

# Making Our Voice Count



**Our Feedback**

1st April 2020 - 30th June 2020

# Making Our Voice Count

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# Making Our Voice Count

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## About Suffolk User Forum (SUF)

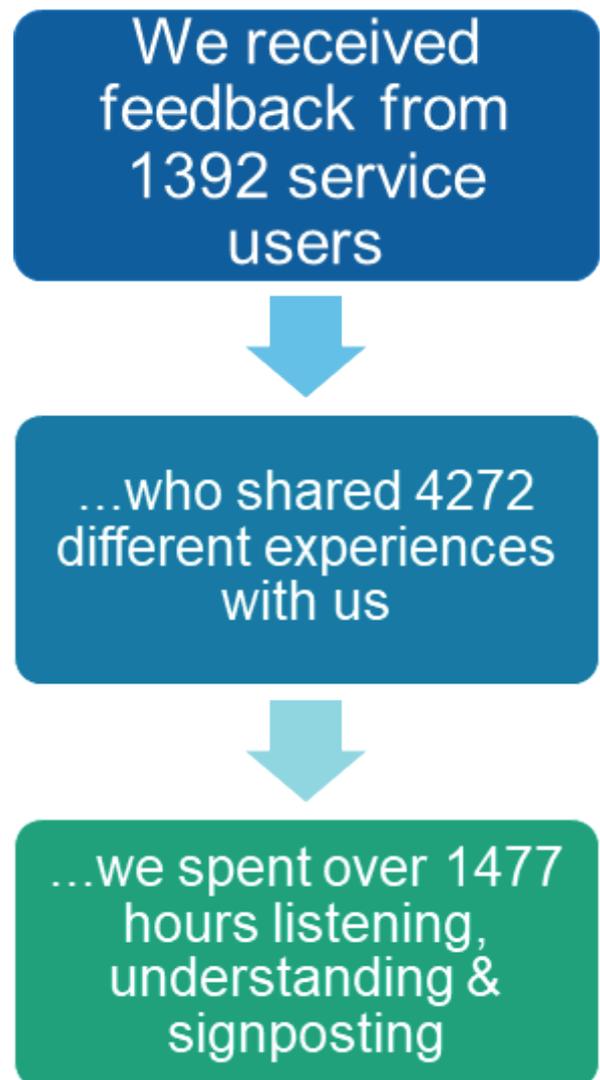
We are the voice for mental health service users in the East and West of Suffolk.

We are a user led charity and everyone in SUF has lived experience of mental health. We provide engagement and inpatient mental health advocacy services, working to give mental health service users a powerful unified voice for their experiences of care and support. We are passionate about continuing to improving mental health services in East and West Suffolk.

One of our key roles is to gather people's views who use mental health services. This report is one way in which we can share more widely the anonymised feedback that we have received. By connecting areas of individual feedback together, we have drawn together key themes and emerging trends for people shielding during COVID-19 and those living with mental health needs, to identify people's needs and report on how people have been experiencing services.

Working together we ensure people's current experiences and views about services are raised at the highest levels, influencing decision making and promoting coproduction, so that providers and commissioners can understand and actively respond to the lived experience of people shielding and those living with mental health needs.

Direct feedback from service users.  
1st April 2020 to 30th June 2020



## About our feedback

We receive a range of feedback from people who use mental health and wellbeing services and support in a range of settings. For the purposes of this report, people's feedback is categorized 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 of best practice.

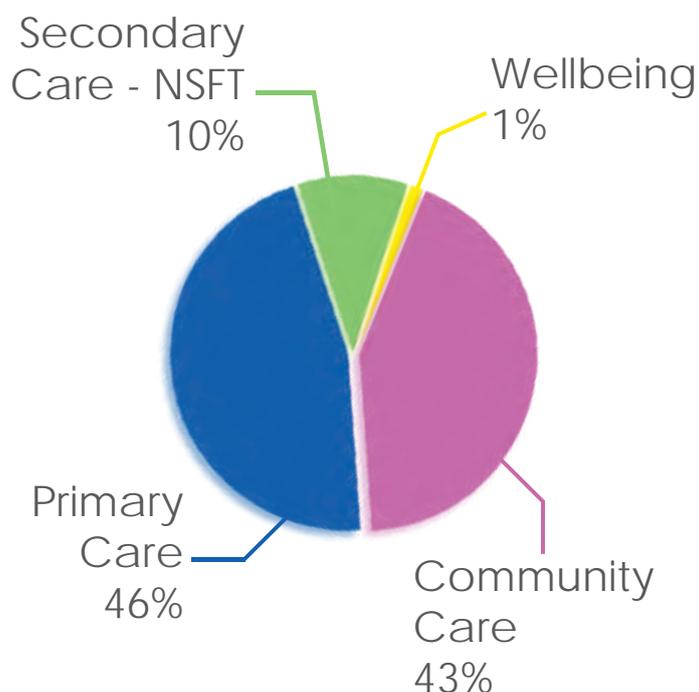
**NEGATIVE** - Where people feel they have not been listened to; that the quality of care or service has been poor or has not fully met their needs or expectations.

This report contains statistical information, alongside some anonymised personal stories which describe people's experiences and views. Where we have received a range of feedback about a service, with stories that describe both positive and negative experiences, we always reflect the range of experience by sharing as many personal stories as possible.

In this reporting period we have gathered feedback from a wide range of health, social care and voluntary organisations. This includes feedback about NHS care, community care and support by voluntary organisations.

## Percentage of feedback per area of care

1st April 2020 to  
31st June 2020



Since a significant part of our work this reporting period year has focused on the needs of clinically vulnerable people who are shielding during COVID -19, this report presents a higher than average level of feedback focused on primary and community care. It also includes feedback about the mental health service provided by Norfolk and Suffolk NHS Foundation Trust, including new services developed during the pandemic.

These are categorized in this report in the following ways.

