healthwatch Norfolk

Community Based Mental Health Services in Norfolk and Waveney.

Year Two
Community Transformation Steering Group Evaluation
June 2022 – June 2023

Contents

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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Summary

This is the second year report of a three year evaluation. Healthwatch Norfolk explored how well a Steering Group (managed by Norfolk and Waveney Integrated Care Board and Norfolk and Suffolk Foundation Trust) delivered on the transformation of community based mental health services in Norfolk. In our first year we made several recommendations and this report looks at how the Steering Group has responded to them.

To complete this evaluation, Healthwatch Norfolk regularly attended Community Transformation Steering Group meetings to find out what progress they were making. We also spoke to adults severely affected by mental illness, their carers, Transformation Leads, Experts by Experience, local Voluntary Community and Social Enterprise (VCSE) representatives, mental health staff and primary care managers to gain their views on the transformation progress.

Outcome one focused on adults severely affected by mental illness, particularly people diagnosed with an eating disorder or a personality disorder, people being treated for perinatal mental health issues and individuals receiving rehabilitative support. Adults severely affected by mental illness revealed variable experiences with community mental health services. A Transformation Lead told us that the I Statements from year one had been updated by the Experts by Experience and these had been presented to the Steering Group. Each workstream is now being benchmarked against the relevant I Statement outcome. Healthwatch Norfolk recommended that the Steering Group should ensure there is a process so that adults severely affected by mental illness and their carers can feedback on whether they believe the I Statements have been met for them and to use this feedback to see what changes need to be made.

Outcome two explored carers experiences and they reported that they have seen very little change to services. There has been a lack of

continuity of involving carers and loved ones in the transformation process. Healthwatch Norfolk recommended that the Steering Group meets the previous recommendations.

For outcome three Healthwatch Norfolk investigated whether the Steering Group could evidence that they have made changes that positively impact community mental health services. There was evidence that efforts have continued from the Steering Group to engage with the VCSE sector through the Mental Health Providers Forum. Experts by Experience have been involved with many of the workstreams, but there is very little evidence of any Steering Group engagement with wider groups of Experts by Experience through other VCSE partners.

Outcome four investigated whether community-based services report ongoing change and improvements to joined up services and waiting times for community mental health services. VCSE organisations reported that there has been an improvement in the holistic approach taken by the Steering Group, but little change to waiting times.

For outcome five we spoke to mental health and primary care workers to see if they report improvements to community-based services and the progress of integrating new mental health staff into primary care. The integration of the roles has been a successful process. Both mental health staff and primary care managers are reporting that they are becoming more aware of each other and adjusting to cultural working differences.

Change is happening, but many adults severely affected by mental illness and their carers are not yet experiencing this. There are still issues about services not having been joined up, waiting times to access services and people feeling in control of their care. Where there has been significant progress with the Rehab pilot, the success is due to a holistic approach, proper partnership working with a range of stakeholders and embedding the views of Experts by Experience in the design of the service. For continued success with the transformation of all community based mental health services these elements must be at the heart of the process.

Why we looked at this

Healthwatch Norfolk was commissioned by Norfolk and Waveney Integrated Care Board (ICB) to conduct an independent person-centred evaluation of how well the Community Transformation Steering Group delivered the transformation of community based mental health services in Norfolk and Waveney. In the first quarter of 2023 there were approximately 9108 people registered with doctors' surgeries as being severely affected by mental illness (NHS England, 2023) in Norfolk and Waveney.

Throughout this report we have used the terms 'severely affected by mental illness' and 'severe mental illness' to reflect the language used by the people that we spoke to for this evaluation. The Community Transformation Steering Group have partially based their definition of Severe Mental Illness on the definition that appears in the NHS Mental Health Implementation Plan (2019b), which can be found below.

> "The term Severe Mental Illness (SMI) covers a range of needs and diagnoses, including but not limited to; psychosis, bipolar disorder, 'personality disorder' diagnosis, eating disorders, severe depression and mental health rehabilitation needs – some of which may be co-existing with other conditions such as frailty, cognitive impairment, neurodevelopmental conditions or substance use."

This project is a three-year evaluation, which should be completed in June 2024. This interim report covers the period from June 2022 - June 2023. This report is looking at what happened within the second year of the programme. In year one it was noted that large-scale change can take years to achieve, however we would expect to see noticeable changes to services in year two of the Transformation.

Healthwatch Norfolk aimed to evaluate whether community mental health provisions for people diagnosed with a serious mental illness have improved within Norfolk and Waveney. Healthwatch Norfolk explored whether:

- The Community Transformation Steering Group has done what it set out to do.
- Adults diagnosed with a Serious Mental Illness (SMI) have experienced positive change.

- Families and carers of adults diagnosed with an SMI have experienced positive change.

Throughout the second year of this work, we focussed on the same five outcomes as year one.

Healthwatch Norfolk Evaluation Framework Outcomes	
Outcome 1	Adults severely affected by mental illness (SMI) report improvements in and access to community-based services.
Outcome 2	Families and Carers of adults severely affected by mental illness (SMI) report improvements.
Outcome 3	The Community Transformation Steering Group can evidence that they have made changes that have positively impacted on community health provision for adults severely affected by mental illness (SMI).
Outcome 4	Community based services (NCC, District Councils and VCSE sector organisations supporting adults with SMI) report improvements to joined up services and waiting times.
Outcome 5	Mental Health Workforces will report improvements in community-based services for adults severely affected by mental illness (SMI).

This report gives a summary of the findings on these outcomes. The Evaluation Framework that this report is based on can be found as Appendix 1.

Throughout this report, we have used some terms that are commonly used by members of the Community Transformation Steering Group, and they are explained in the Glossary which can be found as Appendix 2.

How we did this

We have engaged with the Community Transformation Steering Group throughout this project, with the Project Lead from Healthwatch Norfolk, attending the steering group meetings. An evaluation plan for year 2 of this work was presented to the Steering Group on 10th January 2023, which was agreed and approved during the meeting. A copy of the evaluation plan can be found as Appendix 1.

Healthwatch Norfolk completed this work by using feedback gathered from the public, mental health workforce, primary care workforce and local voluntary, community, and social enterprise (VCSE) organisations to provide both Norfolk and Suffolk Foundation Trust (NSFT), NHS England and NHS Improvement assurance that the Community Transformation Steering Group is delivering outcomes for adults severely affected by mental illness and their care networks. The Community Transformation Steering Group is responsible for overseeing the changes.

Early in the transformation process eleven "I Statements" were co-developed by the community transformation steering group. The process was led by Access Community Trust in consultation with people with lived experience. The I statements provided a framework to ensure strategic objectives were aligned to expert by experience ambitions. The I Statements are the basis of Healthwatch Norfolk's evaluative framework. A full list of the initial I Statements can be found in Appendix 3.

Feedback for the five evaluation outcomes was collected via two qualitative methods: one-to-one interviews and a focus group.

Outcome	Qualitative Research Method
One Adults severely affected by mental illness	1:1 Interviews n=11 1st Focus Group n=7
Two Carers of Adults severely affected by mental illness	1:1 Interviews n=9
Three Steering Group and Co-production	1:1 Interviews Experts by Experience n=3

	Transformation Leads n= 14
Four VCSE and 3rd Sector Organisations	1:1 Interviews VCSE Partners and 3rd Sector Involved in Rehab Pilot n= 10 VCSE Partners (General) n=11 Norfolk County Council Representatives n= 3
Five Mental Health and Primary Care Workforce	1:1 Interviews GP Practice Managers n=3 Mental Health Practitioners n = 5 Enhanced Recovery Worker (ERW) n= 1 ERW Service Manager n= 1 Primary Care Network Service Manager n= 1 Social Prescriber n = 1
Total Number of 1:1 Interviews for Year 2	73
Total Number of Focus Group Attendees for Year 2	7
Total Number of People Engaged with for Year 2	80

Who we spoke to

In year one, the Community Transformation Steering Group identified several priority cohorts that would be included within the planned transformation workstreams. These priority cohorts included adults diagnosed with one or more of the following conditions:

- Personality Disorder
- Eating Disorder
- Perinatal Mental Health issues
- Rehabilitation needs due to Complex Psychosis and/or a dual diagnosis

For year two we undertook a series of interviews and focus groups with adults severely affected by a severe mental illness (with people living with one or more

of the conditions listed above), their carers and loved ones, Experts by Experience, key stakeholders such as those from the voluntary, community and social enterprise sector and representatives from the Community Transformation Steering Group to help us gain information and feedback on the community-based transformation process.

