Making Our Voice Count

Suffolk user forum

Our Feedback

1st October 2020 - 31st December 2020

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.

Contents

Making our Voice Count	**2-4.**
Feedback - At a glance	**5-6.**
1. Primary Care, GP services and Wellbeing Suffolk.	**7-10.**
2. Secondary Care, Norfolk & Suffolk NHS Foundation Trust	**11-12.**
2.1. Broad themed Feedback	**12-15.**
2.2. Access to services, Crisis Care, First Response Service and Unmet Needs	**16-23.**
2.3. Community mental health at the Integrated Delivery Teams.	**24-26.**
2.4. Complaints	**27-28.**
2.5. Service User & Family Carer Participation	**29-30.**
2.6. Inpatient care at Wedgwood and Woodlands	**31-34.**
3. Appendix One - LISTEN Model for Crisis Care	**35.**

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. Our key role is to 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, and for true coproduction to happen.

This report provides feedback for the period 1st October 2020 to 31st December 2020 when Covid-19 restrictions were in place and the rules preventing face to face human interaction made using health services even more difficult than usual

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. Service user experience received via our online form asks respondents to verify their email identity. Any other personal information is not required to leave feedback, but we find most people provide personal information for further contact with SUF for more help and support.

By connecting areas of individual feedback together, we have drawn together the key themes and emerging trends for people receiving MH 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.

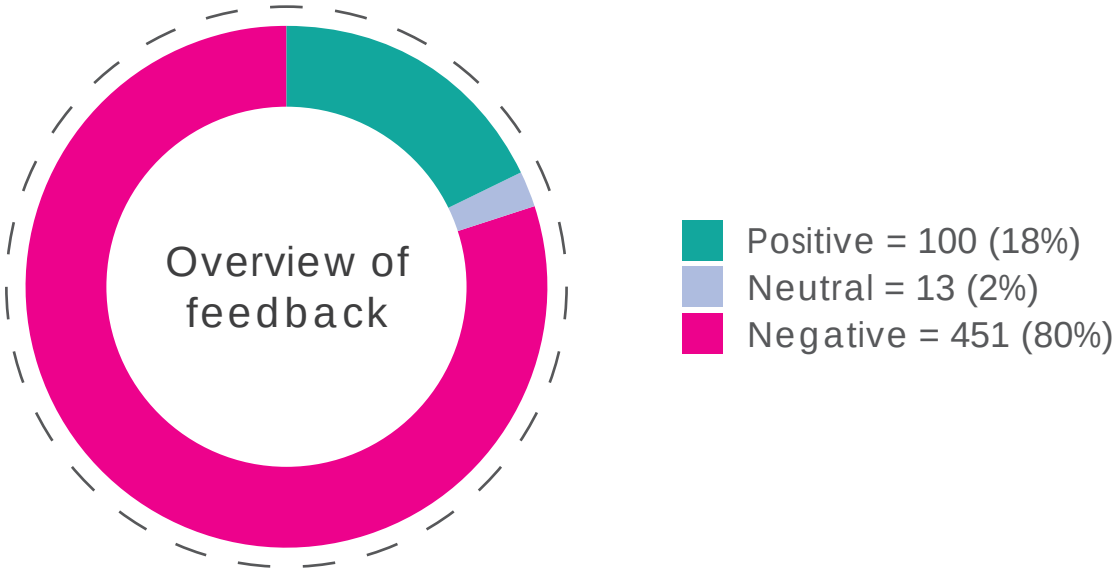
NEGATIVE - Where people feel they have not been listened to; that the quality of care or service has been poor or has not fully met their needs or expectations.

Our report contains 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. Some feedback received has been excluded. This includes historic experiences outside of this reporting timeframe.

This report is set out in two main feedback areas, primary care, and specialist mental health services, called secondary care. During this feedback quarter SUF also worked with service users for the coproduction of the suicide prevention strategy in Suffolk, gathering over 140 pieces of feedback about professionals' responses to people in distress, who are living with suicidal thoughts. This report can be read on our website at: www.suffolkuserforum.co.uk/wp-content/uploads/2021/02/Coproducing-for-Suffolk-Suicide-Prevention_V6.pdf

During our work with service users, they have described the most important elements of personalised care and support, which are important to them. These are now presented as coproduced outcomes, written as 'I' statements that describe what good care and involvement looks like from an individual perspective. This document can also be read on our website:
www.suffolkuserforum.co.uk/wp-content/uploads/2021/04/SUF-Coproduced-Outcomes-in-Mental-Health_April2021.pdf

Feedback at a glance



Opinion of Services from **564** pieces of feedback

In total, from 1st October 2020 to 31st December 2020, SUF has received 564 individual experiences of mental health care. This includes 142 feedbacks received from coproduction for suicide prevention (see separate report) and 184 people providing feedback more generally about mental health care and treatment in primary care, wellbeing, community care and mental health secondary care services.

Across the mental health system, we have seen a small decrease in positive feedback this quarter, with a drop from 29% to 18%. Negative feedback has increased from 58% to 80%.

Key themes from all feedback received includes general concerns about the impact of COVID-19 on people mental health, concerns about the likely increased demand on services, at a time when they are already stretched, and worries about our children and young people, given the long waiting times for mental health support in the Wellbeing Hub, the Single Point of Access for children and young people's mental health. Service users have also highlighted concerns about a lack of service provision for people living with Personality Disorders and Eating Disorders. See page 15.

Service users have identified the need for increased understanding and flexibility for people with mental health needs, in both primary and secondary care, asking for more reasonable adjustments to ensure services are more accessible, and better able to meet people's needs.

However, we can report an increase in positive feedback about other crucial crisis services, including the First Response Service (FRS), Access and Assessment and Home Treatment Teams. This is a very positive up turn, and we know that teams have been working hard to address previous service user feedback and to embed the coproduced LISTEN model in crisis care and the new commissioning of services.

Service users have recommended that LISTEN is built into NSFT's service user feedback forms, which can then be used by service users through this link:
www.yourserviceyoursay.com/feedback

In our last report we commented on an increase in positive feedback about service user participation. However, with the closure of the East Suffolk Working Together Group and the fact that the West Working Together Group has not met since the start of the pandemic, service user involvement and participation has been an area of significant concern for service users, and we have received negative feedback about this situation.

We continue to receive positive comments about the kindness of staff across all care areas. There continues to be mixed feedback around care coordination and care planning. Discharge for non-engagement, or missed appointments continues to also be a theme.

