Making Our Voice Count

Suffolk user forum

Our Feedback

1st July 2021 - 30th September 2021

Foreword: This publication has been made possible through the feedback received from service users and family carers who have trusted us to share their very personal lived experiences of mental health services. Thank you to everyone for your time, involvement, and feedback, your feedback has been invaluable and will make a difference.

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Making Our Voice Count

Suffolk User Forum (SUF) is in the unique position of being the main charity that represents the independent voice of mental health service users in East and West Suffolk. We gather, collate, and analyse service user and family carer feedback to promote service improvement. Commissioners and service providers understand the importance of feedback from people who have lived experience of their services, and our feedback is used to review and improve services provided. SUF is recognised by commissioners and service providers as an independent user led organisation that enables service users' voices to be heard, facilitating opportunities for coproduction. This report provides feedback for the period 1st July to 30th September 2021.

Feedback has been received through our engagement work with service users, family carers, SUF community members, our mental health advocacy, professionals, and service users volunteering within Mental Health (MH) services, and from other contacts including our information and signposting service. SUF receives feedback via phone calls, virtual meetings, email, social media and via our online feedback form on our website.
By connecting areas of individual feedback together, we have drawn together the key themes and emerging trends for people receiving Mental health care and support during this period, as well as views about the development of future mental health services in East and West Suffolk.

This includes feedback from SUF's wider role in supporting service users in coproduction with providers; and our partnership work for suicide prevention and SUF's role as a coproduction partner for mental health transformation in East and West Suffolk, known as #AVeryDifferentConversation. For the purposes of this report, our feedback is categorised in the following ways:

POSITIVE - Where people have reported their experiences as being positive, helpful, and meeting their needs.
NEUTRAL - Where people have shared views that are neither negative or positive, but are more of an observation on a service, an idea for development or recommendation for best practice.
NEGATIVE - Where people feel they have not been listened to; that the quality of care or service has been poor or has not fully met their needs or expectations.

Our report contains some statistical information. Where we have received a range of feedback about a service, we provide, with permission, anonymised stories that describe both positive and negative experiences. Our conclusions are evidence-based and aim to be objective, balanced, and fair. This report is set out in two main feedback areas, primary care, and specialist mental health services provided by Norfolk and Suffolk NHS Foundation Trust NSFT).

Feedback at a glance

Opinion of Services from **148** pieces of feedback

- Positive = 19 (13%)
- Neutral = 0 (0%)
- Negative = 129 (87%)

Between 1st July to 30th September 2021 SUF has received 148 individual experiences of mental health care. Across the mental health system, we continue to see a decrease in positive feedback which has further reduced to 13% this quarter. Negative feedback has increased to 87%. Key themes from all feedback received:

• Positive experiences of using online GP registration forms and the kindness of GPs. Service users reported a positive experience of the First Response Service appreciating the kindness of staff who valued them, listening, and supporting them when in distress.

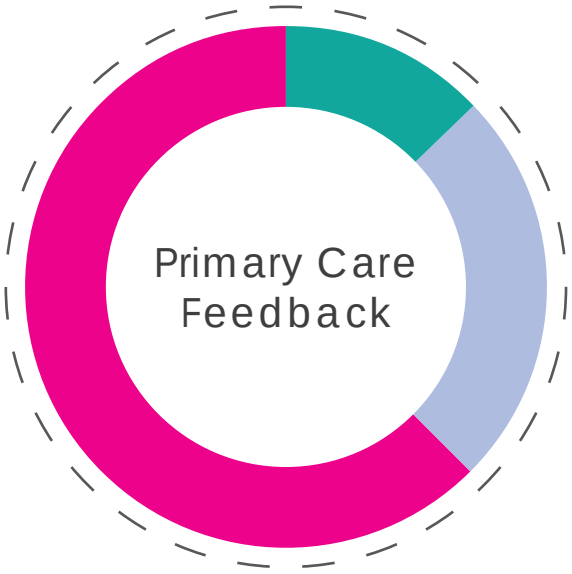
• We continue to receive feedback about the unmet needs of people living with personality disorders, eating disorders and the mental health needs of young people (under 25 years).

• Service users raised concerns about the support provided by the Integrated Delivery Teams (IDT) and in particular Ipswich IDT (Mariner House), stating that they do not feel listened to, reporting poor communication about treatment, changes in treatment plans and support without their involvement, including discharge for 'non engagement' in treatment plans.

• Whilst we received positive feedback about inpatient wards, there has been a significant increase in negative feedback, with concerns raised about staffing levels and staff attitude. Inpatient's reported feeling ignored, unable to ask staff questions. They reported not receiving one to one time and a lack of involvement in care planning. Inpatients said they did not receive information they needed to understand their legal rights or to access advocacy services. Family/parent carers stated that they needed to be more involved in their loved one's care and discharge planning.

