

Supporting co-production and lived experience leadership: **Summary sheets**

Introduction

This collection of summary sheets outlines the key takeaways from our guidance for wards. These sheets include important information for people with lived experience, which can be used to learn more about co-production. Each sheet is presented as questions from people with lived experience and their loved ones, then the answers are summarised from the guidance for wards. The information is about co-production in relation to:

- patient care ([Section 1](#), summarised from Chapter 2 in the guidance)
- Culture of Care work ([Section 2](#), summarised from Chapter 3)
- lived experience leadership ([Section 3](#), also summarised from Chapter 3)
- the impact of power ([Section 4](#), summarised from Chapter 4)
- diversity of voices ([Section 5](#), summarised from Chapter 5)
- working with:
 - ▶ people from racialised communities ([Section 6](#), summarised from Chapter 6)
 - ▶ autistic people ([Section 7](#), summarised from Chapter 7)
 - ▶ people who have experienced trauma ([Section 8](#), summarised from Chapter 8)
 - ▶ people with a learning disability ([Section 9](#), summarised from Chapter 9)
- training and support for people with lived experience ([Section 10](#), summarised from Chapter 11)
- payment for work ([Section 11](#), summarised from Chapter 12).

If you would like more information, including all the practical advice for wards and organisations who are committed to embracing co-production, please see our full guidance document:



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

Definitions of key terms

Co-production is a collaborative process in which individuals with lived experience of a particular mental health challenge 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.

Lived experience* means people who have had life-changing lived experience of mental illness and of accessing mental health services. This could be as a patient, a carer or a family member.

* We recognise that, for many people, their lived experience is more accurately described as **living experience** because their challenges with mental health may be ongoing.

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1. Co-production in patient care



Discuss experiences, preferences and goals for treatment. Staff should involve you or your loved one in creating and reviewing a personalised care plan. This care plan should outline treatment goals, therapeutic interventions, and any specific needs (such as cultural or spiritual considerations). Staff should hear and value your (or your loved one's) voice and opinions.

Build therapeutic relationships with the staff. Staff should have empathy and non-judgmental attitudes, and they should listen to you (or your loved one). Staff should take the time needed to build trusted relationships with them.

Get involved in making decisions about your or your loved one's care. You can get involved in decisions such as choosing therapeutic activities, setting daily routines and discussing medication options. You can share your preferences with staff, as well as any concerns you have. Staff should then genuinely consider your preferences and concerns in care decisions.

Encourage holistic care approaches. You can ask for a range of therapeutic modalities, such as psychotherapy, occupational therapy and recreational activities. All patients should have access to exercise, healthy nutrition, and opportunities for relaxation and mindfulness. Also, patient care should be culturally sensitive, ensuring that the diverse backgrounds of patients are respected and accommodated for. This may include language interpreters, culturally relevant therapy options, or recognising and supporting religious practices.

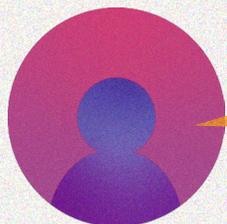
Encourage good communication from staff, and give feedback. Let staff how you or your loved one would like to discuss information, and how often. Also, if you have any feedback about the service, you can provide it – this can help to improve services.

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2. Co-production in Culture of Care work



How can I get involved in co-producing the improvement work a service is doing on the Culture of Care programme?

You can ask staff at the service how to get involved.

Across the wards involved in the Culture of Care work, we know that many involve patients and parents/carers in the following ways:

- Asking for feedback from patients and carers – and then acting on it.
- Reviewing complaints and compliments – and then acting on it.
- Listening to patient's and carers' thoughts and feedback when chatting informally.
- Ward meetings with patients.
- Using advocates.
- Connecting to voluntary, community and social enterprise organisations (VCSEs).
- Providing good information to patients and families about Culture of Care.

Here are some ideas for increasing lived experience involvement:

- Involving patients and carers in the ward's fortnightly Culture of Care project meetings, to discuss the ward and what could be done differently.
- Collaboration between patients, carers and staff to plan culturally appropriate/informed holiday celebrations and activities.
- Acting on ideas from patient ward meetings (for example, planning activities and providing food choices based on patient suggestions).
- Co-developing a menu of different medication and therapy options on the ward, to facilitate offering choice.
- Hiring peer workers.
- Inviting patients and carers from a trust-wide involvement bank to be permanent project team members, and paying them for their time.
- Fully debriefing all incidents with patients and carers, and involving all parties in the next steps following incidents.

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3. Co-production and lived experience leadership



You can ask staff at the service about their lived experience leadership.

Across the wards involved in the Culture of Care work, there are many trusts making great progress with co-production and lived experience leadership. Trusts value the Culture of Care programme and [Standards](#), seeing them as an opportunity to radically improve the care that is delivered.