Healthwatch Norfolk developed a range of promotional materials to encourage participation from the stakeholders listed above with a goal of reaching as many people as possible. Healthwatch Norfolk promoted the opportunity to be part of a one-to-one interview to talk about their experiences of community mental health services via several different channels. These included:

- Social media accounts (LinkedIn, Facebook, Instagram and Twitter).
- Healthwatch Norfolk newsletter and website.
- Promotion by VCSE and third sector organisations that support adults diagnosed with a Serious Mental Illness and/or their carers and loved ones.
- Promotion by attendees of the Community Transformation Steering Group.

Interview questions were like those asked in year one to allow a comparison between the answers and identify if any change has occurred. The interviews were semi-structured and open ended, which encouraged conversations to develop between the researcher and the interviewees.

All interviews were held online and recorded using a Dictaphone, with prior consent from the participants. The recordings were transcribed and then analysed using thematic analysis and the themes are reported in the 'What we found out' section of this report.

We offered £10 e-vouchers to those participants with lived experience of SMI and their carers to encourage participation and to compensate people for their time. Copies of all the interview questions for each of the outcomes can be found in Appendices 2-9.

For outcomes 1 and 2 Healthwatch Norfolk conducted eleven one-to-one, semi structured interviews with the adults severely affected by mental illness and nine one-to-one interviews with carers and loved ones online via MS Teams. All participants had given consent for their answers and feedback to be shared in this report anonymously. Each participant received an e-voucher.

The interviewer had a list of broad topic areas and questions that mirrored the ones asked in the first year to allow a comparison of the answers and measure change as part of the evaluation process.

Healthwatch Norfolk hosted one focus group, which was supported by two employees from the Waves programme. This programme supports people either diagnosed or living with traits of borderline personality disorders (BPD) or emotionally unstable personality disorder (EUPD). Waves provides a 12-month, one day a week course that incorporates psycho-educational workshops and social sessions to help each participant to explore their needs with their peers in a safe environment. Before the focus group commenced, Healthwatch Norfolk explained the purpose of the session, the format and what would happen with any feedback given. Informed consent was established, and it was explained that participants could withdraw from the session at any point. The focus group lasted an hour and a half and invited attendees to work in pairs and answer questions about their recent experiences of community mental health services. These experiences were then fed back to the whole group and audio recorded (with prior consent) to be thematically analysed. Once the focus group concluded, the group were debriefed, thanked for their time and each received a £10 voucher.

For outcome three, Healthwatch Norfolk wanted to explore whether the Community Transformation Steering Group (CTSG) can evidence that they have made changes to community mental health services since the transformation began. We interviewed each of the Transformation Leads to identify their key actions for each priority cohort and workstream, what improvements they expect to see as a result of the changes they are planning or have made, what impact they expect to make on joined up services and waiting times, how this work has been co-produced with Experts by Experience and key partner organisations and how the changes to services can be linked to the outcomes that adults severely affected by mental ill health want for themselves (as reflected in the I Statements).

We also engaged with Steering Group members about the progress of the Physical Health Check workstream to understand how they are ensuring that system data for physical health checks is reflected in primary care systems. To help monitor any change in the number of physical health checks being offered compared to those being attended by adults severely affected by mental illness we requested data from the Community Transformation Steering Group.

Co-Production and Partnerships

Healthwatch Norfolk wanted to understand if partner organisations within the voluntary and community sector believed they were involved in the community mental health transformation process and felt able to influence the plans.

Healthwatch Norfolk interviewed representatives from nine local organisations in the Voluntary, Charitable and Social Enterprise (VCSE) sector. We have anonymised the organisation names in the report to encourage open and honest feedback. We also regularly attended the Mental Health Provider's Forum.

We conducted three one to one interviews with Experts by Experience to help us understand the level of co-production by people with lived experience of SMI in the transformation planning and process. To help us do this we engaged with Rethink who have supported the involvement of Experts by Experience within the Steering Group and co-production work within each of the transformation workstreams.

For Outcome four, Healthwatch Norfolk identified the organisations that are involved in the rehabilitation pilot and interviewed them about their role in the pilot and the impact it has made.

Healthwatch Norfolk also interviewed representatives from ten voluntary and community groups and three Norfolk County Council representatives that support people severely affected by mental health issues. During the semi-structured interviews, Healthwatch Norfolk asked the VCSE providers for their feedback about the impact of changes to community-based services that have taken place over the last year. These include changes to joined up working and services, waiting times, people feeling in control of their care and the ongoing changes that the VCSE sector have seen.

For outcome five Healthwatch Norfolk interviewed a selection of Mental Health Practitioners, Enhanced Recovery Workers and Social Prescribers. This enabled us to gather feedback on their roles, how they feel they are contributing to the transformation of community-based services and how integrated they feel with the wider primary care workforce within their GP surgery. We also interviewed GP practice managers about the new mental health roles and the impact they are having for patients.

Limitations

There were some limitations in collecting data and feedback for this evaluation. During the first quarter of 2023 there were 9108 people registered with doctors' surgeries with a clinical diagnosis of a severe mental illness (NHS England, 2023) receiving or waiting for treatment and care in Norfolk and Waveney. We cannot say that the sample sizes (n=80) of this work are representative of the entire Norfolk population, but it does provide insight into

mental health service experiences of people severely affected by mental illness.

For outcomes one and two Healthwatch Norfolk received a total of 27 responses from adults severely affected by mental illness (n=18) and their carers (n=9) wanting to be interviewed about their experiences of community based mental health services. Previous research has shown that people who provide feedback about a service are more likely to leave negative feedback. We are also aware that people who are severely affected by serious mental health issues and their carers may struggle to engage. It was difficult for Healthwatch Norfolk to engage directly with people diagnosed with an eating disorder or with perinatal mental health difficulties. We required the support of specific mental health services and specialist organisations to reach these cohorts.

In outcome three, we were able to interview three out of twelve Experts by Experience, and this is a low response rate (25%). The small sample size could be due to several reasons, for example: people becoming fed up with taking part in interviews or being too busy. The number of Experts by Experience has grown due to a recruitment drive this year and it was decided that we needed to interview the original Experts by Experience who would have been present during year one of the transformation to gauge any changes in feedback. There were also a small number of Experts by Experience present in the first transformation year that had decided to leave for personal reasons. We acknowledge that the themes in this section are based on a small number of participant interviews. The findings may not be representative of the whole Expert by Experience Reference Group.

For outcome five we attempted to engage with the Primary Care Networks (PCNs) in Norfolk and Waveney to understand the impact of the new mental health workforce roles in primary care and for wider stakeholders. Due to the reorganisation of Norfolk and Waveney Clinical Commissioning Group into an Integrated Care Board (ICB) and time constraints, this was more difficult than anticipated. Therefore, we must be cautious when drawing conclusions from the data as it is unlikely to be representative of all primary healthcare professionals in Norfolk and Waveney.

Due to decisions made by the Norfolk and Waveney Integrated Care Board, Waveney will not be included in year three of the evaluation.

Outcome one
What we found out

Adults severely affected by mental illness

Outcome One

This outcome is focused on adults severely affected by mental illness (SMI), in particular people diagnosed with an eating disorder or a personality disorder, people being treated for perinatal mental health issues and individuals receiving rehabilitative support. Outcome one explored whether adults diagnosed with an SMI report improvements in, and access to, community-based services. Our recommendation from year one was that the Community Transformation Steering Group should use the I Statement outcomes as the benchmark for the transformation process. In particular that:

- Transformation plans and care pathways should always indicate which of the I statement outcomes will be met as a result of any changes. This will ensure that the needs of adults severely affected by mental illness are always at the heart of any plans.
- The steering group should use the I Statement outcomes as their evaluative framework – the "so what has changed for adults severely affected by mental health illness?" to evidence and measure any change to community mental health services.

