



**Camden and Islington**  
NHS Foundation Trust

# Service User Experience and Involvement Strategy

2021 - 2024

## Version Control

<b>Version</b>	<b>Date</b>	<b>Description of changes</b>
1.0	25.06.2021	Initial first draft summary for comments
2.0	28.06.2021	Structural revision following review by Task and Finish Group
2.1	06.07.2021	Presented to Quality and Safety Programme Board and Executive Committee for comments.
2.2	08.07.2021	Structural revision and updated content following feedback from Quality and Safety Programme Board and Executive Committee. Additional content added
2.3	12.07.2021	Structural revision and updated content following feedback from Director of Nursing and Quality
2.4	13.07.2021	Updated content to strengthen commitment to carer experience and involvement.
2.5	02.09.2021	Structural revision and updated content following feedback from Quality and Safety Committee, Governors' Working Group and Camden Mental Health Carer Group. Additional content added from service users, carers and staff.

## Contents

Introduction .....	4
What do we mean by “service user experience”? .....	5
What do we mean by “carer’s experience”? .....	6
What do we mean by service user and carer involvement? .....	7
Why is this important? .....	8
How our strategy was produced .....	9
Where do we want to be? .....	9
How will we measure success? .....	15
A Service User’s story: My journey into mental health services.....	16
Referenced documents .....	19

# Introduction

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A key theme in Camden & Islington NHS Foundation Trust's Clinical Strategy 2020 – 2025 is recognising service users and carers as equal partners in their care; giving them a say in the design and delivery of our services and our organisation. The Clinical Strategy gives many examples of issues, concerns and ideas raised by service users and carers and to how we aim to respond to the issues that matter to them, recognising that they are experts due to their lived experience.

Evidence suggests that if a service user feels listened to and involved in their care, they will respond better to medical, nursing and therapy interventions and be better able to manage their own care.

We want to work in partnership with our staff and service users, their families and carers to seek opportunities to improve the quality of care that we provide. We want to actively listen to our service users to understand what matters to them. We also recognise that sometimes we don't always get it right, but we will work with service users, families and carers to understand where care has not met expectations and put things right.

This strategy sets out a structured approach to ensure the best possible experience of person-centred care for all service users. It describes how staff will understand their responsibility in ensuring each service user receives excellent clinical care delivered in a manner that treats them as an individual, recognises their needs and cares for them with empathy and compassion.

The behaviours and approach that underlie how we do things are described in the Trust's four cultural pillars:

1. **We value each other** - this involves supporting each other's wellbeing and development
2. **We are empowered** - this means taking action and responsibility to do what is best for your services and team
3. **We keep things simple** - this means cutting out bureaucracy when it adds nothing
4. **We are connected** - this means working collaboratively across services and organisations, rather than in silos

## **What do we mean by “service user experience”?**

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‘Service user experience’ might mean different things to different people. To a service user, it might be about many different aspects of their care:

- **Am I known / treated with respect and courtesy?**
- **Am I heard – do I have a voice in my care planning?**
- **Am I supported to understand – do I get proper explanations?**
- **Is my care coordinated – do teams talk to each other so that it’s a seamless journey for me?**
- **Did I have to wait – to get an appointment, to be discharged, when I called for help, did staff explain delays?**

The Department for Health and Social Care and NHS England / NHS Improvement require NHS organisations to publish data on the views of patients regarding the quality of services provided. These include national surveys on adult inpatients, community mental health, the Friends and Family Test, complaints and compliments received.

But there are various other methods used to find out what service users think, for example:

- Healthwatch
- Local Advocacy Services
- Social Media
- Independent Complaints Advocacy Services
- Correspondence with MPs, Health Service Ombudsman, commissioners
- Interviews and focus groups
- Feedback from voluntary and community sector groups

We will work with service users to develop systems which gather and monitor feedback to improve their experience. We will do this by developing guiding principles that allow us to gather meaningful feedback relevant to the particular service, and that demonstrates improvements.