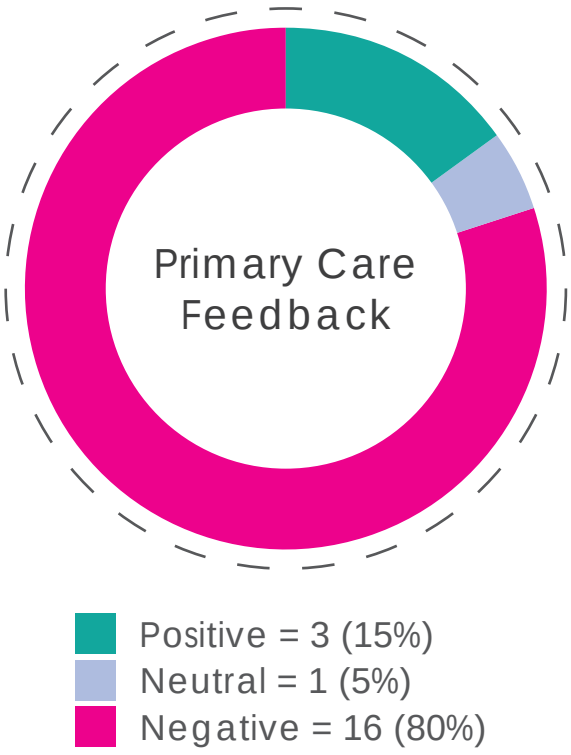
1. Primary Care Feedback

Mental health support provided at your GP surgery or medical practice

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).

Opinion of Primary Care from **20** pieces of feedback



Three service users reported that their GP had given excellent support for their mental health needs. They stated:

I have always received an excellent service by my GP. I have always been listened to, understood and everything they have said has been validated.

My GP has been kind and as professional as ever.

My GP in Felixstowe is fantastic and always tries to instill the importance of supporting mental health in the other GP s at the practice.

Negative feedback about mental health support in primary care included the following concerns.

- The availability of Link workers (mental health professionals working in primary care). Link Workers support people at surgeries and offer specialist mental health support to GPs. They are currently employed as part of the Suffolk Wellbeing Service, provided by Norfolk and Suffolk Foundation Trust (NSFT)). GPs can make referrals for people to see the Link worker at their surgery. We have generally received very positive feedback about the support provided by Link workers; however, people have raised concerns about the break in support from these specialist mental health workers, when individual Link workers are unfortunately off sick or leave their jobs. Concerns include the late cancellation of Link worker appointments, and the delays in receiving a new appointment, sometimes up to eight weeks.
- The lack of support and reassurance provided to shielded people during the pandemic, who needed to attend routine blood tests and appointments at their surgery.
- The length of time it takes people to get an appointment to see the GP, especially when people are struggling with their mental health and need their GP's support and help.
- Medication being used as the first and only option for help and support for people experiencing mental health problems.
- The level of training GPs have received to enable them to support patients with mental health problems.
- That GPs after the initial appointment do not routinely arrange follow up appointments for mental health needs, by recommending the patient/service user books a follow up appointment to review how they are managing their mental health or to review changes to medication.

• A lack of consistent information about the services provided by Suffolk Wellbeing services.
• That receptionists and GPs do not necessarily always make reasonable adjustments when making appointments for people who have difficulty retaining information. Writing down appointments and information would help patients/service users and their parent/family carers to support their loved one with attendance for future appointments.

I am concerned about Mental Health provision in primary care, especially when Link workers are absent/on leave/ off sick, there is no one to cover their absence.

There is a problem contacting Link workers at GP surgeries. I missed their call and then had to call the surgery to get them to call me back as they are working from home and the surgery cannot give out their numbers. It is just another barrier.

Luckily, I was fortunate enough to be able to afford private counselling. But what about those who are too low or unable to access help? They must just fall right through the net. Particularly at the present time!

I have had depression for 25 years and been on medication for most of that time. I have been told "You should get help" but the Doctor did not say where or who! I am lucky to have supportive friends and family, so I am ok, but my heart goes out for those that do not.

I had my medication increased by my GP, but no one has checked with me to see if this is helping me and if everything is ok. It would be great if GPs could follow up things like this.

I think people get prescribed medication and then feel that you are forgotten about.

GPs need to do a follow up appointment maybe in a month to see how things are going, some surgeries do this but not all do.

Some GPs just give medication and just want to get rid of you - they just do not want to know.

GPs can be hit and miss. You get good ones who understand and will give you medication. They then follow you up with an appointment in a few weeks and others do not.

We need to understand what training professionals and GPs have had around mental health and suicide awareness.

I went into my GP surgery and one in Diss – they did not have anything about suicide prevention or wellbeing on display. There needs to be consistency across Suffolk. We also need to look at the root cause of what is going on and not just giving people medication and sending them on their way.

Wellbeing Suffolk

Wellbeing Suffolk provides a range of support for people with common mental health and emotional issues, such as low mood, depression, or stress. They help you to make changes that can improve your wellbeing and quality of life. Their services are free and are available to people and for people aged 16 or over. For more information about Wellbeing services in Suffolk visit: www.wellbeingnands.co.uk/suffolk. We have received five positive feedbacks about the range of support services that have been provided by Wellbeing services, three of which are provided below.

I signed up with Wellbeing for a webinar on Life after lockdown, it was really useful, had some really positive information in it. It was full of young people but that was ok, I did choose to do the one early evening so I guess they had been at work, I will definitely sign up for more.

I signed up to a Suffolk Wellbeing Webinar on relaxation, it was brilliant, it was Mindfulness and we did a body scan, I will certainly sign up for another one, the two ladies doing it were really calm and friendly.

Wellbeing have offered a fantastic range of online support during the pandemic. Many of the courses have been really helpful and can be accessed without having to make a referral. These have really helped me a lot.

2. Secondary Care

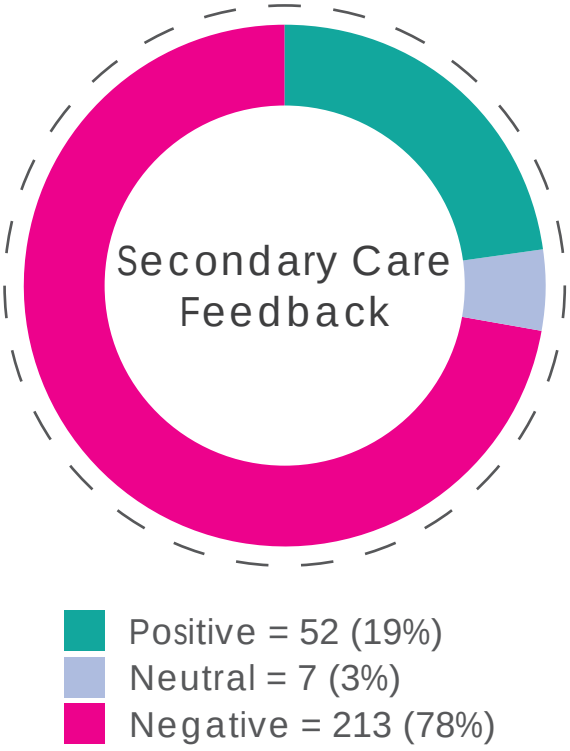
Specialist mental health services provided by Norfolk & Suffolk NHS Foundation Trust (NSFT)

Norfolk and Suffolk NHS Foundation Trust (NSFT) is a large mental health trust that provides services in Norfolk and Suffolk. Its headquarters are at Hellesdon Hospital, in Norfolk.

