Patient, carer and public involvement strategy
2019-2023
engage / support / develop

Wellbeing for life
With thanks
We would like to thank the many CNWL patients, carers and staff members who worked together to create this document.

A note about language
In this document, we use the terms ‘involvement’, ‘partnership approach’ and ‘partnership working’ because these are words that people can understand and they explain what we’re trying to achieve.

We refer to ‘patients’ and ‘carers’ because the patients and carers who helped produce this document preferred these terms. We also felt that these words work well for people using physical health services as well as mental health services. We recognise that ‘service users’, ‘family and friends’, ‘survivors’ and ‘experts by experience’ are popular and useful terms too.
Patient, carer and public involvement strategy
2019-2023

A partnership approach for patients, carers and staff

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Foreword

Welcome! We’re excited to present our strategy for improving the way that patients, carers and staff work together from 2019 to 2023. This document has been produced by the CNWL Patient and Carer Involvement Team, the Patient Involvement Forum and the Carers’ Council, with input from other patients, carers, Third Sector organisations and CNWL staff. This strategy applies to all CNWL services and the children, young people, adults and families who use them.

We’ve written this strategy because we believe that the best health services are ones that are planned, shaped and delivered by patients, carers and staff working together. People with lived experience of health services understand what works well and what doesn’t, so we want to increase the role they have in the design, delivery and improvement of services.

There are already excellent examples of carers, patients and staff working in partnership in CNWL. People with lived experience are working in clinical settings, joining in with collaborative projects and making decisions in boardrooms. Our partnership working is making a huge difference and changing the way we work, but we want to build on this and do more. We want to create further opportunities for involvement so that more people and services can benefit from this. We want to improve the quality of involvement activities too. We will move away from the ‘tick box’ culture that some people still experience, towards a genuine partnership approach, where involvement is well planned and power is more equally shared.

We believe that this strategy will help provide a future where CNWL maintains the best possible services, improving the wellbeing of patients, families and communities.

We hope that whether you are a patient, service user, carer, member of the public or staff member, you’ll get involved and help us deliver our vision. By working together as one, we believe that great things can happen and we hope you will join us on this journey.

Members of the CNWL Carers’ Council and Patient Involvement Forum

Supported by:

Robyn Doran
Chief Operating Officer, CNWL

Maria O’Brien
Chief Nurse, CNWL
Our vision

Between 2019 and 2023 and in line with national NHS policy, we will develop, support and expand a partnership approach between patients, carers and staff across CNWL services. We will increase partnership working opportunities for staff, patients and carers and put involvement at the heart of the way we design, improve and deliver services. On the following pages you’ll see the details of what we plan to do and what we hope this will achieve.

What is patient and carer involvement?

There are many different ways that patients, carers and the public can influence health services and here are some commonly used terms:

- Inclusion
- Coproduction
- Collaboration
- Partnership working
- Consultation
- Big I little i
- Improvement
- Co-design
- Engagement
- Participation

These words have different meanings and different methods to follow. We will be producing guides to some of these in the future.

Whatever form it takes, we believe that involvement should:

- Happen at the earliest possible stage
- Value diversity, reflecting the CNWL patient and carer population
- Enable patients and carers to use their influence and power
- Be valued by the Trust
- Be considered ‘business as usual’ at all levels of CNWL, with support from senior leaders
- Be well planned, with clear roles for everyone involved
- Be recognised and rewarded in a fair and transparent way
- Be used to improve and develop services
- Be monitored and reviewed to see what impact it is having.
What is a partnership approach to involvement?

A partnership approach means supporting:

- Closer working between patients, carers and staff
- Better partnerships across different staff teams
- Closer collaboration between carers, patients, staff and community networks.

“When we say partnership working, we mean patients, staff, carers and the public working together to make sure that CNWL services are of the highest quality.”
What is good about partnership working?

**Better services**

“Engaging people in evaluating, designing, improving and overseeing services can have great results because people with lived experience provide a unique perspective – some would say the most helpful view of all.”

“Engaging people with lived experience in projects to improve CNWL services has been transformative.”

**Greater wellbeing**

“When involvement goes well, it can lead to greater wellbeing, confidence and satisfaction for the service user.”

**Improved patient and carer experience**

“People who are fully informed and involved in decisions about their care and treatment are more likely to have a good experience.”