## **What do we mean by “carer’s experience”?**

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This strategy aims to ensure that the vital role of carers is recognised and valued as being fundamental to strong families and stable communities and respected as expert partners in care.

The strategy explains the tools and processes we will use to gather feedback from carers from their lived experience of the services we provide, and how we will use this to inform service design and delivery. There will be clear protocols to record when things go wrong and how resulting actions are implemented and fed back.

We will identify clear systems to measure progress in carer experiences and the impact of its implementation on carer satisfaction, complaints and untoward events, details of which will be routinely reported to the Trust Board and the Quality and Safety Committee.

### **We want to ensure that carers:**

- are identified early
- feel supported and valued
- have a choice in and about their caring role
- get good quality information when they need it
- feel respected as expert partners in care
- feel included as part of the [Triangle of Care](#), which is a therapeutic relationship between the person using our services, staff member and the carer that promotes safety, supports recovery, and sustains wellbeing
- do not have to take on inappropriate levels of caring because of the disability of parents/family member

## What do we mean by service user and carer involvement?

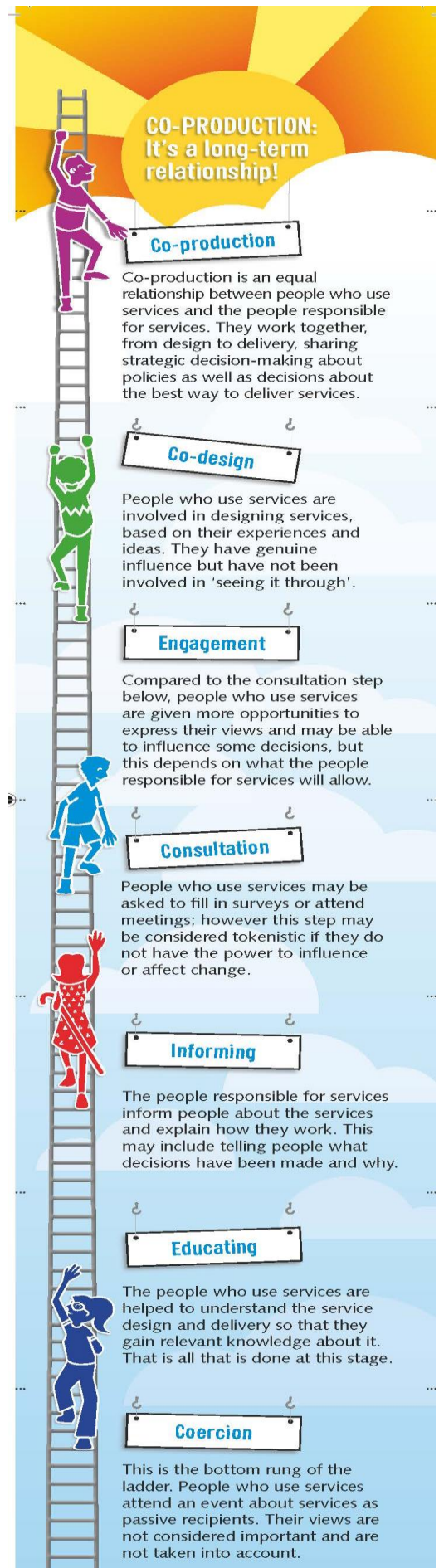
By service user and carer involvement, we mean taking every opportunity to hear from our service users, carers and their relatives, encouraging their active participation in shaping the way the trust provides its services.

This includes having service user and carer representatives on boards and committees and involving the Trust membership and the public in planning future services, fundraising and volunteering.

In this way we will make sure our services are delivering the care that people want in the way that works best for them.

It is sometimes helpful to think of service user and carer experience and involvement activities existing on a continuum, where the amount of influence people can have over decisions varies.