Over the last quarter we have seen a reduction in positive feedback of 6%, a reduction of 8% in neutral feedback and an increase of 14% more negative feedback regarding to NSFT services.

The Trust's mental health services are regulated by the health and social care regulator, the Care Quality Commission (CQC).

Opinion of Secondary Care from **272** pieces of feedback



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 through 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 and can be read through the link below: www.api.cqc.org.uk/public/v1/reports/9f33098f-d5a9-44cf-aa66-f140cf071873?20210122080048

2.1 Broad themed feedback about NSFT services

During this period, service users have raised broad concerns about specific services and care pathways, including the impact of COVID-19 on people's mental health. Feedback includes:

• Dual Diagnosis

Service users are concerned that people with both mental health and drug/alcohol issues are still not receiving a mental health service. They have asked for information and updates about the NSFT dual diagnosis strategy.

• Lack of inpatient beds in East and West Suffolk

Service users are concerned about mental health service users being placed out of County due to shortage of beds, and that those needing mental health care have not been admitted as mental health inpatients, due to shortages of beds. They cited two recent press reports, which included the death of a lady who travelled 240 miles returning to Suffolk, and who very tragically died during this journey, and a man whose death, as commented on by the Coroner, 'would not have occurred' had he been admitted as a mental health patient.

• Lack of Eating Disorder services

Service users have said they want and need an improved Eating Disorder Service in East and West Suffolk, particularly given the increase in people living with eating disorders during the pandemic. "We need more, not less. I have tried to access an eating disorder service and there wasn't one!" SUF has asked the Clinical Commissioning Group about development of new services for people with eating disorders and has been advised that coproduction for this will commence in 2021.

• Personality Disorder Strategy and Services

Service users have continued to raise concerns that there is still no Personality Disorder strategy for East and West Suffolk, and still no holistic range of services for people with Personality Disorder who need mental health support. A new strategy is being coproduced with service users, professionals and SUF involvement. This should be completed by March 2021 and new services, including staff training, will begin to be put in place from June 2021.

• Classification for mental illness

Concerns that the new American Psychiatry Diagnostic and Statistical Manual of Mental Disorders (DSM–5) has so many new mental health diagnoses, "This is unhelpful for people and money making for others". For more information use this link: www.psychiatry.org/psychiatrists/practice/dsm

• A need to explore different ways to understand mental health

Service users have recommended that SUF run an event to explore different ways of understanding mental health, suggesting an event on the Three Principles led by Dr Bill Pettit. The "Three Principles" is an approach exploring the gifts of Mind, Thought, and Consciousness — that are universal to all human beings. SUF is currently working with service users and Bill Pettit to run an event called 'Living the dream – The pursuit of truth regarding mental health', on 10th May 2021.

• Alternative ways to contact FRS/reasonable adjustments

At present the First Response Service (FRS) only offers a telephone line. There are no other ways in which people can make contact. This is not always helpful for people who feel unable to communicate verbally when distressed, or for those who have speech and language difficulties such as a stammer or Tourette's, or those who have hearing loss, and some people prefer text or email.

Service users have asked that training for FRS staff includes how better to support callers who have difficulties with spoken language, using learning from calls made to other 111 type services, and in particular learning from serious incidents, where a call handler's negative attitude has significantly impacted on someone's mental health, contributing to them taking their life. Services users alongside SUF have asked that the LISTEN model for crisis support is embedded in FRS.

We recommend that other ways of making contact are explored and developed so that this service makes reasonable adjustments, enabling access for those people with a range of physical and mental health needs.

Whilst the NSFT website page for the FRS provides a helpful overview of what people can expect from the service, signposting for the INTRAN translation service is only provided in the website footer. SUF recommends that this is made clearer on the webpage to better support those who need translation services.

• Zero Tolerance Policies

Service users have stated that they know they sometimes swear or get angry, and that this is borne out of a frustration with the system and not with the person they are speaking to. However, they are concerned about Zero Tolerance policies, which they know are in place to protect staff. They would like to see an system wide universal policy for mental health, so that it is the same approach in FRS, as it is in A&E, IDT etc.

• Impact of COVID 19 on people's mental health

Service users have fed back to SUF, stating that their mental health has been adversely affected by this second lockdown much more than the first. They report a significant increase in suicidal thoughts in those who have long term mental health needs, alongside an escalation in self harm and eating disorders. There has also been an increase in anxiety and depression in family carers and those who have previously not had previously diagnosed mental health needs. It is noted that Suffolk Constabulary has recently stated that 50% of all incidents it is attending are mental health related. These findings and issues are consistent with recent reports in national publications for example: www.socialworktoday.co.uk/News/People-in-mental-health-crisis-at-highest-recorded-levels%2C-says-charity

An increase in mental health needs (anxiety and depression) has also been reported nationally, in one of five people who have had COVID, alongside the depression is now being experienced by those living with long COVID. www.theguardian.com/world/2020/nov/10/nearly-one-in-five-covid-patients-later-diagnosed-with-mental-illness-study

Much of this is still being researched to be better understood, but it is likely to have a significant impact on demand over the next couple of years. Service users are concerned and want to ensure NSFT can meet an increase in demand. They are also concerned that the longer-term impact of COVID on our children's and young people's mental health, may also increase demands for mental health services. They have expressed concerns that many will have experienced by adulthood a long period of their young lives living through COVID; and more immediately the continuing uncertainty about their GCSEs/A levels in the summer of 2021. This concern is raised alongside the long waiting list for mental health support for children and young people.

• Children and Young People's Mental Health

Service users have raised concerns about the long waiting list for children and young people who are waiting for mental health support through the Suffolk Wellbeing Hub. Service users are concerned about the increase in mental health needs of young people during the pandemic and cited the following information. They referenced the following two links:

Survey conducted in July 2020 shows one in six children having a probable mental disorder: www.digital.nhs.uk/news-and-events/news/survey-conducted-in-july-2020-shows-one-in-six-children-having-a-probable-mental-disorder

Children and young people mental health review: Update on local actions: www.cqc.org.uk/publications/themed-work/children-young-people-mental-health-review-update-local-actions

2.2 Access to services, including crisis care, First Response Service (FRS), and unmet needs

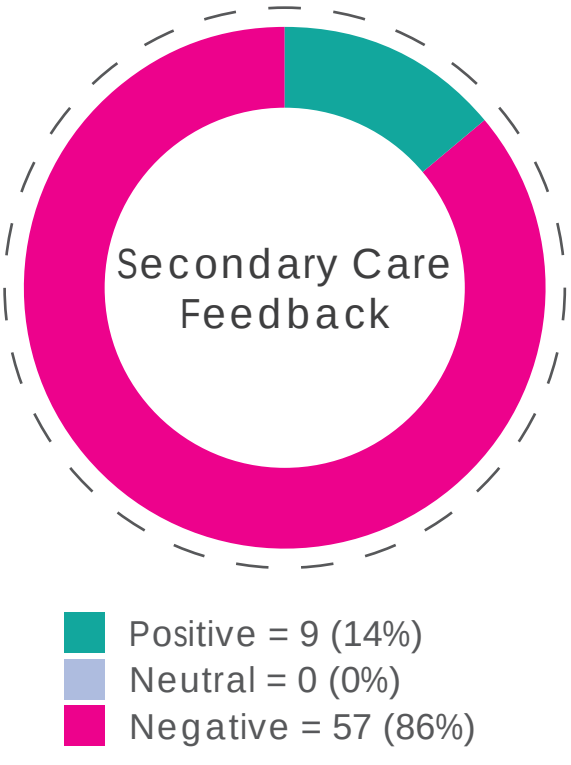
Access to services

In this publication we are featuring, with consent, an in-depth feedback from one family carer's and service user's experience when trying to access mental health support in crisis.