- **PRIMARY CARE** – This includes care and treatment received through GP surgeries, including GP's, community nurses, link workers, receptionists etc.
- **WELLBEING SERVICES** – This is feedback about the wellbeing services provided by Norfolk and Suffolk NHS Foundation Trust (NSFT).
- **SECONDARY CARE** – Care and treatment received by providers including Norfolk and Suffolk NHS Foundation Trust (NSFT), including the Recovery College; East Suffolk and North East Essex NHS Foundation Trust (ESNEFT) and West Suffolk Hospital Trust (WSHT).
- **COMMUNITY CARE** - Including support and services from Suffolk County Council, voluntary sector partners and peer support groups

We also provide feedback on specific areas of involvement and coproduction, where we have successfully helped to shape and develop services for the better and where our voice has made a real difference.

During this period, SUF has worked together with service users on wider community issues including suicide prevention exploring ways in which we can work together so that the press can provide reliable and agreed supportive information that signposts people to support services, when they report on inquest verdicts that relate to verdicts of death by suicide or sudden, unexpected deaths.

## HEADLINES ON OUR FEEDBACK ABOUT SERVICES

### Community & Primary Care overview for shielded patients.

- 96% reported positive experiences of primary care support and treatment
- 99% had arrangements in place for medication and food deliveries
- 80% had questions about shielding
- 4% needed additional support for carers needs

### NSFT - Secondary Care

49% reported negative experiences of care in the following areas:

- Access/Unmet needs
- Professional response in COVID-19
- Listened to & Understood
- Quality of Services
- Historical mental health care
- First Response Service

41 % reported positive experiences of care in the following areas:

- Inpatient care
- Professional response in COVID-19
- Listened to & Understood
- First Response Service

## Why our feedback is important!

During this reporting period SUF has worked alongside strategic partners from the voluntary sector and statutory services, led by Suffolk County Council to support the county's response to our communities in COVID-19. Our key objectives for this work have included a partnership approach to:

- Build a picture of the range of support available to vulnerable groups during COVID-19.
- Supporting communication about the range of resources and support across our communities to ensure they are clear and accessible.
- Identifying gaps and emerging needs due to the impact of COVID-19.
- Identifying unmet needs and gaps in support, working with partners to bring forward ideas and recommendations seeking to address them.

We have continued to base our work on the principles that to understand the quality of health, wellbeing and mental health services, service providers and commissioners must consider the experiences of people who use them currently. It is only by finding out what service users think that valuable information can be obtained about problems with the way in which services are delivered and how they can be improved as new services are designed and delivered. This enables people's voices to support developments and improvement processes.

### OUR SUF CORE FEEDBACK OBJECTIVES

- To provide a platform for mental health service users and family carers to have an equal voice in local health and care system and ensure their voice is listened to.
- To utilise the knowledge and feedback from service user engagement to contribute to improving existing services and shaping design of future models.
- To ensure the voices of service users & family carers are at the heart of mental health transformation known as #AVeryDifferentConversation
- To actively contribute to Suffolk suicide prevention by drawing on the insights and feedback from service users and family carers, including those with lived experience of suicidal thoughts and bereavement by suicide.
- To gain insights about inpatient care, through mental health inpatient advocacy.

# Our Voice in Primary Care

## Overview of our feedback

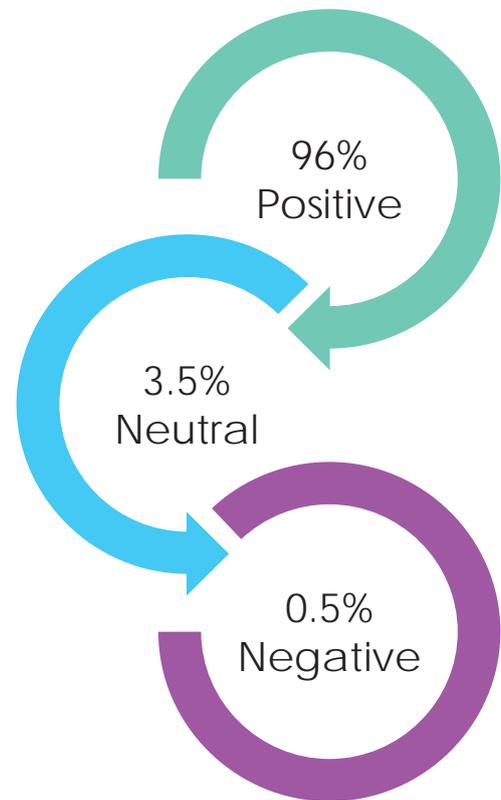
One of the major changes in primary care during the COVID-19 pandemic has been a rapid move to digital appointments, including online triage through eConsult being used more widely in Suffolk; telephone appointments, the use of email and video consultations in some areas, so that patients do not have to attend a practice in person and clinical staff can work remotely if needed.

In this reporting period which includes the 'lockdown' due to the pandemic, SUF has worked closely alongside primary care to support people who are clinically extremely vulnerable with physical and, mental health needs who are shielding. We have therefore gathered a higher than average level of feedback about primary care services, receiving feedback from 473 people.

Whilst some initial contacts at the start of the pandemic related to how people could now access their GP surgery, more information was needed. Surgeries quickly made arrangements clear on their websites, swiftly developed digital solutions, supported by government guidance for clinically extremely vulnerable people and general health and wellbeing during the pandemic.

People overwhelmingly valued digital support. 96% of those that received telephone calls from their surgery whilst shielding, stated that they felt cared for and appreciated the support and opportunity to clarify any questions they had about their illness including, care, treatment and support.

We received feedback about Primary Care from 473 people



- 96% of shielded persons felt very supported by their GP practice.
- 99% had arrangements in place for medication and food deliveries.
- 6% reported that their ongoing treatment at acute hospitals and specialist services had been postponed due to the pandemic.

From 1st April 2020 to 11th June 2020, 80% of shielded people had questions about shielding and many had been confused by the Government messages, however this figure reduced considerably by 30th June 2020 to 35%, as lockdown began easing.

Negative feedback included people's concerns about being unable to consistently see the same GP, which causes them to have to repeat their story each time; difficulty contacting the surgery around working hours; delays in receiving telephone appointments and feeling that they were not listened to and understood by their GP.

