Culture of Care

Supporting co-production and lived experience leadership across the Culture of Care work

Guidance for wards

Version 2

Preface

The Culture of Care standards set out a brave and bold new vision for inpatient mental health care. A vision where people are consistently able to access a choice of therapeutic support, and to be and feel safe. A vision where inpatient care must be trauma-informed, autism-informed and culturally competent.

The Culture of Care programme at the National Collaborating Centre for Mental Health (NCCMH) is a series of four support interventions to help embed the Culture of Care standards across every provider of inpatient mental healthcare. One intervention is Quality Improvement (QI) support for wards.

At the heart of both the NHS England standards and the NCCMH programme is co-production and valuing lived experience. The culture change imagined relies on hearing and acting on the voices of people and families, and valuing experiential knowledge.

We recognise from the early sessions that many wards and organisations are in different places with co-production. Some with the knowledge, experience and resource to embark on their QI work in a meaningfully co-produced way. Others are very new to this way of working and don't have much existing infrastructure to support.

We hope this guidance offers some pointers and practical advice for wards and organisations who are committed to embracing co-production.

This guidance was developed by a collaboration of the people with lived experience in the delivery team at NCCMH, including colleagues from Black Thrive Global, Neurodiverse Connection and the Trauma Informed Care Collaborative at Camden and Islington NHS Foundation Trust. It was updated in May 2025, with four new chapters added, on working with people with a learning disability (Chapter 9) working with carers (Chapter 10), patient and carer survey responses (Chapter 15), and professional/clinical reflections on co-production (Chapter 17).

Contents

Chapter 1. Definitions: What do we mean by co-production and lived experience?

Co-production

Co-production is a collaborative process in which individuals with lived experience of a particular issue or service work together with service providers as equal partners. It's a relational approach in which professional knowledge and experiential knowledge are both held and valued.

This approach recognises that the most effective solutions often come from people who have directly experienced the challenges and understand the needs of the community.

However, co-production goes beyond simply incorporating lived experience; it aims to empower individuals with lived experience to take on leadership roles that recognise and value their special expertise, knowledge and advocacy skills. It enables individuals to actively participate in decision-making processes, shaping the direction of services.

Lived experience

We use 'lived experience' to mean people who have had life-changing lived experience of mental illness and of accessing mental health services. This could be as a patient, or as a carer or family member.

Within the Culture of Care programme, we focus on people with lived experience of using inpatient services, either directly as a patient or as a carer/family member. We're also focused on people with lived experience of using services who are autistic, who identify as having experienced or lived through trauma, and people who are from racialised minorities in line with the key equity principles.

We recognise that, for a lot of people, their lived experience is more accurately described as *living experience*, in that their struggles and challenges with mental health may be ongoing.

Lived experience brings the unique knowledge and understanding gained through personal experience, and plays a central role in co-production. It brings invaluable insights and perspectives that can inform and shape services, making them more relevant, responsive and effective.

The spectrum of participation

Co-production is often understood as the gold standard of participation, with power being shared equally and people with lived experience being involved from the very beginning. This is well represented by Think Local Act Personal's ladder of co-production, which shows the range of engagement that can happen with co-production at the top.

We suggest that participation is valuable across the whole spectrum (see *Figure 1*) and to co-produce well involves working with people across all levels. This may involve:

- co-producing individual care plans
- having community meetings on wards
- having lived experience leadership, right up to executive level
- having peer workers embedded within multidisciplinary teams
- having people with lived experience embedded in QI process and governance groups
- valuing all individual patient feedback
- valuing complaints.

The important message is, co-production isn't all or nothing, and we don't want perfect to be the enemy of good. All wards and organisations can take steps to strengthen their approach to co-production and make more space to really listen to and value the experiences of patients and families. In *Box 1*, we describe the benefits of co-production and of valuing lived experience.

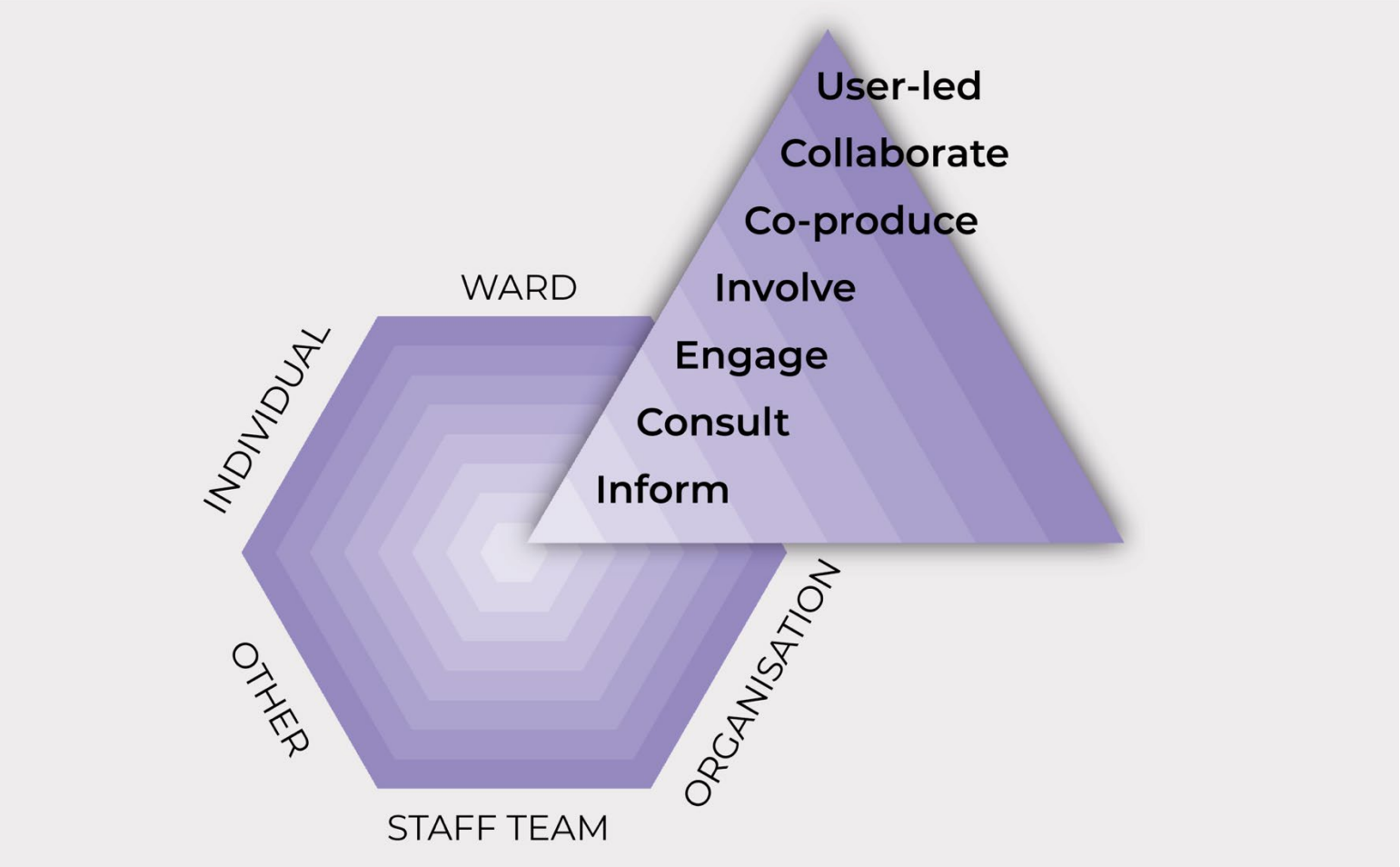

Figure 1: The spectrum of participation

Box 1: Benefits of co-production and valuing lived experience

- Brings about change in services
- Brings different knowledge and expertise
- Builds trusted relationships
- Challenges health inequalities
- Challenges stigma and discrimination
- Connects staff with their values
- Grounds discussions in reality
- Helps humanise healthcare
- Helps spot problems, provide early warning signs
- Improves patient experience
- Improves service outcomes
- Increases individual self-worth and confidence
- Prioritises person-centred perspective
- Reduces waste
- Right thing to do
- Saves money
- Supports individuals, both patients and staff to develop new skills
- Supports justice for harm caused
- Supports people to be heard and believed about their experiences
- Way of valuing people and families.