This experience highlights the complexity of our mental health system, and the number of times this family reached out for help, to six different parts of our mental health system, including Ambulance and A&E, and still did not receive support for their mental health crisis and suicidal feelings.

It shines a light on these people's real experience of our system, the sheer frustration and distress people feel and the desperation when they feel abandoned, unheard, and not supported.

Opinion of services from **66** pieces of feedback



This experience was presented by our SUF CEO at the National Eastern Region NHS Clinical Senate to demonstrate the urgent need for change and mental health transformation in crisis care.

Please note, some people may find this feedback distressing and it may be a trigger if you have had similar experiences.

Monday, 2nd November 2020

'My daughter was brought in by ambulance to Ipswich A & E about 7am Monday morning after having spent the last three weeks with acute anxiety and suicidal thoughts, constant vomiting, that has been ripping her stomach lining, so she has been bringing up blood.

She has a long history in her teens of anorexia and now has not eaten for five days; she had been eating very little for weeks and has now been unable to keep fluids down; she has had no sleep for four days and has been constantly pacing, crying, pacing, with suicidal thoughts continuously.

Last Thursday my daughter spoke to her GP and he put in an urgent request/referral to NSFT for her to be seen by the IDT.

On the Friday she spoke to her GP again and he said it will be a month until the IDT call her back even though the referral is marked urgent; he advised her to go to A&E and see Psychiatric Liaison team.

Friday, Saturday, and Sunday she spoke to 111 three or four times. The first time they said call the FRS number.

My daughter called FRS. They were no help at all just told her to try breathing exercises; so, my daughter hung up as she had already told them she knows all this and had been trying to do this, but it had gone far beyond this.

She called 111 again and then received a call back from the GP on call. The first GP did not listen to my daughter and the call lasted about 1min 30secs. One of the questions he asked was, 'Are you feeling suicidal?' to which she replied yes; to which he said nothing for a while, and then said she must call her GP on Monday - this was on Saturday Night!

She made another call into 111 and they said call this number and gave her a number. My daughter was going to call the number but luckily, I was there, and I said No, she will not call them, that is the FRS, and she has tried that – things are beyond that.

So, then another on call GP called her back and said phone your GP on Monday or go A&E and see the Psych team. My daughter was in no state to go to A&E.

Another call into 111 and another on call GP called back. This was a lot better as the GP listened to what my daughter was saying and how she felt. This GP said my daughter needs to go to A&E and get assessed by the Mental Health team there. My daughter was in no fit state to go to A&E.

The 111 service were very helpful each time and took time with my daughter as all calls were on speaker phone, so I know this.

Early Monday morning, my daughter called 999 and was taken to A&E by the paramedics; she was alone in the ambulance and arrived at A&E by herself.

My daughter had to wait in the reception area by herself despite the extreme distress she was in. My daughter asked at the A&E reception if she could see the Psychiatric Liaison team; she also asked how long she would have to wait. She was told by the receptionist that they had no idea how long she would wait and that they could not ask the Psych team to see her, and she would have to ask when she was triaged and to ask the triage nurse if she could see Psychiatric Liaison. ***This was chance 1 missed.*** *This made my daughter even more upset.*

I arrived at A&E and the woman who was on the first 'COVID' desk would not let me see my daughter or my daughter's partner/carer who by then had met me there.
I asked why I could not see my daughter and was told it was the rules.

I explained that my daughter had been calling me in distress and that she was threatening to walk out of A&E reception as she could not cope and needed to see me. I explained to the receptionist that my daughter has Mental Health problems and is saying that she will leave A&E. I also explained that she needs to be seen by the Psych team and that this is what GPs over the weekend had been telling her to do, I explained that she was suicidal, and she needs to be referred to Psych liaison team as this might be the ONLY CHANCE we have, to which the woman said 'well, she has not told me that'. I then said I am not making it up I will show you all the txt I have just received if you think I am lying. I said again that I need to be with my daughter. ***This was chance 2 missed.***

The receptionist then said that she could not make that decision, but she would ask the lead nurse. She then came back and said that the lead nurse said no, they would not call Psychiatric Liaison and I was not allowed in to support my daughter I then said to her no wonder the suicide rate is so high. ***This was chance 3 missed.***

I then asked for her name as her ID badge was the wrong way round, she said that "I did not need to know her name". I said well I do need your name because my daughter is suicidal and if she does walk out of A&E, we could have a big problem, she refused to tell me her name again when I asked.

The sign outside A&E states that under exceptional circumstances immediate family or carers are allowed in A&E, I was not, why because it was Mental Health - I can only presume as no one me or my daughter saw that morning cared about mental health.

In total and utter despair at trying to ensure my daughter saw someone from Psychiatric Liaison I called them myself. The number was answered by the administrator unfortunately, she was no help at all and did not know much about anything I asked, as they were all in a meeting and it was only her. ***This was chance 4 missed.***

I spoke to my daughter and she had at last been to triage after waiting in A&E for 105mins in an extremely distressed state. She said that when she went into be triaged that she had a big panic attack, and that the door was left open so people waiting to be triaged could see her. The Dr finally did shut the door and told my daughter to stop breathing like that as I cannot understand what you are saying. My daughter tried to explain what had been happening with her physical and mental health. The Dr said well then what are you here for your physical or mental health. My daughter said both as I have been told that I need to see the Psych team to which the Dr replied well that will not be happening and looking at your records your GP has made a referral to IDT anyway and that was it. No No No if I had of been allowed in by A&E to support my daughter, I could have challenged this as my daughter was in no state to. She had asked, as told by three GPs to do and myself, and just had her request dismissed. This would have been on her notes!! ***This was chance 5 missed.***

My daughter called and said that she was now on a drip and I asked if Psychiatric Liaison had been called. She told me they had refused to call them.

I called Psychiatric liaison and spoke to the Admin person again and asked to be put through to someone from Psychiatric Liaison at A&E. I got told they are all in a meeting and that there is no one. The admin did not know for how long and said they might be out in possibly an hour, because it has been a busy weekend.