Camden and Islington NHS Foundation Trust is committed to involving service users and carers in a meaningful way in the planning, delivery and organisation of services. It is the wish of both the Trust and Service Users engaged with C&I to create a culture of partnership, joint decision making and collaboration.



## We believe that Service Users can expect:

To have their views taken into account in decisions about their health care

To be treated as experts about themselves and their own experience of mental health

To be invited to take part in Service User involvement activities

## Some of the ways a service user can get involved are:

Attending Service User groups within the Trust

Representing Service User groups at the Service User Alliance

Generating and participating in Quality Improvement Projects

Participating in staff recruitment

Contributing to staff induction and training

Collecting Service Users' feedback

Participating in the Patients Council

Auditing and reporting on the quality of services

Helping to produce or commenting on policies

Helping with the design of Trust letters, leaflets and publications

Participating in Trust Committees

As an elected Service User Governor

Strategic opportunities to work across organisational boundaries

## Why is this important?

The insight we can get from service users, users and the public, from involvement activities, feedback and surveys or through simply listening and observing, can help us to improve the quality of services we provide and design better services and pathways based on users' experiences and expertise.

We want to listen to our service users, families and carers to understand what is important to them, to value their ideas and to learn when care doesn't meet expectations. We want to work in partnership with our communities when reviewing services and let the 'expert by experience' be instrumental in redesigning and shaping future services.



In line with our Digital Strategy, we will harness the use of information technology in existing and new ways to support how we collect and use feedback and how we communicate with our service users, families and carers. We will look at the opportunities to use multimedia technologies to help reach those at risk of exclusion from involvement using traditional methods and enable participation and communication on the individual's preferred terms.

## How our strategy was produced

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This is the first integrated Service User Experience and Engagement Strategy for C&I but builds on three previous Service User Involvement strategies and the great strides made over the last 10 years in the Trust in moving towards a co-production ethos.

In 2019/20, Leeds Beckett University undertook a review of service user experience in the Trust and found some positive evidence:



## Where do we want to be?

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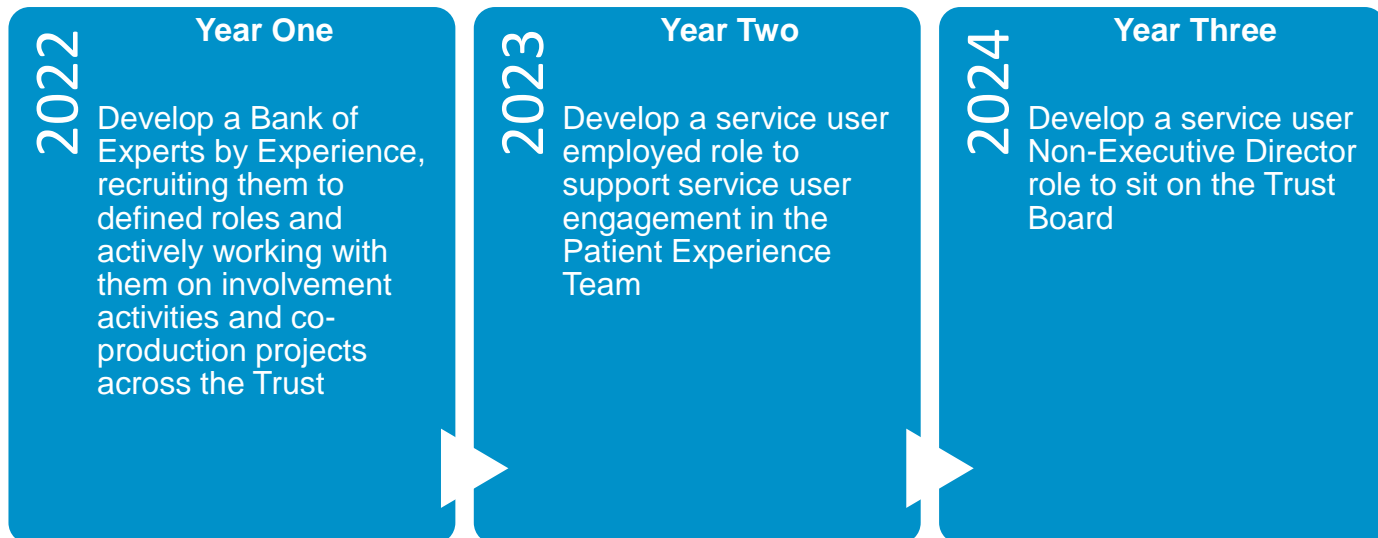
There needs to be greater clarity on role and support for service users and carers who are involved in the Trust and clearer routes of progression to ensure that pool of experts by experience is constantly being refreshed.

