

Listening, involving, acting?

A review of service user experience and involvement

Summary report based on a full report by Professor Mark Gamsu, Leeds Beckett University

First Published: March 2019

Introduction

Leeds and York Partnership NHS Foundation Trust is committed to putting service users and carers at the heart of everything we do. To ensure that we are doing this in the best way, we asked Professor Mark Gamsu from Leeds Beckett University to look at how people currently share their experiences of our services and how they are involved in the Trust, and make suggestions about how we can improve.

We want this piece of work to help us to be clear about how we involve our service users and those close to them, so we can develop a plan that shows how we will do this and the resources we will use to make sure that it is effective.

In order to fully understand how the Trust involves service users and carers and ensures that their experiences are shared and heard to improve services, Professor Gamsu came into the Trust and held a series of interviews, conducted surveys and reviewed a number of reports and documents.

The Trust asked Professor Gamsu to:

- understand the ways that service users and carers share their experiences at the moment
- review the Trust's current processes for involving service users, carers and members of the public
- look at the resources and support that the Trust gives to involving service users
- suggest ways that all these things could be improved

What does service user involvement mean?

When we say involvement, we mean the way that service user experience is shared. It is about making sure that our services, activities and policies are shaped by the people best placed to know what works – our service users and those closest to them. They are experts by experience. This is important, because the more a service user is 'involved', the more likely they are to use their experience to improve our services and get better outcomes from their own care and treatment.

The NHS sets out a framework for how Trusts should involve people well:

- senior leaders should be committed to involvement, and this should show in their words and actions
- all staff should be focussed on their service users and want to help to improve services for them
- there should be several ways for service users to give feedback
- the Trust should have a good process for looking at and understanding feedback, and should consider it alongside other information, like safety data
- the Trust should always ask for service user feedback, and use it to improve services

Why should the Trust involve service users?

Quite simply, listening to the experiences of our service users and carers and involving them in the continuous improvement of services is the right thing to do.

This is particularly important for our Trust, as the mental health and learning disabilities services we provide mean that many of the people we support will be supported for a long time. People might also find it hard to share their experiences because of their mental health or learning disability.

The NHS sees service users as a very important part of healthcare, and advice and guidance as to how involve them in Trust business is included in a number of its key plans.

Service user experience

There are a number of ways that service users and carers can give their feedback to the Trust:

Friends and Family Test

The Friends and Family Test, or FFT, is compulsory for all NHS service providers. Feedback is collected on a monthly basis. The test asks the following questions:

We would like you to think about your recent experience/s of our team/service

- How likely are you to recommend our wards/service/team to friends and family if they needed similar care or treatment?
 - Extremely likely
 - Likely
 - Neither likely or unlikely
 - Unlikely
 - Extremely unlikely
 - Don't know
- Overall, how would you rate the care you received from us?
- What has been good about the service you have received?
- What could be improved?

The Trust has a low response rate of 0.5 percent for the FFT. The average response rate for mental health trusts in the country is 3 percent.

National surveys

The Trust takes part in two national patient experience surveys:

Community Mental Health Survey

This is a compulsory survey by the Care Quality Commission (CQC). The survey takes place every year and shows how our Trust is performing against other trusts.

Inpatient Survey

In 2017 the Trust came together with 18 other trusts to take part in a service user experience survey. It compares the Trust's performance with other trusts.

Patient Advice and Liaison Service (PALS)

The Patient Advice and Liaison Service, or PALS, is confidential and free and helps to guide people through the different services available at the Trust. The team can help find ways to resolve any concerns people may have about the care being provided by our Trust, and is available to anyone who wants more information about services and support groups.

The team is based at The Becklin Centre but the staff go out and about across the Trust to speak to service users and carers. They also work with organisations outside the Trust, and attend patient experience meetings, HealthWatch complaints meetings and liaise with Leeds Independent Health Advocacy. The team supported 1800 people last year.

Interactive feedback

The Trust provides a number of ways for people to leave feedback, comments, reviews, complaints and compliments. This is mainly done through the website, which links to PALS, Care Opinion and NHS Review. People can leave feedback anonymously if they wish.

Involvement

There are a number of ways that people can be involved with the Trust:

Membership

As an NHS Foundation Trust we have freedom from central government which allows us to shape the future of our services locally to meet the needs of service users and the local community. People can help to shape the future of services by becoming a member.

Anyone over 16 can become a member of our Trust including service users, their friends, family or carers. Members are split into constituencies depending on where they live and whether they are:

- a member of staff
- a service user
- a carer (or friend or family member of a service user)
- a member of the public

The Trust has approximately 15,000 members. Nine thousand of these are members of the public, 2500 are staff and 3,400 are service users and carers. The members are represented by the Council of Governors.

