Culture of Care

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

Guidance for wards

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 upon 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 quality improvement 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 document offers some pointers and practical advice for wards and organisations who are committed to embracing co-production.

This document 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.

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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 those 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 unique 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 are 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.

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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 the 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 and to co-produce well involves working with people across all levels. This may involve:

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

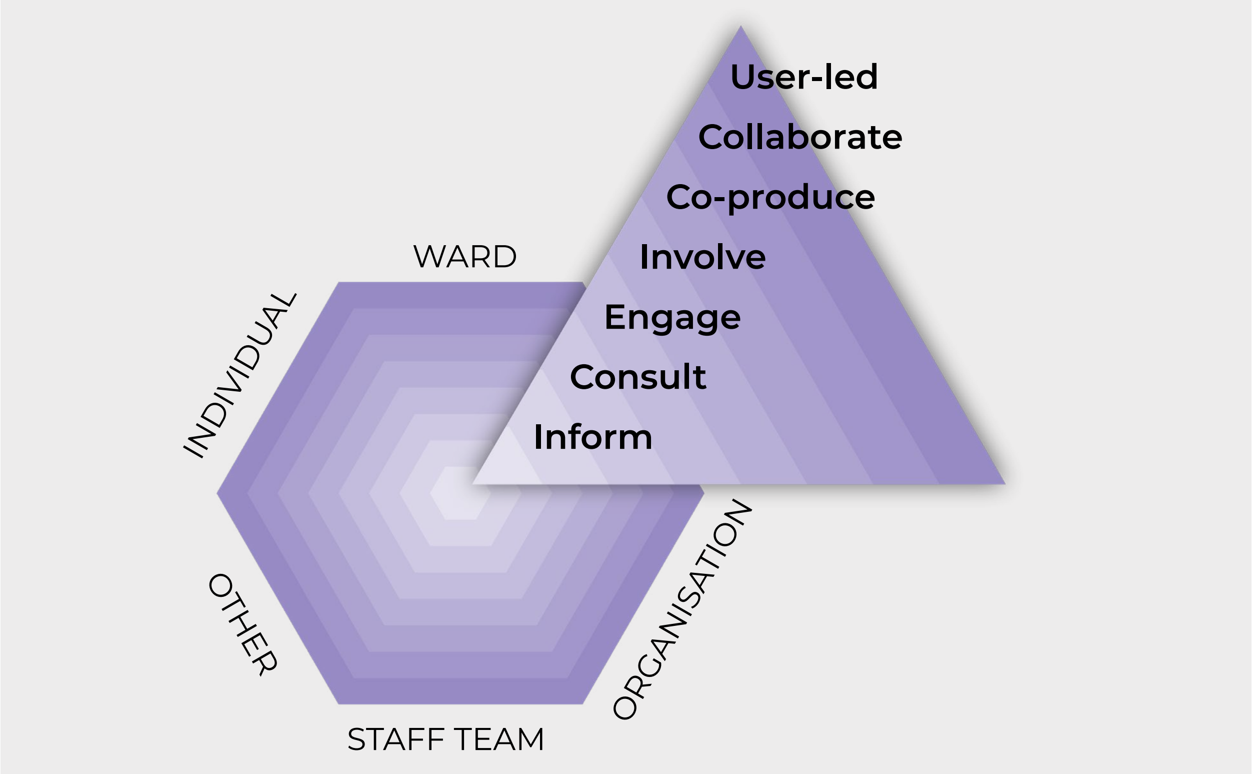

Figure 1. The Spectrum of Participation

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The important message is, co-production is not 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.

Benefits of co-production and valuing lived experience

- Bring about change in services
- Improve service outcomes
- Right thing to do
- Help humanise healthcare
- Reduce waste
- Improve patient experience
- Bring different knowledge and expertise
- Connect staff with their values
- Build trusted relationships
- Help spot problems, provide early warning signs
- Save money
- Challenge health inequalities
- Support people to be heard and believed about their experiences
- Support individuals, both patients and staff to develop new skills
- Challenge stigma and discrimination
- A way of valuing people and families
- Prioritise person-centred perspective
- Support justice for harm caused
- Ground discussions in reality
- Increase individual self-worth and confidence.

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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 not forget 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.

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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 well-being**. 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.

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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 well-being.

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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 are 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 is 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 upon 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?

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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

An example of getting started with coproduction 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.

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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 is 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:

- Using the Patient and Carer Race Equality Framework (PCREF; see also Chapter 6) to ensure transparency and collaboration that is culturally conscious.
- 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.
- Inviting patients and carers from a trust-wide involvement bank to be permanent project team members, and paying them for their time.
- Patients collaborating with staff on planning culturally appropriate/informed holidays celebrations and activities.
- Hiring peer workers to the multidisciplinary team, to support the delivery of compassionate care.
- Involving peer leaders in project team and valuing their insights and wisdom.
- 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.

