# Access to Mental Health Services

## A Conversation with Service Users and Carers

## February 2019

Talk to us...

healthwatch North Yorkshire

Improving Health & Social Care Together

# Introduction

## What does Healthwatch North Yorkshire do?

Health and social care works best when people are involved in decisions about their treatment and care. But this doesn't always happen. That's why Healthwatch strives to help make sure that those designing, running and regulating health and social care listen to people's views and act on them.

We do this by:

- Making sure you have a say in how health and social care services are provided.
- Gathering information about local health and social care services.
- Listening to people's views and experiences of local services.
- Signposting people to health and social care services across North Yorkshire.
- Providing information about who to talk to if things go wrong.
- Using local knowledge from communities, charities and voluntary organisations to influence service providers.
- Encouraging Health and Social care providers to deliver more joined up services.
- Conducting Enter and View visits to services to ensure best practice.

## The Harrogate Service User and Carer Involvement Group

In September of 2018, Healthwatch North Yorkshire was invited to the Harrogate Service User and Carer Involvement Group to conduct an hour-long focus group about the experiences of individuals accessing mental health service in the area.

At present, services are provided in the area by Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) and commissioned by Harrogate and Rural District Clinical Commissioning Group (HaRD CCG). HaRD CCG *purchases* the services (for example, community mental health care or substance misuse services) that TEWV *delivers* to local people. The Harrogate

Service User and Carer Involvement Group is hosted jointly by TEWV and North Yorkshire County Council.

The following focus group was structured as a broad discussion with a group of eleven individuals and letting the conversation flow as naturally as possible. It was assisted by Lizzie Rosewood, Voluntary Independent Chair, who ensured that every person with a comment had a chance to speak without interruption. The conversation was recorded with consent to assist with thematic analysis.

For the purpose of this report, it was asked that any CCG, Council or Trust staff members did not attend. The group was comprised of individuals who had lived experience of mental health problems and carers. There were a range of different disorders represented, along with a range of severity. A significant proportion had experience with care in an inpatient unit.

Writing a summary of a discussion like this is an inevitably subjective experience. As Healthwatch North Yorkshire, we have listened to many stories by people using services and this will colour the way that we view any feedback. Our goal in this piece is not to imply that this captures all experiences of care in Harrogate District, but rather to develop a narrative snapshot that represents the opinions of a group of people at one moment. We have done our best to represent what the Harrogate Service User Involvement Group shared with us. Certain quotes have been slightly shortened or altered in order to improve readability, but we have done our best to ensure the original meaning is the same.

A follow up visit was conducted in December so that members of the group could provide feedback about the thematic groupings that were established.

# What Did They Say?

## Services should speak more to each other

The need for greater communication between services was raised in almost every possible combination (e.g., mental health and social care, mental health and physical care, primary care and secondary care, children’s services and adult services.)

Group members described the lack of communication as leading to situations where core parts of their care team were left in the dark about important developments.

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*“I was discharged at half past four, mental health didn’t even know that I’d been in hospital”* – Service User describing an experience of being admitted to hospital for physical care.

*“A lot of the teams don’t communicate with each other. And you have to be… A go between. So, for example, obviously now I have a lot of medical teams involved from my fall… You tell them that you’ve got mental health, everyone*

> *jumps on that bandwagon, she'll need special treatment… It's like you get these labels."* – Service User speaking about working with two teams.

Individuals spoke of being "in the middle of two services" and constantly having to retell and relive their stories, adding to the stress and frustration of their experience. This was also highlighted as a function of high turnover of staff, meaning that even when attending the same service, there was still a need to repeat their stories over and over again.

> *"Every NHS is supposed to be making every contact count. In other words, you tell your story once, and then never again... The gap between primary and secondary is a cliff."* – Service User referring to the Making Every Contact Count (MECC) initiative championed by Health Education England, which lists one of the priorities as "Improving Mental Health and Wellbeing".