1. Primary Care Feedback

Mental health support provided at your GP surgery or medical practice and local community support



Opinion of Primary Care from **11** pieces of feedback

- Positive = 4 (36%)
- Neutral = 0 (0%)
- Negative = 7 (64%)

Primary care services provide the first point of contact in the healthcare system, acting as the 'front door' of the National Health Service (NHS). GPs are responsible for treating patients with a wide range of mental health conditions, including people with high levels of need and complexity. GPs refer people for more support to Suffolk Wellbeing Services, which includes counselling and other therapeutic support known as Improving Access to Psychological Therapies (IAPT). For those who need more specialist support, GPs refer patients to secondary mental healthcare services, which in Suffolk are provided by the Norfolk and Suffolk NHS Foundation Trust (NSFT).

During this reporting period we received four positive feedbacks about primary and community care services. Two people appreciated being able to register with a new GP after moving house through online registration forms. They found these quick and easy to use. One person stated that their GP had shown them kindness and compassion following their recent bereavement, supporting them to quickly have an assessment with the Suffolk Wellbeing service which they found helpful and re-assuring. One person raised concerns about the difficulties they had experienced trying to get support for self-harm. The care navigator at their surgery, advised them to call 111. The 111 call handler advised them to call their GP surgery. The GP surgery refused to offer an appointment. SUF has supported this person to get an appointment with GP and have provided self-harm support information. Five people raised concerns about the NHS Digital collection, whereby personal data is being 'grabbed' by the Government, stating that personal information may be accessed by third parties, or make personal data, identifiable. They asked SUF to support people to ensure they are informed about their rights. For more information visit our website: www.suffolkuserforum.co.uk/new-national-health-service-database-and-your-gp-records.

2. Secondary Care

Specialist mental health services provided by Norfolk & Suffolk NHS Foundation Trust (NSFT)

Opinion of Primary Care from **316** pieces of feedback

- Positive = 53 (17%)
- Neutral = 3 (1%)
- Negative = 260 (82%)

Norfolk and Suffolk NHS Foundation Trust (NSFT) is the large mental health trust that provides secondary and specialist mental health services in Norfolk and Suffolk. Its full range of services including inpatient and community services can be found of the NSFT website: www.nsft.nhs.uk. Its headquarters are at Hellesdon Hospital, in Norfolk.

The Trust's mental health services are regulated by the health and social care regulator, the Care Quality Commission (CQC). The CQC has rated the Trust as Requiring Improvement overall. NSFT is rated as requires improvement in four areas: well-led, responsive, effective, and safe. Caring is rated as good. The CQC report can be read via this link: www.cqc.org.uk/provider/RMY. The latest inspection report, following the CQC inspection in November 2020, focused on places of safety and crisis care.

During this reporting period, service users have provided the following feedback.

2.1 First Response Service (FRS) and Access and Assessment Team (AAT)

SUF continues to receive positive feedback about the first response service. Service users who have been hesitant to make a call for mental health support have reported feeling care for, commenting that FRS staff have listened to them, offered re-assurance and support. One person reported a negative experience regarding the risk assessment process and wellness planning undertaken by FRS. They raised concerns that advice to have a bath may be a patient safety issue for someone feeling suicidal, or at risk of suicide, especially if an individual has lived experience of self-harm or self-injury.

Another service user also said that a similar patient safety issue applies to 'going for a walk.' Whilst walking in a green space may be helpful for some people, supporting a connection with nature and mindfulness, for others it may be a risky activity, especially if they are suicidal. There is a risk they may walk to areas that may further trigger self-harm, suicidal thoughts, or actions. We have recommended that FRS staff review risk assessment and wellness/safety planning support.

One service user also asked if FRS could offer an anonymous service, as sometimes sharing personal identifiable information can be off putting, making them feel more vulnerable. Positive feedback incudes:

"I called first response and spoke to a lady who listened to me without judgement. She very kindly said that if I needed, I could call back again and have another conversation. This helped me feel reassured. I know I can get help again if I need it."

"For about the last three months I have found that at various times I have had to call the FRS line. During this time, I have only had one bad experience, all the other call handlers have been good."

"I was very skeptical about calling the FRS line. When I did call them, I spoke to a male staff member for over an hour. He was very good. I felt listened to, not judged, and valued. I would be happy to call them again if I ever needed to because of my positive experience."