I explained again that my daughter was suicidal, and that A&E have said that that Psychiatric Liaison will not see her, to which the admin woman said, 'well I don't know how they could say that, as they are all in a meeting'. ***This was chance 6 missed.***

I said well I am not lying, and the admin lady replied 'Mmmmmm'.
I then asked for someone to call me back as soon as they come out of the meeting. I was told that it is up to them if they would call me as it is not the usual way of doing things. She then took my mobile number as I said she would need it to get someone to call me back, she said that she will see if they will call me. (No one did call me back) ***This is chance 7 missed.***

I said that is why we have so many suicides in Suffolk. She said nothing to this. I then asked does she know who is in charge of Psychiatric Liaison. She found the details and told me his name. I asked if he were in the meeting and was told no, that he is at Woodlands, so I said I would call him there then.

I understand that it is not her fault but who can run a CRISIS service and they are ALL in a meeting? When no one knows how long it will be? And who is supposed to be covering A&E?

This is the one and only chance my daughter has of getting the help she needs, and no one cares. Let us hope she does not kill herself. ***This is chance 8 missed.*** *Even if she does it will just be a "We have learned lessons from this" article in the paper, NO, NO, NO, NSFT & Ipswich hospital you NEVER learn.*

My daughter told me that no one was helpful at A&E. Even when she wanted to just go and see me briefly outside reception told her, 'well I'm not going to keep an ear out for you being called'. So, my daughter did not see me, she only wanted to see that I was there as reassurance and would have been about 1 minute. There were only about five people in A&E this morning (at 7am). They always in the past tell you if your name has been called if you pop out and this has been packed at times. My daughter was in so much distress, was so alone and frightened, she needed to see me and her partner/carer for reassurance, as he like me was not allowed to be with her. I must explain that at A&E they have temporary solid high dividers block the view from A&E to outside because of COVID so my daughter could not even see us at all.

My daughter told me that when the DR checked on her after she had had the fluids said, "You look well everything is medically fine off you go". The only person who was good was a nurse who sat down with me whilst I was having my fluids and spoke about her panic attacks she has had for the last few months.

My daughter feels worse than when she arrived at A&E. She is home now; she is suicidal ...state vomiting not eating hardly drinking, continuous pacing, in floods of tears and no sleep and all we can do is call her GP again on Monday what a terrible service for an extremely vulnerable young woman.'

For those reading this experience, please know that SUF supported this family carer and their relative received a very good service and support from the Home Treatment Team, the following week. However, this experience reveals the complexity of our crisis services in mental health system and the real frustration that service users and family carers experience when reaching out for help, when trying to keep themselves and their loved ones safe at a time of extreme distress.

Psychiatric Liaison

We received one positive feedback about Psychiatric liaison at West Suffolk Hospital:

I had been taken to A & E at West Suffolk Hospital and the psych liaison had been helpful and supportive. I was then admitted into hospital.

We continue to receive negative feedback about the response provided by Psychiatric Liaison at Ipswich hospital. See Section three Coproduction Feedback for Suicide Prevention. People continue to report that they attend A&E because of a mental health crisis and associated self-harm. Service users have raised concerns about the approach by A&E staff at Ipswich hospital and mental health psychiatric liaison staff, also at Ipswich hospital. They describe psychiatric liaison staff as being unhelpful and that staff do not provide support for people's distress. People are concerned that they only receive support after many mental health crises and numerous visits to A&E and feel that they are often left feeling very unsafe. We have received positive feedback about Psychiatric liaison at West Suffolk Hospital.

The expertise of Psychiatric Liaison is essential in delivering comprehensive integrated healthcare for patients, which enables patients to access the right care in the right place and at the right time. It is essential that the team use the LISTEN model and ensure that people are listened to, supported and that there is an agreed plan that enables the person to be supported and safe.

'What's the point of 24/7 liaison services if they are not providing the necessary service and function as set out in this NICE document?'
www.nice.org.uk/guidance/qs88/resources/evidencebased-treatment-pathway-for-urgent-and-emergency-liaison-mental-health-services-for-adults-and-older-adults-guidance-pdf-4362198589

I am unhappy and concerned about my treatment at Ipswich A&E and Psychiatric liaison/MH service as they did not listen when I was feeling very suicidal. I was not treated with dignity & respect at A&E.

I am concerned that there seems to be no records of people seen by psychiatric Liaison, who then are just discharged home. I would like to know how data is recorded. How do we know how many people do not get a service following a serious self-harm incident or suicide attempt?

First Response Service (FRS)

First Response is a helpline for members of the public and professionals of all ages in Suffolk who need urgent mental health support. The helpline is available all day, every day.

I have called First Response on a few occasions and they were very reassuring and caring.

NSFT's LISTEN strategy is excellent - Really being listened to has helped rebuild my self-esteem and confidence. I have realized getting distressed and frustrated only adds to my issues. Instead I comfort and soothe my hurts. This is helping me to rebuild my relationships with my family.

I have used the First Response service and most of the time this was quite good, but it did depend on who answered the phone.

I used the professionals' line for FRS, and it worked really well.

I used the FRS professionals' line; they were really helpful.

When I called FRS about a family member who had taken an overdose, they advised me to put the ownership back on her and let her make her own choices about suicide. On the day she told us she had taken the overdose, I contacted 999 and the police were great. I feel that the advice I was given by First Response was not helpful or good enough, I was left wondering what to do.

It was my understanding that the helpline was for individuals in crisis, but also for others (professionals) to report concerns about someone's welfare; clearly based on my experience it is not. I called and expected someone from NSFT would contact the person I was concerned about, to check on his welfare/discuss with him – NSFT said they could not call him and suggested he call the Samaritans.

We have fed back these two concerns to NSFT and recognise the work of several key NSFT transformation and leadership staff who have actively promoted and embedded the coproduced LISTEN Model into crisis care and the FRS. The origin of the wording for LISTEN came from service users in 2013/14 who when feeling suicidal were told by mental health professionals "Well it's your choice". We are concerned that this language and approach is still being used but value the leadership commitment to change the language and to support staff awareness through the webinars, including the promotion of SUF's coproduced publication called LISTEN for suicide prevention: www.suffolkuserforum.co.uk/listen-for-suicide-prevention

A NSFT/SUF staff suicide prevention webinar using LISTEN is now planned for April 2021.

Access and Assessment Team (AAT) and Home Treatment Team (HTT)

The HTT were very nice, and they listened to me.

The home treatment team was a lifesaver.

AAT and HTT have been very good, very responsive. I feel I have had had a very good service from these teams.

Family carer stated AAT/HTT has worked well. My relative has been supported to manage their mental health crisis and are now awaiting handover to the IDT.

HTT were very supportive. They gave their time. They did not rush anything, listened to my relative and reassured her.

I was referred to AAT by my GP for an urgent assessment by NSFT. They called me within the 72 hours and took time to listen to me. they validated my concerns about my mental health and wellbeing, and I have now been referred to the IDT.