In year two we have looked at the work being undertaken in five workstreams that aim to improve the service and support provided to adults severely affected by mental illness through the Rehabilitation Pilot, perinatal mental health, eating disorders and people with personality disorder and complex emotional needs. We also looked at the work to improve the rate of physical health checks being undertaken.

Progress made by the Community Transformation Team

Following the publication of our year one report, the Steering Group developed a "Healthwatch Norfolk Recommendation Implementation Plan" to address the report recommendations. The Steering Group actions relevant to this outcome included:

- Have a refreshed set of I Statements for Community Transformation.
- Strategic and operational leads to include which I Statements fit their work, as part of the monthly workstream updates.
- Complete analysis of which I Statements fit to each workstreams and make recommendations where there are gaps.

- Repeat the exercise six monthly.

I Statements

For outcome three, Healthwatch Norfolk spoke to a Senior Programme Manager from the Community Transformation Steering Group about the progress that had been made with the development of the I Statements.

"It's really important to recognise, that [the I Statements] are very much seen as evolving. Seen as something that will require a regular review as the programme develops and also as we build capacity, as a system, to work with experts by experience around them and around their development."

With a new group of experts by experience coming on board the decision was made to revisit the I Statements and update them. A series of workshops and discussions were undertaken in autumn 2022 and the revised statements were adopted by the CTSG in November 2022. An Expert by Experience presented the updated I Statements to the Steering Group and a Senior Programme Manager reflected on the significance of each of the Statements.

"One of our experts by experience, very powerfully spoke to them all (the CTSG) and provided some personal insight in terms of-- just examples, her personal insights, as to why they were important."

A full list of the updated I Statements can be found included in Appendix 4. The I Statements were aligned to each of the workstreams, which was presented to the CTSG in July 2023. Each workstream lead completed a self-assessment about which I Statements would be aspirational for their areas of work within Community Transformation.

For each CTSG meeting, the progress of each of the workstreams is now reviewed via self-reported benchmarks (in relation to the relevant I Statements) and presented to stakeholders within each of the workstream progress reports.

"These are the voices of the people that we are trying to help. So it's really important that we keep them at the forefront of our planning and our minds and to make sure we're actually delivering on what they want. We've had some thoughts about how we can do this. The first thing we want to do is introduce them into the steering group. All steering group members have had the I Statements and as part of the workstream reports, we need our workstream leads to say which of the I Statements that they're looking to meet as part of the work."

This is a positive and significant development since our initial evaluation report and aligns with the outcomes from the CTSG's "Healthwatch Norfolk Recommendation Implementation Plan." The plan indicates that the Transformation Leads will use the I Statements to benchmark progress and their intention to create a self-assessment toolkit "*which will be used for strategic planning and providers of services.*" The toolkit will benchmark how different parts of the system are meeting the I Statements and will identify where improvements are needed to provide *"evidential assurance to the people needing support for their mental health that services are meeting their needs as described by them."*

Although Transformation Leads have identified the relevant I Statements their workstreams are taking into consideration, the workstream update reports presented to the Steering Group do not yet include their expected impact. But there are plans to annually review the I Statements and transform them into system outcome measures and quality indicators that can be used to measure progress and impact. The first meeting to start on this strand of work was held in September 2023. There were discussions around how the Steering Group members and Experts by Experience can work together to make this happen. There are also plans to develop system wide I Statements. A Senior Programme Manager reported that *"we've also been asked to write some I Statements for the Urgent and Emergency Care steering group."*

One of the Experts by Experience explained that they believe this work is the Reference Group's *"biggest achievement"* from the last 12 months and *"is a piece of work that has been really co-produced".*

Rehabilitation Pilot

The Rehabilitation Pilot (Rehab Pilot) has been the establishment of a multidisciplinary, multiagency team that work together to provide wraparound support to adults severely affected by mental illness. It can support up to 90 people. The pilot is fully funded by the Norfolk and Waveney Integrated Care Board and is available for people with complex psychosis who have experienced three or more psychotic episodes. It officially launched in August 2022 but was originally due to begin in June 2022, and was delayed due to difficulties with recruiting nurses, particularly specially trained nurses able to administer depot injections. A depot injection is a liquid based, slow-release form of medication. Depot injections can be used for various types of drugs, including some antipsychotic medication which is slowly released into the body over several weeks.

The Rehab Pilot is based in North Norfolk, South Norfolk, and Norwich and makes up 50% of the demand for services. The other 50% of demand for services comes from West

Norfolk and East Norfolk. During the early stages of the Rehab Pilot formation, there was a wide range of stakeholders involved in the working group, from Experts by Experience (both those who are affected by a serious mental health issue and those who care for them), housing providers, Norfolk County Council, district council, social care and VCSE sector representation from Change, Grow, Live (CGL), Norfolk and Waveney MIND and Norfolk Integrated Housing and Community Support Service (NIHCSS). Norfolk Community Advice Network (NCAN) were also involved, which led to a legal advisor from Norfolk Community Law Service (NCLS) becoming part of the Rehab Pilot team.

When we interviewed the Rehab Pilot Transformation Leads, they explained that the Pilot is based on a multi-disciplinary style of working: *"there's a real fresh feeling, I feel, being new to this, amongst the ICS at the moment that true integrated partnership working is taking place".* The Multidisciplinary Team involved within the pilot are working together to support "*a number of people who've been in and out of hospital to try and maintain them in the community"* with the aim to *"reduce some of those long hospital stays and potentially allowing people to live for longer in the community generally in supported accommodation, but some also in the independent accommodation."*

During the initial interview with the Transformation Lead, they estimated the Rehab Pilot caseload *"was around 90 for capacity…which is really strengthening the discussions for expansion into different areas (and) highlights the need for such a service. It's easy to look and say, well, it's already at capacity, less than one-year in. But actually, that strengthens conversations to highlight just how important it is to have this service and how important the need is for the population".*

From NSFT, there are also six Nurses, two Occupational Therapists and a part-time Pharmacist based within the pilot who are part of *"the NSFT-based rehab team who are the central specialist team that coordinate care pathways".* The Transformation Lead explained that the Pilot also has an allocated Psychiatrist, a lead Allied Health Professional, a lead Psychologist and a Clinical Lead Nurse that *"makes up the shared leadership".* The pilot is *"a shared leadership model" that also includes staff from Norfolk County Council; a social work manager for one day a week and two full-time social workers with an information sharing agreement with them. They sit in the same office."*

The Transformation Lead added that *"these roles are being very carefully thought about for what the care needs of the patients or the service users (are) and are based on the outcomes that we want to see. So it's not just about recruiting a title because the title fits. It's thinking about what the service user needs clinically and holistically and then designing the role around that".*

The Pilot involves a partnership with Change Grow Live (CGL – a national charity for people whose lives are adversely affected by substance misuse and other issues) as "*most of our cohort have got or have had involvement with heavy alcohol use and substance misuse*". The Transformation Lead explained that *"the CGL workers are very much embedded in the team, and they go on home visits, and they go out with people, and they help to look at those kind of needs*".

Dual Diagnosis

The Rehab Pilot workstream identified the difficulties that people affected by a dual diagnosis face when trying to receive support from services. The Transformation Lead explained that *"when we talk about dual diagnosis, I'm referring to specifically the work that we are doing with the drug and alcohol partnership and the rough sleeping because what they're finding is, when they're looking at the cohort, they are the same people. But they are struggling to be treated as people that are rough sleeping because they've got a drug and alcohol problem…. And then drug and alcohol services are struggling to treat them because they're rough sleeping. So they're constantly finding barriers and blockages in the services. And I'm hoping that part of my role is about unblocking that and clearing the pathways and just keeping all the doors open through dual diagnosis."*

The partnership with Change Grow Live (CGL) aims to address this. The Transformation Lead explained that *"the CGL workers are very much embedded in the team and they go on home visits, and they go out with people, and they help to look at those kind of needs*".

