Culture of Care

National Learning Session 2

Tuesday 15 October 2024, 11am – 3pm

NATIONAL COLLABORATING CENTRE FOR MENTAL HEALTH

Neurodiverse Connection

Global Black Thrive

NCISH

Welcome and housekeeping

Jill Corbyn,
Neurodiverse Connection

Sal Smith,
National Collaborating Centre for Mental Health (NCCMH)

Culture of Care

Schedule of Events

Time	Event
11:00 - 11:10	Welcome & Housekeeping
11:10 - 11:25	Who's in the room
11:25 - 11:40	NHSE- Valuing Lived Experience and Coproduction
11:40 - 12:05	Valuing coproduction and lived experience
12:05 - 12:15	**Break**
12:15 - 13:00	Introducing the CoC Lived Experience Guidance document
13:00 - 13:40	**Lunch Break**
13:40 - 14:15	Valuing lived experience voices in the CofC learning community
14:15 - 14:45	Panel Discussion
14:45 - 15:00	Next Steps and wrap up

Shared principles

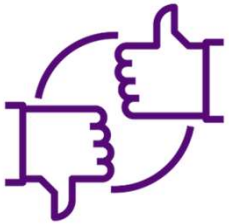
Listen with respect and openness

We value learning from all people and remain open to finding new ways of doing things.

Confidentiality

People may share something they wish to be kept confidential. We require your agreement not to share any of the content of this meeting without permission.

Shared principles (II)



Disagree with the point, not the person

We seek to resolve conflicts and tensions, using a constructive approach.

Use plain English

We seek first to understand, then to be understood. Where possible we avoid using jargon, and if we need to use acronyms, we define them.

Shared principles (III)

Collaborate

We base our decision-making on consensus agreement. Everyone's input is valued equally.

Contribute

We actively share ideas, ask questions and contribute to discussions. We can also choose not to participate if we are unable to or uncomfortable with doing so.

Respect Timing

Recording

We will be recording this event and posting it to the Culture of Care programme webpage.

If there is anything that you would not like to appear on the webpage, please let us know by emailing cultureofcare@rcpsych.ac.uk.

Support Space

On-Call Support Space Facilitator:

Andrea Davies

Join at any time:

Support space link

Meeting ID: 389 545 587 916

Passcode: QC9hye

The link to the support space will also be available in the chat.

Lived experience leadership

Jill

Becca

Lucy

Jacqui

Erica

Jason

Julie

Sophie

Molly

Antonia

Grace

Jo

Sal

Mark

Brendan

Culture of Care

Who’s in the room?

Opportunity to hear from people in a range of Lived Experience roles in the delivery team

Who are you? Who do you work for and what is your role in the programme?

What do you enjoy about working in Culture of Care?

What are your hopes for the work and/or this session?

NHSE: Valuing Coproduction and Lived Experience

Pea Meyer Higgins
Mary Pappin
Sophie Shaw

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Co-production and lived-experience leadership

P. Meyer Higgins, Mary Pappin, and Sophie Shaw

15th October 2024

Mental Health Learning Disability and Autism Quality Transformation Team

Co-production is central to the whole programme and is crucial in the design, development and delivery of all our projects.

Roles

- 4 **senior lived experience roles** in the team
- Large pool of **Public and Patient Voice partners**. Some partners work with us regularly on a long term basis, some work with us on shorter more specific pieces of work.
- Members of our **Lived Experience Advisory Group** and **Restrictive Practices Oversight Group** – These groups are part of our governance processes for any projects/documents we deliver.

Culture of Care Standards

Core team includes: Senior project manager with lived experience, x2 key PPV partners

Design group: Meet x3 to coproduce the standards. Includes a large diverse group of people with lived experience

Drafting and redrafting: Senior project manager and PPV partners remained central to these processes throughout

Governance: Presented to LEAG for sign-off

Procurement of delivery partners: Senior lived experience advisors involved in scoring for all 3 delivery partner procurements

CO-PRODUCTION

Culture of Care Support Offer

Ward Level: There are 3 different, complimentary support offers available to wards