Chapter 2. Co-production in individual patient care

When we think of co-production and lived experience leadership, we often think about service design and delivery. But we must also remember that working in partnership with people in their individual care is an essential part of co-production.

Inpatient mental health wards serve as critical environments for the stabilisation, assessment and treatment of individuals experiencing acute mental health crises. To work effectively with people under their care, these wards must implement a holistic, patient-centred approach that fosters trust, respect, and active collaboration between staff and patients. Below are five key strategies to begin working effectively with patients in an inpatient setting:

1. Initial assessment and collaborative care planning

The first step in working with patients is conducting a *comprehensive and compassionate initial assessment*. This involves gathering detailed information about the patient's mental health history, current symptoms and any previous treatment. It's essential that this process is collaborative, engaging the patient in discussions about their experiences, preferences and goals for treatment. Patients should feel that their voices are heard and valued, which can enhance their sense of agency and willingness to participate in their care.

After the assessment, a *personalised care plan* should be developed in collaboration with the patient. This plan should outline treatment goals, therapeutic interventions and any specific needs the patient might have, such as cultural or spiritual considerations. Regular reviews and adjustments to the care plan are necessary to reflect the patient's progress and any changes in their condition.

2. Building therapeutic relationships

The foundation of effective care in inpatient mental health wards lies in *building strong, therapeutic relationships between patients and staff*. This requires staff to demonstrate empathy, active listening

and non-judgmental attitudes. Establishing trust can be challenging, especially for patients who may have experienced trauma or have a history of being harmed by healthcare. Therefore, consistency, transparency and reliability in staff–patient interactions are critical. We may also need to *pay attention to people who may need additional time to build trusted relationships*, such as autistic people and people from racialised minorities, who may have good reason not to trust the system.

Staff should also be trained in *trauma-informed care*, which recognises the impact of trauma on mental health and emphasises safety, choice and empowerment. By acknowledging the role of trauma and avoiding practices that could re-traumatise individuals, staff can create a safer, more supportive environment for healing.

3. Promoting patient autonomy and involvement

Promoting patient autonomy is essential in inpatient settings where individuals may feel a loss of control over their lives. *Involving patients in decision-making processes*, such as choosing therapeutic activities, setting daily routines and discussing medication options can help restore a sense of control and self-efficacy.

Staff should *encourage patients to express their preferences and concerns*, and these should be genuinely considered in care decisions. Providing opportunities for patients to engage in peer-support groups or recovery-oriented programmes can also empower them and promote a sense of community within the ward.

4. Holistic care approaches

Inpatient care should address not only the mental health needs of patients but also their *physical, social and spiritual wellbeing*. Integrating a range of therapeutic modalities, such as psychotherapy, occupational therapy and recreational activities, can support a more comprehensive recovery process. Patients should have access to exercise, healthy nutrition, and opportunities for relaxation and mindfulness.

Culturally sensitive care is also vital, ensuring that the diverse backgrounds of patients are respected and accommodated. This might include providing interpreters, offering culturally relevant therapy options, or recognising and supporting religious practices.

5. Continuous communication and feedback

Maintaining *open lines of communication between patients, their families and the healthcare team* is crucial for effective care. Regular meetings where patients can discuss their progress, express concerns and receive feedback are important. These discussions should be two-way, allowing patients to provide feedback on their care, which can be used to improve services.

Summary

In summary, working effectively with patients in inpatient mental health wards requires a patient-centred, holistic and collaborative approach. By focusing on building therapeutic relationships, promoting patient autonomy and addressing the full spectrum of patient needs, wards can create environments that support recovery and empower individuals on their journey toward mental health and wellbeing.

Chapter 3. Co-production within Culture of Care improvement work

Getting started

This programme provides an opportunity to pause and reflect on how you already listen to and value patients and families. This can be through formal and informal ways.

- What are you already doing within your ward environment that creates space for patients and their families to be listened to and heard?
    - How is that knowledge valued and influencing the care you provide?
- How might you strengthen what you're already doing or create capacity to build on it?

Things you may already have in place

Patient and carer feedback

- How might we hear from more people, particularly those who have had a negative experience?
- How can we make it safe for people to give honest feedback?
- How do we ensure the team hear and value the feedback, and that it's acted on?

Ward meetings with patients

- Where and when might we hold these to ensure all patients can access?
- How might we bring in an independent facilitator or peer facilitator?
- How do we hear and value and act on what is shared?

Complaints and compliments

- How do we encourage people to raise concerns without fear of reprisals for their care?
- How do we as a team hear complaints to learn without feeling defensive?

Use of advocates

- How might we support more people to have access to an advocate?
- How do we ensure that advocates are culturally competent, trauma-informed and autism-informed?

Connections to VCSE organisations

- Which voluntary, community and social enterprise (VCSE) organisations in our community are well placed to amplify patient and family voice?
- How might we strengthen our relationship with them?

Listening to what patient and families say informally

- What are the things that we know already, that patients always say? For example, that the doors are noisy or staff are always in the office.
- How do we start to address the feedback we already all know?

Good information for patients and families, including about Culture of Care

Box 2 shows an example of how one ward started their co-production journey, and the actions they took, which went on to inform their first change idea.

Box 2: getting started with co-production – an example to consider

Lark ward is a female acute ward with short lengths of stay and high acuity. The ward team thought the only way to authentically co-produce was to have someone on the project team.

However, the first two people they asked were quicky discharged, and the third didn't feel able to contribute as they were worried it would impact on their care.

But they noticed that lots of patients had things to say about the food, about the occupational therapy room and about the new Oxevision system.

They decided to set up a weekly community meeting for everyone on the ward. They held it in the activities room and provided good snacks. The meeting was held the day before the Culture of Care project team met. It was independently facilitated by an activity coordinator who wasn't based on the ward.

The first area of concern was that the food was served at 4.45pm and people were hungry again by 7.00pm. This informed the first change idea.

Deepening the work – progressing participation

Once you have embedded and strengthened the ways in which you already inform and hear from patients and families, this programme offers an opportunity to take steps to try something new with involving people with lived experience. This moves up the ladder of co-production from informing, consulting and engaging with, to more partnership working – really involving patients and families in the QI work and in embedding the standards.

Again, there is opportunity to pause and reflect on what exists already:

- Do you have a trust-wide involvement service?
- Do you have existing peer workers as part of your workforce?
- Are there user-led organisations in the community?

It's important, as you progress to more partnership working, to think through how to do that safely. What might people, patients and staff need to be able to contribute in a way that feels safe? It may feel daunting, and co-production may feel miles away, but how might you take one step towards amplifying lived experience?

Here are some ideas of what amplifying lived experience might look like:

- Acting on ideas from patient ward meetings, for example that the activities provided come from patient suggestions, and that food choices reflect the suggestions of patients.

- Co-develop a menu of different medication and therapy options available on the ward, to facilitate offering choice.
- Fully debriefing all incidents with patients and carers, and involving all parties in the next steps following incidents.
- Hiring peer workers to the multidisciplinary team, to support the delivery of compassionate care.
- Inviting patients and carers from a trust-wide involvement bank to be permanent project team members, and paying them for their time.
- Inviting patients and families to their formulation meeting from the beginning.
- Involving current patients and supporters in fortnightly project meetings to discuss the ward as a whole and what could be done differently over the next 2 weeks.
- Involving peer leaders in project team and valuing their insights and wisdom.
- Patients collaborating with staff on planning culturally appropriate/informed holidays celebrations and activities.
- Using the Patient and Carer Race Equality Framework (PCREF; see also Chapter 6) to ensure transparency and collaboration that is culturally conscious.

Box 3 shows an example of how one ward started their co-production journey and the actions they took, which went on to inform their first change idea.

Box 3: progressing participation – An example to consider

Swallow ward is a mixed PICU (psychiatric intensive care unit). Due to the acuity on the ward, they worried about how to embed participation in their QI work. They recognised that they were doing well at really listening to patient feedback, as the ward manager shared all qualitative comments at the start of team meetings and they endeavoured to act on them.

At the start of the Culture of Care work, they contacted the trust involvement team and recruited two patients and one carer, all with lived experience of a PICU (psychiatric intensive care unit) service, to join the project team.

The colleagues with lived experience attend all project meetings, review all change ideas and take a lead on reviewing patient feedback. They are paid for their time, including preparatory work, in line with the trust involvement policy (£150 per day). The psychologist on the project team is their lead contact and provides a weekly pre-meet and debrief. They are also offered a reflective space by the trust's involvement team.