Housing Support

Housing support has been the key element of this pilot and the aim was to establish a team that could meet all the needs of an individual returning to the community from inpatient care. Norfolk County Council has made a commitment to fund 180 housing placements over the next three years, approximately 40 of which will be for people with complex mental health needs. This housing support model will be vital to ensure that those housing placements are successful as *"a lot of people with SMI are kind of in situations where their housing is not necessarily sustainable".* The Rehab Transformation Lead reported that the aim of the programme has been "*designing an appropriate care setting for patients who perhaps have not found the right care setting for them to be placed in, based on their clinical needs".*

The Norfolk Integrated Housing and Community Support Service (NIHCSS) supports adults (aged 18 and over) with severe and enduring mental health needs, including individuals with complex needs. The service supports people across the whole of Norfolk in supported living and within the community. The NICHSS partnership is another element of the Pilot who employ support workers through Together who *"already work with a lot of the same service users… people that have complex needs, may be hard to engage with, have complex psychosis, or difficulties with ADL tasks [assisted daily living] or have repeat admissions to hospital".* The Transformation Lead reflected on the success of introducing Support Workers into the Pilot due to the *"flexibility in what a support worker can do… they're really kind of doing the things that that person thinks are important. They haven't got a mental health agenda. They're sort of going into support with; is it getting a food parcel? That's something we've done a lot of from a food bank. Is it getting something fixed? Is it sorting out their broken window? Whatever it is that's actually important to that person and makes sense as a way of supporting them is what those people could do."*

One of the biggest successes reported by the Transformation Lead was in "*in moving people out of hospital with us [Rehab Pilot Team] as a support towards their support accommodation… we've had a lot of people who've been receiving sort of more visits than they would have been able to receive from a community mental health team."*

There are two Peer Support Workers involved in the Pilot providing who use their lived experience to help people receiving support from the Pilot and to "*build rapport and get alongside people that might have had poor experiences of services*". The Transformation Lead commented that *"knowing that someone's been through the same thing as you, it can have sort of exponential potential for them to then engage and trust us and want to do something with us, which I think is really valuable*".

Legal Support from Norfolk Community Law Service

Another aspect of the Pilot is legal support offered by Norfolk Community Law Service (NCLS) who attend team meetings, take referrals, and support people with legal advice, for example: debt advice, immigration issues or familial issues. The Transformation Lead disclosed that they *"haven't yet made full use of that [NCLS services] I don't think, but that's probably because we're just taking people on and building the rapport. But I think once we start to identify those issues, that will become an ever more important part of what we're doing, because again, it's about those issues that matter to the person and maybe really impact on their life".* There is also a Mind Employment Worker embedded within the Rehab Pilot which *"has been really useful already".*

Rehab Pilot Challenges

When asked about the potential challenges facing the Rehab Pilot, the Transformation Lead mentioned that whilst recruitment into the team had started off well, they still experienced "*the challenges in rehab (that) a lot of NHS areas are experiencing at the moment with recruitment and retention*". Another area that the Transformation Lead identified as a challenge is "*trying to sort out the computer systems because the social workers IT systems and our IT systems won't have any crossover. We just need to kind of ask them what's on their systems, and they need to ask us… that's been the main issue.*"

A third area of challenge to the Rehab Pilot that the Transformation Lead spoke about was incorporating looking after the physical health needs of the people they support, *"we've got a physician associate to try and focus on some of that physical health stuff. But unfortunately, hiring has been a bit difficult. We're probably not doing as much work around physical health as we will be when that person is in, but obviously, we're still monitoring everyone's physical health."* The Transformation Lead reported that the Rehab Pilot didn't have a *"physical health kind of expert"* at the time of interview but clarified that the whole Rehab Pilot team have a responsibility towards physical health checks and this has been reinforced by a lot of the Rehab Team completing the NSFT Physical Health Training "*where they train you to look out for things like signs of diabetes or hypothermia or whatever might be the issue with that service user".*

Future Priorities – Expanding the Rehab Pilot Model

Healthwatch Norfolk asked the Transformation Lead about the priorities for the Rehab Pilot over the next 12 months. The Transformation Lead listed three priorities for the year ahead:

- Expanding the Rehab Pilot across Norfolk.
- A reduction in re-admissions and the average length of stay in hospital for Rehab Pilot participants.
- Capturing metrics to evaluate and provide evidence for the need to expand the Rehab Pilot model.

> "We started to put in regular meetings with the informatics team, their head of transformation from NSFT, myself, and another senior program manager to start to really focus on that. So I think, looking at the metrics, we'll start to be able to evidence and pick out trends and perhaps areas of focus that we need to improve on. And that's going to strengthen the

conversations that we're having around the evaluations, costings, and budgeting for expanding the model."

Healthwatch Norfolk asked the Transformation Lead how they will ultimately measure the success of the Rehab Pilot and they responded that *"it's about understanding what success means for the service user on an individual case basis and these things take time."* The Transformation Lead expressed excitement to be part of the Rehab Pilot and pride at having *"a level of ownership and accountability"* for the workstream and that they *"can't wait to see the positive improvements it's going to make for people's lives that integrate with the service."*

For year two of this Evaluation, Healthwatch Norfolk have created a case study that represents each of the key stakeholders involved within the Rehab Pilot, including:

- Adults severely affected by mental ill health
- Rehab Pilot Transformation Leads
- VCSE Organisations
- Social Workers

The views of people being supported by the Rehabilitation Pilot

Paul's* Story

Paul lives in Norfolk and enjoys listening to music and going out for walks along the coastline *"I like going to sea, just watching it and seeing the calming influence"*. Paul has also been living with Schizophrenia for over 30 years. He experiences distressing auditory and visual hallucinations, *"living with schizophrenia is quite hard, you can hear voices, and sometimes, you see things. It can be very frightening"* and has been in and out of secure hospitals multiple times over the years.

A few years ago, Paul was sectioned because he stopped eating, stopped taking his medication and he became seriously unwell. He spent a long time in a secure unit under section 3 and was only recently discharged with a section 117 aftercare plan to help reduce the risk of him becoming unwell again and possibly needing re-admission to

hospital. This has been a difficult and daunting process for Paul because he has public anxiety attacks.

"That's what I'm doing now; trying to go back into the community, stop having panic attacks, because when I do go out to the community, I really do get panic attacks. It's really hard for me to go outside. I have to push myself just to go out, do some shopping".

For the past 11 months, Paul has been living in residential care and receives support from the Rehab Pilot staff *"there's about 20 other people who live here, which is okay, but I'm honestly used to living on my own".*

Paul spoke about the accommodation that he currently lives in with 20 other people and described it as being *"not too bad"* but remarked that there are *"no activities to work on here"* and that "*everyone's left to their own devices".* Paul finds taking part in activities therapeutic and would like to find more activities to be part of, *"I either watch TV at nighttime or listen to music. I don't go out every day, but once a week, at 2pm, I just go shopping, and I take that two hours to go out, and then I come back… it's also quite nice to go for walks on the weekend if the weather's nice."*

As part of the Rehab Pilot, Paul is supported by a Social Worker, a Support Worker and a Peer Support Worker. His social worker is working with Paul to find more suitable accommodation to suit his personal needs.

"Tomorrow, I'm going to have a look at another place to live, and that will be like a flat. It'll be supported living, but I'll be doing more things like shopping. So I will be getting back into community, doing more things".

This opportunity will provide Paul with help to be as independent as possible, without removing the safety net of having support from the specialist Rehab team.

"My social worker is helping to sort my benefits out, and then they'll take me shopping and do other things that I like as I find shopping a calming influence."

Paul's Peer Support Worker visits regularly to check in on his progress and provide social support, but Paul has become frustrated with how this is working out *"my relationship with my Peer Support Worker is getting a bit strained now, as I told my Support Worker as all the Peer Support Worker wants to do is catch up and it's supposed to be going out to do fun things with me like taking me out and doing activities"*. Paul

communicated this to his Support Worker, and they are now working on finding a more suitable Peer Support Worker as this interaction is the *"highlight of the week"* for him.

Paul explained that he also contacts the Transformation Lead directly if he has any problems and feels listened to and valued. Paul described how the Transformation Lead will *"talk to the staff for me if I've got a problem or if the staff have got a problem with me, because sometimes I do get upset. I'm very sensitive*". One example of the personalised support that Paul has received from the Rehab team is applying for funding to publish a book that he has written about his experiences.