We will develop a coherent approach to ensure that experience and voice activity are mapped across the whole organisation, presenting a system level view back to Divisions to help validate

and empower services that are already working on this agenda and motivate those areas who have more to do to engage. In addition to our existing involvement activities we want to broaden our approach to make it easier for our service user's voice to be heard by concentrating on the following strategic priorities:

## Strategic Aim 1: Increase Involvement and Co-Production Opportunities

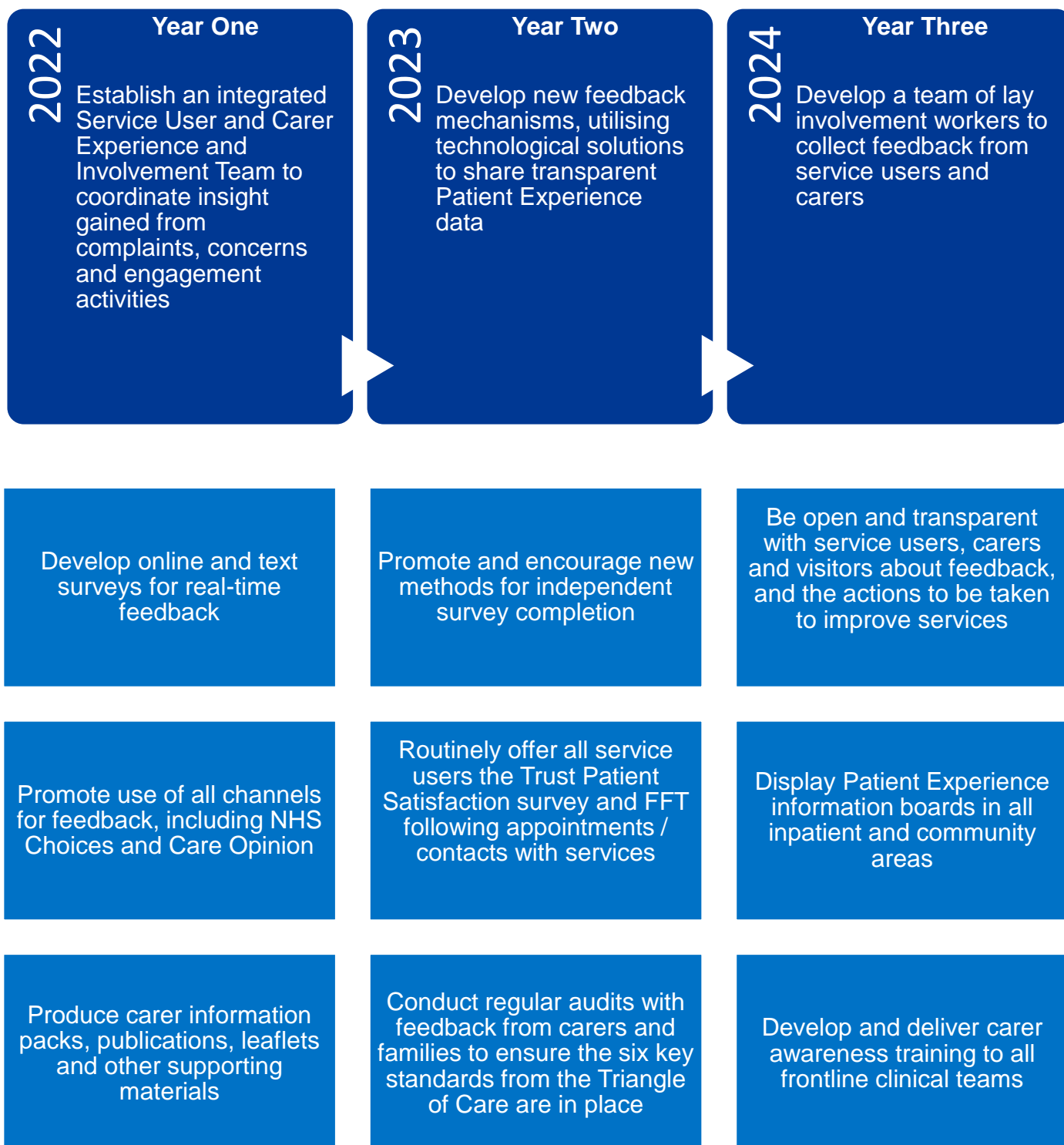
*“We will broaden the Trust’s network of service user and carer representatives by identifying and promoting a range of defined roles to more appropriately involve lay representatives in specific projects”.*