“

*I feel really supported by my GP surgery. My GP and everyone has done an amazing job - thank you.*

*The NHS are doing a cracking job - thank you.*

*I moved from one surgery to another recently and have never looked back. The service is great and the people on the reception desk are really helpful.*

*I have contacted my MP and left a message to say my GP surgery is wonderful. The doctors have been fantastic. It was great to get appointment over the phone and medication was sorted straight - away fantastic service.*

*My mental health had not been very good prior to COVID-19, it has deteriorated over the last few weeks. But my GP has been very helpful, I am now having regular appointments with my GP link worker, one or two calls a week and I feel really supported.*

”

“

*I wish the doctors would call when they say they are going to.*

*I was expecting a call at 8.30 this morning, called surgery at 9 to be told I am next on the list, but I am still waiting at 10.30.*

*I would like to talk to the same doctor each time.*

*I speak to a different doctor every time. I have to repeat myself and this wastes time.*

*I speak to a different doctor every time, each with different solutions.*

*Continuity would be more beneficial. It took nearly 14 weeks for my health problems to be sorted.*

*Trying to get through to the Doctor in my lunch break, which is 1-2pm is very difficult, as that's when they close! Sometimes I feel the doctors don't listen to me.*

*I have to jump through hoops to see a GP that I know.*

”

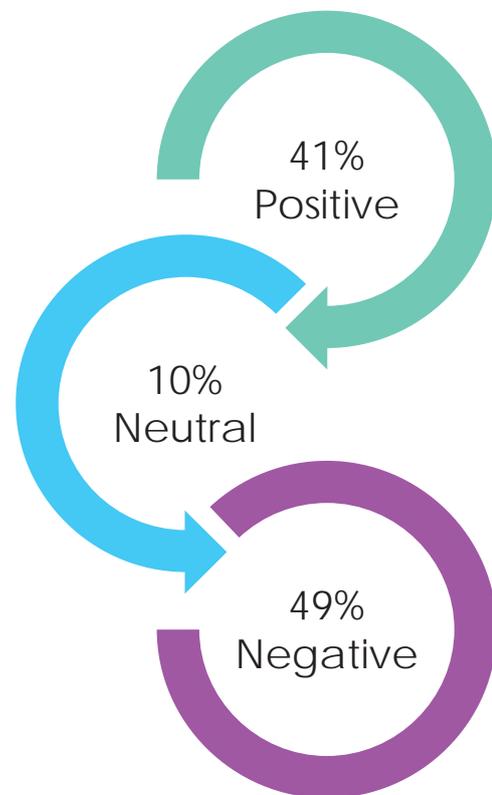
# Our Voice in Secondary Care

## Norfolk & Suffolk NHS Foundation Trust

Norfolk and Suffolk NHS Foundation Trust (NSFT) is the provider for secondary mental health care in Suffolk and Norfolk, including Waveney.

Feedback about NSFT services in this report is divided into five main sections;

1. Feedback from service users continuing to receive community support from Integrated Delivery Teams (IDT -community mental health teams) during the pandemic.
2. Feedback about discharge from IDT's to the new Suffolk Mind Connect Service, introduced to support NSFT during the pandemic to build capacity for the staff to be available to support the NHS response to the pandemic.
3. Feedback about the new NSFT First Response Service (FRS), a 24/7 helpline offering immediate advice, support, and signposting for people with mental health difficulties during the pandemic.
4. Feedback from NSFT's experts by experience (service users) who volunteer as Critical Friends at Wedgwood House, supporting the ongoing improvements to inpatient care.
5. Feedback about our work in Suffolk User Forum with NSFT during this reporting period.



### During this reporting period:

We received feedback from 77 people.

Who provided 126 individual pieces of about people's experiences of NSFT services.

Positive feedback about NSFT's services has significantly increased from 24% (Making Our Voice Count November 2019 to March 2020) to 41% in this reporting period.

Out of the 52 positive comments received, 44 related to the care, treatment and support provided at Wedgwood House.

## Feedback from service users continuing to receive community support from Integrated Delivery Teams.

The majority of feedback related to professionals' response to service users and quality of care issues during the first six to eight weeks of lockdown.

People positively reported the continued appointments for depot injections and reported that staff quickly had the required Personal Protective Equipment (PPE), which they found re-assuring.

One reported being able to ask for specific support which they could access at home and appreciated the approach by their care coordinator who made them feel listened to and understood.

One NSFT Volunteer reported really appreciating personal contact and regular supportive calls by NSFT staff during the lockdown period.

However the majority of feedback related to negative experiences of care and support, particularly during the first six to eight weeks of the lockdown.

Service users reported a significant gap in continuity of care, describing poor communication about arrangements for appointments that had been scheduled prior to the lockdown announcement and poor support by care coordinators, therapists and psychologists, describing feelings of abandonment and frustration with trying to make telephone contact with professionals involved in their care and mental health support.

“

*Service user called SUF to talk about the arrangements in place at Mariner House Integrated Delivery Team, for those people attending for fortnightly depot injections. 'My personal experience for my biweekly visit to the depot clinic is that staff thankfully had the all-important PPE this time.*

*They were in good spirits considering the circumstances...the staff are taking great risks (more risks than normal) delivering their treatment to service users.*

*Service user stated that they had raised concerns with their care coordinator, about the level of support they were receiving in the early lockdown. They felt listened to and understood when the Care coordinator called back and made arrangements for them to be supported at home, in the way that they needed.*

*Service user who has volunteered for NSFT for a number of years stated that they were appreciative of staff in NSFT, as they have been receiving a phone call each week from a NSFT staff member since COVID-19 started. They felt valued and cared for.*

”

“

*"I don't understand, I had an appointment booked with my care-co on Tuesday, so assumed she would call me instead, but she didn't, I heard nothing. I don't feel this is good enough, she could have sent me a message."*

*"I've been having sessions with a psychologist, I thought they were really useful until it moved to telephone contact only because of lockdown. Since then it's just been CBT which I've done before, I haven't enjoyed it much"*