**Stronger connections**

“Partnership work reminds us all that we have plenty in common and we are all more than the label, diagnosis or job title we happen to have.”

“Involvement work can strengthen the links between local services, people and their communities.”

**Meeting national policy and legal requirements**

“Good quality patient and carer involvement helps us meet legal and best practice requirements.” (See resources on page 15 for further information)
How will our partnership approach work?

CNWL’s Patient and Carer Involvement Team, Carers’ Council and Patient Involvement Forum will work with other patients, carers, staff and local community organisations to deliver a partnership approach. Our ultimate aim is to improve engagement and create more opportunities for people to work together as equal partners. Some examples of different levels of working are below:

**Equal Partnership**
- Patients, carers and staff having an equal say in CNWL policies and genuinely influencing practice
- Patients, carers and staff working together to design, improve, oversee and deliver services
- Staff valuing the expertise of patients and carers as equal to the expertise of staff, and vice versa
- Patients and their carers leading in decisions about their own care and treatment
- Patients and carers leading in involvement, quality improvement and research activities, with staff supporting and facilitating this where helpful

**Engaging**
- Engaging patients, carers and the public in activities, committees, projects, research studies and forums
- Listening to and taking action on what patients and carers say about services or their individual care
- Using the expertise of patients and carers to help recruit, influence and train staff

**Informing and Consulting**
- Communicating clearly with patients, carers and the public
- Notifying people about changes to services
- Asking people what they think about CNWL services
- Strengthening links with local organisations and community groups
What are we already doing?

Patient and carer involvement

• Patients and carers are on many boards and committees
• Patient stories are used in board meetings and in staff training
• Patients and carers speak at many CNWL events, including our Annual General Meeting and the festivals held in different divisions
• We involve patients and carers on many staff recruitment panels
• We have patient and carer involvement groups across CNWL, where people are actively involved in designing and running events, workshops and training sessions
• We have social, supportive and educational groups for patients and carers including groups led by people with lived experience.

Experience and feedback

• We respond to concerns, compliments and complaints received by our Patient Feedback and Complaints Service
• We collect feedback from patients and carers using the Friends and Family Test
• We take part in many national and local surveys of patient experience
• We use ‘You Said, We Did’ display boards and reports to explain how we are acting on feedback
• We have improved patient and carer experience, with campaigns such as ‘hello, my name is…’ and the LGBT+ lanyard scheme where staff sign up to become a safe listening ear for patients and staff.

Staff partnership

• We have a dedicated Trustwide Patient and Carer Involvement Team, as well as staff dedicated to leading our Peer work and Recovery-focused work
• We were one of the first NHS Trusts in the UK to set up a Recovery and Wellbeing College, where people with lived experience collaborate with other staff to run high quality courses open to patients, carers and staff
• We have a growing number of Peer Workers who have been trained to use their lived experience of recovery to support the delivery of clinical work and/or Recovery and Wellbeing College courses. As a Trust we have been recognised for our innovative work in this area
• We have created diverse staff networks that includes support for staff with disabilities, staff who are carers and staff with lived experience of mental health issues
• We have a User Employment Programme, to help people find work placements and employment
• We have many volunteers and staff members in the Trust who have lived experience of using services or caring for someone who has.
What are we going to do next?

Partnership Approach Action Plan

To deliver our Partnership Approach we have created a four year action plan to develop, support and expand partnership working to:

- Empower staff, patients, carers and other stakeholders to take part in more partnership working
- Make sure that the quality of partnership working gets better every year
- Create a culture where partnership working is embedded across CNWL.
1. To support opportunities for partnership working, we will **develop**:

- A single point of contact for staff, patients and carers to seek advice on involvement
- Information for patients, carers and the public about how to get involved in CNWL activities
- A database of patients, carers and members of the public who are interested in partnership working
- A database of key CNWL staff involved in partnership working
- A Trustwide Volunteer Service with a dedicated manager.

2. To create best practice in partnership working, we will **develop** co-produced guidance, training and protocols for staff on:

- How to recruit patients and carers and provide them with a good induction
- How to involve people meaningfully in a range of activities, including committees, research projects, Quality Improvement (QI) projects, staff interview panels and others
- How to pay and reward people for their time
- How to provide people with support and opportunities for development
- How to set up a patient and carer forum
- How to set up social, creative and recreational groups for patients and carers
- How to involve people from groups and communities that are currently under-represented.