Facilitating lived experience leadership and co-production

We know there are many trusts that are making great progress with co-production and lived experience leadership, and that value the standards and this programme as an opportunity to really push what is possible.

Within this part of the spectrum, we can really consider power:

- How is lived experience knowledge embraced and reflected in policy and practise?
- How is the peer workforce held up and their wisdom amplified?
- How do we create and support roles that reflect the ambition in co-production for things to be *equal*?

- Is there the ambition and appetite to have a ward-level lived experience lead, an executive-level patient lead, and for peer workers to be on every team?
- If your workforce is 500 staff, what is the ambition for lived experience roles?
- There may be people in the team who have a lot of fear or anxiety about co-production and lived experience roles. How might you hold space to talk about this without fear of being judged?
    - Transforming the way we work to value experiential knowledge is a significant change, it's okay to recognise that this will be hard.
- How are lived experience leaders linked to broader communities of patients and families?
- How do we ensure the leadership roles don't become co-opted, and that they remain able to challenge and bring that lived experience lens?

Here are some ideas of what lived experience leaders and power might look like:

- Commitment for all staff to be trained by people with lived experience in the equity principles.
- Freedom to speak up guardian for patients.
- Grow and expand peer workforce, considering recruitment, training, support and supervision.
- Patients and families able to feedback directly to commissioner.
- Patients developing advanced directives for their care with care coordinator in the community.
- Peer workers lead the ward meeting, and act as conduit between ward meeting and project team.
- Peer/lived experience leadership role co-leading the QI ward level work?
- People with lived experience to review complaints and feedback and develop recommendations.
- User-led VCSE organisation invited to join the project team.
- Using NHS England funding to employ a band 7 lived-experience lead role for Culture of Care.

Box 4 shows an example of how one brought lived experience leadership into their ward.

Box 4: lived experience leadership – An example to consider

Birch ward were excited to see lived experience as a standard in the Culture of Care as they have been working towards this for a while. They have a well-established daily community meeting facilitated by peers. They have two band 4 peer support workers, professionally supervised by a band 7 peer lead, and they are part of a broader peer-led structure that provides robust lived experience-led support and training.

The ward have worked hard to increase feedback, using anonymous online surveys, and having assistant psychologists collect qualitative feedback post-admission, as well as using voice diaries to gather people's experience. Feedback and the resulting actions are displayed on the ward. They have a contract with a local user-led organisation that provides culturally competent advocacy. They have noticed changes in the culture because of this work.

They have decided to spend the NHS England money on a lived experience lead for inpatient care. This person will work in partnership with the matron to strengthen the governance and quality assurance of these services.

Chapter 4. Impact of power – what must we consider?

Many patients will have experienced powerlessness in their lives.

We know the prevalence of trauma and adversity in inpatients is high. People may have experienced powerlessness when they have faced interpersonal violence and abuse, and many through experiences of oppression. Powerlessness can be heightened for people whose identities span multiple intersects, and for people who face multiple disadvantages and/or are discriminated against in multiple social and political ways.

The experience of powerlessness may also be compounded by mental health challenges and the impact mental illness may have had on people's lives. For example, many people have experience of losing jobs, safe housing, relationships and loss of prospects or hope. This can compound the sense of powerlessness.

This, of course, may all also be true for many staff working within services. Then, for example, staff may connect with the experiences of trauma, racism or poverty.

It's important to consider the impact of power when thinking about co-production. People who have used services may have been subject to detention, to forced medication, to being labelled and to being described in their notes. They may have experienced powerlessness at the hands of the system. Whereas professionals (whatever their personal circumstances) are part of the system that has had power over people.

For people who have been under mental health services for a long time, that sense of powerlessness can become deeply ingrained and embodied.

For co-production to be meaningful and safe, we must pay attention to power and the impact it has:

- How can we acknowledge power disparities within a room?

- How do we work to mitigate against power disparities and amplify lived experience perspectives?
- How might we inadvertently disrespect lived experience? For example, by responding to it as though it's just anecdotal.
- What language do we use that might exclude people?
- Where and when do we hold meetings so they feel safe for everyone?
- Who is holding the pen?
- Who isn't even invited to the table?
- Whose knowledge is most respected or holds the greatest weight?

Chapter 5. Diversity of voice – how do we hear from people who have been impacted the most?

Diversity of voice is the inclusion of the perspectives, opinions, thoughts and influence of people from a range of backgrounds and experiences.

Co-production naturally introduces diversity of voice into service design and delivery, because it embraces service-user views in spaces that are typically led by clinicians and professionals.

However, it's important to ensure that co-production spaces are diverse, and involve people with lived experience from different backgrounds and experiences.

It's helpful to think about the nine protected characteristics (protected under the Equality Act 2010) when considering diversity of voice. Is there good representation of different ages, ethnicities, sexualities, gender identities, religions and so on?

Diversity of voice is important in co-production as it allows organisations to reflect on their services from the perspectives of different groups and individuals, to ensure all communities' needs are being adequately met. Services may be meeting the needs of one social group well while inadvertently harming another.

These gaps and harms can't be identified unless a range of different voices from different communities are involved in co-production.

While individuals can't represent entire communities, having diversity of voice in co-production spaces allows organisations to start considering services from different social and cultural perspectives. Sometimes, lived experience leaders can act as a bridge between services and wider communities.

Diversity of voice also means including perspectives that may be challenging to hear. True co-production is involving diverse individuals with lived experience to share their honest thoughts and

opinions – not ‘cherry picking’ the thoughts and opinions of people that align with what services already believe or want to hear.

Diversity of voice challenges ideas of ‘difficult’ patients and carers who are unhappy with the way services are being delivered.

Diversity of voice leads to innovation and creativity in service design, because different people with different experiences and backgrounds share their thoughts and ideas.

Here are some questions about diversity of voice to think about:

- Who are the communities of people who are over- or under-represented on your ward?
    - Which groups of people have poorer outcomes or experience?
    - What does the data tell you?
    - Is this the same or difference for other/less acute services in your area?
- Are there existing initiatives in your provider that could support you to think about diversity?
- Are there local community groups or VCSE organisations already working well with marginalised communities that might be able to help?

Chapter 6. Working with people from racialised communities

The concept of co-production is increasingly promoted as a strategy to enhance engagement and participation with racialised communities. In particular, this is done by involving patients and service users directly in addressing inequities within mental health care.

Historically rooted in civil rights and social care movements in the United States, co-production embodies a collaborative approach to service delivery that moves beyond traditional models of consultation. In England, this approach aims not only to improve services for individuals but also to address broader social systems and determinants of health.

Central to the concept of co-production are its foundations in anti-racism practices, fostering an inclusive process that challenges existing power dynamics and actively seeks to dismantle systemic barriers faced by racialised communities. This approach emphasises the co-creation of services that are more equitable, responsive and culturally competent.

However, the success of co-production efforts is often compromised by power dynamics, systemic racism and histories of oppression. For marginalised groups, especially Black and Brown people, interactions with mental health services often involve racial trauma and experiences of institutional racism. This is partly due to longstanding patterns of violence and the prevalence of involuntary treatment.

While partnerships with community-based organisations and other stakeholders have been initiated to build trust and address power asymmetries, many co-production initiatives still heavily rely on mainstream knowledge systems. In co-production efforts with racialised communities, mainstream knowledge systems refer to dominant forms of knowledge, practices and frameworks that often come from institutions shaped by Western, Eurocentric and professionalised perspectives. These systems typically marginalise and/or overlook the lived experiences of racialised groups, and the institutional racism towards and knowledge about them.

This reliance often reinforces existing power dynamics and perpetuates systemic racism, rather than challenging it. Critiques of co-production have highlighted the limited tangible outcomes achieved and the persistent silencing of marginalised voices, which continues to undermine effective engagement and contribute to frustration among racialised communities. Despite ongoing efforts to involve service users and communities, co-production processes often feel tokenistic, failing to fully address the complex needs and concerns of racialised and marginalised groups.

To overcome these limitations, there is a growing emphasis on adopting more participatory approaches, which focus on addressing structural racism. One example is the PCREF, which seeks to create more meaningful engagement with racialised communities by embedding racial equity into mental health service delivery and addressing institutional racism. These approaches aim to shift from tokenistic involvement towards genuinely collaborative models that transform both services and the wider systems that shape health outcomes for marginalised populations.