Here are some ideas of what lived experience leadership could look like:

- Employing a band 7 lived experience lead for the Culture of Care programme, using NHS England funding.
- A peer or lived experience leadership role co-leading ward-level quality improvement work.
- Patients and families sharing their feedback directly with commissioners.
- Having a [Freedom To Speak Up Guardian](#) for patients.
- Peer support workers leading ward meetings, and linking between ward staff and the Culture of Care project team.
- Growing and expanding the peer workforce, considering recruitment, training, support and supervision.
- Making a commitment that all staff will be trained by people with lived experience in the equity principles (anti-racist, autism-informed and trauma-informed care).
- Inviting a user-led voluntary, community and social enterprise (VCSE) organisation to join the Culture of Care project team.
- Asking people with lived experience to review complaints and feedback, and then to develop recommendations for the ward based on the learning.
- Asking patients to develop advanced directives for their care with a care coordinator in the community.

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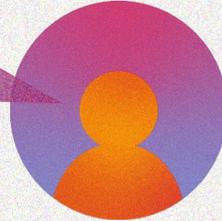
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4. The impact of power on co-production

I feel powerless, from trauma I have experienced and from being on mental health wards for some time.

How can co-production be made meaningful and safe for people who feel powerless?



It's important to us that we **pay attention to power and the impact it has on patients and carers** when thinking about co-production.

Many patients will have experienced powerlessness in their lives, and we know the prevalence of trauma and adversity in inpatients is high.

Powerlessness can be heightened for people with intersectional identities, and for people who face multiple disadvantages and/or are discriminated against in multiple social and political ways.

Feelings of powerlessness can also be compounded by mental health challenges and by the impact mental illness may have had on people's lives.

Therefore, **we ask all wards to consider the below questions, to help co-production feel meaningful and safe:**

- How can we acknowledge power disparities within a room?
- How do we work to mitigate against power disparities and amplify lived experience perspectives?
- Whose knowledge is most respected or holds the greatest weight?
- Who is responsible and makes decisions about the ward?
- Who is not even invited to the table? So, consider who is missing from the conversation: Have we invited all the relevant stakeholders, including people with lived experience?
- Where and when do we hold meetings, so they feel safe for everyone?
- What language do we use that might exclude people?
- How might we inadvertently disrespect lived experience? For example, by responding to it as though it's just anecdotal.

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5. Diversity of voices



Should services consider the diversity of the group they are co-producing their Culture of Care work with?

It's important that services make sure that co-production spaces are diverse, and involve people with lived experience from different backgrounds and experiences.

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

Diversity of voices also allows organisations to ensure all communities' needs are adequately being met, by reflecting on the service from the perspectives of different groups and individuals. Services may be meeting the needs well of one group, 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.

Equality Act (2010) protected characteristics:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race (including colour, nationality, ethnic or national origins)
- Religion or belief (or lack of religious belief)
- Sexual orientation.

How can services ensure that they hear from people who have been impacted by the system the most?



Ensure that services hear people who have been impacted the most:

To do this, it's helpful to think about the nine characteristics protected under the Equality Act 2010 (shown on the right).

We would encourage each service to consider:

- Is there good representation of different ages, ethnicities, sexualities, gender identities, religions and so on?
- 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 show?
- Does your provider have any initiatives that could help you think about diversity?
- Are there local community groups or VCSE organisations that are working well with marginalised communities, and that might be able to help?

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6. Working with people from racialised communities



How can organisations enhance engagement and participation with racialised communities?

I'm worried that people from racialised communities might be underrepresented in lived experience roles.

Anti-racism practices are central to co-production. It should be an inclusive process that challenges existing power dynamics and actively seeks to dismantle systemic barriers faced by racialised communities. This approach supports the co-creation of services that are more responsive and culturally competent, addressing inequities within mental health care.

However, we do know that the success of co-production efforts is often compromised by power dynamics, systemic racism and histories of oppression. This is because for marginalised groups, especially Black and Brown people, interactions with mental health services often involve racial trauma and experiences of institutional racism.

To enhance engagement and participation with racialised communities, organisations should focus on addressing structural racism. One example is the [Patient and Carer Race Equality Framework \(PCREF\)](#), 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 services and the wider systems that shape health outcomes for marginalised population. To be rated as outstanding for co-production, according to the PCREF:

- Racialised and ethnically and culturally diverse patients and carers and their families are:
 - ▶ **fully integrated within the governance structure of the trusts**
 - ▶ **co-evaluating care pathways**
 - ▶ **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 positive practice are:

- peer support and advocacy
- community-based networks (these may provide spaces for open discussions on institutional racism in mental health)
- giving communities a platform to voice their own experiences, challenges and needs)
- funding.