*"I have been with my care-co for 10+ years, we get on well, but I have to say I'm really disappointed that he has not contacted me for over 3 weeks now, especially since we are in lockdown."*

*I had a hospital stay last summer and he has been supportive since with regular calls, I don't know why I haven't heard anything and it's such a hassle trying to get hold of him"*

*"I still haven't heard from my care coordinator, it's been nearly six weeks now, I feel so abandoned, I know we are social distancing, but a phone call would be good."*

*"I called and left a message for my CAT therapist to call me last week, she only works on Tues/Weds, I was seeing her regularly before lockdown but have had only one call since."*

*I had a missed call on my phone from her at 6:45pm, I was in the shower as I expected her to call in work hours, I have no message facility on my phone and now I will have to wait till next week to see if she calls"*

*"I'm really fed up with my care coordinator. I have only heard from her once before during lockdown and had to leave messages for her to call me. She didn't seem interested in how I was doing, she just kept telling me about the muffin she was eating and how wonderful it was. I still don't know when or if I will be seeing her again, Just feel this is really not good enough."*

*I am concerned that in Mental Health secondary care there is not a lot of contact with service users at the moment. Perhaps I am being unfair given the lockdown and COVID situation, but people are not hearing from their care coordinators and are feeling unsupported with everything that is happening. (2nd April 2020).*

*I am still struggling from day to day due to sleep deprivation which causes more Anxiety and Depression. I feel that my care coordinator and psychiatrist have never taken my sleep issues seriously and to be honest with you, I think they are running out of ideas about how to help me."*

”

“

*My psychiatrist wasn't prepared to change my medication or introduce anything else to help me. The service must understand the detrimental effect of a lack of sleep has on someone's mental health.*

*I ended up in A&E last week due to the fact I was at the end of my tether because I have not been able to get in touch with of my care-co. This is a long-standing issue with the IDT.*

*Service user stated that they feel mental health care only looks at their issues from their perspective and do not take into account the experiences service users have had in their life and how issues such as childhood neglect/abuse and domestic abuse have impacted on them and affected their life.*

*Service user spoke about the long-term impact of medication for a serious mental illness describing it as having placed them in an almost vegetative state for 41 years while medicated.*

*They stated that they now felt they could begin caring for themselves, now they were no longer medicated and that such long-term medication started in 1968 leads to ongoing ignorance by mental health professionals who continue to over rely on medication as the solution to mental health problems in the current day.*

*My overall experience with the NSFT services has been very poor.*

*Service user said she had an appointment with a psychologist but felt they were not helpful as they just wanted to prescribe medication and did not offer any psychological support. She felt this was a waste of time.*

*Service user raised concerns that neither Psychiatric liaison at Ipswich Hospital or the Crisis team really understood historical trauma and how this can impact on someone. They were concerned that professionals only considered medication as a solution to their experiences of disassociation and suicidal thoughts.*

*When I was at A&E the Doctor called psychiatric liaison to assess me, but they refused to come. They classed me low risk, so I was then put in a taxi and sent home. The A&E staff were lovely and also were frustrated that no one came to see me, and they could do no more as my problems are not physical. It's now been passed back to my GP to try and get support for me again via the crisis team, so I am just going round in circles.*

”

## Discharge from NSFT Integrated Delivery Team (IDT) to the Suffolk Mind Connect Service

The main issues raised were about the way in which service users were discharged in West Suffolk from NSFT's Integrated Delivery Teams to the new Suffolk Mind Connect Service. People stated they were very unhappy that there had been no conversation with them by their care coordinators and that they had only received a letter informing them they had been discharged and referred to the new Suffolk Mind Connect Service. This caused distress and resulted in service users not being involved in their discharge planning.

Service users also expressed serious concerns to SUF about discharge and the cancellation of psychiatrist appointments, citing information on the Suffolk Mind website which states 'any appointments you may have booked, including any with a psychiatrist, will now be cancelled. We recognise that this will be disappointing, however please discuss any concerns you have about this with the Suffolk Mind Connect Worker or your GP'.

They expressed concerns that there had been no consultation with them or for other service users in the design of the Suffolk Mind Connect service or the discharge from NSFT to the Suffolk Mind Connect service. They were concerned about care planning, discharge planning and the Care Plan Approach, feeling that there was no clarity about how these were integrated into the discharge plan for Suffolk Mind Connect.

This issue was raised by SUF with the West Suffolk Care Group leadership. It was acknowledged that the initial service users discharged had only received a letter from NSFT staff, informing them of their discharge from NSFT care and providing information about the new Suffolk Mind Connect Service. It was confirmed that this affected approximately 50 service users.

NSFT leadership confirmed that following service user feedback this process had changed and those people who were subsequently discharged from IDT's to Suffolk Mind Connect Service were contacted by telephone and the discharge arrangements discussed with service users by care coordinators.

“

*'I have now been discharged from Bury IDT. I am concerned. I have not been contacted by my care coordinator; I just received a letter in the post over the weekend. The letter told me I am now discharged and said I could contact Suffolk Mind Connect. I understand that with COVID-19 there is a capacity issue, but I find this process disgraceful.'*

*'I have now been discharged from NSFT IDT which does concern me.. I now feel penalized for trying to get better.'*

”

“

*Service user said that they had recently been discharged from NSFT (IDT) to the new Suffolk Mind Connect Service. 'I was not happy about this but thought I would give it a go. I waited for a couple of weeks then someone called from Connect'.*

*The service user said that the call was not really helpful and that it felt scripted. 'I was then told that they would not be calling me, but that someone else would as they do not hold caseloads so it could be someone different calling every time.'*

*I am not very comfortable with this as it takes some time to build a relationship and I do not want to go over the same things with different people.*

*I have been discharged from the IDT to Mind support. I have had to wait a few weeks for someone to contact me. I only had a couple of calls then I was transferred back to IDT. Then I had to wait again for someone to contact me. I felt unsupported during this whole time.'*

*I have told NSFT please do not send out discharge letters over a weekend...this was hugely distressing for people.*

”

## Crisis Care and the new First Response Service (FRS)

On 15th April 2020, the new Norfolk and Suffolk NHS Foundation Trust's, First Response Service (FRS) went live, offering a free phone number to the general public, professionals, and voluntary sector for mental health.