2.2 Community Mental Health delivered by the Integrated Delivery Teams (IDT) including psychiatry

We received 45 feedbacks about the poor quality of services, communication and support by care coordinators and psychiatrists as delivered by the NSFT. Service users particularly raised concerns about the support provided by Ipswich IDT, also known as Mariner House. Service users state that they do not feel listened to or understood by care coordinators and some psychiatrists, reporting poor communication about treatment, changes in treatment plans and support without their involvement, including discharge for 'non engagement' in treatment/care plans. Service users stated:

"With Ipswich Integrated Delivery Team (IDT) there is only one option - my psychiatrist, who stuffs me full of drugs."

"Ipswich IDT are appalling. The length of time between my appointments is around four months."

"I have not seen my psychiatrist face to face or even over Zoom. I started receiving support from Ipswich IDT a year ago."

"When I asked my care coordinator at Ipswich IDT about the medication I am on (which is a lot of different types), as I wanted to reduce them, she told me to "Just ween yourself off" then left."

"I asked my care coordinator at Ipswich IDT if I could see a copy of my care plan. When I read it, it was the same as my old one. All they had done was change the date. It had my care coordinator down as someone who had left, lists of things I needed to engage with and do, all of which I had done. Nothing had been updated."

"I have been under NSFT services for two years at the IDT. I have had a very good relationship with my care coordinator and support worker. I now have a new care coordinator who said I needed a medication review, but all this meant was my medication was increased. She now wants me to do a specific therapy, but I am not ready for this. I am having bad panic attacks and am worried that of the other treatment I have been offered and waiting for will be taken away from me, after waiting two years"

"My care coordinator has taken away my support worker after two years of support. This was not discussed with me or my support worker. We have worked well together, and they have been very helpful and supportive."

2.3 Discharge from IDT's

Discharge from NSFT services has been a long-standing area of poor experience and concern from service users. Negative feedback in this reporting period continues to raise concerns that service users and family carers are not involved in discharge planning and that service users are discharged for non-engagement. Service users continue to request that discharge planning is an area for Quality Improvement (QI) in NSFT. They have stated that although a discharge letter is sent to GPs within 72 hours of discharge from NSFT, this does not improve the experience of the person being discharged. Concerns also continue to identify that service users with ongoing treatment plans are being discharged for non-engagement or discharged before their treatment plan is complete.

"My care coordinator at Ipswich IDT who I had only met once for less than an hour, did not listen to me or read my notes. They just told me that because I was not willing to engage with a specific person from the IDT, that I was not engaging, and they discharged me. I have been engaging with everything else; I have never refused anything before, and this individual is only a small part of my treatment and care plan. I did not feel it was a major issue. My previous care coordinator was always telling me I was making progress. My GP is livid and spitting feathers that the Ipswich IDT discharged me and will be writing to them today. I have also contacted NHS complaints and CQC."

"Even though my GP, link worker, Turning Point and counsellor have all said that I am not fit to be discharged, Ipswich IDT still discharged me."

"I was referred to the IDT after my husband died. I have bipolar disorder and have managed well with a three weekly depot injections, although I coped better when my husband was alive as he recognised the early warning signs. After he died, I needed mental health support.to tide me over a crisis and to manage the funeral but was told, and I quote: "That's not we're here for". They could have been more sympathetic to understood how my husband's death affected me and my mental health."

2.4 Personality Disorder Strategy and Services

Service users have continued to raise concerns about the lack of services for people living with personality disorders. This reporting period we had conversations with five people who were hopeful for the new service offer for Dialectic Behavioral Therapy (DBT). They stated that the delivery of DBT needed to be accessible to people and delivered over a period of time, offering both group and individual sessions. They were keen to ensure that people could easily access this support and to ensure that service users living with personality disorders receive the treatment they need and are no longer bounced around the system.

2.5 Eating Disorder services

Service users continue to raise concerns about the lack of eating disorder services as raised in our previous reports. Service users fed back their experiences of services in a short film that won Best mental Health film award in the Suffolk and North East Essex (SNEE) How do we help everyone heal, Equalities Film competition. This film can be viewed on this link: www.vimeo.com/547421255/585439cb10

2.6 Inpatient care

- Positive feedback

Service users have commented very positively about the new peer support worker at Woodlands (East Suffolk) and the difference that their support has made during their inpatient admission. Service users on Wedgwood have commented positively about different activities that have taken place, including being able to use the gym and a recent summer BBQ.

"I have really enjoyed the activities on the ward. The BBQ we had was good and enjoyed by everyone who went. It was nice for us just to talk to the staff about other things."

"The Service User Peer Support Worker from on Poppy is amazing she has been so very helpful and supportive."

"Access to the gym is so important, I went the first time yesterday and it was the best I have felt for months."

"Until I went to the gym I just sat here and did not talk to anyone, I then went to the gym, and I felt like a different person, and I now sit and talk to people."

"Some staff are brilliant."

"The food is good."

"The cleaners are very good and nice."