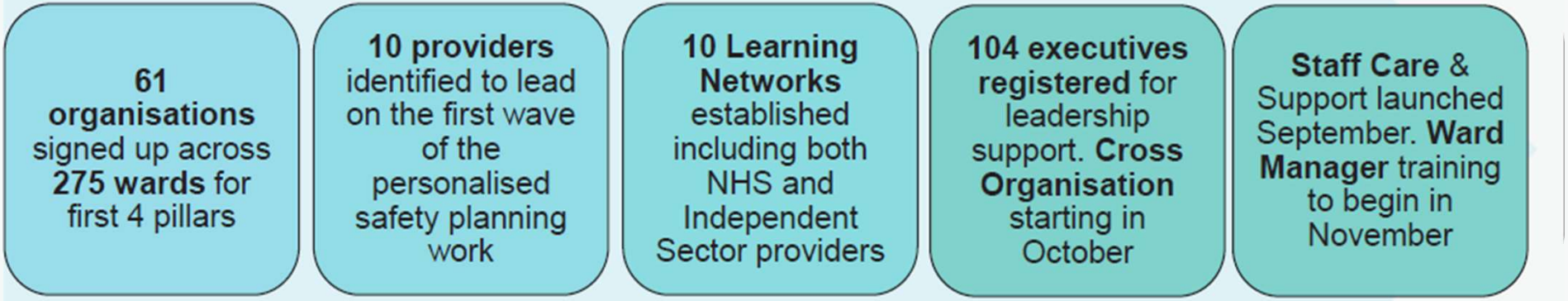
- Quality Improvement Coaching, delivered by NCCMH
- Staff Care & Development, delivered by PSC
- Ward Leadership & Development Programme, delivered by FoNS

Cross Organisational: quality improvement coaching support across teams such as HR, nursing, governance, comms, estates etc. Delivered by NCCMH

Executive Leadership: coaching & support to enable organisational culture of continuous improvement. Delivered by NCCMH

Risk Stratification: Support theory and practice shift from risk assessment tools to predict risk, to co-produced, personalised approaches to safety planning. Delivered by NCCMH.

Progress


61 organisations signed up across **275 wards** for first 4 pillars
10 providers identified to lead on the first wave of the personalised safety planning work
10 Learning Networks established including both NHS and Independent Sector providers
104 executives registered for leadership support. **Cross Organisation** starting in October
Staff Care & Support launched September. **Ward Manager** training to begin in November

The role of a lived-experience in the Culture of Care workstream

Citizenship and Belonging; The antidote to Othering

Citizenship

Know your *people*

Localisation

Bring people *home*

Continuity

Keep people *close*

Belonging

Value *everyone: 'all means all'*

The person at the centre and as citizens in their own communities

SERVICES, COMMISSIONING & POLICY

Valuing coproduction and lived experience

Jill Corbyn,
Neurodiverse Connection

Sal Smith,
National Collaborating Centre for Mental Health (NCCMH)

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We’d like to ask you 4 questions on Mentimeter

- Lived experience colleagues: How valued do you feel in your ward or organisation's CofC work so far?
- Teams/organisations: How confident do you feel to coproduce and value lived experience in your CofC project?
- All: What are you currently doing on your ward/in your organisation related to coproduction?
- All: What do you feel are your biggest challenges/barriers to coproduction?

We’d like to ask you 4 questions on Mentimeter

Or join at www.menti.com and use code **6121 7634**

The first lived experience network meeting

26th September 2024

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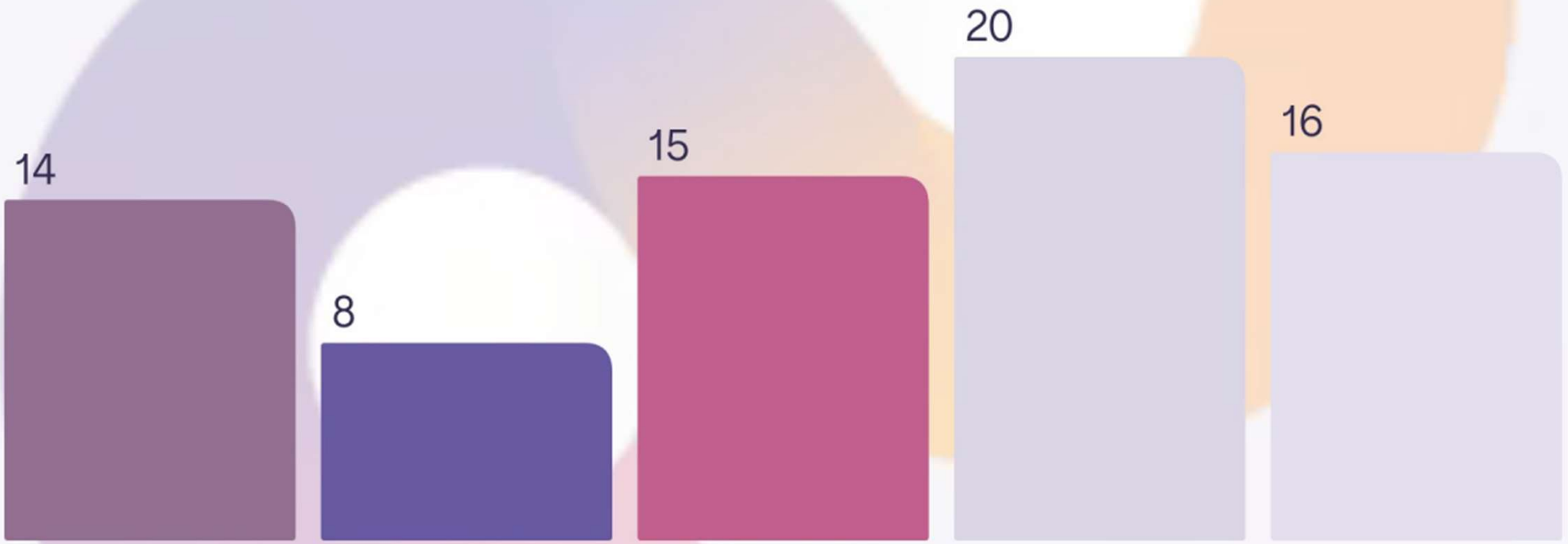
Experience in the room