This was in response to a request from NHS England to provide mental health advice, guidance, and support during the pandemic.

Many people may know from the mental health strategy 2019-29, that there has been work to develop a NHS 111 option 2 for mental health in East and West Suffolk. This is still the intention, but in the light of the pandemic and the need for a 24/7 support line was made more urgent.

Commissioners have stated 'Once the system is in a recovery phase the NHS 111 option 2 work will be recommenced but using the FRS as a basis. Currently this provision is instead of it'.

Initial feedback included negative comments about the timeliness of calls being answered; the background music played when holding.

There has also been a lack of clarity about which number people should call if they are receiving mental health secondary care by NSFT and need crisis support.

Prior to the FRS, service users in mental health crisis would have care plans that included crisis support from the NSFT Crisis Team. Service users who have called the FRS, for crisis support have been told to speak to their care coordinators and not to call the FRS. This has led to some confusion for people about who they can call at a time of mental health crisis. We are urgently seeking clarification on this matter.

We have received positive feedback in May and June 2020, which has highlighted the kindness of staff, who have had a calm approach, with people feeling listened to and understood, and the FRS service making a difference to them.

“

*Service user said that he had hit rock bottom again and had tried to use the NSFT Helpline number given to him. He tried between 9 and 10 pm on 21st April for approximately half an hour but couldn't get through. He said the phone line was constantly engaged. He managed to speak to the Samaritans.*

*"I called the NSFT new helpline again this week, he told me I shouldn't call it as I have a care co, I should only call her, that's not fair I thought the line was for everyone, they didn't say that last week when I called".*

*Service user said they had called the NSFT helpline to be told to call her IDT the following day and they would be able to answer her questions. On calling the IDT, they were not able to help her, so she felt she was being batted backwards and forwards again.*

*'The music when waiting for the FRS is an issue, it's not soothing or calming and if you are waiting a while you just feel like putting the phone down'.*

”

“

*Service user stated that she was aware her mental health was going downhill, so she called the new First Response Service (FRS)/NSFT helpline. She said that the service was a million times better than the old crisis service.*

*'I spoke with a woman who was understanding, polite and spoke to me like a human being'*

*Service user who said they were still struggling with their mental health explained they did ring the First Response Crisis Line. They said.*

*'The lady was lovely and very calming, and I felt she helped'.*

”

“

*'I called the new crisis line on Saturday night I got through in a reasonable time. But the music they play when you are on hold was not good or soothing and nearly made me put the phone down as it wasn't good at all. When I got through, I got a good response from the female call handler.*

*The call handler listened to me and I felt I was able just to talk without them butting in. I was able to process my concerns and fears and I felt that the service worked.*

”

## Developments at Wedgwood House & the role of Critical Friends

As part of the improvement work for Wedgwood House, SUF were asked in early May, by the lead nurse of the West Suffolk Care Group, if we could be involved in a new initiative called Critical Friends which was starting in Wedgwood House. This initiative invited experts by experience (ex NSFT service users) to volunteer with NSFT, to evaluate that the quality of the care being provided to the patients was first class.

This role includes meeting regularly with staff and patients, attending various patient meetings as well as staff meetings, to ensure NSFT are getting regular patient feedback, engagement, and involvement in all aspects of everything they do.

Critical Friends also design with patients and staff satisfaction surveys for example Care Planning and the Care Programme Approach. Any issues that the Critical Friends identify are placed on the unit's improvement plan, so they can be monitored, and improvements recorded.

Critical Friends have told us that they are supporting work to progress documentation compliance audits, quality audits and review care plan audits.

The Critical Friends during this reporting period have regularly shared patient feedback together with their findings with us in SUF. Feedback has included positive experiences about patients being involved in their care plans.

“

*"My care plan has been built up over the last few weeks"*

*"Making my care plan helped me to get to know a staff member"*

*"Two care plans are required. One for me as an inpatient and a revised copy for the community. (Different needs and requirements)"*

”

The Critical Friends told us that they received mixed feedback regarding ward rounds being undertaken on digital platforms such as Microsoft Teams, during COVID-19. One patient has positively stated "Ward rounds have been less scary over Microsoft Teams" whilst another commented that they found video ward rounds "soulless" because "it's over Microsoft Teams you can't read people's body language".

Feedback regarding the ward environment has highlighted on going issues regarding the showers and lighting. We have been informed that this is currently being investigated by NSFT Estates Department to make improvements. Patients have asked for outside furniture to sit on and this has now been ordered.

During this period, activity groups on offer to inpatients had decreased. Critical Friends have informed us that a range of new activities have been suggested by patients which have been taken forward by staff. The Critical Friends also arrange activities with the support of staff such as picnics at weekends so that patients have events to look forward to.

Feedback on staff was mostly extremely good with patient's saying;

“*No-one can care for me like Wedgwood*”

*"The staff are highly skilled"*

*"Talking about it makes me sad because I'll have to leave them all soon"*



There were some issues raised with night staffing levels, that were immediately investigated by the leadership team. Due to one of the wards being designated a COVID-19 ward during the pandemic, this increased the number of patients on another ward and some patients felt that the staff did not have so much time to spend with them, but did understand the reason why this has changed.

The Critical Friends also provided positive feedback on patients 'One two One' time, with patient's saying that they felt they can talk or cry during this time which they could not do publicly. Other general and positive feedback received includes.