"I am getting support on my end. I might be getting some funding as I want to write a bit about my experiences. It's what I've always wanted to do. Just getting this book on the way so people can read it and they might understand what living with schizophrenia is like. That's something they might agree or disagree. People might not like what I say, but it's my story."

When asked about any improvements the Rehab Pilot could make to their service, Paul mentioned that communication between the multidisciplinary team and partner organisations could be slightly better. Paul spoke about an instance when he was due his medication via a Depot injection, and nobody had informed him or the Residential Care Manager that more than one person was attending that particular day.

"Three members of my team turned up indeed, and the Residential Care Manager only aware of one of them turning up. The Manager usually doesn't have a clue when my injections will turn up".

Paul suggested that the nurses coming to deliver his Depot injection could *"work more together and communicate more so everyone knows what they're doing. Because all these people turning up, it got a bit overwhelming, didn't it?".*

Healthwatch Norfolk asked Paul what the best thing about the Rehab Pilot is and he reported that it's the type of people that make up the Rehab Team. *"The best thing? They're just nice people. I can a have a joke with them [the Rehab team]. They're so laid back. They're not bossing you about, being so polite. And I get on with everyone."*

Paul spoke about his lived experience of living with a serious mental illness and described how he has experienced many care teams throughout the years, but *"this is the best one though".*

* All identifying information has been removed.

Physical Health Checks

As part of this evaluation, Healthwatch Norfolk wanted to explore the progress made with the Physical Health Checks workstream. According to the evaluation plan, we wanted to discover whether:

- The number of physical health checks completed has increased.
- Data provided by the CTSG shows that there has been an increase in physical health checks.
- Adults with SMI report that they are being offered and can access physical health checks.

Everyone living with a severe mental illness (SMI) is entitled to an annual physical health check. An SMI includes anyone with a diagnosis of schizophrenia, bipolar disorder or psychosis. The average life expectancy for people with severe mental illness is up to 20 years less than that of the general population (Fiorillo and Sartorius, 2021). Adults diagnosed with an SMI are at higher risk of poor physical health. Compared with the general population, adults affected by an SMI are at a substantially higher risk of obesity, asthma, diabetes, Chronic Obstructive Pulmonary Disease (COPD) and cardiovascular disease (Fiorillo and Sartorius, 2021).

The annual physical health check was designed to pick up on early warning signs of these conditions and enable healthcare providers to act before these early warning signs become more serious.

An adult living with an SMI should be contacted annually by their GP surgery to invite them for aa physical health check. If they're in regular contact with their mental health team then they may be contacted by the Physical Health Team. This team may offer to conduct the physical health check at home, at a clinic, or at a person's local doctors' surgery.

As part of the NHS England (2019a) Long Term Plan and NHS England (2019b) Mental Health Implementation Plan, a target was set that by 2023/24 a national total of 390,000 adults diagnosed with an SMI will receive an annual physical health check. Originally there was a percentage target of 60% of the population, but this has been changed to an absolute number for each area. The impact of this for Norfolk and Waveney has been an increase in the percentage target.

NHS England has provided guidance for commissioners and providers in primary and secondary care on how they should work together and the action they should take to improve access to and the quality of physical health checks and ensure that appropriate follow-up care is given.

Physical Health Checks for people diagnosed with an SMI should be offered annually to people of all ages. The physical health checks for people with SMI should include the NHS Health Check assessments that are offered every four years to everyone aged 40-74, relevant national screening and immunisation programmes (as recommended by Public Health England (PHE)), medication reviews and additional physical health enquiries about a person's potential substance misuse. An SMI Health Check It is offered to all those with a current or past history of an Severe Mental Illness, for example a psychotic illness, bipolar disorder, paranoid psychosis or schizophrenia. Some anti-psychotic medications can have negative health implications for people. In the first year of an SMI diagnosis a person should be offered a health check to gather baseline information before starting any medication and then receive a series of checks within the first year for regular monitoring for side effects or negative impact on their health through that first year. NSFT have a policy that sets out how regularly somebody should have those monitoring appointments based on when they started on that medication.

In Norfolk and Waveney, the physical health check includes six key elements:

- Height and weight measurements
- Blood pressure checks
- Blood tests to check for the risk of cholesterol
- Blood tests to check for the risk of diabetes
- Smoker status
- Alcohol intake

During the physical health check there will also be access to the interventions for hypertension, high blood pressure and high cholesterol that are on offer (if necessary) as well as lifestyle interventions for weight management and smoking cessation. Dependant on a person's age or gender, there are also checks available for bowel, cervical, and breast cancer screening.

SMI Physical Health Checks within Norfolk

Healthwatch Norfolk interviewed the Physical Health Check Transformation Leads from Norfolk and Waveney Integrated Care Board (ICB) and NSFT and regularly attended the Community Transformation Steering Group meetings. The Community Transformation Steering Group (CTSG) has overview of the progress on reaching the target for completing health checks.

Data about the number of people with an SMI who have had a full physical health check is published quarterly by NHS England and is available to the public (NHS England, 2023). Norfolk and Waveney ICB collect data about the number of people on the General Practice SMI register at the end of each quarter, and how many of these

people received a comprehensive physical health check in the previous 12-months (up to the end of the reporting period).

Norfolk and Waveney ICB work closely with their Delegated Primary Care Commissioning Team who link with Primary Care and hold operational meetings with the primary care locality links. These meetings allowed a flow of information including what's working well, what's not working and how primary care can be supported to improve the delivery of health checks.

The Delegated Primary Care Commissioning Team also have a good working relationship with the Care Quality Commission (CQC). When the CQC undertake an inspection of Primary Care they now include data regarding the SMI Health Check and the uptake rate. If there is an issue with the inspection, SMI Health Check data will be included within the CQC Improvement Plan. This is seen as a positive change that supports the relationship with primary care.

Norfolk's target for the end of March 2023 was the completion of 5,939 physical health checks for adults severely affected by mental illness. The Community Transformation Steering Group anticipate that the target reached is more likely to be 4,748. This figure has been submitted to NHS England, identifying the issues that have contributed to them not meeting the target but also outlining the plan to increase the number of checks to meet the following year's target.

Data provided by the Community Transformation Steering Group shows that in the last quarter of 2022/23 there were 9,474 people recorded as having a serious mental illness. Of these, 4,924 people had all six of the key elements of the health check: BMI or waist circumference measured, blood pressure recorded, cholesterol recorded, blood glucose check, alcohol consumption, and smoking status. This is higher than the predicted total provided to NHS England.

There is some variation in the percentage of people diagnosed with a serious mental illness who received a physical health check. In North Norfolk, Norwich, South Norfolk and West Norfolk the percentage of people who received a physical health check including all six key elements of the physical health check were between 53% and 54%. In Great Yarmouth the percentage of adults living with an SMI that received a physical health check that included all six key elements check was just over 46%.

Area of Norfolk	Total Number of SMI Physical Health Checks Completed in	Total Number of SMI Physical Health Checks Completed Measuring all Six Key	Percentage of Health Checks Measuring all Six

	Q4 (2022-2023) by area in Norfolk.	Elements by area in Norfolk.	Key Elements by area in Norfolk.
Great Yarmouth	2766	1295	46.8%
North Norfolk	1431	778	54.4%
Norwich	2575	1381	53.6%
South Norfolk	1551	851	54.9%
West Norfolk	1151	619	53.8%
Total	9474	4924	

Figure 1: A table to show the number of SMI Physical Health Checks Completed during Q4 (2022-2023) in Norfolk.

During the pandemic, additional funding was made available to undertake outreach to help with the uptake of physical health checks following the pandemic. Together UK (the charity for people with mental ill health) was commissioned to support this work. Doctors' surgeries were informed that if they required assistance contacting people who needed a health check then the data could be shared with Together UK so they could make the initial contact. Together UK would help anyone diagnosed with an SMI understand what a health check includes and why it is important. Together UK could support the individual to book a taxi on account and to attend their annual health check. The Together UK team can also provide (mostly virtual) support to remind people that their health check may be due. The funding for this SMI Public Health Check Outreach Project has been extended for an additional two years. Negotiations are also taking place for Together UK to have access to the relevant database to improve the process.