When there was a measure of coordination or blending of physical and mental health services, this was highlighted as a very positive experience:

> *"I had a physio appointment a couple of weeks ago… When I said I had a mental health problem, she was on it. And saying, look, do you need any additional support. And this is the first time that I've gone in for a physical problem where I've been offered support and to make sure that my mental health needs were being addressed."* – Service User sharing a positive experience in coordinated care.

In the Five Year Forward View for Mental Health (an NHS document published in February of 2016) "an integrated physical and mental health approach" was listed as one of the priority actions for the NHS by 2020/21 (https://www.england.nhs.uk/mental-health/taskforce/imp/mh-dashboard/).

## Anatomy of a Bad Experience

Narratives about various experiences and interactions were shared individually, but patterns quickly emerged around specific trends in what, exactly, makes for a negative experience.

> *"I was admitted as an emergency. I was suicidal. I was sent by ambulance on my own… They put me in a visitor's room, and they left me. For an hour. With all my medications and lots of things that I could self-harm with when I was suicidal. I didn't. I wasn't introduced to a named nurse, I don't know if I had a named nurse... It was appalling."* – Service User discussing care at the inpatient ward in Darlington.

The same service user shared another experience about going to A&E and being told by a doctor there that she was going to be admitted to an inpatient bed. Despite this, she was sent home by the crisis team several hours later, placed in a taxi while still in her pyjamas.

Another group member volunteered their experience around being sectioned at Harrogate hospital:

> *"I often don't get a chance to say anything before I'm sectioned, because I've been sectioned so many times. Last time I went in it was Friday, couldn't be assessed until Monday, I had no leave. I got an hour's escorted leave, but it couldn't be facilitated because no staff. Next day, two hours, but couldn't be facilitated. So I got twenty minutes with a hospital nurse to go down to the hospital store and get clean knickers and washing powder- the hospital washing powder gave me allergies. That is not care."* – Service user discussing care on Briary Ward.

In each of these experiences, the common thread is that basic personal needs were not considered. Each of the stories shared were not necessarily about clinical care or sophisticated and specialised treatments that did not work; instead, the narratives are clearly about feelings of being ignored.

Similarly, discussed in an earlier section, the need to repeat and detail past experiences was highlighted as a stress that it should be possible to avoid:

> *"Only six weeks or so ago, I was discharged, and I had to go through absolutely everything that's already been through and already ongoing. And six weeks ago, I was told that I have to go through it again. It was like I may as well have not seen anybody before."* – Service User speaking about recent experience in Harrogate.

Lastly, in line with national experiences and many other pieces of feedback across North Yorkshire, service users commented on the long wait times and the gap between needing care and receiving it.

## Anatomy of a Good Experience

It is important to note that not all of the feedback about services were negative. Group members also had many positive and encouraging things to say about their experiences with care. Several individuals stressed that it was important to not let negative experiences dominate the conversation.

> *"My sister has a fantastic coordinator. My son went to podiatry at the hospital and they were fantastic. I supported someone with moderate depression, went to group therapy at one of the hotels, more like giving you coping strategies... so*

> *there is good things about there, there is good people, sometimes we just meet the wrong ones."* – Service User sharing some positive experiences in the area.

The impact of a helpful care coordinator was emphasised multiple times:

> *"It only took three or four weeks to get the right help at the right time. My care coordinator has been absolutely fantastic, she's helped me so much... She's helping me get through a time that's hard for anyone."* – Service User speaking about support after a family bereavement.
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> *"[My Care Coordinator] sees me pretty much every week or every fortnight. I'm seeing a psychologist too. It's taken a while, but I feel like something good is happening."* – Service User speaking about recent developments in their care.

When specifically asked 'what makes for a good experience?' there were several key points that were raised, especially in the context of a stay in an inpatient ward:

- Introduction from a named nurse
- Attentive and kind staff
- Drugs being administered on time
- Regular access to occupational therapies and psychological therapies

The key commonality is that each of these actions prioritise the individual and ensure that they are treated with dignity. In the December follow-up, a service user also emphasised that it is important that organisational cultures of mental health service providers support the mental health of their own staff members.