“*I spent the last 30 years avoiding services, because I was scared of them after being sectioned in the past. This is my first positive experience. I have finally got the help I needed.*”

*"Wedgwood is the place that allows me to reach my potential. It is because of this place that I have a life. I could so easily be dead"*

*"I can talk to them at any time about anything"*



“

*"It is so nice to talk to people about things other than our problems. This is how people heal. We should be doing more of this on the ward. The whole world should be doing more of this".*

*"Residents and staff were working in true partnership to improve outcomes, just like the Staff Safety Huddle does. This was a fantastic and productive meeting and is a credit to how the whole ward experience is encouraging a more honest dialogue between residents and staff."*

”

We have recommended that this excellent initiative is expanded to Woodlands and across Community teams.

### **Feedback about our work in Suffolk User Forum with NSFT during this reporting period.**

Working strategically SUF has raised concerns about the disproportionate impact of COVID-19 for people from Black, Asian and Minority Ethnic (BAME) groups, focusing with NSFT leadership on the needs and support for both BAME staff and service users. We have asked NSFT to consider specific needs and concerns when planning appointments through risk assessments and to consider this issue when staff are coproducing with service users their personal care planning, wellbeing, and mental health support.

This has included updating the NSFT website with links for their translation services through INTRAN.

We have also asked NSFT to ensure that care planning takes into account the needs of service users who are dependent on family carers for day to day support, and that care planning includes additional support planning, should those carers become unwell with COVID-19.

Following six service user concerns in this reporting period about local press articles reporting on deaths by suicide, or sudden and unexpected deaths, we have worked in partnership with the NSFT Communications Team and Archant (the local newspaper and magazine publishing company) to agree a way in which press articles can offer improved wellbeing and mental health support to readers who may be affected or distressed by the content contained in articles. The NSFT Communications team have been very supportive and together with Archant, we have been able to agree that articles should include support for readers using the following paragraph;

**If you need help and support, call Norfolk and Suffolk NHS Foundation Trust's First Response helpline 0808 196 3494 or the Samaritans on 113 123. Both services are available 24 hours 7 days a week. You can also download the Stay Alive app on Apple & Android.**

# Our Voice in Community Care

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## Overview of our feedback

Our feedback about community care includes a wide range of community support and services, including social care, safeguarding and voluntary sector support. Within the context of the pandemic we have not categorised these in terms of positive, negative, and neutral feedback areas in this report, but provide insights on the impact of the pandemic on people's wellbeing, mental and physical health. This feedback captures the key issues and themes that SUF has identified and reported weekly to strategic meetings led by Suffolk County Council and Suffolk Public Health.

## Suffolk's Response to COVID-19

The county's strategic response to COVID-19 has brought together the contribution of both statutory and voluntary organisations alongside our communities' commitment to mobilize support for those most vulnerable during the pandemic.

A centralised COVID-19 information resource for Suffolk was developed and regularly updated by Suffolk County Council called the Emotional Wellbeing, Mental Health and Learning Disabilities COVID-19 Information Hub - [www.healthysuffolk.org.uk/covidhub](http://www.healthysuffolk.org.uk/covidhub)

It provides information in different languages and supported by accessible information on the Ordinary Lives website - [www.suffolkordinarylives.co.uk](http://www.suffolkordinarylives.co.uk)

Alongside this, the Home but Not Alone initiative and online resource has delivered support to those in urgent need during the pandemic. [www.suffolk.gov.uk/coronavirus-covid-19/home-but-not-alone/](http://www.suffolk.gov.uk/coronavirus-covid-19/home-but-not-alone/)

## Insights

Working with over 1300+ people we have understood that people have diverse experiences of the pandemic.

- Not everyone has been negatively affected by the pandemic. Some people with mental health needs have told us they been able to use this 'quiet' time to focus on self-care and recovery.
- Others had found new ways to communicate and connect, growing in self-confidence and learning new skills.
- Some who had been furloughed have welcomed the break from work. Others have feared whether they will still have employment when furlough ends.

- From early April 2020, it was nationally recognised that some people were more disproportionately affected in the pandemic. including those in lower income groups, those living with social inequalities and racism, both of which have contributed to the disproportionate impact of coronavirus on people from Black Asian Minority Ethnic backgrounds (BAME).
- We supported 6% of those employed with employment issues, initially supporting 3% of employed people who were shielding to be furloughed and supporting people with mental health needs and those shielding about returning to work when shielding and furlough ends.
- We identified that 2% of the shielded people were from BAME backgrounds and were not shielding due to business or employment demands.
- Many have experienced anxiety. In the first 8 -10 weeks, they missed face to face and physical contact with loved ones, and experienced significant isolation, especially those without digital resources such as smart phones, laptops or tablets.
- Those whose family members worked as key workers particularly spoke of their fears about loved ones being more vulnerable in their job roles to COVID-19.
- Anxiety increased, particularly in the easing of lockdown, with many people finding the Government messages confusing and were not assured that they were based on any scientific evidence regarding a reduction in clinical vulnerability. Many stated that they fear it will never be safe for them to leave their homes whilst COVID-19 is untreatable and not preventable.
- This caused them greater conflict in terms of wanting to see loved ones in person but understanding that nothing had really changed in terms of their clinical vulnerability.
- Some felt that the risk for shielded people had increased with general overall easing of lock down; with more people being out and about, stating that the risk of going out was 'not worth it' as it involved high risk alongside more challenging decisions and choices.
- Some people and especially those who are parents and whose children have been shielding with them stated they are afraid of the risks and worry about the impact on their children's wellbeing and mental health. They reported that their children were expressing fears about their parent becoming infected and fears that they feel they may never be able to leave their home, with fears that the outside world is not safe for their family, alongside feeling isolated from friends and missing school.

- For those living with mental health needs, we identified a significant deterioration in some people's mental and emotional health.
- We have supported on average, two people each week who have been at significant risk of serious self-harm/ suicide, with emotional support, signposting and active support to access and receive services, including safeguarding.