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7. Working with autistic people



Hello, I'm autistic. How can organisations make sure co-production is done in a way that is autism-informed and supportive of my needs?

Inpatient mental health wards should adopt an autism-informed approach, adjusting the physical and social environment to accommodate your individual sensory, social processing and communication needs.

We know that each autistic person has different needs, and their sensory and social needs may fluctuate for a variety of reasons. Organisations should take the time to regularly check in with you about your needs. Here is some **guidance for organisations** on how to do this:

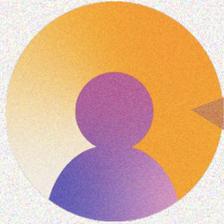
- 1. Give clear information, in as much detail as possible, about tasks.** Examples:
 - Share an agenda in advance, including any expected tasks
 - Make it clear who is attending and where the meeting will be held
 - If there are any changes to the meeting, communicate them as early as possible
 - Provide visual aids for the venue/ room and the people involved
 - Facilitate pre-meets, to discuss any concerns or questions.
- 2. Consider the sensory environment of where any meetings are held.** Examples:
 - Aim to use a room with natural lighting
 - Choose a room with minimal background noise
 - Offer a range of different chairs
 - Aim to keep the temperature constant (not too hot or too cold)
 - Use the same room for each meeting
 - If food is being served, consider doing this in a separate room (to reduce food odours in the meeting room).
- 3. Encourage different forms of communication.** Examples:
 - Provide sticky notes (or private chat if online)
 - Make it possible for people to add further thoughts after meetings have finished
 - Hold debriefs, to allow people to communicate one-to-one
 - If online, encourage using the 'hands up/'raise hand' feature during discussions
 - Make it clear that cameras don't have to be turned on during meetings.
- 4. Be aware of any potentially triggering situations or conversations, and offer information in advance about them.** Examples:
 - Ask for feedback after meetings and act on any suggestions that will support the person's involvement
 - Offer regular breaks
 - Offer fidget toys
 - Offer access to a private/quiet room for decompression if needed, and make it clear where the room is
 - Designate a person who will be available to offer support if anyone needs it
 - Educate yourselves on how best to respond to shutdowns and meltdowns.

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8. Working with people who have lived through trauma



Many patients with lived experience, including myself, have experienced trauma.

How can organisations ensure that co-production work is done in a way that's trauma-informed and doesn't cause more harm?

Inpatient mental health wards should adopt a trauma-informed approach that emphasises safety, trust, empowerment and collaboration. This is to actively avoid practices that could re-traumatise or distress patients who have experienced trauma.

We suggest this is achieved by ensuring there is:

- 1. Safety:** This 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. The ward should be calm, predictable and free from unnecessary stimuli that could cause anxiety.
- 2. Trust and transparency:** These 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 people who have experienced betrayal or abuse.
- 3. Empowerment and choice:** These 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 people with lived experience, valuing their input in improving services.
- 4. Collaboration:** Between patients and staff, there 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. This ensures that services are responsive, respectful and genuinely supportive of trauma survivors.

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9. Working with people with a learning disability

I have a learning disability. How might staff on the ward support my involvement in co-production?

I am a family member of someone with a learning disability. How might staff support my involvement in co-production on the ward?

Inpatient mental health wards should always support the individual sensory, social processing and communication needs of you and your family. For some people, alternative forms of communication are needed, such as:

- Augmentative and Alternative Communication
- Intensive Interaction
- Signing
- Social Stories
- Talking Mats.

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It's essential for inpatient mental health wards to:

1. 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?

2. Avoid using complex words:

- Reword or explain complex words, such as 'stakeholder', 'partners' and 'co-production'.
- Be clear about what the co-production activity involves and why.

3. 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).
- Share the attendance list of meetings in advance, with photographs if possible.
- Use name badges, with photographs if possible.
- Communicate about any changes made to a meeting in good time.
- Think about alternative ways that people can provide feedback; for example, videos, voice memos or by being observed.
- Have a pre-meeting, to run through the co-production activity.

4. Ensure people are supported after meetings and activities:

- Allow time for people to process the experience and offer them support for any distress.
- Allow people to add further thoughts after the meeting has finished.
- Hold a debrief with people involved in the meeting.

Also see Section 7 ([Working with Autistic People](#)), which is also relevant for people with a learning disability when taken alongside the points made in this section.

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10. Training and support for people with lived experience



A variety of training opportunities and support should be available to you.

This is very important, because many people's lived experience is ongoing. They may be facing challenges that mean they need reasonable adjustments to be made so they can access work, and be able to contribute fully and meaningfully. Perhaps more significantly, and for many reasons, lived experience work and involvement can be emotionally difficult.