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- Fully debriefing all incidents with patients and carers, and involving all parties in the next steps following incidents.
- Inviting patients and families to their formulation meeting from the beginning.

An example of progressing participation 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?

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- 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 is 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 roles don't become co-opted and 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:

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

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An example of lived experience leadership 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.

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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 is 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 (irrespective of 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.

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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?
- Whose knowledge is most respected or holds the greatest weight?
- Who is holding the pen?
- Who is not even invited to the table?
- 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 is just anecdotal.

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Chapter 5. Diversity of voice – how do we hear from those 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 is 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 cannot 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 currently 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.

Equality Act (2010) Protected Characteristics

- age
- gender reassignment
- being married or in a civil partnership
- being pregnant or on maternity leave
- disability
- race including colour, nationality, ethnic or national origin
- religion or belief
- sex
- sexual orientation

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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?

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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 frequently 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.

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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 and culturally diverse patients and carers and their families are **fully integrated within the governance structure** of the trusts and are **co-evaluating care pathways**. They are also 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.

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Examples of positive practice: Peer Support and Advocacy

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.

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.

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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.

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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 is 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 is 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. Do 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 is not 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.

- 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
- Provide visual aids for the venue/room and the people involved
- Facilitate pre-meets, to discuss any concerns or questions
- Use name badges if there will be unfamiliar people in meetings
- In the meeting, take the time to introduce everyone and their role.

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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.

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

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

- Provide sticky notes (or private chat if online), so that autistic people can write down any thoughts or contributions they do not 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
- Hold debriefs, to allow people to communicate on a one-to-one basis
- If online, enable people to use the chat functions and encourage using the 'hands up'/'raise hand' feature during discussions
- Make it clear that cameras do not have to be turned on during meetings
- Allow ample time and opportunity for people to ask questions and seek clarification.

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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.

- Provide debrief options to support those with delayed emotional processing
- Ensure there is access to a private room for decompression if needed, making it clear where this is
- Allocate a person to be available to offer support should anyone need it
- Work with individuals to identify and minimise any specific triggers, as well as their ‘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 – educate yourself on how best to respond to these
- Work with autistic people to continually improve the way they participate in co-production – ask for feedback after meetings and act on any suggestions that will support their involvement
- Ensure regular breaks are offered, and that a quiet space away from others is accessible both during meetings and break times
- 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 is not a sign of disengagement

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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 well-being, 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.

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Chapter 9. Working with people with a learning disability

Content to be developed by Inclusion North

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Chapter 10. 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 require 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:

- Lived experience contributors building relationships with a key member of the team
- Good, clear, accessible information about the work and what is being asked of the person in plenty of time before a meeting or event
- Being transparent about the parameters of the work
- Pre-meets and debriefs
- Support with administration and accessing information
- Support with invoicing and claiming payments for the work
- Lived experience supervision and reflection
- Peer support with other lived experience contributors
- Replicating wellbeing offer for all staff for people in lived experience roles.

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.

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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:

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

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 11. Payment for co-production work

Lived experience work should be **appropriately and fairly remunerated**.

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 existing policy around payment for involvement work on a sessional basis. It is recommended that recommended rates around involvement with research within the NHS are not sufficient to recognise the equal contribution and additional emotional burden of lived experience work.

While goodwill payments (covering only expenses, or payment via voucher) are strongly discouraged, if lived experienced roles are not paid via the payroll and are instead paid as sessional work it is 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.

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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 require substantial preparation. For example, chairing or co-chairing a meeting, delivering training or carrying out other discretionary work that requires additional responsibilities.

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Chapter 12. 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?

Red Balloons

Red Balloons is a lived experience organisation in Teesside that is 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.

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Chapter 13. 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 are 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 is 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 like those from NSUN (National Survivor User Network), the Scottish Recovery Network, and the Health Education England NHS Competence Framework for Mental Health Peer Support Workers offer valuable guidance. 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 is 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 unique 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.

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Chapter 14. Considerations for senior leaders

To ensure coproduction 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.

Coproduction 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 org? Does lived experience have an authentic seat at the table when decisions are made (e.g., 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? Is it 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 to people and families co-delivered? 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 NEDs 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?

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

- Have lived experience directors in your exec and lived experience leaders on your board.
- Invest in a career structure for all lived experience workers, including lived exp 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 exp lead. Lived experience leaders should be involved in incident investigations, in supporting teams who are struggling, in improving flow, in 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 upon their own exp 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 NEDs and set our key questions to ask in the board.