“

*'I'm not functioning and have no idea what to do. I'm able to sleep and eat as usual but I'm so traumatized I'm just frozen and critically I am unable to help myself'*

*'I broke down last night with what is going on in my mind; my mind is in a mess what can I do?'*

*'I'm sorry I've been feeling really unwell over the past few days with my Mental Health taking a pounding'.*

*'My suicidal thoughts are horrendous at the moment.. I can't cope with this situation'.*

”

- Twenty people experienced mental health crisis and six people were more vulnerable due to ongoing domestic violence situations. Government messages could be confusing and were not assured that they were based on any scientific evidence regarding a reduction in clinical vulnerability. Many stated that they fear it will never be safe for them to leave their homes whilst COVID-19 is untreatable and not preventable.
- In two cases, more than eight safeguarding referrals had been made by other statutory services, including GP's and the police. Those in mental health crisis, expressed fears about being unable to keep themselves safe.
- Some people have experienced a range of bereavements, including those working as key workers in hospitals and care homes. Where people experienced multiple bereavements, this had in a significant impact on their mental health.
- The closure of schools and home education has for some people been precious family time, but for others has been overwhelming and demanding alongside employment.
- For some, where two parents have continued to work at employment premises, managing childcare, home schooling and employment has been a huge pressure.

- For others working from home, sharing digital technology equipment between work and education; sharing limited tabletop space for day to day living and family life alongside suddenly having to become a school teacher for their child, whilst still having to work, juggling this along with normal parenting and family time had a quite significant impact on the mental health of everyone affected young and old.

- Throughout this period, we have considered the impact for family carers. Just under a quarter of shielded people cared for another person in their family. Some people needed more support for their caring role, including young carers.

- We signposted 58 people to partner organisations for additional mental health, wellbeing, and community support.

- These included FRS, Kooth, Lighthouse, Suffolk Family Carers, Stay Alive App, Suffolk Parent Carer Network, Samaritans, Healthy Suffolk COVID Hub including bereavement support, Living Life to the Full and Wellbeing Suffolk.

- People have overwhelmingly expressed appreciation and thanks to all those organisations who had supported them throughout the lockdown period, valuing a friendly voice and connection.

In recognition of an overall county wide report of public appreciation the Suffolk Says Thank You community campaign, was developed by the Emotional Wellbeing in the Community group offers fun and simple ways to say thank you.

[www.suffolksaysthanks.com](http://www.suffolksaysthanks.com)



*Suffolk Says Thanks – supporting everyday acts of kindness*

# Improving the experience of care for people using mental health services

## Our Feedback - Your priorities

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Across all services staff have adapted to the COVID-19 challenge and several positive developments in wellbeing and mental health support have taken place at pace through this early period of the pandemic. Organisations across Suffolk have rapidly moved to virtual support for their service delivery; new vital support services have been delivered, in particular, the new First Response Service (FRS) 24/7 telephone support and Suffolk Wellbeing, which has provided a helpful range of virtual support offers and publications for people.

Primary care has been more effective in their communication, however providing consistent information about the trust's service criteria remains a key issue for NSFT. We recommend this is built into Quality Improvement Projects.

Whilst there were some early negative comments about the FRS service, many people have praised the support provided, valuing the way in which staff at the FRS have treated them with kindness and compassion.

It is also evident that people have really valued individualised care during this time, which they have reported as making a big difference, which has made them feel cared for.

This is not consistent across NSFT and safeguarding processes. Poor experiences have largely been due to poor individualised care, where people have not felt valued, listened to or understood.

Suffolk Mind Connect has been a helpful service to many. However, the discharge arrangements for the first group of people referred were not undertaken in the most effective manner due to poor communication. Many have understood the reasons for their discharge but would have valued conversations with Care Coordinators, together with the opportunity to ask questions.

When people seek help, access to effective help depends upon availability, speed and ease of access, but the direct experience of making contact with a service provider can impact on whether people trust that the service can actually be supportive and help them. Good communication about changes in services due to the pandemic has been both necessary and invaluable, where it has taken place. It can influence the degree to which people feel able to understand new services and how they feel able to trust and engage with support offered.

There is a need for organisations to ensure that service user and family carer experience is every employee's business and priority, owned by all staff working and embedded in all organisations. The new initiative called Critical Friends in NSFT (West Suffolk), has very successfully made a good start promoting increased service user inclusion to service development and significantly progressed real time service user feedback. There is an opportunity to now expand this to East Suffolk, and to all Community teams in both East & West Suffolk and build its sustainability as a positive user led develop and for further coproduction going forward.

Full representation and inclusion of BAME representatives is required across the Suffolk system to ensure that everyone in our communities are fully included, can be part of our solutions and make change happen. We recommend that attention is given to the Healthwatch Suffolk film 'What we are missing' – the link for this is: [www.drive.google.com/file/d/1dO\\_3P54oqtOegmNB4EQyiZpxWg-LZe4n/view](http://www.drive.google.com/file/d/1dO_3P54oqtOegmNB4EQyiZpxWg-LZe4n/view)

Across the NHS system, many people's longer term health care needs have been 'put on hold' as the NHS has focused on the needs of people with COVID-19. This has negatively impacted on both those with physical and mental health needs, alongside the widely reported increase in mental health needs because of the impact on people's lives during the pandemic.

There is a need to plan how these needs can be met with additional capacity, building on digital solutions that organisations and many service users have found to be successful and helpful.

Consideration also needs to be given to the well documented seasonal trend that shows an increase in mental health inpatient admissions from early summer. SUF has seen an increase in mental health distress throughout June, and we need to understand the wider picture, and whether mental health services have accounted for this historic trend in their resource allocation, and if there is any monitoring or opportunity for reporting on this.

SUF will continue to gather feedback and report on the current issues of experiences of care and support. It is crucial that service providers ensure lived experience is at the heart of all their services and that it is not only listened to, but that action and feedback also happens. Service users and family carers need independent user led organisations that they can trust, to whom they can share their experiences, worries and fears about services and trust that we will raise their voices, so that they are heard, and work alongside providers to ensure this makes a difference. This is why service users feedback their concerns to SUF, because we have a proven track record of all of the above.

# Together We Make Change Happen

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## How we share our voice

During this reporting period we have worked to ensure that our feedback is reported back strategically to support the county response to COVID-19, and to inform service development and improvement.