Ask the organisation what support is available to you. It may include:

- Building relationships with a key member of the ward team.
- Clear, accessible information about:
 - ▶ the work and what is being asked of you, shared in plenty of time before a meeting or event
 - ▶ the ward's safeguarding processes.
- Pre-meets and debriefs around the meetings.
- Support with:
 - ▶ administration and accessing information
 - ▶ invoicing and claiming payments for the work.
- Supervision and reflective spaces.
- Peer support with other lived experience contributors.
- Access to the same wellbeing offer as staff.

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Ask the organisation what **training is available to you**. It may include:

- Introduction to the Culture of Care [standards](#) and equity principles (which are outlined [here, under Our Approaches](#)).
- Models of peer support and peer approaches.
- Human rights in mental health.
- How to influence people who are in positions of power/decision-makers.
- The structure of the NHS and how services are commissioned.
- How to chair a meeting.
- The Open Dialogue social model of mental health care.
- Compassionate approaches to suicide and self-harm.
- Facilitation skills.

A key part of co-production is valuing the knowledge that comes from your experiences. However, training can support your contributions and involvement in the work.

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11. Payment for co-production work



If I'm involved in co-production work, should I get paid for my time?

Yes. You should be paid fairly, according to the level of your involvement in the work.

Payment should reflect the high value of lived experience involvement, as well as the extra emotional burden of lived experience work.

The National Institute for Health and Care Research (NIHR) has a [payment policy including payment rates](#) for people with lived experience:

- £25 for involvement in a task or activity requiring **little or no preparation** that 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).
- £50 for involvement in a task or activity likely to require **some preparation** and which equates to **about 2 hours** of activity (for example, a videoconference meeting with related papers to read, or reviewing documents).
- £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 require **substantial preparation** (for example, chairing or co-chairing a meeting, delivering training or carrying out other discretionary work that requires extra responsibilities).

Payments covering expenses only or that are offered in vouchers are discouraged. However, if you are paid this way, it is important that the organisation discussed this with you individually. Discussions should take into account your preferences around pay schedules and any interaction with benefit payments.

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12. Community and user-led organisation involvement



Yes. Your lived experience voice is valid, regardless of being external to the organisations on the Culture of Care programme.

We know that there can be huge value in engaging with community and user-led organisations, such as peer support, recovery colleges, crisis houses or advocacy services.

The sector has a long history of advocating for patients and working collaboratively.

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.

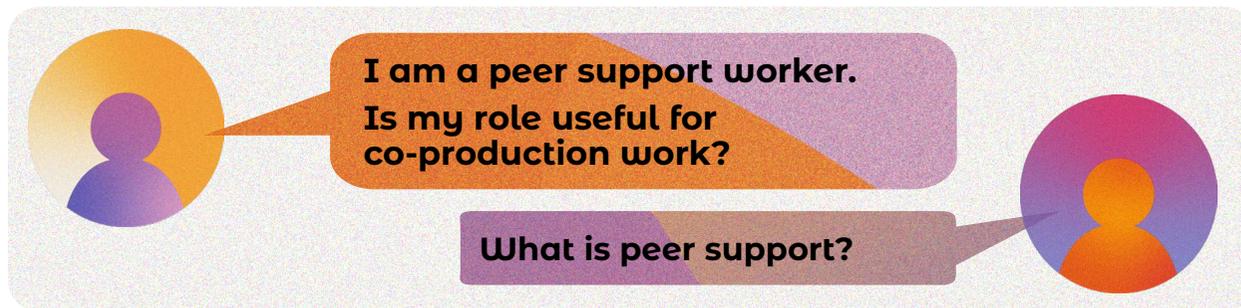
Fun fact: Certain services from Tees, Esk and Wear Valleys NHS Foundation Trust engage with Red Balloons (a lived experience organisation in Teesside), to hear from a broad range of patients and families, and then provide feedback to them on the actions they have taken.

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13. Peer work



Yes, your role is useful. Peer support workers can be key to co-producing the delivery of services.

This is because peer support workers are people with lived experience who are employed and trained to deliver peer support.

Peer support is when people with shared experiences connect and support each other.

Peer support workers also support the co-production of the design, governance and evaluation of services by bringing their own lived (and living) experiences and supporting other people's voices to be heard.

Peer support workers can become involved in co-production work in several ways. For example, they could be:

- provider-employed and embedded in ward teams. These peer support workers can foster culture change by fully integrating lived experience expertise and peer support into the care that is delivered.
- employed by specialised user-led VCSE organisations. These peer support workers can excel at meeting the needs of marginalised groups. For example, those implemented by Black Thrive Lambeth's [Culturally Appropriate Peer Support and Advocacy service](#).

Regardless, 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)
- having well-prepared teams
- peer support training
- continuing development opportunities
- peer support supervision
- access to peer networks.

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