There were also several positive comments about the work being done in the third sector to support service users, such as MIND and Horizons. This was discussed both in the context of how these services can both support and be independent of work in the NHS.

> *"If you have a service provided by the third sector, there's a bit of hand holding... So you're not let go, it's more like... It's much gentler, a much more person-centred approach to care."* – Service User discussing assistance that they received from MIND.

Before moving on, it is necessary to point out that this report presents the good and the bad as being of equal weight in the discussion, with equal space devoted to discussing them. This does not reflect the reality of the meeting.

> “The good things were seen as exceptional because they stood out, whereas the negative things were much more common than we want them to be.” – Service user at December follow up meeting.

Overall, in the follow-up discussion it was agreed that the negative comments reflected a more standard experience and what is expected, whereas the positive experiences were partially celebrated for their rareness.

## Interacting with the System

Lastly, group members discussed what it means to interact with the system as a whole from the perspective of a service user. Several comments addressed the inherent difference in power:

> *“I feel like no matter what I do, or where I go, ‘oh you’ve got this diagnosis therefore… You don’t understand, or you’re manipulating,’ or… And they do use that lovely word, manipulative, and I’m sorry, I have two degrees, I was a teacher, I know how to communicate.”* – Service User discussing frustrations with not being taken seriously.

When asked if there were others who felt that their diagnosis had been used to ignore their concerns, the response from the room was a soft ripple of laughter. The implication was that this was so obvious that it went without saying.

In the face of this frustration, methods for formally making your voice heard were raised and reiterated by members of the group:

> *“You need to complain because it’s the only way that things are documented… it’s the only way to try and get change.”* – Service User responding to some of the issues raised within the discussion.
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> *“I use my experiences to try and help those that are coming into services… Everything that I stand for has been eroded by your stories. And the reason why I’m so passionate is because at no point have you had any say about your care. It’s been done to you, and it’s been… It’s everything that I’m working against the staff not being, and it’s in my own area, and I feel… The messages that I’m trying to get across aren’t getting there.”* – Service User sharing frustration about working to influence services.

Above and beyond work on a local level, it was also pointed out that it is important to apply the experiences and knowledge of service users to guiding policy on a national level.

> *"The NHS 10 year plan – we know what the problems are, I'm an ex nurse, we know what good practice looks like. Sometimes you have to go higher. Go online and put what you want, learning disabilities, old people, what else."* – Service User urging members of the group to engage with the NHS 10 Year Plan through their online platform.

## Conclusion

At the time when this meeting was conducted, TEWV reached out to Healthwatch North Yorkshire and requested that it not be specifically linked to any potential service changes as no final decisions about a formal consultation had been made. As this seemed a reasonable request, we agreed to keep things very broad.

However, our assumption was that further engagement and consultation would be undertaken before any large decisions were made. Despite this, the HaRD CCG board met in December 2018 and decided to proceed with a recommendation on the basis of engagement that was carried out in June and July of 2018. Our formal response can be found on our website: https://healthwatchnorthyorkshire.co.uk/news/commissioner-and-healthwatch-share-concerns-over-mental-health-provision-in-harrogate/.

The central role of this report is service users' voices; as such, it is not an appropriate place to detail potential upcoming changes. However, at Healthwatch North Yorkshire, we are committed to ensuring that patient voice takes centre stage when changes are being made. In this capacity, we will be monitoring the situation closely and doing more work around this issue in the near future.

At the time service users were not aware of the loss of inpatient beds in Harrogate. The absence of comment around this should be taken in that context.

A copy of this report will now be shared with Tees Esk Wear Valley NHS Foundation Trust, Harrogate and Rural District Clinical Commissioning Group and North Yorkshire Health Scrutiny and then published on our website.

*Do you have any comments that you would like to make to Healthwatch North Yorkshire about your experiences in health and social care? We can be reached online at healthwatchnorthyorkshire.co.uk, or you can phone our office at 01904 552 687.*

Healthwatch North Yorkshire

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