We have provided feedback, through regular briefings, reports and verbal feedback at 35 virtual meetings, including weekly meetings for COVID-19 strategic planning. These have included the following.

- Suffolk County Council
- Suffolk Public Health
- Mental Health Commissioners in the Clinical Commissioning Groups for Ipswich and East Suffolk (IESCCG) and in West Suffolk (WSCCG)
- Norfolk and Suffolk Foundation Trust and the NSFT Overview & Scrutiny Group, chaired NHS England.

We have worked alongside our voluntary sector partners, including Suffolk Family Carers, Suffolk Parent Carer Network and ACE Anglia, to share feedback and support a strategic understanding of people's needs through the pandemic.

Alongside this we have continued to support the voice of lived experience in the redesign of mental health, learning disability and wellbeing services known as #AVeryDifferentConversation.

We have supported these by sharing our lived experience and feedback to underpin wider conversations, to ensure our voice is heard, listened to and that changes take place based on our experience and recommendations for improvement.

Responding to the changing pandemic situation we have supporting access to reliable and trusted information on our website and on social media.

- Set up a COVID-19 page on our website providing a range of support and including 'Your Questions Answered' page providing Questions and Answers, focused on the questions you have been asking us about mental health and wellbeing support during the pandemic. [www.suffolkuserforum.co.uk/covid-19-support/](http://www.suffolkuserforum.co.uk/covid-19-support/)
- Expanded our Five Ways to Wellbeing work to provide Thrive with Five publications, producing Connect, which explores ways in which we can grow our connections during lockdown. [www.suffolkuserforum.co.uk/covid-19-support/thrive-with-five/](http://www.suffolkuserforum.co.uk/covid-19-support/thrive-with-five/)

We have worked with service users to be involved in 17 areas of user led involvement and coproduction, which have included.

- Working with strategic leaders we have supported Suffolk Safeguarding information for the Implementation of the Herbert Protocol, which is a national scheme that encourages carers, family and friends to provide and put together useful information, which can then be used in the event of a vulnerable person going missing. This can be found on the healthy Suffolk website: [www.healthysuffolk.org.uk/uploads/herbert\\_protocol\\_leaflet\\_Final\\_May\\_2020.pdf](http://www.healthysuffolk.org.uk/uploads/herbert_protocol_leaflet_Final_May_2020.pdf)
- Based on our service user feedback and ideas for development from our members, we worked with Suffolk Family Carers and ACE Anglia and identified people at risk of missing out on key service information and provision, or losing all family contact because of a lack of technology and communication devices, needed for virtual contact during the pandemic.

Together with wider voluntary sector organisations we are seeking support from local businesses for donations of smart phones, tablets and laptops alongside technical support which can enable people to have on going connection.

[www.fundraising.co.uk/2020/06/17/suffolk-charities-unite-in-call-for-local-business-support/](http://www.fundraising.co.uk/2020/06/17/suffolk-charities-unite-in-call-for-local-business-support/)

- Working with service users, we have supported Suffolk Public Health, NSFT and Grassroots (the App designer for the Stay Alive App) to the design and agree the wording for suicide prevention information during the pandemic, working to provide information in different languages, ensure that the NSFT translation service is made clear on their website, and to update the Stay Alive App with the contact information for the First Response Service.

[www.healthysuffolk.org.uk/uploads/When\\_suicide\\_is\\_on\\_your\\_mind\\_leaflet\\_\(DIGITAL\).pdf](http://www.healthysuffolk.org.uk/uploads/When_suicide_is_on_your_mind_leaflet_(DIGITAL).pdf)

- We have continued to promote the LISTEN approach to crisis support at the FRS and in other mental health services.

[www.nsft.nhs.uk/Get-involved/Pages/LISTEN.aspx](http://www.nsft.nhs.uk/Get-involved/Pages/LISTEN.aspx)

- We have supported the Suffolk Say Thank You campaign, working with service users and Suffolk Public Health.

- Working in partnership with the NSFT Communications Team and Archant (the local newspaper and magazine publishing company) we have agreed how press articles can offer improved wellbeing and mental health support to readers who may be affected or distressed by the content contained in news articles, see page 17 of this report.

- We have provided inpatient mental health advocacy, by telephone promoting people's rights and choices.
- Prepared for national Co-production week (6-10th July 2020) by working with service users and Suffolk Public Health, to coproduce a refresh the county's Suicide Prevention Strategy at this crucial time, launching our user led campaign called 'Change The Language, Save A Life', looking a look at how language is used around in suicide prevention.

[www.suffolkuserforum.co.uk/suicide-prevention-for-a-new-era/](http://www.suffolkuserforum.co.uk/suicide-prevention-for-a-new-era/)

Service users are still reporting to us that some professionals have told them that death by suicide is 'their choice'. Together we have challenged this across the system and in mental health transformation, promoting an understanding that people often feel compelled toward suicide, because, simply, the pain of living has become greater than the resources they have to deal with it - they are losing a fight against intolerable pain, emotional turmoil, and loss of hope.

We know that as people are starting to emerge from lockdown, there are individuals who are hugely anxious, financially troubled, exhausted, lonely. We are seeing a steady increase in mental health issues that have previously struggled with for some time.

Now more than ever we need to listen to people and involve them as experts in suicide prevention. We need to support people, so they do not feel alone, understanding that many of us have had suicidal thoughts at some point in our lives; that these feelings and thoughts are very much part of being human. Although these feelings can sometimes feel overwhelming, we know that with time and non-judgmental support, we can begin to manage these difficult thoughts and come to understand that suicidal feelings will pass.



### ***Change the language - Save a life***

#### ***Suicide is not a choice***

*Suicide is not chosen; it happens when pain exceeds resources for coping with pain. That's all it's about. You are not a bad person, or crazy, or weak, or flawed, because you feel suicidal. It doesn't even mean that you really want to die — it only means that you have more pain than you can cope with right now. If I start piling weights on your shoulders, you will eventually collapse if I add enough weights... no matter how much you want to remain standing.*

Source: [metanoia.org/suicide/](http://metanoia.org/suicide/)





# 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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