Why does coproduction and valuing lived experience matter to you?

To make a positive Changes from within.To challenge staff stereotypes Spread awareness To voice concerns of those who are less powerful/confident

I have lived experience as an inpatient and some of those experiences have cuased lasting trauma. Co prorduction and hearing peoples experiences is essential in order to improve services

Learning from bad experiences. Preventing the bad experiences happening again and encouraging more good ones

Thinking about inpatient care in particular, it's so important to include the voices of people who have experienced this as others can't fully understand what it's like

Bring about real and meaningful change and stop bad and harmful practice

So that something good can come from something bad.

I have had a number of admissions and it has been a VERY mixed experience. I'm passionate about improving outcomes through positive change.

Because we are able to come together and make a meaningful difference collectively.

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Why does coproduction and valuing lived experience matter to you?

2 sides of the coin. Professionals need to see what it's like for those on the receiving end if improvements in care are ever to be made

So important to hear and amplify the voices that are all too often lost or drowned out when accessing services. It is my hope that these are the voices that catalyse meaningful change

To make a difference to people when they're at their most vulnerable

Experiences are powerful

It is essential if we want to improve services and the lived experience voice should influence and drive change.

Because we are able to come together and make a meaningful difference collectively.

Ensuring wards do not cause more harm and are are calm/safe environment

We don't have enough voice in our own care, a lot of the time choices are made about us rather than with us so having other LE voices aiming to help our care is really important

Why does coproduction and valuing lived experience matter to you?

Giving opportunity to everyone. Not gatekeeping

Adjustments for person centred care for learning disabilities

I see lots of people struggle and their voices aren't heard or feel unable to change the system. It's like DWP etc it's all barriers to put people in boxes and make it hard to challenge

Importance to be part of the design of services so that it's not system lead

Commitment to improvement

Understanding the real harm that is being caused outside of boxes that get framed from hearing things back in a certain way

It gives a human angle, away from a purely clinical perspective

To ensure people get the best care on the ward whilst an inpatient and post discharge.

Hopes and fears for the work

High risk we will talk for 2 years and nothing will be experienced as better at the end

My fear , is the wards do too many projects and dont get time for the basics of care . And the risk of QI fatigue , i see it now for both lived experience and staff members

Hope - Practical and emotional Support for staff seeking neurodivergent diagnosis for themselves Fear - staff not supported leaving the NHS and feeling invalidated

The organisational infrastructure of our trust isnt set up for quickly onboarding EbEs, my main fear is that the systemic barriers will mean I cant effectively coproduce due to bureaucratic barriers

Not having enough staff and people being sent out of area for inpatient care may be huge barriers that get in the way of improving the quality of inpatient care

I'm still anxious that some services might be resistant to change, or feel that they "do enough" and bristle when they are asked to reflect of their ethos.

improve things

Hope that people in hospital will receive the support and learn tools to get them out of hospital..... and to prevent readmission.

