

# Together:

## Service user and carer involvement strategy



## Background

This strategy builds upon the previous Service User and Carer Involvement Strategy (2016).

The involvement and engagement of service users carers and staff has been implicit throughout the development of this strategy. This has been achieved through joint workshops, discussion groups and development sessions. Across all of the engagement events conversations have been encouraged amongst people in attendance to consider and respond to the following key questions:

- What does ideal involvement look like?
- What has worked well/not worked so well in the past?
- How do we get to where we want to be?

## Context

The NHS five year forward view says that we need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services. The latest report from NHS England states ‘Making progress on our priorities and addressing the challenges the NHS faces over the next two years cannot be done without genuine involvement of patients and communities.’

Traditional approaches to the way we deliver care arguably emphasises the expertise of health and care workers. It is important to acknowledge that there are two sets of experts: experts who have professional training and acquired experience, who make the best use of research and theories and experts who have personal lived experience of distress (or of caring for a loved one) and recovery, discovery and resilience.

It is important that we recognise expertise by lived experience on equal terms as professional expertise. This suggests a different kind of relationship between health professionals and service users.

### It's about involvement:

- Ensuring that service users and carers are at the heart of everything we do
- Sharing knowledge and expertise
- Working with service users and carers as equal partners

### NHS England defines service user and carer involvement as:

- ‘The process by which people who are using or have used a service become involved in the planning, development and delivery of that service.’

## Our definition of involvement:

When we asked people 'what is involvement?' they said:

- Wherever possible service users and carers collaboratively work **together** with staff in the design, delivery and development of services (**Service design and delivery, workforce**)
- Service users, carers and staff work **together** to make sure that the Trust is able to deliver and develop services that are safe, effective, caring, responsive and well-led (**What's working well and why?**)
- It's about dialogue: being listened to, feeling valued, sharing our views, coming to a mutual understanding, making decisions **together** and working **together** to implement solutions and developments (**Communication**)
- Service users, carers and staff work **together** to make sure that the people we employ share our values and have the skills that are required of them to do what is needed and to develop our work (**Recruitment and selection and training**)
- Service users, carers and staff are **together**, recognised as leaders and given equal opportunity to develop their leadership capabilities (**Leadership**)

When we asked people to identify the signs that involvement is working, they said:

**"It's about a change in culture: We need to see and feel that things are different. This should be demonstrated through the words and actions of everyone."**

## Involvement is about making sure that we

- Devolve power, choice and control to people using services, their carers, communities and to frontline clinical staff. It's about us all working together
- Regard the people who use and deliver our services as an asset, as contributors, as a resource
- Encourage service users, carers and frontline clinical staff to take more responsibility and to share the responsibility for the way we deliver care and manage our services together
- Do all that we can encourage active participation in all that we do

### Involvement is not about

- Asking for service users and carers opinions on ideas, plans, or proposals developed by health and care staff
- Offering choice between options developed by health and care staff
- Asking service users and carers 'what do you want?' with the expectation that health and care staff will be expected to deliver this and then defending your inability to deliver by saying, 'yes, but...'
- Inviting 'one or two' service users or carers onto committees or interview panels
- Defining this group of people only by their status as 'consumers' of services and not by the attributes they may have

### Why is this strategy of relevance, now?

The Trust's strategy, **Caring, Discovering, Growing: Together** highlights both the challenges and opportunities that we need to address over the next five years. This means everyone working differently and 'smarter'. It means altering or completely reshaping services giving people better quality and experience for less money. It means reinvesting any money saved in more and better services and so extending access to care. Only by getting everyone involved and working together, will a network of services be provided which can meet the changing needs of people in the 21st century within the limits of the budgets available. Our Trust is committed, as part of this strategy to work with service users and carers in partnership, to provide excellent care, supporting people on their personal journey to wellbeing.

**'Service users and carers should be at the heart of everything we do and getting this right is the single most important thing we can do to achieve our strategic ambitions.'**

NTW Five Year Strategy, 2017

# Together, service user and carer involvement strategy - strategy on a page

Our seven strategic ambitions:



## **Embedding the strategy: Making it feel real**

Strategies feel real when they become embedded into the way we work; when people start to take practical actions.