Liaise with the Quality Improvement (QI) team to develop a programme of user led QI projects	Co-produce training and develop a resource library for all staff and lay representatives	Support service user and carer involvement in recruitment and retention processes via training programme
Support the employment of Experts by Experience	Develop role descriptions for Trust-wide Expert by Experience committee membership roles	Ensure Expert by Experience group is diverse and inclusive by active recruitment programme
Develop co-delivered carer awareness training as part of corporate and divisional staff induction programmes	Promote access to internal Trust staff training for service user and carer representatives	Utilise new technologies to reach a wider population
Promote opportunities to learn new skills through learning events where appropriate and relevant including through The Recovery College	Increase opportunities for volunteering	Host drop-in sessions, listening events and roadshows in liaison with our community partners

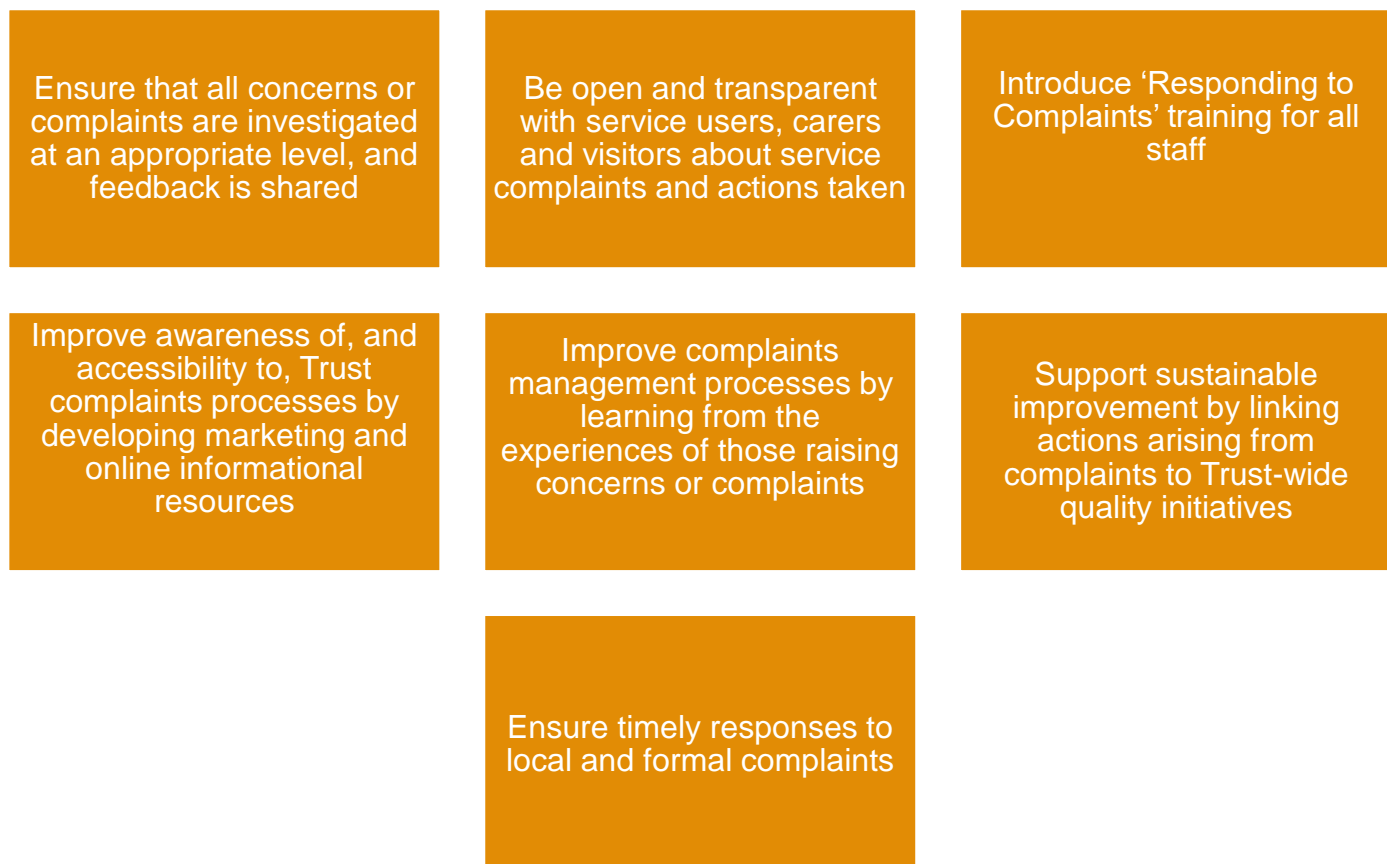
## Strategic Aim 2: Patient Experience Feedback

*“We will develop and strengthen the current systems and processes for evaluating and improving patient and carer experience”.*



### Strategic Aim 3: Managing Complaints

*“We will improve our responsiveness to complaints and concerns received and user satisfaction of complaints / customer service functions”.*



## Strategic Aim 4: Learning from Feedback

*“We will ensure the voices of service users and carers are listened to by the Trust Board and feedback is routinely collected and shared widely across the Trust to influence service improvement and delivery”*



Publish complaints outcomes and actions via staff and patient newsletters

Share all actions and learning with the individual raising the complaint

Report on all complaints and compliment trends, themes and learning

Deliver a 'Learning from Complaints and feedback' training module for all staff