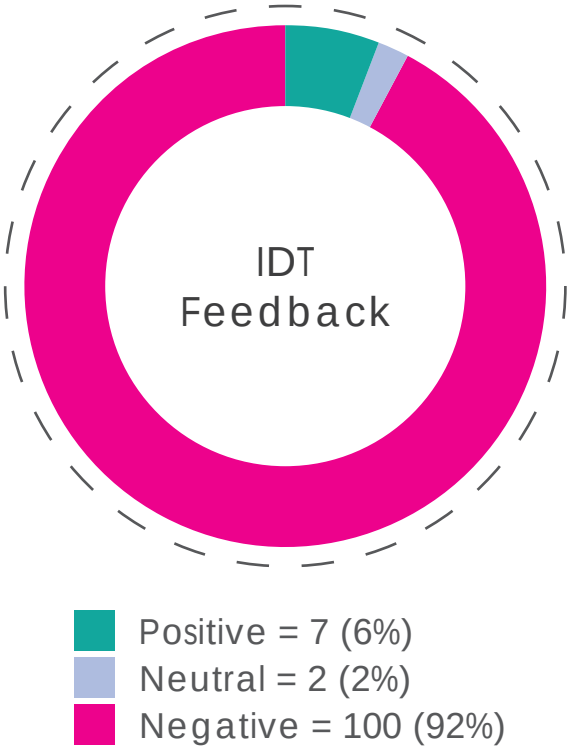
2.3 Feedback on Community Mental Health at the Integrated Delivery Teams (IDT's)

Diagnosis, Care Coordination, Care Planning, Medication, Therapeutic Support, Discharge Planning

This section reports the feedback from service users and family carers about the way in which service users have been involved in coproducing their care and discharge plan.

Whilst some people have had positive experiences of care coordination and have received very helpful support for their recovery others have been frustrated by a lack of good and trusted communication with Care Coordinators, Support Workers and Psychiatrists.

Opinion of IDT's from **109** pieces of feedback



Service users have reported long waits for psychiatrists' appointments, cancellations of appointments at short notice, and in one case, a telephone appointment with a psychiatrist was cancelled 30 minutes after the appointment time.

People have reported poor experiences of meeting with psychiatrists and long waiting times for medication reviews. Some service users continue to report being discharged for non-engagement, when they have missed an appointment, and state that they have not been involved in any discharge planning.

Service users who are receiving community mental health support through the IDTs and who have called FRS for crisis support, out of hours, have reported poor responses from their care coordinators, in terms of a follow up, and they feel that there is poor communication and follow up from these two NSFT services, which is unhelpful when they are in distress.

Service users also continue to report problems contacting their care coordinators and support workers. This issue has been taken up with NSFT, and SUF can now contact senior managers to report when this is a problem to ensure that this issue is addressed. If you are affected by this issue, please contact us in SUF and we can report this matter to NSFT senior staff.

I receive a very helpful response from my care coordinator at Central IDT Stowmarket, I am very appreciative of their support and help.

All along my care coordinator has been great.

I have been sent a provisional driving license as I need to take some top up lessons before my full license can be issued again, my care-co has been helping me with this and she is going to help me arrange some lessons, she has been really supportive as this has been a long process.

I spoke to my care-co Monday, she has been really helpful and listened to me.

I had an assessment with AAT last week, a really nice man that I have spoken to before, I felt that he did listen to me. He said that there is nothing they can offer me at this time as I am with Waves.

I have been made to feel as though people just do not care.

Home treatment made an urgent referral to the Ipswich IDT for ongoing support. However, the IDT refused to see my relative despite the fact they were only being discharged from services due to COVID-19, when NSFT discharged lots of patients. My relative never received EMDR or counselling as originally promised by the IDT before she was discharged.

My support worker came and saw me Monday, I have heard from him a couple of times during lockdown, he has left me a blank care plan to fill in, I have been with them for about a year and have never had a care plan, I am a bit confused about what the goals are.

I feel really down about the fact that I have not heard from my support worker, he was meant to call me last Friday to arrange another visit to complete my care plan. He has done this in the past, more than once, and I know when I get hold of him, he will just say sorry I forgot, but that makes me feel that I do not matter. I will call Mariner House and leave a message for him, but I should not have to.

I met with my support worker to discuss the care plan he wanted me to help write, which as you know I have spent a long time doing. My support worker then said they are going to discharge me in the New Year. I do understand as I am attending Waves, but why ask me to contribute to a care plan after I have been with them over a year without one, then say we are going to discharge you, what a waste of my time and his.

I am under Ipswich IDT, but my care coordinator is off sick at the moment. I must call the duty worker to receive any support. I feel that there is no plan in place to support me. At the moment I am feeling left in limbo.

I have been under mental health services for some time being discharged and re-referred. I am constantly in this cycle.

There is sometimes a long wait to be able to speak with my care coordinator.

I have difficulty communicating with my care coordinator and sometimes I get no response to my questions and/or requests.

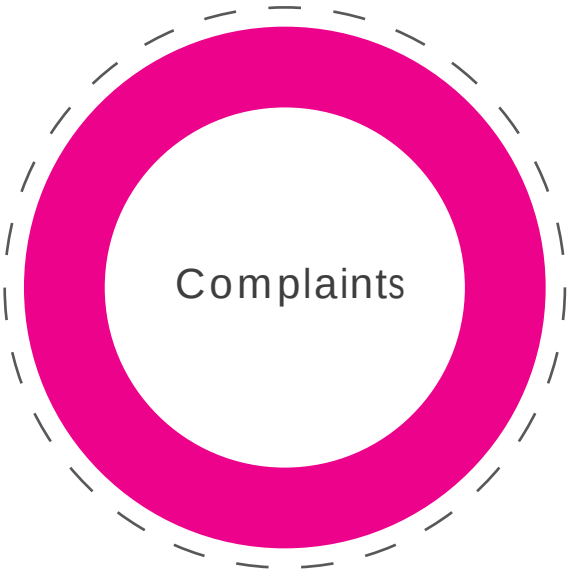
2.4 Complaints

This is the third report in which we have raised service user concerns about the NSFT complaints procedure and response.

Service users continue to state that they experience NSFT staff as being defensive about complaints, although have reported a more helpful response from senior managers. They would like NSFT to ensure all staff work in an open way, whereby staff are comfortable and welcoming about receiving both positive and negative feedback.

Where staff listen to people's experiences and concerns and feel confident to respond quickly to resolve these at an early stage.

Complaints based on
12 pieces of feedback



Positive = 0 (0%)
Neutral = 0 (0%)
Negative = 12 (100%)

Although service users have reported a helpful telephone/virtual meeting response from senior managers regarding complaints, they have in some cases stated that there has been poor follow up of the actions agreed, and some complaints remain unresolved.