- Staffing levels and staff attitude

Although we have received positive comments about staff, inpatients at both Woodlands and Wedgwood house have raised several concerns about staffing levels and the attitude of some staff.

At both inpatient unit's service users state that they understand that staff are busy, but sometimes feel that staff sit behind the glass panels and ignore inpatients requests for support. Some inpatients have said it makes them feel that they are not worthy of staff time, and they feel unimportant. Others have said they feel that staff are just rude and purposely ignore them. Some feel frustrated because they need help and support with a particular issue but do not get any help. They stated that staff frequently tell them to wait, which means they must ask again for the support they need, which makes them feel they are bothering staff. One service user was concerned that although they had asked to appeal their section, staff had not actioned this many days later.

Service users have also stated that staff do not always explain the reasons for certain decisions, for example why they have been refused leave; had medication changed or why they have not received the treatment they have requested for physical health care needs. Two inpatients have commented that the attitude of staff is more like being in a prison than a mental health hospital, as patients are not respected or treated with dignity or respect. Family and parent carers have not felt involved in their loved one's care and would like better communication to help them support their family member and to feel reassured that they are receiving good care and support.

Inpatients at both inpatient units have raised concerns about staffing levels and staff attitude stating:

"There are not enough staff."

"There are hardly any staff on the ward."

"There are not enough staff to do activities."

"There is a lack of activities."

"I do not know who my primary nurse is."

"I do not know what a primary nurse is."

"We need more staff to be able to go out and walk to the green."

"There are not enough staff and patients would not be safe if someone 'kicked off.'"

"Night staff are better than the day staff."

"I have been asking for unescorted leave but all they say is no. They will not tell me why my request has been refused."

"The staff have not treated my infection on my foot despite me asking many times for it to be treated."

"I have asked the staff twice to appeal against my section and nothing has happened still days later."

"There is no communication from staff, no one keeps me updated and I do not know what is happening."

"Information on the ward is out of date, including staff information."

"Some staff are horrible, when you ask for help, they just ignore you and walk away."

"I asked for specific dietary needs and it took four days to sort out."

"Laundry access is not happening three out of four days as there are no staff to take us for our allotted time slot."

"I am still waiting to see the Doctor, but no one will tell me when this will happen."

"I have asked for the lock on my door to be repaired, but it still does not work."

"Staff do not have time to help introduce new patients to the ward. This is very hard especially if they have never been here before."

"When I was admitted to the ward, I had no idea what was going on. This is my first admission and although voluntary, it came out of the blue and happened very quickly due to my crisis. I have not been told hardly any information by the ward staff."

"As a family carer I can only say that it took six days before I was given any information about my loved one. Eventually after a week or so things improved on the ward, and they did finally involve me, but I should have been involved right from the start."

"When I was discharged from the ward, I was only given one days' worth of medication. The staff said that they will make a 72hr assessment with the IDT, but I was not told what this means or involves."

- One to one time

Service users in Woodlands have stated that they are not receiving their one-to-one time, and this is only offered when people are highly distressed.

- Advocacy and rights

Three inpatients have stated that they do not fully know their rights and would like these explained to them, so they can appeal their section. One stated that they had asked for advocacy, but that the referral had not been made. A fourth stated that they did not understand why they were in hospital or why they were on a section.

Staff are required to ensure that inpatients are provided with information about their rights and supported to understand them. They are also required to refer to Advocacy services for an independent mental health advocate (IMHA) and to facilitate inpatients to appeal against their section or to apply for a hospital managers meeting. Rights should be repeated periodically as a matter of routine.

Our SUF advocate supports people to know their rights on both inpatient units. He visits the wards for weekly drop in and can also be contacted by phone using the following number: 01473 907087.

Two inpatients stated that there needs to be more information on the ward, which is kept up to date, helping new patients to have the information they need.

• Cleanliness

Inpatients in Wedgwood have praised the quality of cleaning and kindness of the domestic staff, however in this reporting period we have received concerns from two inpatients at Woodlands about the cleanliness of bedrooms and showers/bathroom.

• Care planning

We continue to receive mixed feedback about inpatient care planning. Some inpatients state that they do not know what a care plan is or if they have one, or they have not been involved in writing their care plan.

"I have been here (Woodlands) for five to six weeks, and I have not seen or been involved in writing my care plan."

"I have not been involved in something called a care plan, I do not even know what one is."

Suffolk user forum

your voice for emotional and mental health

01473 907087

hello@suffolkuserforum.co.uk

Suffolk User Forum

@SUFMentalWealth

www.suffolkuserforum.co.uk

The New Hollies
Unit 3, Grange Business Centre
Kesgrave, Ipswich
Suffolk, IP5 2BY

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