Develop educational resources to support learning from complaints

Develop complainant stories and podcasts to support team learning

Focus on learning from complaints and incidents where carer and family needs fell short of expected standards

## How will we measure success?

Process Measures	Learning Measures	Outcome Measures
<ul style="list-style-type: none"><li>• Numbers of unresolved and overdue complaints</li><li>• Number of complaints about communication.</li><li>• Number of complaints about staff attitude and behaviour.</li><li>• Compliance with cohort sampling of service user surveys.</li><li>• Positivity of service user surveys.</li><li>• Service User representation in Trust / Divisional meetings and groups.</li><li>• Clear and consistent divisional governance systems to assure local ownership and evidence of co-production.</li><li>• Family and friends national data, online carers feedback and direct to services, concerns and formal complaints and compliments, operational services qualitative data, and operational performance data</li></ul>	<ul style="list-style-type: none"><li>• Routine, scheduled review of Division activities with an appreciative inquiry approach on what went well and what could have been improved.</li><li>• Routine, scheduled review of the Service User Experience and Involvement Strategy by a range of stakeholders on learning what we are doing well, what we could do better, what is having the best outcomes.</li><li>• Review of qualitative and quantitative feedback about service user experience and involvement across the Trust.</li></ul>	<ul style="list-style-type: none"><li>• Achievement of agreed service user experience and involvement action plans each year.</li><li>• Analysis of service user survey results and actions undertaken to address/improve.</li><li>• An established carer support network, including relatives, friends and supporters across all services.</li><li>• An effective system to measure carer experience</li><li>• The Triangle of Care self-assessment tools</li></ul>