Some service users have recognized that the offer of a meeting is helpful but have stated that they would like written responses to their concerns, as sometimes they just do not feel up to meetings or talking one to one, and because they want to be able to read the replies more than once to understand better what is being said and meetings do not allow this.

Service users have asked NSFT to see complaints as a source of free improvement feedback to the Trust. They have stated that a successful response to a complaint is that the Trust understands the underlying reason for the complaint, has identified the change that is required to address the complaint, and has kept the service user, as the provider of this "improvement information" involved in the investigation, assessment, and identification of change arising from the complaint.

Service users have emphasized that the Trust should only consider the complaint closed (and fully dealt with) when the change identified has been shared with the complainant/service user, and when they (the complainant/service user) have confirmed back to the Trust that the change has been made (not just promised or planned) and that the change identified and made has addressed the root cause of their complaint.

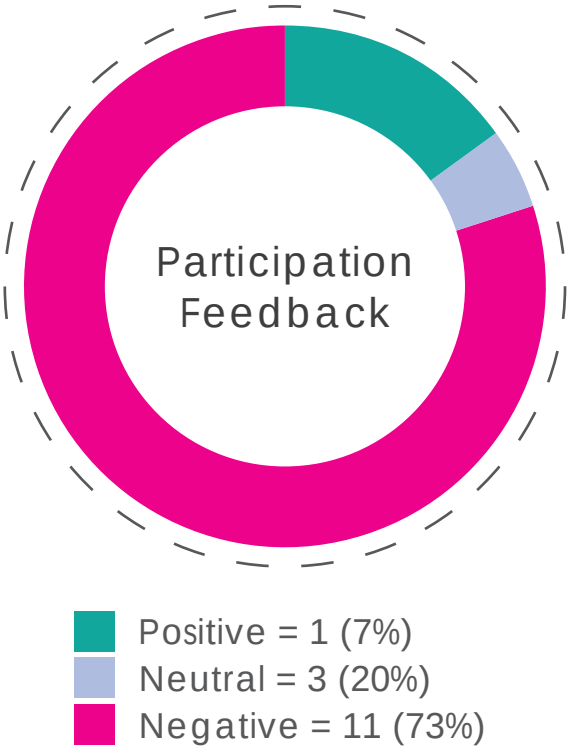
2.5 Service User & Family Carer Participation

In our last report we noted a positive upturn in service user participation. At the time of writing this report there are no participation groups running in community services in NSFT.

The East working together group has been closed and the West Working Together Group has not yet restarted since the appointment of a new People Participation Lead for West Suffolk.

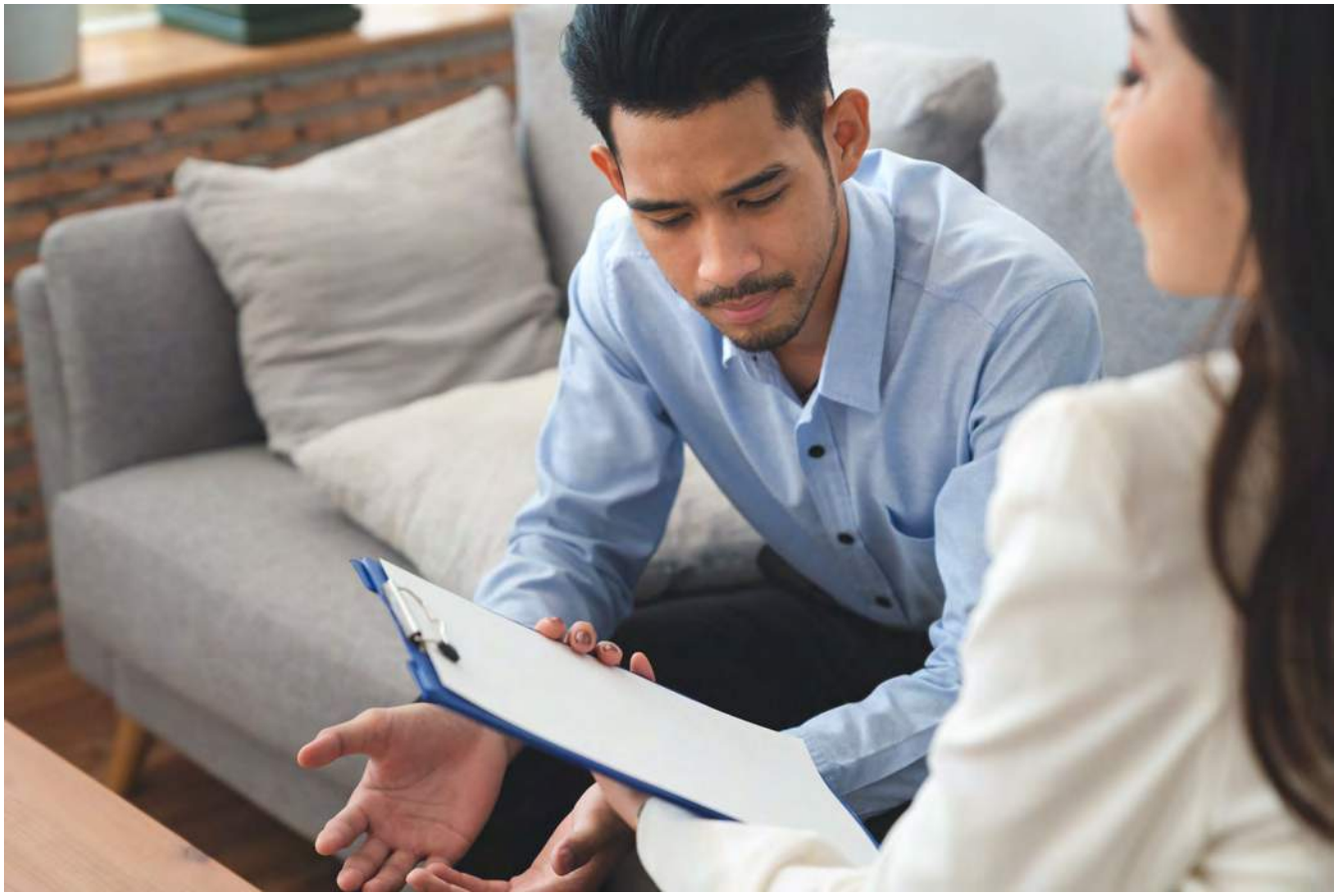
There continues to be significant gap for community-based service user and family carer participation and involvement. Regarding in-patient involvement, we continue to report very positive patient/service user outcomes at Wedgwood House, through the involvement of the Support Friends Group.

Opinion on Participation from **15** pieces of feedback



With meetings now being held virtually, it has been agreed with both NSFT and commissioners that all online service user/family carer events, should include the offer of an after-meeting support session, available to service users who may feel impacted by or distressed through their involvement and participation in meetings.