Prior to the pandemic, Experts by Experience helped to update the patient invite letter, patient information leaflets, posters, and digital resources for the SMI physical health checks. They wanted to make these more user friendly and less clinical. The current Experts by Experience group have also co-produced videos about SMI physical health checks to use as educational resources and for promotional purposes.

The Transformation Lead reported that the aim of the videos is to provide information about what the health check is and why it is important. The videos use *"the voice and words of somebody who has had their health check and seen the importance and the impact of it for them".* There has been a delay in completing and publishing the videos on the website. It was hoped that the video will be made available at the end of July 2023, but this is still awaiting sign off..

Training has been made available to GP surgeries in Norfolk and Waveney to show primary healthcare staff how to code patient's records correctly on their electronic patient record. 89 out of 105 GP practices took part in the training, which enabled them to check and re-code patient data, resulting in more accurate patient data and Quality and Outcomes Framework (QOF) figures.

There is a physical health check monitoring and intervention group which includes patient participation leads, which used to meet monthly. Last year it was recognised that there are health checks already in place for several priority cohorts. These include people diagnosed with a learning disability or an eating disorder. There is a physical health check for people with autism that is currently being piloted nationally, which is likely to be adopted in Norfolk and Waveney. It was therefore agreed that it would be more efficient and would allow the sharing of knowledge and best practice to bring this together in one working group where possible. From July 2023 this group will be meeting quarterly and will have a new strategic focus.

Physical Health Checks for people diagnosed with an Eating Disorder

Ongoing physical and mental health support is important for people diagnosed with an eating disorder and regular physical health checks should be available. People diagnosed with an eating disorder who are not receiving treatment should be offered a check-up with their doctor at least once a year. These physical health checks will be offered more frequently for people under the care of a specialist Eating Disorder Team. A physical health check should involve monitoring a person's weight, BMI, blood pressure and by a blood test. It might be necessary for some people to have to have an electrocardiograph (called 'ECG' for short) to check that their heart is healthy. One interview participant described how they *"go three monthly for weight, height, blood pressure and a blood test"* due to an eating disorder diagnosis. Their physical health check was conducted by a doctor who also asked, *"questions about, every single part of my body and the functions, whether things were working, about what support I had and after that, there's been a document written up."*

This interview participant was advised that they might need an ECG to check their heart rate and rhythm, but this discussion continued for over six months and it was not communicated to the service user why the wait had been so long.

"There was a discussion around me having an ECG. The discussion lasted for about 6 months because one person was going to speak to someone else, and then they were going to get them to do it. Only it went on for quite a while. So, I then asked what was happening and it turns out that the person that they were going to ask has been off on

leave for of a substantial period of time, which was fine. However, had that been communicated to me, then I could have known."

Another interview participant suggested that a document outlining the questions and physical health checks that take place during an annual review could be sent when inviting patients to attend. *"I think that sending out the document empty so that we or anyone knows what sort of thing they're going to be asked so that you can prepare the answers would be helpful".* This interview participant also mentioned that an option to edit the document would be useful so that adults severely affected by mental illness can personalise their health information and make sure that it's correct.

"It is a document that's supposed to be useful. As a document, it's fine, but if it's meant to be of use for me and to professionals, then it's missing quite a bit of detail."

We asked the Transformation Lead about the provision of Physical Health Checks for people diagnosed with an eating disorder. The Lead explained that they are not a trained clinician, but a mental health change manager. They reported that a person with an eating *disorder "will have health professionals going in checking on them anyway"* and this would involve checking their blood pressure, height and weight. The Transformation Lead spoke about *"medical monitoring"* that takes place and primary care services can also monitor people with eating disorders.

"There is something that happens within the eating disorder space called medical monitoring, which contains very specific eating disorder monitoring. But I think some of these actually marry up with the elements in the health check arena. "

Smoking Cessation

People diagnosed with a long-standing mental health problem are twice as likely to smoke, with the highest rates among people living with bipolar disorder or psychosis (Public Health England, 2020). One of the reported successes of this workstream has been the work around smoking cessation. As part of the NHS England (2019) Long Term Plan around prevention is a focus on tobacco-smoking cessation which is targeted at supporting three main groups of people, including people diagnosed with an SMI. Norfolk was invited to be a national early influencer site for SMI tobacco-smoking cessation. Norfolk was successful in their application and received funding to support a rollout of a primary care model. When people have their health check and are identified as a smoker, they can be referred to the tobacco-smoking cessation programme. Work was undertaken with the Experts by Experience to understand the needs of those living in Norfolk who have been diagnosed with an SMI to look at national evidence on the

impact of using a bespoke smoking cessation support model. Evidence was gathered from the Smoking Cessation Intervention for People with Severe Mental Ill Health (SCIMITAR+) Trial (2015).

The SCIMITAR+ trial was designed to test a bespoke smoking cessation intervention for adults severely affected by mental illness, compared to standard NHS care. Trial participants were heavy smokers that said they would like to cut down or quit smoking. Those allocated to the bespoke smoking cessation intervention received support to help them quit from a mental health professional who had undergone brief but rigorous training (SCIMITAR+, 2015).

Together UK and the Experts by Experience Group were asked to develop the role for the cessation mentors to see what could be offered and to create the title for those mentor roles. The Experts by Experience fed back that their experience was that they have had previous attempts at stopping smoking and that they had used the services, but what would have been helpful to them would have been a *"buddy"* to help them through.

SmokeFree Norfolk have joined up with Together UK for Mental Wellbeing and launched the new service to support patients with a Severe Mental Illness (SMI) and their carers to quit smoking. Their programme of behavioural support includes the provision of Nicotine Replacement Therapy (patches) or a free vape and can provide up to six months of support. This programme employs a team of five Wellbeing Mentors who are working across the pilot area. This area is based in Norwich North and Central, Great Yarmouth and Gorleston. Their role is to coach adults diagnosed with a serious mental illness to quit and they can also help with referrals to other specific support services and organisations to boost their wellbeing and mental health.

The Wellbeing Mentors are part of a wider team that supports people to stop smoking . They act as peer support to help the individual with their resolve to quit. This can include finding activities to distract from the craving (for example: going for a walk).

The Transformation Lead explained that because the model is relatively new there *"is scope to try lots of things and learn what works".* Therefore, no targets have been set for the Wellbeing Mentors regarding the numbers of people they need to see. In fact, there is still uncertainty about how much support a person will need to successfully quit smoking, therefore data will be collated to help develop the service.

Together UK will remain part of the core team and will be responsible for contributing to the feedback on the success of the project to the Steering Group, along with the data that is gathered. Ongoing feedback from those who were allocated a Wellbeing Mentor will be used to continue to shape and develop the service.

Physical Health Checks Roadshow

Between 31st March and 6th April 2023, Norfolk and Waveney Integrated Care System hosted a series of five public, locality-based roadshows about physical health check for people diagnosed with a serious mental illness. The roadshow events were hosted in collaboration with Norfolk Integrated Housing and Community Support Service. In total, the event was attended by over 280 people in King's Lynn, Norwich, Great Yarmouth, Thetford and Aylsham.

One of the barriers to health checks that has been identified from feedback from Experts by Experience is that people are concerned that the check might involve an intimate examination. The aim of these roadshows was to invite adults severely affected by mental illness and their families and carers to come along and learn about health checks. They would be able to discover what is involved and making everyone, not just those with SMI, aware that physical health checks exist for lots of different reasons.

The roadshows included information from services to support people to stay healthy, such as slimming clubs and support for smoking cessation. The roadshows also intended to get feedback on the new locally commissioned service website for SMI health checks, which is still developing. They wanted to get feedback from people and staff about what is helpful and what information should be accessed with just a few clicks. Plans for any future roadshows include better event promotion and input from Community Mental Health Nurses and approaching carer organisations (for example, Carers Matter) and local care agencies to attend.

Challenges

The Covid-19 pandemic had a negative impact on the number of health checks being completed by primary care because during this time people were struggling to access their GP. During the pandemic if somebody was considered very high-risk and a blood test was required as part of the health check then people were more easily able to access their GP for their health check. But if it was a routine appointment, they were not taking place during the pandemic. This has now improved, and the number of health checks being undertaken is higher than before the pandemic.