3. To expand partnership working, we will **develop**:

- An up-to-date list of partnership work taking place across CNWL
- Agreements with service, borough and divisional leads on how to expand and monitor partnership working
- Closer links between the Patient and Carer Involvement Team and other areas of CNWL including peer support colleagues, the Quality Improvement Team, CNWL Recovery and Wellbeing College, the User Employment Programme, research colleagues, the Equality Diversity and Inclusion Team, Safety Team, CNWL staff networks and Human Resources
- Closer links with local patient and carer networks, community groups, research groups and third sector organisations.
4. To **develop** the skills of patients and carers we will create:

- A guide to being involved in CNWL activities and a clear induction process
- Individual skills passports for patients and carers, so that skills can be developed over time
- Information for patient and carers on different involvement methods and how to influence others
- Training opportunities for patients and carers, for example in Quality Improvement, research, co-production and other involvement methods. Some of this is likely to be delivered by the Recovery and Wellbeing College.

5. To **expand** and **develop** patient and carer influence we will:

- Involve patients and carers in planning and delivering more staff training, including leadership training
- Include patient and carer stories in more meetings and workshops
- Form a small panel of patients, carers and staff to advise on CNWL documents, leaflets and policies
- Review the terms of reference for the Patient Involvement Forum and Carers’ Council and promote these groups through communications and events
- Increase the number of patients and carers involved in staff recruitment
- Train more patients and carers in Quality Improvement (QI) methods
- Increase the number of patients and carers on QI projects.

6. To **expand** the use of patient and carer feedback we will:

- Make sure that everyone knows how to give feedback and make complaints
- Make better use of creative ways to collect feedback from patients and carers, including often overlooked groups
- Provide support and training to staff to help them respond to feedback and complaints and report on what action is being taken.
7. To support a better carer experience we will:

- Help CNWL services meet the Triangle of Care standards
- Create carer’s awareness training for staff across the Trust, co-delivered by carers and staff
- Co-produce information packs for carers, for both community and mental health services
- Provide clearer information about how people can access carers’ assessments and support in the community
- Make sure that CNWL policies and procedures address the needs of carers
- Consult with young carers about their experience of CNWL services.

8. To share ideas across CNWL we will develop:

- A regular involvement newsletter written by patients, carers, staff and members of the public
- Regular events bringing together patients, carers and staff, including a regular Carers’ Conference and regular Patient Conference
- Greater use of social media to share ideas
- An annual summary of our involvement work.

9. To support and celebrate excellence we will create:

- Awards for volunteers and patient and carer contributors
- Ways to celebrate achievements through events, reports and communications.
Who will oversee this?

The Patient and Carer Involvement Team will be responsible for overseeing the work, working closely with patients, carers and staff to make sure we deliver on our promises and to regularly report on progress.

How will we monitor progress?

We will keep you informed and involved as we develop and deliver our action plan by:

- Keeping track of which actions are being delivered and reporting this back to our Patient Involvement Forum, Carers’ Council and CNWL quality and safety meetings
- Asking patients, carers and staff what impact this strategy is having
- Reviewing the strategy and making changes where needed

How can I get involved?

Please contact the CNWL Patient and Carer Involvement Team at involvement.cnwl@nhs.net or by calling Grace Levy or Lucy Palmer on 020 3317 3735 or 020 8637 6195
Useful links and further information

• 4Pi National Involvement Standards (https://www.nsun.org.uk/FAQs/4pi-national-involvement-standards)

• Beyond the usual suspects, towards inclusive user involvement, Peter Beresford, Shaping Our Lives (https://www.invo.org.uk/beyond-the-usual-suspects-towards-inclusive-user-involvement/)


• Coalition for Collaborative Care – Co-production model (http://coalitionforcollaborativecare.org.uk/coproductionmodel)

• Experienced Based Co-design Toolkit (https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/)


• In Health – Engagement Cycle Model (http://engagementcycle.org/introduction-to-the-engagement-cycle/)

• The Kings Fund – Patients as Partners (https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Patients_as_partners.pdf)


• NHS Improvement Patient Experience Improvement Framework (https://improvement.nhs.uk/documents/2885/Patient_experience_improvement_framework_full_publication.pdf)

• NIHR – Patient Public Involvement Resource (https://www.rds-london.nihr.ac.uk/Patient-Public-Involvement/Resources.aspx)

• Patient Experience Journal (https://pxjournal.org/journal/)