The Patient and Carer Race Equality Framework (PCREF)

The PCREF has been instrumental in advancing co-production and embedding race equity in systems change. The PCREF aims to empower mental healthcare providers and communities to systematically identify change methods and collaborate inclusively, improving mental health care, experiences and pathways for racialised communities.

Under the PCREF, co-production is defined as a process whereby ethnically and culturally diverse patients and carers are treated as equal partners in decision-making for their care and treatment plans, as well as actively participating in the design, development and review of care pathways for all age groups.

To be rated as outstanding for co-production, according to the PCREF:

- Racialised and ethnically/culturally diverse patients, carers and families:
    - are *fully integrated within the* governance structure of the trusts
    - are co-evaluating care pathways
    - are participating in assessing the impact of systemic racism across all mental health services.

- *Empowerment mechanisms* (such as peer advocacy and community support) enable racialised and culturally diverse patients and carers to have a meaningful voice in co-produced care and treatment plans.

Examples of good practice include the Race Equity Community Leader post in Sheffield Health and Social Care NHS Foundation Trust, which is hosted by a local community organisation and reports into the Trust's governance. South London and Maudsley NHS Foundation Trust also adopts a triple-leadership governance model that supports PCREF development and promotes power-sharing and accountability.

Examples of positive practice: Peer Support and Advocacy

Box 5: Culturally Appropriate Peer Support and Advocacy (CAPSA)

CAPSA is a culturally grounded peer support and advocacy service, designed by and for people from Black African and Caribbean backgrounds. The service was funded by the Living Well Network Alliance and led by Black Thrive Lambeth who co-designed the service with Black people with lived expertise of mental health services, healthcare professionals and the VCSE sector.

The service delivers one-to-one and group-based peer support and advocacy, in community and inpatient settings. Most of the team have lived experience of using or working within mental health services, or acting as carers. They support local people in community settings to access mental health services early. They help people who are in contact with services to navigate the mental health system, so their needs are met. Once a service user leaves hospital, they also support them to connect with the local community (including accessing employment, benefits, and day-to-day living) and bridge the gap between the communities and services, to ensure that the person and their culture are integrated into their own care.

The service intentionally addresses service-user experience of anti-Black racism and takes a systems approach to reducing barriers for Black communities. The team gathers data from service users, and intelligence through their work with communities and the VCSE sector. They use this data to work with the senior leadership team at the Living Well Network Alliance to find solutions.

Box 6: Gaddum

Gaddum deliver culturally appropriate advocacy in partnership with African and Caribbean Mental Health Services in Manchester. Culturally appropriate advocacy is advocacy that meets the cultural needs of the individual and addresses racism. Outcomes from Phase 1 include that 54–83% partners reported feeling they have more say in their care and treatment under the Mental Health Act 1983. Of partners, 56–70% reported that working with a Gaddum advocate has met their cultural needs on the ward.

Examples of good practice: Community-based networks and funding

Establishing community-based networks as part of co-production efforts with racialised communities is essential for creating inclusive and equitable mental health services. These networks provide spaces for open discussions on institutional racism in mental health, giving communities a platform to voice their own experiences, challenges and needs. An example is the integration of independent advisory groups (IAGs) within the South London and Maudsley NHS Foundation Trust's PCREF governance structure. The IAGs consist of community representatives who collaborate with the Trust to ensure that the perspectives of racialised communities are central to decision-making processes, particularly around race equity in mental health services.

Funding is another crucial aspect of supporting effective co-production. Adequate financial resources allow for the development and sustainability of culturally appropriate services that meet the needs of racialised communities. An example of this is the Culturally Appropriate Mental Health Service Fund established in Greater Manchester, which provides financial support for community organisations to develop innovative, culturally appropriate mental health services. This fund fosters partnerships between mental health providers and local community organisations, enabling the co-design of services that resonate with the lived experiences and cultural backgrounds of service users and communities.

True co-production goes beyond tokenistic engagement; it involves dismantling systems of oppression and institutional racism, and creating space for the inclusion of culturally relevant, community-driven solutions. By empowering racialised communities through both networks and sustainable funding, co-production can challenge existing inequities and promote more just and effective mental health care.

Chapter 7. Working with autistic people

Autism is a lifelong neurodevelopmental difference, with autistic people experiencing differences in their sensory and social processing and communication. When working with autistic individuals, it's important to take these differences into account and support them by providing accommodations to the physical and social environment to meet their individual needs. Every autistic individual is unique and, while there are commonalities, each autistic individual will have their own preferences, strengths, challenges and sensory profile. Sensory and social needs may also fluctuate for a variety of reasons, including environment and physical wellbeing, so it's vital to allow time to understand each individual's needs and regularly review wellbeing and accessibility plans.

- Allow for and schedule time to meet with your autistic colleague well in advance of the first work session. The meeting should allow for a confidential conversation around needs and preferences.
- Check whether they would prefer to meet in person, online or by phone, and if they would like to split the discussion across several sessions to build rapport and fully consider their needs within your specific context.

Below are some prompts to discuss and examples to of accommodations to consider. This isn't exhaustive, but designed to prompt discussion.

Give clear information, in as much detail as possible, about tasks

Knowing exactly what is wanted and expected from us during meetings can help reduce anxiety, allows for additional preparation and processing time, creates predictability and in turn will improves autistic people's ability to participate.

- Before the meeting:
    - Share an agenda in advance, including any expected tasks
    - Share any questions you will ask

    - Make it clear who is attending and where the meeting will be held – you can do this in the meeting invite
    - If there are any changes to the meeting, communicate them as early as possible
    - Facilitate pre-meets, to discuss any concerns or questions
    - Provide visual aids for the venue/room and the people involved
- During the meeting:
    - Use name badges if there will be unfamiliar people in meetings
    - Take the time to introduce everyone and their role.

Consider the sensory environment of where any meetings are held

The environment can have a significant impact on autistic people's ability to engage in discussions.

- Aim to keep the temperature constant (not too hot or too cold)
- Offer a range of chairs
- Choose a room with minimal background noise, which may come from fans, doors being closed, other meetings and so on
- Minimise visual clutter
- Turn off any bright lights – aim to use a room with natural lighting
- If food is being served, consider doing this in a separate room to reduce food odours in the meeting room
- Use the same room each time you meet.

Encourage different forms of communication, acknowledging that this may change in different situations

- If online, make it clear that cameras don't have to be turned on during meetings
- If online, enable people to use the chat functions and encourage using the 'hands up'/'raise hand' feature during discussions

- Provide sticky notes in person, or private chat if online, so that autistic people can write down any thoughts or contributions they don't feel able to verbalise
- Check if people would like to be prompted to add to discussions or given the chance to add, or whether they would prefer to give feedback in another way
- Make it possible for people to add further thoughts after meetings have finished
- Allow ample time and opportunity for people to ask questions and get clarification
- Hold debriefs, to allow people to communicate one-to-one.

Be aware of any potentially triggering situations or conversations, and offer information in advance about these

Having a clearly defined support process ahead of time can help to ensure that autistic people who have experienced previous trauma are well supported both practically and emotionally.

- Allocate a person to be available to offer support should anyone need it
- Work with individuals to identify:
    - any specific triggers, and minimise them
    - 'warning signs' or signs of distress, and how you can help
- Be aware that emotionally challenging situations can be a trigger for meltdowns or shutdowns, and:
    - educate yourself on how best to respond to these
- Offer fidget toys and movement breaks, and:
    - be aware that autistic culture is different to neurotypical culture – not making eye contact or moving around a lot isn't a sign of disengagement
- Ensure regular breaks are offered, and:
    - ensure that a quiet space, away from others, is accessible during both meetings and break times
- Ensure there is access to a private room for decompression, if needed, and:
    - make it clear where the room is
- Provide debrief options to support those with delayed emotional processing

- Work with autistic people to continually improve the way they participate in co-production, and:
    - ask for feedback after meetings
    - act on any suggestions that will support their involvement.

Chapter 8. Working with people who have lived through trauma

Inpatient mental health wards can work effectively with people who have lived through trauma by adopting a trauma-informed approach that emphasises safety, trust, empowerment and collaboration.

Trauma-informed care requires staff to understand the pervasive impact of trauma on an individual's mental and emotional wellbeing, and to actively avoid practices that could re-traumatise or distress patients.

Safety is the foundation of trauma-informed care. This involves creating a physically and emotionally safe environment where patients feel secure. Staff should be trained to recognise triggers and signs of distress, and the ward environment should be calm, predictable and free from unnecessary stimuli that might provoke anxiety.