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Hopes and fears for the work

that it works and fear that it won't

Hopes - families and carers feeling part of the process and involved in their loved ones care, when appropriate. Support and knowledge given to all

Being realistic but aspirational!

my hope is that culture of care can adrdress a key issue that I see on the ward is that it is very hard to rock the boat when you are in it. Challenging poor practise wen you need your teams support

Change is positive and long term

ears are how much this will really make a difference and what happens when the programme ends. How will it be sustained

Fears ... That 'Lip service' wins again and there is no real action from those at the top!! Hope ... I want Board Members/Trustees to be seen and be more accountable!

I hope together we can make a difference for women given a bpd label who are often neglected in services

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Responses to today's menti questions

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Break

12:10 – 12:20

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Introducing the Culture of Care Lived Experience Guidance document

Sal Smith,
National Collaborating Centre for Mental Health (NCCMH)

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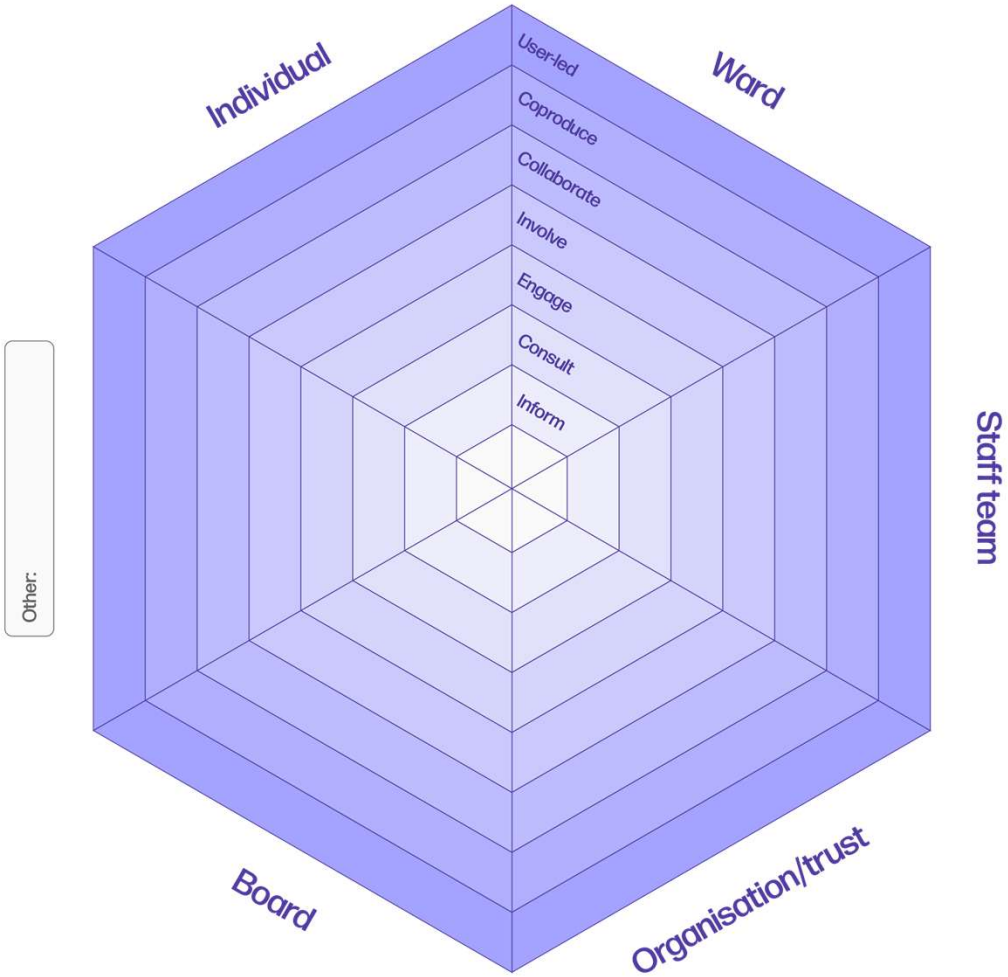
- Governance
- Service design
- Service delivery (Peer support)
- Quality improvement
- Service evaluation
- Research



Getting started

- Ethos of making space to listen to and value patients and families
- Don’t let perfect be the enemy of good
- Pause and reflect on what you do well already
- Ward meetings, patient feedback, advocacy, partnership with VCSE, complaints
- How can we strengthen, amplify, pay more attention to?

Progressing participation

- CofC gives impetus to be brave and try to progress this agenda and move to more partnership working
- Explore existing involvement and peer support structures in trust
- Explore existing user led and community organisations locally
- How to safely bring people into project team as equal partners
- How to remunerate people fairly
- How to support people well

Lived experience leadership

A broad term used to describe what happens when people use their Lived Experience to lead change, shape or create something to benefit others in the broad field of mental health

What more is needed?