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Chapter 15. 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 ongoing reflective 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.

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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 are 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. Currently being reviewed by lived experience groups at Norfolk and Suffolk NHS Foundation Trust.

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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

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Black Thrive Global

NCCMH

Neurodiverse Connections

Trauma Informed Care Collaborative, Camden and Islington NHS FT

Contact: cultureofcare@rcpsych.ac.uk

Cite as: National Collaborating Centre for Mental Health, Neurodiverse Connections, Black Thrive Global and Trauma Informed Care Collaborative. Supporting co-production and lived experience leadership across the Culture of Care work: Guidance for wards. London: National Collaborating Centre for Mental Health; 2025.

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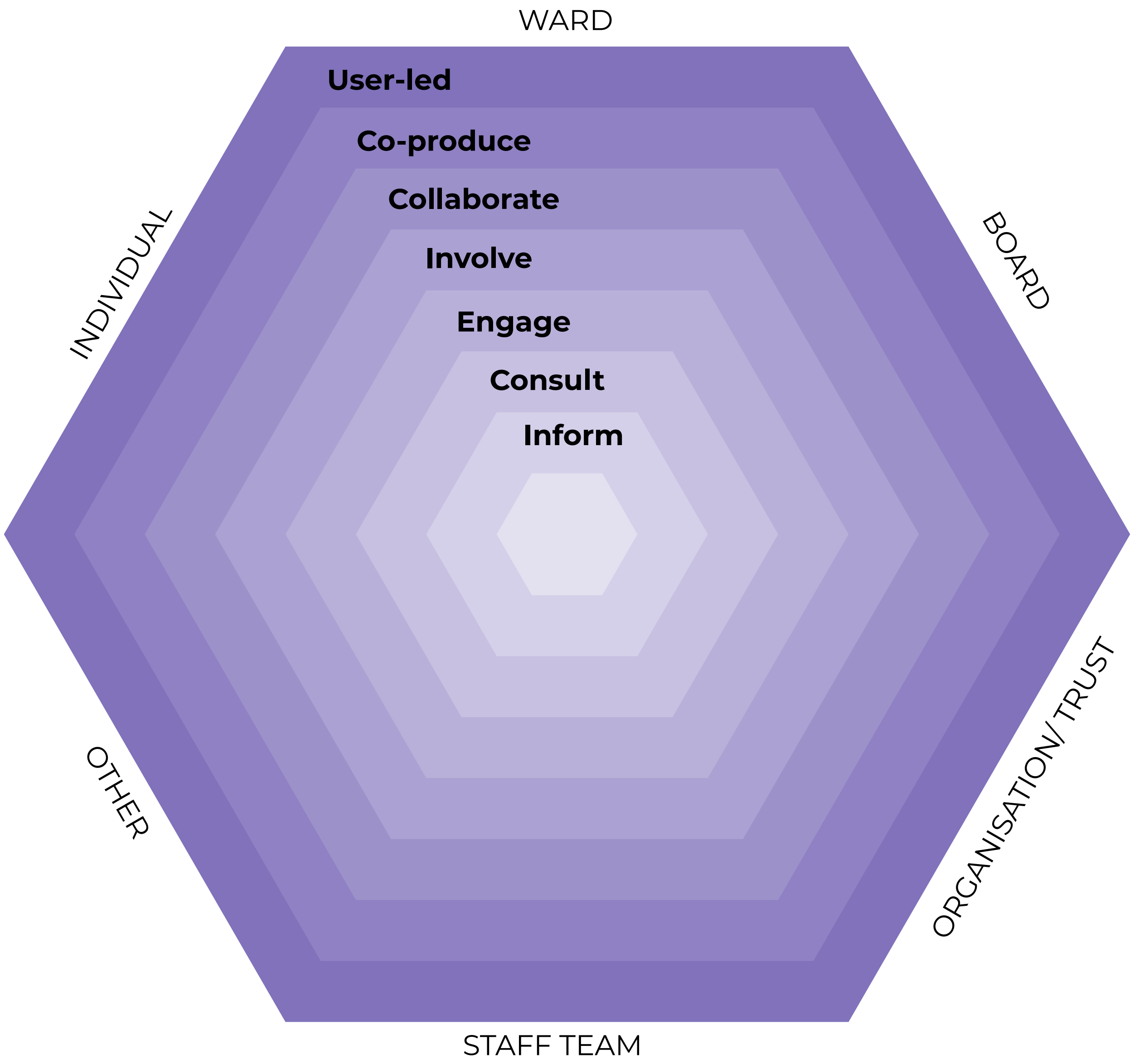
Appendix: Spectrum of Participation figure



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