Trust and transparency are crucial in building therapeutic relationships with trauma survivors. Staff should be consistent in their interactions, clear in their communication and honest about treatment processes. This helps to establish a sense of predictability and reliability, which is particularly important for individuals who have experienced betrayal or abuse.

Empowerment and choice are central to trauma-informed co-production. Patients should be involved in their care planning and decision-making, ensuring they have a voice in their treatment. Good co-production respects the expertise of individuals with lived experience, valuing their input in shaping services and care approaches.

Collaboration between patients and staff should be a partnership, with patients viewed as active participants in their recovery. Effective trauma-informed co-production involves regular feedback loops, where patient experiences and insights directly influence care practices and policies, ensuring services are responsive, respectful and genuinely supportive of trauma survivors.

Chapter 9. Working with people with learning disabilities

Each person with learning disabilities is unique, with their own likes, dislikes, strengths, support needs and approach to life. Diversity among people with learning disabilities is as widespread as it is in the whole population.

What is a learning disability?

A learning disability is a lifelong disability that begins before the age of 18. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information or interact with other people. Some people with learning disabilities may have difficulty with everyday activities such as household tasks, socialising or managing money. Some people may need to be fully supported for their whole life (adapted from Mencap, About Learning Disability web page, 2019).

Learning disabilities or learning difficulties?

A learning disability isn't the same as a learning difficulty. A learning difficulty 'does not affect general intellect' (Mencap, Learning Difficulties web page), but presents as a particular difficulty in one area. For example, dyslexia is a learning difficulty not a learning disability.

People can have 'both a learning disability and a learning difficulty' (Mencap, Learning Difficulties web page): a person with a learning disability can also be autistic and have other neurodiversities.

Why co-produce with people with a learning disability and their families?

People with learning disabilities typically have poorer health and social outcomes than the general population, and often experience marginalisation within society. Sharing these experiences and those of their families can bring valuable insight and learning to an inpatient setting.

Working with people with learning disabilities and their families in co-production can provide enormous benefits to services, when it's done thoughtfully and not in a tokenistic way.

Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. Even when people leave home, they don't leave the family. Families continue to offer a lifetime of involvement, support and advocacy (HM Government, *Valuing People Now: A New Three-Year Strategy for people with learning disabilities;* 2009, 1.19).

Families typically know their loved one well, and have a great deal of understanding of their loved ones needs and how they communicate. For example, families can tell many things by the body language of their loved ones, such as whether they are happy or distressed.

Families have often spent years advocating for their loved ones and may have experienced trauma at the hands of systems and services, being sidelined, disbelieved or ignored. This trauma needs to be held in mind when working with families, and trust may need to be built before effective co-production can begin.

Points to consider when co-producing with people with learning disabilities and their families.

When considering co-production with people with a learning disability, it's important to involve people who:

- don't use words to communicate
- have a concrete understanding of the world
- have an experiential understanding of the world.

For some people, alternative forms of communication are needed, such as:

- Augmentative and Alternative Communication
- Intensive Interaction
- Signing

- Social Stories
- Talking Mats.

It's essential to:

- Consider the content of the information and its accessibility:
    - Does it contain complicated abstract language and information?
    - If it does, how can this be simplified?
- Avoid jargon and corporate language:
    - Words and concepts such as stakeholder, partners and co-production are complex, even though they are commonplace in parts of the NHS
    - It's important to be clear about what you're asking within a co-production activity.

It's easier to involve people with a mild or moderate learning disability in co-production than it is to involve people with a severe or profound learning disability. However, this isn't a reason to exclude people with the greatest support needs from co-production. If co-production activities are designed for people with the greatest support needs, they will be accessible to all. Far too often, co-production and involvement activities are differentiated from a mainstream activity and don't go far enough to include people with severe or profound learning disabilities, resulting in the loss of potentially valuable information and potential discrimination.

The Challenging Behaviour Foundation's What Matters to Me project demonstrates how the experiences, preferences and views of people with severe and profound learning disabilities and their families can be sought.

People with learning disabilities can and should be involved in decisions about their care. This may need some planning and preparation. Lack of time is never an acceptable reason for not doing it.

The guidance in Chapter 7: Working with autistic people is relevant for people with a learning disability when taken alongside the points made above.

Before the meeting

Give clear information with the right amount of detail about tasks:

- All information should be provided visually, to support understanding
- Provide visual aids that are person centred (for example, Easy Read and other visual supports)
- Share the agenda in advance, and consider an Easy Read or pictorial format
- Share the attendance list in advance with photographs if possible
- Use name badges with photographs if possible
- Share the questions in good time, to allow people to provide an answer in a way that's meaningful for them
- Be open to suggestions of new ways to seek a person's views
- Communicate about changes that are made to a meeting in good time. Family carers are often time-poor, with competing demands
- Think about alternative ways that the person can provide feedback, for example videos, voice memos or by being observed
- Have a pre-meeting, to run through the co-production activity.

After the meeting:

- Allow time for the person to process the experience and offer them support for any distress
- Allow the person to add further thoughts after the meeting has finished
- Hold a debrief, to ensure the most has been gained from the experience
- Be curious about the experiences people with a learning disability have on wards and as co-production partners.

The advice from Chapter 7. Working with autistic people, 'Be aware of potentially triggering situations or conversations', is relevant to people with a learning disability and their families.

A new toolkit, Co-production in Research, has recently been published by Warwick University. Written to support researchers to co-produce their research with family carers of people with a learning disability, the advice is relevant across many areas.

A note of caution:

- Co-production without following action risks objectifying the people who are giving their time and expertise
- All co-production should be carried out with knowledge of previous lived experience contributions (for example, points shared in previous meetings or events)
- The needs of people with learning disabilities have been very clearly stated in policy and papers including:
    - Valuing People 2001: A New Strategy for Learning Disability for the 21st Century (Department of Health, 2001)
    - Valuing People Now: Summary Report March 2009 - September 2010 (Department of Health, 2010)
    - Building the Right Support: A National Plan... (NHS England, Local Government Association and Directors of Adult Social Services, 2015)
- Scoping is of no value without accompanying action.

Chapter 10. Working with carers

Carers can be family members, parents, loved ones or members of someone's support network. We know that some people don't see themselves as a carer or identify with that term. When we refer to 'carers' in this chapter, it includes all family members, loved ones and people who are part of a patient's support network, however they identify.

Carers are often crucial in patients' mental health journeys. Good carer relationships are critical to mental health recovery, and research shows that carer support can lead to significant improvements in mental health.

Carers may be the people who first pick up on their loved ones becoming unwell, and they may then have to go through a difficult and potentially traumatic process of getting their loved ones admitted to an inpatient ward. It may be that the period just before admission is particularly difficult and stressful for a carer, while they try to support the safety of their loved one. Once their person is admitted, the carer may find themselves feeling disconnected or shut out.

> *'Carers of people with psychosis report high levels of stress, burnout and can experience social isolation, as well as physical and mental health problems. These difficulties can impede their ability to provide support, which may, in turn, impair the recovery of the person they care for.'*
>
> – Millard et al. Experiences of participation in an education and support group for carers of people with longer-term psychosis: a qualitative study. BMC Psychology

The experience of mental health carers is often institutionally undervalued. Despite carers often having significant expertise and understanding about the person they care for, they may sometimes be ignored or treated as a nuisance by ward staff. Even when carers aren't ignored, there may not be a culture of proactive engagement. For example, some carers may not be contacted promptly with updates about their loved one's care, or not invited to care planning or discharge meetings. The lack of communication with carers can negatively impact the quality of care planning and is often highlighted in serious incident reviews. It also increases the carer burden.

Sometimes lack of understanding around confidentiality becomes a barrier to supporting carer involvement.

It's important that carers have a central part in co-production, right through from supporting an individual patient's care to being involved in service design and delivery including carer peer support. The carer perspective should be threaded through all initiatives and shouldn't be treated as an afterthought.