1. The first step is to talk to others about the strategy, to have conversations together. Not everyone will agree with the content and some may perceive the ambitions as a threat to the way they work.
2. The second step is for each and every one of us to think about what each of the ambitions means and to reflect on what we might need to do in order to achieve our ambitions. Change happens because we want it to.
3. The third step is for groups of service users, carers and staff to talk about the strategy together. To agree on and to develop joint actions. To work together.
4. The fourth step is for the organisation, as a whole, to think about what it might need to do differently, in order to support the embedding of the strategy. Staff should not do this in isolation however, all staff (including corporate and business teams) need to think about how they involve service users and carers, as equal partners, in this work. Working together.

Along the way we need to bring people with us, we need to embrace and support each other and recognise that change means different things to different people. This strategy will challenge the beliefs of some people. We cannot legislate for its implementation. Change will happen because the time is right and because people want to change.

## **How will we know we have made a difference?**

We have identified a series of strategic ambitions that identifies the way forward, and have emphasised the importance of everyone making sure that the doing of it, is part of their business. So far we have heard about many practical suggestions from those of you who have attended some of the engagement events that might help us to embed the strategy; to make it real. We don't want to be prescriptive about this though. We want you to drive these changes. We will do what we can to support you and our Council of Governors and Board of Directors will ensure that we are able to deliver on it.

**These are peoples comments on developing the strategy. When we asked people to identify how we might achieve each of the strategic ambitions, this is what they said:**

### **Service design and delivery – this is what we heard:**

#### **What does ideal involvement look like?**

- Service users and carers are involved, as equal partners, in the design, delivery and evaluation of the way that care is provided

#### **What has/has not worked in the past?**

- Has: Some good examples of work e.g. recovery colleges
- Hasn't: This is not locally consistent

#### **How do we get to where we want to be?**

- Harness and learn from examples of good practice and build on it
- Grass roots involvement of service users and carers in all aspects of the way that care is shaped and delivered
- This ambition needs to be owned by everybody; built into the personal objectives of staff and teams, and we need to give serious consideration as to how we can nurture and support service users and carers to feel like they can make a difference and learn from their experiences, good and not so good

### **Training – this is what we have heard:**

#### **What does ideal involvement look like?**

- Service users and carers are involved in the design and delivery of training and development initiatives

#### **What has/has not worked in the past?**

- Has: Examples of successful initiatives involving service users and carers leading on or co-producing training
- Has: Recovery college volunteers
- Has: Service user deliver insight/awareness into the pathway for individuals, tell the story, make it real at the Carer Champion Forum
- Hasn't: Some examples of good work but this is not consistent; not enough opportunities

#### **How do we get to where we want to be?**

- Go back to the beginning, grass roots, get the basics right
- Involvement needs to be at the heart of training and development initiatives



## **Communications – this is what we have heard:**

### **What does ideal involvement look like?**

- Service users and carers help shape the way that we communicate – helping to develop effective, accessible, targeted, meaningful and jargon free methods of communication

### **What has/has not worked in the past?**

- Has: Service user involvement in the 'Write To Me' pilot to reduce the jargon and the ensuring that letters are sent to them first and copied to the GP
- Hasn't: Some good examples of work but this is not consistent
- Hasn't: Communication is often jargon laden and 'hit and miss,' it is not always easy to speak to the right person at the right time

### **How do we get to where we want to be?**

- Harness and learn from what is good and build on it
- Involvement in the design and delivery of the Trust's communications strategies, communication tools and initiatives

## **What works well and why - this is what we have heard:**

### **What does ideal involvement look like?**

- Service users and carers are involved, as equal partners, in all aspects of the assurance process - to ensure that our services are safe, effective, caring, responsive to people's needs and well led
- Examples of monitoring and evaluation initiatives could include meaningful involvement with Points of You questionnaire and the Care Quality Commission (CQC) inspection process

### **What has/has not worked in the past?**

- Has: Service user identified for each ward area to assist in collecting feedback
- Hasn't: From the engagement work completed to date, few examples have been given. Question was asked; has service user and carer monitoring become a thing of the past? Clarity over what the word 'assurance' means was requested

### **How do we get to where we want to be?**

- Grass roots involvement of service users and carers in all aspects of the assurance, monitoring and evaluation process; what's working well and why?