Nurturing lived experience – any support should be underpinned by principles of;

- being LE-led,
- learning from the past,
- acknowledging inequalities and harm,
- and being visibly, genuinely diverse.

Creating supportive contexts for LEL – as so many challenges were linked to systemic problems, there is an urgent need to focus on contexts and organisations people with LE are trying to work in. This includes leading by example (in the case of mental health charities, ensuring LE is embedded at all levels), highlighting the value of LEL, supporting organisations to embed LEL, making a substantive commitment and investing resources, and having brave intra-organisational conversations. **(Rai Waddingham NSUN, 2021)**

Facilitating coproduction and lived experience leadership

- Re-imagine what is possible. In a work force of 5000, how many lived experience roles might you have?

- 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 coproduction for things to be **equal?**

- 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?

Power

- Many people will have had experiences of powerlessness in their lives.
- Trauma, especially inter-personal trauma has a 'power over' element.
- Patients entering the mental health system may be subject to forced medication, detention, being labelled, being described in their notes. They may experience powerlessness.
- For people in services for a long time this can be ingrained and embodied.
- We must think about power and the impact in order to support safe and meaningful coproduction.

Diversity within coproduction

- Diversity of voice is the inclusion of perspectives, opinions, thoughts and influence from people from a range of different backgrounds and experiences.
- Coproduction naturally introduces diversity of voice into service design and delivery.
- Diversity of voice is important as it allows organisations to reflect on their services from the perspectives of different groups and individuals, to identify gaps and harms, and to ensure all communities needs are being adequately met.
- It’s helpful to think about the nine protected characteristics when considering diversity of voice.
- It is also important to ensure that coproduction spaces are themselves diverse.

Working with people from racialised communities

- Not enough to say 'we are not racist' or that the door is open to everyone. Must be actively and intentionally anti racist and reflecting anti-racism practice.
- Cultural curiosity- willingness to explore what you don’t know and be open and curious to learn.
- Acknowledge and understand the impact of racism and racial trauma for black and brown people accessing services.
- Building trusted relationships may take time and investment, may require a trusted community bridge.
- CofC is not a separate endeavor to PCREF, they are intrinsically linked.

Working with autistic people

Autism is a lifelong neurodevelopmental condition with autistic individuals 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 with providing accommodations to both the physical and social environment to meet individual needs.

Some accommodations to consider:

- **Give clear information, in as much detail as possible, about tasks.**
- **Consider the sensory environment of where any meetings are held.**
- **Encourage different forms of communication, acknowledging that this may change in different situations.**
- **Be aware of any potentially triggering situations/conversations and offer information in advance about these.**

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 emphasizes 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	**Trust**	**Empowerment**	**Collaboration**

Training and support

- For lots of people their lived experience is ongoing, and they may face current challenges that require reasonable adjustments in order for them to access work and be able to contribute fully and meaningfully.

- But perhaps more significantly lived experience work and involvement can be emotionally difficult for lots of reasons.

- We must be thoughtful and robust about training and support for everyone working in lived experience roles.

Support

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

Training

- **Introduction** to the CofC 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 **structure of 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**

Payments and remuneration

- 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 patient involvement work more widely. Payment should reflect the important 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.
- Whilst there is no national standard on lived experience payments, align with your local practice in your organisation or ICB.
- If creating new roles, these could be adapted from similar roles within the organisation.
- Many organisations will have a payment policy in place for service user involvement.

Peer support

- What is peer support and how is it part of the spectrum of coproduction?
- What to consider if you are introducing peer support on your ward?
  - Model of peer support
  - Defining and protecting the remit of the role
  - Peer leadership
  - Team preparation
  - Training
  - Ongoing support and development

Lunch Break

13:25 - 14:00

Culture of Care

Valuing lived experience voices in the CofC learning community

- Somerset NHS Foundation Trust
- Greater Manchester Mental Health NHS Trust

Gardener Unit Participation Group

GET INVOLVED
IMPROVE SERVICES
RESEARCH AND INNOVATION

The last Thursday of each month, 3-4pm, in the lounge

FOCUS: CULTURE OF CARE PROGRAMME

Ideas included:

When care was good- Everyone is happy, it feels calm and safe, people spend time out of their room, there are lots of activities to do, staff are engaging, staff are compassionate, young people are engaged in college, seeing progress towards discharge, teamwork, collaboration, feeling motivated.
When things have gone wrong- spending time in room, not feeling safe, feeling uncared for, feeling unmotivated to engage, boredom, things not happening when planned, staff shortages, people being argumentative, being away from home, staff not engaging young people.