Things to think about when working with carers:

- It's important to:
  - proactively reach out to carers
  - provide clear and accessible information about participation opportunities. (For example, within the Culture of Care QI work, there are opportunities to include carers in the project team).
- When staff do the following, carers will be more likely to engage in co-produced activities on the ward:
  - build relationships based on trust with carers
  - involve carers in decisions relating to their loved ones
  - invite carers to care planning meetings (with consent).
- Consideration of carers' needs and avoidance of acronyms and inaccessible jargon may increase carer engagement. Carers can be confused and intimidated by the language used of the ward. (For example, they may not know what 'restrictive practices' or 'Section 17 leave' are, and they are often not given a welcome pack or orientation to the ward).
- Carers often have a valuable insider/outsider perspective on wards.
  - Carers are insiders in the sense that they are intimately concerned with the care their loved ones receive, but at the same time they can look at the ward with the fresh eyes of someone who is outside the institutional mental health care system.
- When doing co-production, it's important to create safe spaces where carers feel comfortable sharing their thoughts and feelings.

- The toll of being a carer can impact their ability and inclination to engage. Carers may be physically and mentally exhausted by:
    - the difficulties of caring for a loved one who is deteriorating
    - the difficulties associated with them being admitted to an inpatient ward.
- Carers often have high demands on their time.
    - As well as looking after their loved ones they may have jobs or other commitments which can make it difficult to attend meetings on wards.
- Covering the costs of looking after a loved one while a carer is engaged in a co-production activity may increase carer engagement.
    - Combining co-production activities with 'me time' and offering refreshments may also make the offer more attractive and relevant to carers.
- Validating the experience of carers by making sure they feel heard and understood in co-production meetings may encourage them to continue with co-production activities.

Opportunities for carers to get involved with Culture of Care

- Completion of carer experience survey
- Carers to be part of QI project team
- Carers participation group to inform change ideas
- Development of carer peer roles under lived experience standard
- Change ideas that focus on carer support. For example:
    - a carer welcome pack
    - carer coffee mornings
    - setting up ward/hospital-based carer support groups
    - signposting carers to support
    - ward staff routinely asking carers about their welfare and offering support.

Chapter 11. Training and support for people with lived experience

Working with people across the spectrum of participation, from involving current patients in your project teams through to employing a patient director, requires significant thought about the support and training provided.

For many people, their lived experience is ongoing. They may face current challenges that need reasonable adjustments, so they can access work and be able to contribute fully and meaningfully. Being flexible and adaptive is a way to demonstrate how we value lived experience, but it can also be an approach that then benefits all staff.

Perhaps more significantly, lived experience work and involvement can be emotionally difficult, for many reasons.

It can be from reconnecting people with traumatic memories, it can be from interacting with a system that harmed you, it can be from facing micro aggressions and discriminatory attitudes, it can be from not being listened to or believed. It can replicate traumatic experiences of mental health care, and it can be difficult to try and contribute to change but not see it happen fast enough.

Support across the spectrum of participation might include:

- being transparent about the parameters of the work
- good, clear, accessible information about the work and what is being asked of the person, in plenty of time before a meeting or event
- lived experience contributors building relationships with a key member of the team
- lived experience supervision and reflection
- peer support with other lived experience contributors
- pre-meets and debriefs
- replicating wellbeing offer for all staff for people in lived experience roles
- support with administration and accessing information

- support with invoicing and claiming payments for the work.

A key element of co-production is valuing the knowledge that comes from experience. However, it may be helpful to offer training to people with lived experience to support their contributions.

Training can help develop people's confidence so they are able to contribute meaningfully, can help address power imbalances in terms of what knowledge is respected, and can connect people with to broader scholarship around lived experience. Much of the training may be delivered by people with lived experience.

Here are some examples of the sort of training that might be useful:

- Developing facilitation skills
- How to chair a meeting
- How to influence up
- Introduction to the Culture of Care standards and equity principles
- Models of peer support and peer approaches
- Open Dialogue
- Training on compassionate approaches to suicide and self-harm
- Training on history of service- user activism
- Training on human rights in mental health
- Training on the structure of the NHS and how services are commissioned
- Training on voice-hearing and unusual beliefs.

Safeguarding

It's possible that people will share current and/or past experiences of harm, including from on the ward. It may be beneficial to provide clear information about safeguarding processes as part of the 'contracting' or working agreement, and when setting out how information will be heard and responded to.

Disclosure and Barring Service checks

If a role involves working directly with children or vulnerable adults, the role is eligible for a Disclosure and Barring Service (DBS) check. We recommend using the Government DBS checker to determine whether a role requires a DBS check or not.

The requirements will be specific to each role; for example, checks on a peer worker in a clinical team on a ward will be very different to checks on a service-user involvement member who reviews policy documents from home.

Chapter 12. Payment for co-production work

People should be appropriately and fairly paid for lived experience work.

Payment for lived experience work should be aligned to the values of both the Culture of Care programme and wider patient involvement work. Payment should reflect the high value of lived experience involvement and represent equal involvement between experts with experience and experts by training. Additionally, payment needs to reflect the additional emotional burden of lived experience work.

While there is no national standard on lived experience payments, align with your local practice in your organisation or integrated care board. If creating new roles, they could be adapted from similar roles within the organisation – but consult with human resources colleagues around the job matching process to ensure the unique elements of lived experience are recognised within the job evaluation process.

Most organisations will have a policy on payment for sessional involvement work. The recommended rates for involvement with research within the NHS aren't sufficient to recognise the equal contribution and additional emotional burden of lived experience work.

While goodwill payments (covering only expenses, or payment with vouchers) are strongly discouraged, if lived experienced roles aren't on the payroll and are instead paid as sessional work it's important to discuss payment on an individual basis. Discussions should take into account preferences around pay schedules and any interaction with benefit payments.

The National Institute for Health and Care Research payment policy recognises that payment for the involvement may vary depending on the level of engagement. Level of engagement in Culture of Care may vary over the lifespan of the programme and projects, but meaningful lived experience involvement will be at the higher end of this scale. National Institute for Health and Care Research payment rates are set out as follows:

- £25 – for involvement in a task or activity requiring little or no preparation and which is equal to about 1 hour or less of activity. For example, participating in a focus group to provide feedback on a proposal, or reviewing a short guidance document.
- £75 – for involvement in a task or activity where preparation is required and is equal to about half a day's activity. For example, participating in a meeting to interview candidates who have applied to join a committee, participating in a focus group or delivering training.
- £150 – for involvement in all-day meetings or training.
- £300 – for involvement in all-day meetings that need substantial preparation. For example, chairing or co-chairing a meeting, delivering training or carrying out other discretionary work that requires additional responsibilities.

Chapter 13. Broader community and user-led organisation involvement

Across the spectrum of co-production there can be huge value in engaging with community and user-led organisations. The sector has a long history of advocating for patients and working collaboratively, and could be a great partner in moving towards realisation of the standards.

For people who have been harmed by healthcare, user-led or community organisations can feel safer to interact with. Such organisations can also act as a bridge to communities of people that are historically marginalised and/or underserved by the NHS.

Again, this could be an opportunity to pause and reflect.

- What user-led or community organisations do we have in our local area?
    - This might include providers of peer support, recovery colleges, crisis houses or advocacy services.
- How might we build better relationships with these organisations?
- How can we lean in to the wisdom and knowledge they have?

Box 7 shows an example of one lived-experience organisation that works with their community and with services.

Box 7: Red Balloons

Red Balloons is a lived experience organisation in Teesside that's committed to bringing about change. They run four lived experience forums in community buildings across different towns. They are well attended by 60+ local people with mental health experiences, and facilitated by people trained in peer approaches.

Specific services from Tees, Esk and Wear Valleys NHS Foundation Trust engage with Red Balloons, in order to hear from a broad range of patients and families and then provide feedback to them on the actions they have taken.

Chapter 14. Peer work

Peer support is when people with shared experiences connect and support each other. Peer support workers are people with lived experience who are employed and trained to deliver peer support. As peer support workers, we're the key to co-producing the delivery of services. We also support co-production of the design, governance and evaluation of services by bringing our own lived (or living) experiences and supporting other people's voices to be heard.

Developed as a user-led alternative to mainstream services, peer support is now a vital part of those services. To preserve what makes it unique and meaningful, it's essential that peer support worker roles are rooted in core peer support values. For example, peer role remits must not include control and restraint.

Established values frameworks offer valuable guidance, such as those from:

- NSUN (National Survivor User Network)
- Scottish Recovery Network
- Health Education England's Competence Framework for Mental Health Peer Support Workers.

Peer support values can also be co-produced internally, as seen in the Tees, Esk and Wear Valleys NHS Foundation Trust Peer Support Service.