One of the key challenges is the impact of the Covid-19 pandemic on Primary Care. Historically, the approach undertaken by Primary Care was to have a big push annually to complete the health checks. This has resulted in lots of health checks expiring at the same time, and coupled with the backlog resulting from the pandemic, it has been logistically difficult to manage. Primary care has different ways of managing their health checks, so the Delegated Commissioning Team are trying to encourage GP

Practices to produce a monthly trajectory of health checks coming up for renewal and those missed, to help them plan. This would help to balance the workload across the year and help to meet the target. The team is also reaching out to some of the practices to find out how they have successfully managed to complete many health checks. This learning can then be shared with other practices and on the website.

The Recovery Action Plan has also identified the responsibility for health checks within NSFT as a concern, as there was not a Physical Health Lead in place. The work around health checks has been embedded within the care groups, but the leadership to bring this together wasn't there. A Physical Health Lead was appointed within NSFT at the end of 2022 as a permanent post dedicated to the provision of SMI Health Checks. It's hoped that if Assistant Practitioners have appropriate leadership and supervision, and a suitable point of contact (with coordination across the care groups) they will be able to easily escalate things that need a response.

The Early Intervention in Psychosis Team (EIP) have a responsibility to complete physical health checks but these dropped off during the pandemic. There is now a renewed focus on completing these. The Physical Health Lead within NSFT will also link with this team, learn from their experience, and connect them into NSFT and the system. The Physical Health Lead will provide leadership both internally and clinically.

Collating data about physical health checks can also pose a challenge. Data comes from two different clinical computer systems within NSFT and Primary Care, but the data is not readily compatible. There is a risk that the target for completing physical health checks will not be met because the data gathered is incomplete, and not because the checks have not been conducted. There will also be changes to how data is gathered in the future. Data regarding physical health checks will be collated nationally from within primary care. This change is due to start in April 2024. The challenge will be to ensure that the data relating to any activity taking place within NSFT is either replicated or recorded within primary care systems to allow this data to be included within the national data and work is already underway to plan for this change.

Future Plans and Priorities

The Physical Health Check Transformation Leads are optimistic about the recovery of the health checks post-COVID. They would like physical health checks to become routine and for people to feel empowered to take responsibility for their own health. The group has been looking at how to develop the patient health record. People currently get a paper record (a green sheet) but the Experts by Experience are keen for a *"passport style"* record to be developed, like the one produced by Equally Well, which people can download, print off or fill in virtually. Primary Care has been encouraged to use this and they are hopeful that it can be included within the patient records.

This would be a big achievement. They would like to develop a health passport of some style, especially one that allows a consecutive record of each annual check, so that people can monitor the changes in their health over time. The Transformation Leads are having conversations with NHS England regional colleagues (within the SMI Health Checks and NHS Digital teams) to see if it is possible to get something like this embedded within the NHS app. It is also hoped that patients will be able to input their own health information, for example: their smoking status, alcohol intake and lifestyle information. The conversations with NHS England are focussed on how this can be achieved and if it could be rolled out nationally. The next step for the Steering Group is to look further into Health Inequalities data to inform future plans for the Physical health Check workstream.

Perinatal Mental Health

One woman in five experiences a mental health problem during pregnancy or after they have given birth. (RCOG, 2017) and the most common mental health problems during pregnancy and after giving birth are depression and anxiety (Centre for Mental Health, 2023). Maternal mental health difficulties are more common than people realise and without the right care, treatment, and support, they can have serious consequences and long-lasting effects for women, birthing parents, and their families. Suicide is the leading cause of death among women in the year after pregnancy (MBRRACE-UK, 2022).

A 2017 survey conducted by the Royal College of Obstetricians and Gynaecologists engaged with 2300 new mothers and birthing parents. Their report revealed several reasons why they might not feel comfortable talking to healthcare professionals about their maternal mental health problems.

These reasons include:

- Feeling worried that their mental health problems would be noted on their medical records (40%)
- Worrying about potential stigma attached to mental health problems (28%)
- Feeling embarrassed (28%)
- thinking that it was 'normal to experience mental health problems as part of pregnancy and having a baby' (27%
- Perceiving their clinicians to be unapproachable (23%)
- Not being asked if they are experiencing any mental health difficulties (19%)

The NHS England Long Term Plan (2019) pledge a significant expansion and improvements for perinatal mental health support The Mental Health Implementation Plan (NHS England, 2019) stated that:

> "By 2023/24: At least 66,000 women with moderate to severe perinatal mental health difficulties will have access to specialist community care from pre-conception to 24 months after birth with increased availability of evidence-based psychological therapies. Their partners will be able to access an assessment for their mental health and signposting to support as required. Maternity Outreach Clinics will be available across the country, combining maternity, reproductive health and psychological therapy for women experiencing mental health difficulties directly arising from, or related to, the maternity experience."

Most of the additional funding allocated for Integrated Care Systems to provide perinatal mental health care in their area (a total by 2023/24 of £239 million nationally) has been earmarked for specialist community services, to be used flexibly according to local needs, (NHS England, 2019).

Integrated Care Systems should provide access to an adequate provision of specialist Mother and Baby Inpatient Units to prevent women being separated from their babies if they need to be admitted to hospital. The voluntary sector, including peer support, also plays a vital role and needs to be commissioned and properly funded to extend this offer of specialist perinatal mental health support. (Centre for Mental Health, 2023).

Progress Made by the Community Transformation Steering Group

Healthwatch Norfolk explored what work the Community Transformation Steering Group and Transformation Leads have been undertaking over the past 12 months to improve the service provision for people experiencing perinatal mental health difficulties. We interviewed the Transformation Leads about the progress that has been made. One of the Leads explained that they come from a background in Public Health, which involves intergenerational and whole life approaches and how these can be affected by common health issues and challenges. The Lead reflected that if the service provision is not right or comprehensive enough for people experiencing perinatal mental health difficulties, the effects will be experienced by not only the parents, but their children and immediate support systems.

> "Unless we're getting it right for babies and parents of babies, we're probably going to see the repercussions of that in children's mental health services and then in adult mental health services for many, many, many years."

The Department of Health and Social Care (2021) states that the first 1,001 days of a child's life are pivotal and crucial to their development and can influence the state of their future mental health. The Transformation Lead explained that the Perinatal Mental Health service provision needs to be reframed and extended after pregnancy and birth, to prioritise the parent's and child's needs and relationships within those first 1001 days of life. Providing good mental health support for parents and support to provide their babies and infants with good nutrition, safe environments and help to form nurturing early relationships, will help reduce future risks to these children's cognitive, emotional, or physical development. The Transformation Leads recognise how stressful having a baby can be, and how vulnerable it can make parent's feel and affect their mental health.

"Having a baby is possibly one of the most stressful and most significant changes anyone can face. Therefore, it's only natural, I think, that we should be thinking and proactively targeting this group as a particularly vulnerable cohort."

Family Hubs

Norfolk County Council has been chosen as one of 75 local authorities receiving a proportion of £302 million for new Family Hubs and Start for Life funding. The family hub project and programme are bringing in an additional £6 million investment into Norfolk, of which £1.9 million will be allocated to support perinatal mental health services and supporting parent/infant relationships. The Family Hubs agenda is a new piece of work that will be funded until 2025. The Family Hubs network will give families a single access point to support services that are integrated across health (physical and mental health) and social care, as well as voluntary and community organisations and education, utilising a whole family approach. There are plans to provide at least seven physical Family Hub sites within existing community buildings, which families will be able to access, but services will be delivered largely on an outreach basis.

The Family Hubs network will provide simple access to 'Start for Life' services, which provides support to parents and babies for the first 1,001 critical days from conception to the age of two. The Start for Life services will provide:

- Perinatal mental health and parent-infant relationships support for families who are expecting a baby or have a baby under the age of two
- Infant feeding support services
- Parenting support for parents of children aged 0-2
- Home learning environment support for parents of children aged 3-4

"There is a significant focus on the Family Hubs of being able to support those first 1,001 days of life, and therefore, all of the transformation work that sits under the perinatal work stream and the parent/infant mental health work stream in terms of this steering group feeds into the ambition in terms of delivering better integrated perinatal and parent/infant mental health services across Norfolk. "

The Parent-Infant & Perinatal Steering Group has been restructured so that the Transformation Leads co-chair the group and there are representatives attending that fall outside of adult community mental health services, including from NSFT's Children, Young People and Families (CYPF) team.