Individuals were invited to be part of the project team!

FOCUS: CULTURE OF CARE PROGRAMME

Young people reviewed the set of standards that have been developed. These standards aim to create a culture which feels like care is at the centre of it and patients and staff feel cared for.

Young people considered change ideas they would like to see happen based on these standards. Ideas included:

1) More support around side effects of medication
2) Staff being upskilled in therapeutic skills
3) Staff being more aware of individuals preferences around support
4) Access to IT equipment and the intranet

FOCUS: CULTURE OF CARE PROGRAMME

Young people reviewed the set of standards that have been developed by the Culture of Care Programme. These standards aim to create a culture which feels like care is at the centre of it and patients and staff feel cared for.

Young people considered change ideas they would like to see happen based on these standards. Young people identified which ideas they would like us to prioritise:

1)the development of a sensory room
2)Increasing staffing to ensure there is enough staff to facilitate activities
3)Family event days
4)Improving care plans

Young people also completed the Patient CARE survey. They were encouraged to complete this questionnaire regularly. The results will help us to identify what we need to improve.

OUR EXPERIENCE

- We already had an established group in place to discuss QI projects
- The group has other purposes apart from Culture of Care
- Important to choose a time and day that is convenient!

- All staff on shift support the group → emphasize the VALUE

TOP TIPS

- Use of activities instead of discussion
- Small group tasks
- Using flip charts
- Encourage movement around the room
- Invite your IMHA to join

Panel Discussion

Chair: Brendan Stone

Sophie Bagge, Norfolk & Suffolk NHS Foundation Trust

Mark Allan, Tees Esk & Wear Vally NHS Foundation Trust

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Next Steps and wrap up

Jill Corbyn,
Neurodiverse Connection

Culture of Care

We’d like to ask you 4 (more!) questions on Mentimeter

Or join at www.menti.com and use code **6121 7634**

Feedback

Please can the QR Code to share your feedback

Dates for your diary (2024)

- **November**: **Learning Networks Event** (see next slide for time/location)
- **4 December: Lived Experience Network** (virtual, 1-3pm)
- **9 December**: **Learning Networks Workshop** (virtual, 1-3pm)

Upcoming learning network events

Learning Network Pairing	Organisations	Date of Event	Venue
4 & 7	Humber, TEWV, Pennine, Navigo, SW Yorkshire, Leeds and York, Sheffield, The Priory, Rotherham Doncaster and South Humber, Bradford, Northumbria	12/11/2024	Shay Stadium (Halifax)
8 & 9	Hertfordshire, NELFT, North London Partnership, SABP, SWLSTG, CNWL, Kent and Medway, Oxleas, SLaM, Sussex, West London	19/11/2024	10 Union Street, London
2 & 5	Oxford, Norfolk and Suffolk, Northamptonshire, Nottinghamshire, Cambridgeshire and Peterborough, Berkshire, Lincolnshire, Essex, St Andrews Healthcare, Leicestershire, Derbyshire	26/11/2024	Leicestershire football club
1 & 6	Elysium, Gloucestershire, Hampshire and Isle of Wight, Dorset, Devon, Livewell Southwest, Avon and Wiltshire, Somerset, Bramley Health, Cornwall	27/11/2024	Sandy Park conference Centre (Exeter)
3 & 10	Black Country, Cygnet, GMMH, Coventry and Warwickshire, Gateshead Health, Herefordshire and Worcestershire, Midlands, CNTW, Birmingham, Cheshire and Wirral, Lancashire and South Cumbria, North Saffordshire, Merseycare	28/11/2024	Aintree Racecourse

Upcoming Training

Event Name	Type	Format	Length	Cycle	Design and Delivery
Dialogical and Relational Training Taster Days (DARTT)	Ward-level sign-up	Virtual	7 hours	Monthly	NELFT (North East London NHS Foundation Trust)
Autism informed training	Ward-level sign-up	Virtual	3 hours	Bi-monthly	Neurodiverse Connection
Anti Racism Training	Ward-level sign-up	Virtual	TBC	TBC	Black Thrive Global
Preventing Sexual Harm	Ward-level sign-up	Virtual	TBC	TBC	Trauma Informed Collaborative