reflect back to participants to check they have understood what is being expressed. This prevents assumptions being made.
- An awareness to read the room is necessary. Service users in hospital may be less lucid than service users who live at home. The workshop can be adapted to tailor to people's needs. It can be made simple or more complex as appropriate.
- Include breaks so people are not concentrating for too long.
- Lighting needs to be considered. Some service users will be more sensitive to light because they are generally more sensitive. Avoid glaring lights and use dimming where possible. Bright lights are also not calming.
- Reassure people it's OK to feel emotional and have some tissues at hand.

What's needed?

- Cut out card circles for each participant with dots pre coloured from the middle to the edges.
- Cut out people shapes in different sizes and colours.
- Red, amber and green flash cards.
- Pens, notebooks, colour pencils, felt tip pens, crayons, examples of facial expressions (which could be on a whiteboard)
- A whiteboard with pens and wiper.
- Other mediums like felt, sequins, and coloured paper.
- Glue sticks and scissors

Why be creative?

- Creativity speaks when people are unable to be verbal.
- Creativity dulls anxiety, which leaves people feeling more confident to share.
- Creativity focuses the mind on the task in hand.

Running the workshop

1) Start with an ice breaker. A group of strangers may be more open to talking about issues if they feel at ease with each other. Possible questions include "If you were a superhero what would your power be? And what colour would you have as a suit?" This is also about encouraging people to think of themselves in a positive way.
2) Explain the workshop. Things will be broken down step by step. If a participant doesn't understand what is being asked, they can tell that to the facilitator, who could prepare different ways of explaining the same thing. They would give an overview such as "We are going to be exploring how you feel about the care you receive. Who has the power? Today we are going to make ourselves out of card. And our doctors and carers."
3) Ask participants to choose 3 cut out people.

4) Encourage participants to decorate them, providing examples for inspiration.
5) Ask them to choose a circle.
6) Ask them to choose expressions, which could be pre-made or drawn on the whiteboard. They could use happy and sad faces. A straight line might mean “I don't know how I feel”. A cross over the mouth could mean “I feel my voice is silenced”. A wobbly line could mean “feeling overwhelmed, unsteady emotionally”. Participants can also draw their own expressions.
7) Give each person 3 flash cards – red, amber and green. Explain these represent emotions. Red is for difficult feelings like anger, sadness, frustration. Amber means “I am unsure how I feel”. Green means “I'm content, I feel good”.
8) Ask the participants to place themselves in the circle. The middle dot means they feel they have total say in their care. Show examples of these on the whiteboard. If the doctor is in the middle, then they have all the say. They can place their carer too. To represent no say at all, they might place themselves outside the circle. Have examples of their carer being close to them or the doctor. An ideal would have the 3 cut outs standing side by side. But it's up to the participant to decide.
9) The participant can move their cut outs in response to questions. “Do you feel you have a say in your care?” “Do you understand what medication you are taking and why?” “Does the doctor speak to you or your carer when in a meeting with them?” Questions from the feedback survey could be used. This opens up conversations. To empower the participant, they could be asked if they know what could help for them to have equal power.

Guide in Toolkit 8

Running a Creative Feedback Workshop

Objective

Allow service users to:
1. feel heard
2. express their emotions
3. start conversations about the service user experience
4. have their say about their care.

Creative workshops can help bring autonomy to service users and find ways to help increase co-production discussions between service users, clinicians, and carers.

Resources

For each participant
1. Cut out card circles
2. People cut outs x 3
3. Flashcards in red, orange, and green.

Other
1. A whiteboard with pens.
2. Decorating materials such as glue sticks, scissors, pens, pencils, felt, sequins, coloured paper etc.

1 Ice breaker

This will help bring the group together and become more comfortable in the space.

EXAMPLES What would be your superhero power? What colour would your superhero suit be?

2 Introduce aims

Provide an overview of the workshop and break down the activity into steps. Opportunity for participants to ask questions.

EXAMPLE 'Today we are exploring how you feel about the care you receive through a creative activity.'

3 Resources

1. Three cut-out to decorate (provide examples for the participants)
2. A circle
3. Give each person three flashcards: Red, Orange, and Green.

4 Explain resources

Explain how each colour represents a different emotion.

Red = anger, sadness, frustration.
Amber = I am unsure how I feel.
Green = I'm content, I feel good.

The cut-outs represent:
A doctor, a carer, themselves.

Allow time for participants to decorate cut-outs.

5 Apply

Ask the participants to place themselves in the circle relative to how involved their feel in decisions made about their care.

The closer to the middle of the circle = the more say that cut-out (doctor, carer, themselves) has about their care.

EXAMPLE Doctor in the middle = doctor has all the say.

They may place themselves outside the circle.

Have an example of the ideal: 3 cut outs standing side by side.

6 Questions

Ask the participants situational questions to further discussion and see if the positions of the cut-outs move closer or further the centre.

EXAMPLE:
1. Do you feel you have a say in your care?
2. Do you understand what medication you are on and why?
3. Does the doctor speak to you or your carer when in a meeting with them?

You could also use the questions from the survey.

7 Close discussion

Be sure to thank participants
Remind them the aims of the project and how they have helped
Let them know how you will let them be involved with the project as it continues and how you will feed back at the end of the project.