Council of Governors

The Trust's Council of Governors has 30 members. Ten places on the Council of Governors are specifically for service users, and eight are reserved for members of the public.

Volunteers

The Trust has a current network of 144 volunteers, of which 43 are service users and 24 are carers. Service users and carers are also involved in the Trust-wide research group and in staff recruitment through the People's Panel.

Service User Network (SUN)

The Service User Network (SUN), and SUNRAYs groups, encourage people to express their views, share their experiences, explore what works well in our Trust and provide valuable feedback around areas which may need improvement. It encourages people to get actively involved with both their own care and treatment, and in future developments within the Trust. Members of staff with lived experience are also welcome to attend. The review found that the meetings are run in an inclusive way which promotes discussion and involvement. It is unclear whether the meetings are a good example of genuine involvement or whether they simply provide an opportunity for people to meet socially and talk about issues of concern.

What Professor Gamsu's review found:

- opportunities for sharing stories and experiences are more powerful than simple scores
- national surveys have limited value, as they only take place once a year and very few service users take part
- some areas, such as PALS, are well connected and active
- the Trust's responses to online comments and feedback have improved and become more personalised
- the Friends and Family Test question is too general, and because it is not specific enough to Trust services, it is of little value
- Care Opinion could be made better by increasing the number of people who use it and respond to it
- there are a range of channels that provide meaningful up-to-date information, including NHS Reviews, PALS, Care Opinion, complaints and compliments
- people can share their views through a range of off- and online channels, including digital, face-to-face, IT with support, telephone and paper based
- SUN and SUNRAYS groups are run in an inclusive way that promotes discussion and involvement
- the feedback and data is given and gathered at a Trust level, rather than a service level, and so it is hard to tell how well the Trust is hearing from specific groups of service users or carers

As part of the review, Professor Gamsu interviewed a number of people, including senior leaders, service managers and clinicians. He also spoke to people in outside organisations with an interest in experience and involvement. Many examples of good practice were highlighted in the

interviews, including a good use of patient experience and involvement in care plans. Other examples of good practice included:

- Learning Disability Service, who employ some experts by experience
- Personality Disorder Network, who use user involvement and feedback
- Rehabilitation and Recovery
- Annual Members' Meeting
- Mill Lodge young people's forum, which involves young people in service decisions
- Gender identity services employ outreach workers as an alternative way of engaging
- engagement with voluntary groups
- inpatient wards, with 'you said, we did' examples
- Board meetings, which include 'Sharing Stories' sessions
- Triangle of Care is being used on one or two wards
- START, a psycho-social education programme
- family intervention and family work team

There were some concerns however that the Trust does not have a formal strategy, or plan, for how it involves people and listens to feedback about service user and carer experiences.

Without a clear plan, there is a risk that involvement is inconsistent across the Trust, that it is not resourced or supported as well as it should be, and that people whose voice is not as strong, because of their mental health or learning disability, are less likely to be involved.

Conclusions

The review found that the Trust is committed to improving the way it hears about and responds to the experience of service users and their carers. It found that the Trust collects service user experience data from a number of channels, but it needs to find a way for this information to be used to tell a clear story that is up-to-date and relevant to the Trust's services, as well as being in line with requirements from NHS England and the Care Quality Commission.

The Trust involves service users and carers in a number of ways, but they are not coordinated and work separately from each other. It noted that SUN meetings are a way to provide information on a range of issues, to give attendees an opportunity to ask speakers questions, and are a social opportunity for those who attend. However it also found that the SUN was not as strong as it could be for driving service user involvement. There was also a question around whether the Trust was using its relationships with voluntary and community organisations as well as it could.

There are many examples of good practice at work across the Trust, but there needs to be an overarching strategy to make sure that this happens well, and the Patient Experience Team needs to be fully resourced with a clear role and function.

What next?

The Trust wants to refresh, re-energise and strengthen its approach to including people and listening to the experiences of service users and carers. A strategic group will be established who will develop a plan detailing how to do this. The plan will be called the Experience and Involvement Strategy.

The group will be led by the Trust's Director of Nursing, Professions and Quality, Cathy Woffendin, and will include:

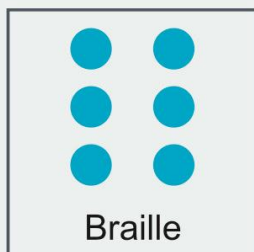
- service users and carers – “experts by experience”
- members of the senior management team
- members of the Council of Governors
- voluntary and community organisations

The group will:

- agree the vision and objectives for service user experience and involvement
- agree what the Trust understands by ‘involvement’ and ‘experience’
- be clear about its ambition to capture experience from all services and groups of people and have a clear plan for doing this
- provide support to service managers to improve practice
- share learning and good practice across the Trust

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