Different models of peer support offer their own advantages. For instance, provider-employed peer support workers who are embedded in ward teams foster culture change by fully integrating lived experience expertise and peer support into the care that's delivered. Similarly, in-reach models led by specialised user-led VCSEs, such as those implemented by Black Thrive Lambeth's Culturally Appropriate Peer Support and Advocacy service can excel at meeting the needs of marginalised groups. Utilising both approaches while networking the peer support workers across the system can maximise the collective offer.

Using lived experience as a peer support worker in inpatient settings involves significant emotional labour. Providers should ensure there is an appropriate supportive framework around roles. Best

practice involves committing, for example, to providing peer support workers with dedicated peer leadership structures (including peer roles at leadership levels), and having well-prepared teams, peer support training, continuous development opportunities, peer support supervision and access to peer networks. Learning from peer leaders who have successfully established ward peer support workers is recommended.

Grounded in values of compassion, relational safety, inclusion and social justice, peer support workers are essential to implementing Culture of Care principles and standards. By providing a bespoke form of support and co-producing care delivery in real time, these roles can have a positive, transformative impact on ward team cultures and care practices.

Chapter 15. Patient and carer survey responses

Receiving and acting on feedback from all people and families being supported in inpatient wards is a key part of co-production. One way to routinely receive feedback is through patient and carer experience surveys.

Hearing and acting on patient experience will help our services to be more safe and compassionate. Survey responses help wards and organisations to know where to focus their efforts, and help them understand the impact of change ideas.

Things to consider when trying to increase patient and carer responses:

Ward staff confidence in talking to patients about the surveys:

- Do all staff in your ward team know and understand the surveys and feel confident to talk to patients about them?
- Do all staff have time to talk to people and, where required, support them to complete the surveys?
- Do staff see the surveys as a priority and their responsibility?
- Are staff nervous about negative responses?
- Might staff be drawn to sharing with more compliant patients?

Patients feel safe that completing surveys won't have negative consequences on care.

As a patient, it can feel unsafe and scary to give feedback while on an inpatient ward, especially if you're detained. It can be difficult to be desperate for help and so not want to say anything negative about the help you're offered, for fear of help being withheld.

People and families can worry that what they say will impact their care, and impact decisions about their treatment and length of stay.

This may be exacerbated for people from marginalised groups who, based on their own previous experiences and the broader historical context, have more reasons to distrust services (for example, people from racialised communities).

- How might patients be reassured about the surveys' purpose and their anonymity?
- What might help patients feel safe to give feedback?
- How might staff and services demonstrate trustworthiness and build trust with patients and families?

Accessibility

People may not have access to a mobile phone, adequate technology or Wi-Fi to use the QR code and complete the survey. Some people may find the QR code difficult; for example, if they are experiencing paranoia and hold any unusual beliefs, they may worry about the impact of using the QR code. Some people may not have the ability to leave the ward to post the survey. Leave is precious – posting a survey could be the last thing on the person's mind.

- How do we ensure the surveys are accessible to all patients on the ward?

General barriers to completion

People experiencing acute distress may find it difficult to be able to access and understand the surveys. It can also be extremely difficult to be motivated to complete a survey when, for example, you're feeling desperate or experiencing an unusual reality. The surveys may not be a priority for people.

People may feel 'surveyed out' and have already shared their experiences and not seen changes.

Some suggestions to support increasing the survey responses:

- Ensure that the patient and carer surveys are explained to patients and families so they understand what is happening with the data.
- Ensure a closed feedback loop. For example:

- How will people know what has happened to their responses?
- How does it link to changes that are happening on the ward?

Communicating the changes is part of changing the culture.

- Learn from wards that are doing well – understand what they are doing and share stories. Capture good practices and share them at Learning Network events.
  - Might the number of responses be a proxy measure for the culture on your ward?
- Are all staff aware of the patient feedback forms, including:
  - what they are
  - how to complete them, and
  - why they matter?

Do you have clear communication about who is responsible for what?

- Are staff encouraged to routinely share with patients the opportunity to complete surveys as part of induction and care planning meetings? Are the feedback surveys part of conversations from the beginning of an admission?
- Do you provide choices in how people complete experience surveys? For example:
  - hospital devices
  - paper copies
  - post box on ward
  - QR codes on walls
  - wallet sized cards
  - in bedrooms.
- Can peer workers/advocates/involvement members play a role in supporting people to complete? Do you offer staff who are independent from wards and/or have lived experience to help people feel they will be believed and not pathologised?
- Understand what different communities may need to feel safe to complete the surveys. Can there be a focused approach to support people who face multiple disadvantages to complete them?

- Are the ward team seeing and using the data and feedback that comes from patient and carer surveys? Seeing the feedback can help ward teams to understand why completing surveys is important.

Chapter 16. Considerations for senior leaders

To ensure co-production is meaningful in your organisation, experiential knowledge needs to be valued alongside learned experience. This requires leaders to challenge themselves at every layer of your organisation, in every aspect of how they operate and question whether the balance of power is equal.

Co-production, when done properly, will disrupt the status quo and won't always feel easy. But valuing experiential knowledge can play such a key role in driving culture change to benefit everyone.

Here are some examples of aspects to consider:

- How are *important decisions* made in your organisation? Does lived experience have an authentic seat at the table when decisions are made (for example, executives)? How would those making a decision know if people with lived experience have co-produced the recommendation?
- How do you *assess the quality* of your services?:
    - Do you rely solely on information reported by people with learned experience?
    - How much patient feedback do you hear?
- How is the patient feedback collected – through staff or lived experience workers?
- When things go wrong/the organisation is in business continuity, does lived experience and co-production disappear? Or is that the time you lean in and listen to patients more?
- Are your services co-delivered to people and families? Does every aspect of your service offer peer support?
- How is the operation of your services to patients co-led? Do you have lived experience leaders as part of your operational management structure, alongside operations, clinical and quality?
- How would your non-executive directors know how to interrogate the organisation for authentic co-production? Do they know what good looks like?
- Would the communities you serve recognise co-production with them as being common in your organisation? Do you know which communities don't access your services? How do you approach reaching them? Do you go to them, ask them how to build trust, invest in people from that community who can work with you to make your services meet their needs?

Box 8 provides practical suggestions on how to improve co-production and lived experience leadership in your service.

Box 8: Some practical suggestions for improving co-production and lived experience leadership

- Have lived experience directors in your executive and lived experience leaders on your board.
- Invest in a career structure for all lived experience workers, including lived experience-specific supervision and support.
- Work with your communities to understand what authentic co-production would look like for them.
- Embed lived experience in your quality oversight, assurance and improvement approach. Employ people with lived experience to work in those teams.
- Invest in lived experience feedback mechanisms designed by patients.
- Enable patients to report their own incidents.
- Invest in advocacy and ensure there is a feedback loop into your quality oversight. Invest in culturally competent advocacy and advocacy for marginalised groups.
- Given the challenges with recruitment, especially in inpatient wards, invest in significant peer support in your services. Free up clinical staff to do the things only they can do.
- Embed lived experience leaders as part of your operational structure. Give them true responsibility – for example, all incidents should be reviewed by the quality lead and the lived experience lead. Lived experience leaders should be involved in incident investigations, supporting teams who are struggling, improving flow and working with partners.
- Don't hire professionals with lived experience into lived-experience-specific roles. There is huge potential in supporting our staff in clinical and other roles who have lived experience to draw on their own experience in a way that feels safe to them. But employing people who have had power over patients into a lived experience role misunderstands the criticality of the lived experience voice.
- Lived experience leaders and staff should offer reflective supervision to the chair and non-executive directors, and set our key questions to ask in the board.

Chapter 17. Professional reflections on co-production

This guidance has mainly been developed and written by people with lived experience. However, we mustn't lose sight of the relationships and togetherness that underpin successful co-production. We have therefore included the following reflections on co-production from a professional perspective.

Anna Burhouse, Leadership Coach

During my career, I have embraced any opportunity to work alongside people with lived experience to undertake Quality Improvement work. Co-production has directly contributed to the successful outcomes of the programmes, because the strong voice of lived experience has ensured that we think more creatively about the underlying issues. The voice of lived experience has also made us better able to identify and implement novel solutions to complex or thorny problems. We often take longer in the initial 'discovery' phase of the work, to deeply understand the problems we are all committed to trying to improve. But, the powerful insights gained then help us to accelerate implementation and reduce waste, because the improvement ideas are more likely to be effective.