## **Recruitment and selection - this is what we have heard:**

### **What does ideal involvement look like?**

- Service users and carers involved in all aspects of the recruitment and selection process – designing jobs and job adverts, and developing interview questions, being on panels, being informed of outcomes

### **What has/has not worked in the past?**

- Has: Some involvement in designing questions and on panels
- Hasn't: This is not consistent

### **How do we get to where we want to be?**

- Involvement should not be an afterthought
- Develop a bank of people who want to and can be involved

## **Workforce - this is what we have heard:**

### **What does ideal involvement look like?**

- Service users, carers and staff have lived experience, and are valued for their unique insights and acquired expertise
- Service users and carers are employed on the basis of the contribution that they can make

### **What has/has not worked in the past?**

- Has: Employment of peer support workers
- Has: Time to Change campaign
- Has: Volunteers participating in recovery colleges

### **How do we get to where we want to be?**

- Review/revise recruitment and selection processes
- Grass roots involvement of service users and carers in workforce planning, policies and procedures

## **Leadership - this is what we have heard:**

### **What does ideal involvement look like?**

- Leadership development has a key role to play in improving our ability to deliver great care. Service users and carers have unique insights and acquired expertise and need to be embraced, as equals, as leaders
- Leadership development initiatives should be open to and directed at enhancing the capabilities and maximising the contribution of service users and carers

### **What has/has not worked in the past?**

- Has: Successful programmes developed and provided for over 140 people in past five years
- Has: We have a dedicated resource and a committed number of people who want to make this work
- Has: We have more initiatives planned and have network of service users, carers and staff working on this, supported by key organisational leaders
- Has: The Trust is leading the way regionally and asking the local leadership academy to support the development of leadership initiatives for service users and carers
- Hasn't: Joint programmes comprising service users, carers and staff have not always worked well

### **How do we get to where we want to be?**

- Continue to co-produce leadership development initiatives open to service users and carers
- Ensure service users and carers are afforded the same opportunities as staff, and that this is backed up at a regional and national level

## Glossary of terms used:

**Co-production** - Co-production is where service users, carers and staff share power to plan and deliver services together, recognising that both partners have a vital contribution to make. Co-production acknowledges that service users and carers are experts in their own circumstances and capable of making decisions, while professionals must move from being fixers to facilitators. Co-production requires a relocation of power towards service users and carers. Where activities are co-produced, both services and communities become far more effective agents of change.

**Engagement** - Engagement is about understanding and involving the different groups interested or impacted by the work you do, and building relationships with them. The purpose can be to develop a long-term conversation and dialogue, or to reach a specific goal through collaboration. But good engagement isn't a tick-box exercise – it needs to employ different routes and techniques to reach groups and make sure they are involved. Engagement is about listening, hearing and attending to needs and by doing so we value, care for and respect others.

**Equal partners** - Ensures that the people who use our services, our staff, partner agencies and the wider public are fully engaged and involved in all aspects of the planning, shaping and delivery of our services; and that individuals are fully involved in their own care and support. Equal partners covers many levels of involvement and inclusion, each implying a different level of relationship between service providers, patients/service users, carers and citizens.

**Inclusion** - Inclusion is 'the state of being included.' It is used by rights activists to promote the idea that all people should be freely and openly accommodated without restrictions or limitations of any kind. It is described by some as the practice of ensuring that people feel they belong, are engaged, and connected. It is a universal human right whose aim is to embrace all people, irrespective of race, gender, disability or other attribute which can be perceived as different.

**Involvement** - Service user involvement is the active participation of a person with lived experience of distress in shaping their personal health plan, based on their knowledge of what works best for them. As the wider benefits of inclusion have become apparent and recognised, it has also come to mean the active inclusion of the perspectives of service users collectively in the design, commissioning, delivery and evaluation of services, as well as in policy development locally and nationally. This has been the accepted definition for many years, though progress towards achieving genuine service user involvement across the health sector has been gradual.

## Get Involved

Sign up to become a Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust member

 [www.cntw.nhs.uk/membership](http://www.cntw.nhs.uk/membership)

 0191 245 6827

 FREEPOST NTW MEMBERSHIP

Membership is completely free and as a member you can:

- Give your views on the Trust's plans and any issues that interest you
- Vote in the governor elections or stand as a governor yourself
- Receive regular information about the Trust

Service users and carers can register their interest with the Involvement Team, in order to be made aware of and get involved and bring their expertise to future activities and evaluations being undertaken within the Trust.

Contact us on:

Telephone: 01670 501 816 or

Email: [involvement@cntw.nhs.uk](mailto:involvement@cntw.nhs.uk) for further information.

**If you would like to know more about the  
Service user and carer involvement strategy please contact:  
Patient and Carer Involvement Team: 01670 501 816**

© Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust

UP PIC - November 2019 V3