## **A Service User's story: My journey into mental health services**

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At 38 my life was going well. For some unknown reason I hadn't been sleeping and developed insomnia. After not sleeping for a week, I became manic and had my first psychotic episode. I had never had a mental health issue and had no idea what was going wrong. At the same time, I had a chest infection and went to Whittington A&E for an X-ray.

Medics noticed I was acting strangely and took me to a room that can best be described as a police cell with nothing but a blue mattress on the floor. I was immediately placed on the floor by three security staff who restrained me, restricting my breathing in the process.

When I told them to get off, they held on tighter which made me struggle more. This continued for over half an hour. When medical staff finally came into the room, it wasn't to tell the men to get off, it was to give me an injection. When the police arrived, I thought at last someone can see what they are doing is unjustified; instead, they also restrained me, and after a further struggle, I was transferred to HMHC Coral ward. When I tried to explain what had happened at A&E, I was not shown any compassion; instead I was shown to my room.

In the coming days staff told me to take risperidone medication. When I refused, no one attempted to explain how I might benefit from taking it. I was just told if I refused, it would be injected. The medication caused me to over salivate and dribble. A service user (SU) suggested that procyclidine may help with these side effects, but staff dismissed my request. It was only when my partner visited, noticed the dribbling, and raised it with staff that procyclidine was prescribed.

At no point was I told I could appeal, have free legal representation or have an advocate. Again, it was a SU who told me about my rights. I felt like I wasn't receiving the care, empathy or dignity I should be and grew so frustrated that I decided to break a window and leave the ward.

After going AWOL I arrived at a family member's house. He convinced me that he needed to call the LAS and police so they could bring me back to hospital. On my return, I was very disruptive and would frequently go AWOL. I was discharged briefly on a few occasions but was eventually brought back in and placed on a section 3. I continued to be a challenging SU.

It took a few months before I engaged with staff and that was only because I moved ward a few times and met a support worker called Abas. He took the time to describe how I would benefit from working with staff and explained how consistently taking medication would help reduce the systems of psychosis that I was experiencing. What meant the most to me was that he showed me kindness and compassion, trust and understanding. He took time to talk to my partner when I asked him to, so she too could have a better understanding of mental health.

For the first time, I felt I could trust a member of staff. He helped me engage with other staff where that trust had broken down. This was when my recovery started. Following some escorted then unescorted leave, I was finally discharged.

### **Giving back**

I felt my experience could help other SUs who found themselves in a similar situation, so in 2015 I joined the trust as a volunteer, helping with refreshments, gathering feedback and eventually taking patient debriefs after a restraint. I also helped a mental health charity do advocacy and peer support on the wards, which was hugely rewarding.

With amazing support from my manager Jo, my confidence and knowledge grew, and when Jo encouraged me to apply for a job at C&I, I gained a position in the crisis team as a peer support worker, which I really enjoyed.



Due to the pandemic, I was redeployed to a Place of Safety (POS). Here, I found I could empathise with SUs who had come in on a Section 136. I helped guide them through the process by keeping them informed at every stage. When a permanent post became available at POS, I successfully applied and have been there since.