Working together, we pay close attention to the importance of building trusting and respectful relationships, trying to build a shared space where everyone feels their voice is heard and their improvement ideas are valued. There is always deep personal learning about how each group attempts to share power, challenge normative group processes, understand past trauma or current inequities, and be open to challenging unconscious assumptions and biases. When this is done well, the co-production process can be a really enriching learning experience for everyone involved, and I have witnessed it change people's lives and careers.

The constant challenge in the current national context is how to 'prove' to people who have never worked in this way before that co-production 'works', and to secure adequate financial and emotional

investment in the process. The other national challenge is the variation in the quality of work because it's all too easy to label a programme as 'co-produced' when, in reality, a very superficial consultation approach has been used. Hopefully, as the evidence base grows and we actively recruit more leaders with lived experience, and share our collective learning about how to do this well, high-quality co-production will become the norm.

Caitlin Cockroft, Quality Improvement Coach

I've worked alongside people in lived and living experience roles in the mental health space for the past 3 years, and it has been professionally game-changing and ultimately, life-changing. It has given me a lot of insight into how to show up differently in my work and my life. Some of these reflections are below.

Person first. I hold close that, even as professionals in jobs, we are not robots – we are humans with feelings. Those feelings are important to help us connect with others, and as signals that tell us something is going on in the outer world that needs to change. Experts by experience are asked to speak from this place regularly, which is vulnerable and courageous, and often brings connection. As experts by occupation or training rather than lived or living experience, this is not asked of us and sometimes even is viewed negatively. I think experts by experience turn this, rightly, on its head.

How can I show up more authentically in my job every day?

Perspective. When I'm stuck, don't know if I'm getting something right in how to move forward on a particular project, task or activity, or am certain I'm right (and, therefore, realise I probably need to reflect), taking it to a lived experience colleague invariably gives me a new and incredibly helpful perspective that I wouldn't necessarily have had from an expert by occupation colleague.

Do we have lived experience colleagues, current or past patients, or carers and family members we can turn to for a new perspective on something?

Grounding in purpose. Working alongside experts by experience grounds me in the meaning and purpose of the work we do. Every single time I've heard a story that comes from lived or living

experience, I'm reminded why I do what I do. In the Culture of Care Programme, watching other experts by occupation hear these stories at events or trainings, and seeing the same thing happen that I feel every time, is by far the most powerful learning and motivation for change in this work.

Where can we ask for people with lived and living experience to share their experiences, while ensuring wraparound support is in place for them, to help our colleagues remember why we do what we do?

Simple, but not always easy. Wards are full-on. Staff are busy. Capacity is limited. Understanding of lived experience involvement is varied. It can feel overwhelming. It doesn't have to be if we start where we are, take small steps, and reflect often, with people with lived and living experience.

What do we do already to involve people in their care? How can we do that in the wider service design, delivery and evaluation even if on a small scale?

Ask first. Every time I think of planning something or doing something, based on assumptions about what people with lived experience will want, and think, I'll just plan or do it and then ask a lived experience colleague, I remind myself that a) it's not best practice and b) it will inevitably take more time and effort.

Just go ask! It will save you time and energy in the long run, it'll get you into a good practice of reflecting with people who really get what the solution to the problem can be, and it will absolutely help you with your plan and iron out challenges beforehand.

Kate Lorrimer, Expert Advisor – Relational Care, North East London Foundation Trust

NHS England's Culture of Care Standards were co-produced from start to finish. To champion and model the culture of care we were setting out, it was fundamental to the development of the Standards that lived experience was central to every element of the process. This co-production, integrated at every level, included:

- A senior lived experience project manager role within the Culture of Care project team that led the development of the Standards.
- System-wide scoping groups with a diverse range of people with lived experience, clinicians, academics and operational leaders with expertise in mental health inpatient services.
- Scoping groups for people with lived experience only, to provide additional space and opportunity for voices to be heard safely and openly, acknowledging potential fear of power imbalances.
- Visits by people with lived experience, to inpatient services, to engage people using inpatient services with both scoping and ongoing development of the Standards. Including specific focus groups with often under-represented people.
- A large system-wide design group comprised of a diverse range of people with lived experience, clinicians, academics and operational leaders with expertise in mental health inpatient services. This design group met in person three times over the course of the development and were included in every iteration of the document, throughout.
- A core writing team of eight to nine people, five of whom were experts by experience.
- Wider system engagement with a much larger group of key stakeholders, including lived experience-led organisations/groups, before finalising the draft.
- Sign-off of the final document by NHS England governance groups that included people with lived experience.

The benefits of this approach were far-reaching and felt at every level of the system responsible for developing the work. Subsequently, the benefits were felt in the wider system that the Standards apply to, in terms of the now nationally delivered Culture of Care Programme that is co-led by people with lived experience. The Culture of Care Standards have been recognised as ambitious, innovative and distinct, in the way they centre the voices, perspectives and experiences of people who use, and in many cases have been harmed by, services. At the same time, the Standards acknowledge the pressures and challenges inherent to mental health inpatient settings and staff experience.

This balance was achieved through not shying away from genuine and challenging conversations. In these conversations, the voices of people and families who have used services, and those of professionals who work across the system, were all given equal value. The tension that could sometimes

occur between the two was openly explored. Further to this was the principle of equity. In this, it was acknowledged and accepted that to achieve something different from before (in terms of system reform that has any chance of addressing the complex and nuanced dynamics that underpin the very culture of mental health services), we in some part also had to give primacy to or amplify the voices of those that have direct and life-changing experience of it, and who have previously been silenced or unheard.

This process was a personal career highlight. It was at times painful, and required an ability to recognise and own our individual part as professionals for at times, over our careers, possibly perpetuating, or at best being ignorant to, the harms caused to so many. But overriding that pain, was the enormous privilege of bearing witness to the experiences of those who have experienced those harms, to truly hearing those experiences and seeing the extraordinary bravery it takes to place oneself in the position of reliving those harms to try to change the system and outcomes for others. Being even a small part of that collective effort has been some of the most meaningful work I have ever been involved in.

Chapter 18. Our offer of support to promote co-production across the programme

Leadership coaching for executive-level colleagues

Lived experience advisors employed by Black Thrive Global and Neurodiverse Connection will co-facilitate coaching conversations with executive-level colleagues from each provider alongside our leadership coaches.

Lived experience learning network

We have launched a lived experience learning network aimed at all patients, carers, involvement members, peer workers and lived experience leads who are working as part of the programme.

The network will meet quarterly, and provides space for:

- Formal training and development
- Sharing of good practice across organisations
- Peer support for lived experience work
- Sharing challenges and overcoming barriers to change.

Lived experience input into all programme events

We aim that all our events will have lived experience input and some will have a focus on co-production and lived experience.

Support intervention for teams that are struggling

If we know a ward or organisation is struggling with co-production, we will offer:

- Co-production training for the project team
- Reflective space for project team led by lived experience members of the delivery team.

As they progress to change ideas, this will include training and support for embedding peer support.

Support for QI coaches

Support for QI coaches includes:

- A session on co-production prior to their first visit
- Formal training on co-production, lived experience and peer support
- Monthly reflective supervision, to think about co-production and the lived experience element.

Sharing online resources

- Our website will include information and resources to support co-production and lived experience leadership, including videos.

Recruit five patient and carer national advisors

- These national advisors will be two patients, two carers and one member of the NCCMH Equality Advisory Group, to provide lived experience input alongside our delivery partners.

Lived experience governance group

- As part of the governance of the programme, this group will be a 'check and challenge' and assurance space. It will be made up of members of the NCCMH Equality Advisory Group, user-led organisations, VCSE organisations and people in lived experience roles in providers not involved in the work.

Safety delivery group

- To ensure that the risk/safety intervention is co-produced, we're setting up a monthly safety delivery group with the National Confidential Inquiry into Suicide and Safety in Mental Health.

Ensuring patient experience is central to the measurement strategy

- We have developed a patient experience measure that reflects the standards, which is under review by lived experience groups at Norfolk and Suffolk NHS Foundation Trust.

Abbreviations

CAPSA	Culturally Appropriate Peer Support and Advocacy
DBS	Disclosure and Barring Service
IAG	Independent advisory group
NCCMH	National Collaborating Centre for Mental Health
PCREF	Patient and Carer Race Equality Framework
QI	Quality improvement
VCSE	Voluntary, community and social enterprise

Developers

Black Thrive Global, London

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Neurodiverse Connection, London

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