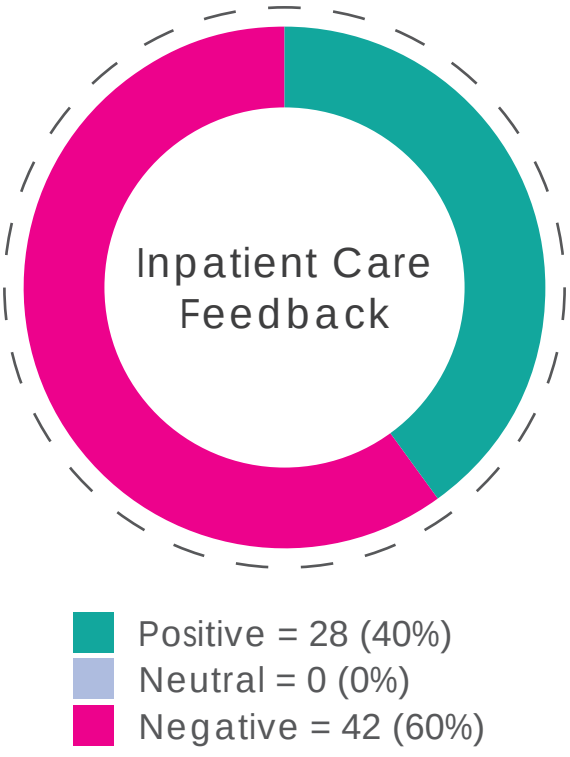
2.6 Inpatient care at Wedgwood House & Woodlands



We have received mixed feedback about the quality of inpatient care.

At Wedgwood House in Bury St Edmunds feedback included positive experiences about the kindness of staff, and most service users confirmed they had a care plan. People reported that there were good levels of activities on the ward, the food was good and that they felt safe on the ward. Discharge planning was highlighted as an issue by three people, to ensure that people are involved in their discharge plan, have telephone numbers for support and that they are provided with the right dose of medication in a timely way.

Opinion on Inpatient care from **70** pieces of feedback



We received three positive feedbacks about the staff at Woodlands in Ipswich, reporting that staff are kind caring and listen. However, nine people raised concerns about staff attitude and behaviour, this particularly related to agency staff. They stated that agency staff were not accessible to inpatients, and that they did not engage or communicate well with patients. Patients were concerned that they had not received information they had requested, and delays in communication impacted in discharge dates and leave time.

Seven inpatients at Woodlands said they did not know if they had care plan and that they had not been involved in writing their care plan.

Whilst four people reported that the food was good, two felt that it was not good.

People reported fewer activity opportunities at Woodlands and four people reported frustrations with not having more gym access and/or only being able to use the gym on limited days of the week.

Feedback about evening routines on Poppy ward suggest that staff prepare early for 'bedtimes' with four patients reporting that night medication had been starting at 21:00pm which is too early, as it is prescribed for 22:00pm; two that lights are turned off too early in the communal areas and one, that there were limitations for getting hot drinks in the evening.

Wedgwood House (Southgate and Northgate wards)

Positive partnership feeling, where everyone is genuinely appreciated.

Staff are good and caring.

The food is fantastic and a good variety.

I feel safe on the ward.

I love the new recovery tree on Southgate.

I am happy with the current activity planner.

Some of the agency staff are on a power trip.

It took five days to sort out my medication.

I was discharged from Northgate Ward, Wedgwood without any telephone numbers to call or any support. I did not speak to anyone for over a week following my discharge.

During my admission, my medication dose was changed. But I was discharged with the wrong dose of tablets and could not take the increased dose which the doctor said I needed.

Woodlands (Poppy, Lark and Avocet wards)

Staff are very kind to us.

The staff are lovely, they listen if you have any problems.

Staff are supportive on the ward.

I want to say a big thank you to all staff for having to work with those masks and visors.

I thought the environment on Poppy ward was positive.

The food is great, and I am a fussy eater but there is always something to eat.

Food is great and we get to much of it. I am a vegetarian, and my needs are being met with food.

The food is fantastic and a good variety.

Waiting times are a problem, especially when you want to speak with someone or when you need something. The staff are all in the office and not out with service users on the ward.

Some agency staff do not always seem to care.

There was poor engagement and poor communication with a lot of the staff, even when they are in the communal areas. They do not talk with service users despite being in communal areas.

There is sometimes a long wait to be able to speak with staff.

It is sometimes difficult to talk to staff. Sometimes I get no response to my questions or things I have asked for.

I would like to get feedback from questions I have asked the doctors and other medical staff.

If staff are in the office, they ignore you, they do not even acknowledge you. I had five minutes left for my last fag break and the staff member ignored me so I could not even have my last fag break of the day. (Note NSFT has a no smoking policy for inpatients an patients are encouraged with smoking cessation resources, but can still smoke outside in the garden).

I was supposed to have my review so I could have leave two days ago but the Dr still has not seen me and I want my leave.

One to one time does not always happen.

I think the environment on Poppy is Toxic.

*Food is s***, we need fresh cakes. I cannot get any coffee at night.*

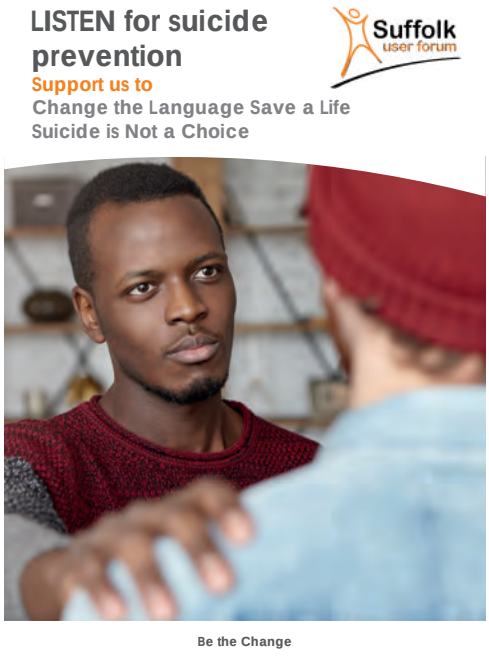
Lights are turned off too early by the main door in the small communal area – the communal nights should not be turned off, only corridor lights.

It is boring on the ward and we need more to do.

Access to the Gym is not good, it is hardly open for us.

3. Appendix One – The coproduced LISTEN model for Crisis Care

If you would like to find out more about the background to the coproduction for LISTEN, you can find out more on our website:
www.suffolkuserforum.co.uk/coproduction-projects/listen



Read more about how LISTEN can support people in crisis and distress, with our coproduced LISTEN for suicide prevention,
www.suffolkuserforum.co.uk/listen-for-suicide-prevention

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

Suffolk User Forum (SUF) is a Registered Company Number 06946785 and a Charity Number 1133457.

Copyright © 2021 by Suffolk User Forum

All rights reserved. No part of this publication may be reproduced, distributed, or transmitted in any form, other than the following. The publication can be printed for personal use only. The publication may be shared on social media on the condition that it is shared in its entirety and acknowledge the source of the material.