In the early stages at POS, I met Abu who was role modelling a 'least restrictive' approach on the unit. I was instantly drawn to this approach as I knew most of my disruptive behaviour as a SU had come from unnecessary restrictions and boredom. I instantly recognised this could be a better way to build rapport, gain trust and start a therapeutic relationship, helping recovery start sooner for SUs.

Now, when SUs come through POS, we always use a least restrictive approach in what can be a very restrictive environment. Small things count in this situation, and allowing a service user to, for example, keep a personal item after a risk assessment, can help avoid unnecessary conflict between staff and SUs.

I feel there have been some big improvements in the Trust since I was a SU, mainly the training Abu delivers to staff around being least restrictive and the peer restraint debrief that allows someone neutral to help unpick incidents. They allow learning on both sides to help prevent further incidents.

Recently I have been seconded to a 'Volunteer to Career' lead designed to give volunteers with lived experience of mental health the skills and experience to move on to paid roles in the NHS or other organisations by supporting them so they can meet the requirement on the job applications and help with the application process for roles such as peer support worker or health care assistant.

The strategic aim of the program is to positively impact NHS workforce recruitment needs at a local level. The C&I strategic priorities we hope to influence are expansion of the peer work force and recruitment of local people.

"Hearing my story brings it home to people.... It helps them to understand and know what to do and how to help".

**John**

"My experience of being mentally ill is valued"

**Peter**

"The best part of service user involvement would be keeping active, having a routine and also being able to engage with staff and other service users".

**Jayne**

"We had a service user with us when we were doing some process mapping for our service development – their input was fresh, immediate and based on their actual experience of being in an A&E department – the staff really listened and took notice, it meant we were able to cut through a lot of the task more quickly as we could get to the heart of the issue from the outset"

**Debbie May, Senior Service Manager**

“Service user co-facilitation, involvement and co-production changed my attitude as a practitioner to the purpose of my role and our work in the caring profession. Without insights and involvement, I would never have understood how my work and interventions might be perceived, and also how reactions and responses from users of services, could be understood. My best work has happened during a co-production approach”

**Dr Farha Choudhary**

“Co-production has been fundamentally important to the development of peer coaching services in the Trust. Service user representatives have inspired us to aim high with a personalised and flexible approach to supporting others. They not only provided direct ideas about what peer working roles could do but how the service can operate well in relation to other systems. They continue to provide inspiration and support to adjust our documents and methods plus recruit new workers into our team. In short service user reps have been key in all elements of service development and as a result we work in a style that is high quality”

**Cerdic Hall, Nurse Consultant**

“Just wanted to highlight how grateful we are to Bev and Nick for their regular attendance as service users reps and valuable contributions they make at our quality forum each month. It really is powerful to have service user reps sitting alongside consultants, directors and heads of services”

**Dr Chris Curtis**

**Consultant Psychiatrist, Clinical Director, Community Mental Health Division**

“I work at the Hive, a mental health wellbeing service for people aged 16-25, which started with a board of young people designing the service, what the building looked like, what evaluation should be used etc. This philosophy has continued, young people are used in all staff interviews, they designed our expected behaviour policy and their opinion is sought in how we are doing every 3 months. I cannot imagine not working alongside the people who use our service, it always adds to quality, it makes the service a happier environment and keeps the service a learning environment.”

**Katie Clayton,**

**Clinical Team Leader**

## Referenced documents

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[NHS Constitution](#)

[NICE Quality Standards for Service user Experience in Adult NHS Services](#)

[NICE guidelines for service user experience](#) and [mental health service user experience](#)

[NHS Operating Framework 2012/13](#)

[NHS Outcomes Framework](#)

[Quality Accounts](#)

[Statutory Duty to Involve](#)

<http://www.skillsforhealth.org.uk/news/latest-news/item/576->

<http://hellomynameis.org.uk/>

[always-events-toolkit-v6.pdf \(england.nhs.uk\)](#)

<http://www.respectprocess.org.uk/>

[Triangle of care](#)