"We relaunched the steering group, making sure we've got the right people there. It's not just adult community mental health. It's a recognition that it's sort of an all-age issue... There is representation from midwifery all the way through to the Mother and Baby Unit, Lotus [Maternal Therapeutic Outreach Team] and the perinatal team. They all sit on there. The Healthy Child Programme sits on that. The local authority sits on that. Public Health sit on that. So it does really cover that whole spectrum of need."

The Lotus Maternal Therapeutic Outreach Team is a dedicated service for women and birthing people in Norfolk and Waveney, providing help and support for trauma related mental health difficulties during pregnancy, birth and afterwards.

Workshops

During the perinatal mental health steering group meetings, it became clear that *"there was a lot of jargon being used and not everybody knew who everybody was*." As a result, the Transformation Leads hosted two workshops to deal with these issues and how to move forward by using the monthly steering group to start putting the strategy together.

"The first workshop was to do a bit of a mapping exercise. "So who do we have? What services do we have, and what's the offer?" ... The second one was about of tying it together. It was the wider CT transformation. "So how is it going to link to primary care and all the new roles that are embedded within primary care ... how do they liaise with the youth teams... how's it all going to better work together ultimately so that the individuals in this space get the best support if they still need support after their perinatal offer of support has ended?"

The workshops covered the *"different offers of support" available* within local perinatal mental health services and shared *"current areas of good practice and current areas of focus that are happening" with attendees.*

Integrated Perinatal Pathway

NSFT have developed a specialist, multi-disciplinary team that deliver a care pathway for perinatal mental health service users called the Integrated Perinatal Pathway (IPP). The IPP is a service provided by clinicians employed within the specialist perinatal community mental health team that can sit within the Wellbeing service and process referrals and triage a person if they are referred to the specialist team but need a *"mild to moderate level of support"* so they don't have to re-refer into the wellbeing service.

"They kind of just hand that referral over internally, and kind of there's that better integrated offer ultimately. So the best offer of support gets to that family and that parent as soon as possible, which is what we, again, want to build on, with that wider integration piece. But it's certainly building all good foundations."

Most of the services available via the Parent and Infant Pathway are already in existence, but the Transformation Lead explained that *"it's about refining and improving them."* The Transformation Lead reported that with the new Family Hubs, it will be about *"building on what we have"* and not confusing people by claiming that this is a brand new service.

"We actually just want to refine and expand on what we already have in place and better offer that support so that it provides almost a seamless pathway that people don't even always have to think about it. They're on the perinatal and parent/infant pathway. And if you're a father, if you're a mother, if you're a co-parent, if you're a partner, that process will equally be as refined and be as robust, particularly with a focus on those groups that we know are currently underserved."

As part of the workshop sessions, the Transformation Leads facilitated a conversation with attendees about missed opportunities. The main topic of conversation hinged on where and how community mental health services could spot people presenting with mental health issues that may not have been previously picked up. Some of the suggestions included interacting with parents and carers when babies go for their immunisations when staff have concerns about their mental health and involving primary care staff (for example: Mental Health Practitioners and Recovery Workers to make pregnant people and new parents aware of all the support services available to them. The Transformation Lead reflected that *"it was really, really helpful to get everybody around the table so everyone's aware of what there is, what the opportunities are, and where we can work on integration where we're not integrated already."*

Extended Service Provision / 1001 Days Ambition

The Transformation Lead continued to talk about the long-term plans for perinatal specialist mental health services within NSFT. The intention is to extend service availability to parents with "*really complex referrals*" until their child turns two.

"What actually is quite nice about the extension to two years for those that have got an SMI, or are really complex, is that a referral could be made when the baby's eight months, when the baby's one year, and actually, then there's still something for them."

The extension of services links into the 1,001 days ambition and being *"able to give people a bit more leeway"* for example, when a partner returns to work or their maternity leave ends. The Transformation Lead continued by describing how there is sometimes need for further support for parents and carers after their child turns two and *"they don't leave perinatal without any further mental health support needs."* These families may have "*lower level support needs*" and the Transformation Lead explained that they need to consider "*a continued offer of support that can help them to go on to live really fulfilling lives"* that could include peer support groups or support from voluntary sector organisations.

Future Plans and Priorities

Healthwatch Norfolk asked the Transformation Lead what the priorities are for the workstream over the next 12 months. The Lead informed us that the steering group will be working on putting a Parent and Infant Perinatal strategy in place and this will be informed by the themes arising from the workshops. Another priority identified by the Lead involves "*increasing access to support across the whole system… raising awareness of the offers of support that are available and making sure that those individuals get to the right support."* As previously mentioned, the steering group will be also focusing on fathers, co-parents and wider support networks as a priority cohort moving forward with their plans.

"We need to recognise that there's a spectrum of need here. And if we integrate services more effectively and efficiently, then actually, what will happen is mums, dads, and babies won't fall through the gaps, and we'll be able to pick up any needs as soon as possible without them escalating into crisis, or from my perspective, turning up at CAMHS services when they're six or seven or eight years old because those needs haven't been met when they were an infant."

A big ambition within the long-term plan under the perinatal service is to assess every father or co-parent of someone receiving support from perinatal services to make sure their mental health needs are also being met.

"When you're thinking about 1,000 women every single year needing to be supported by perinatal services, that's potentially 1,000 partners, co-parents, and fathers that also need to be assessed and supported."

Currently, there is work being undertaken to establish a process whereby the Wellbeing Service can take referrals for fathers or co-parents. This would involve access to a mental health assessment and accessing more intensive support as required. The

steering group are also investigating how mental health services may be better equipped to support siblings and children because *"there are so many hidden parties when it comes to pregnancy, and we often focus on the person that gave birth and actually, it's about everybody else in their support network that may need support and adjustment time."*

The views of mothers and birthing parents

Healthwatch England (2023) conducted nationwide research into mothers' and birthing parent's experiences of maternal mental health care and are using the findings to continue guiding the shaping of NHS services and policy changes. For their report "Left unchecked – why maternal mental health matters", Healthwatch England (with the help of local Healthwatch organisations) researched the issue through a national survey of 2,693 people, 42 Freedom of Information (FOI) requests to Integrated Care Boards (ICBs), NHS trusts and GP surgeries, and 20 interviews with new mothers. This research was prompted by reported systemic failures in maternity services, outlined in the Ockenden review.

Healthwatch Norfolk requested the survey data from survey respondents living in Norfolk. It was not possible to obtain specific data from the Waveney population. The findings from the Norfolk population have been included as baseline data for this evaluation. This will enable Healthwatch Norfolk to evaluate potential changes to perinatal mental health services in year 3 of this work. It should be noted that transformation of services takes time and the Perinatal Mental health Workstream began in year two of the community mental health transformation.

Who we heard from

There were 40 respondents to this survey. All 40 respondents shared that they were women, 38(95%) were aged 25 to 49, 38 (95%) were White British/English/Northern Irish/Scottish/Welsh, and 34 (85%) were heterosexual or straight.

All had given birth since April 2020. Of these, 15 (38%) had given birth between April 2020 and March 2021, 15 (38%) between April 2021 and March 2022, and 10 (25%) had given birth since April 2022. For 31 (78%) of the respondents this was their first experience of giving birth.

Nearly two-thirds of the respondents shared that they did not have a mental health condition before becoming pregnant (26, 65%), while only 13 (33%) respondents told us they had a diagnosed mental health condition and only one (3%) shared that they had an undiagnosed mental health condition.

When asked what best describes their experience whilst they were pregnant and after birth, 13 (33%) shared that they did not experience any mental health difficulties. Of those who said they did experience mental health difficulties (26, 65%), 11 said they experienced them for the first time, nine experienced a mental health problem that they had previously recovered from, and six said they experienced difficulties in addition to their current mental health problem(s). This is displayed in *Figure* 2.

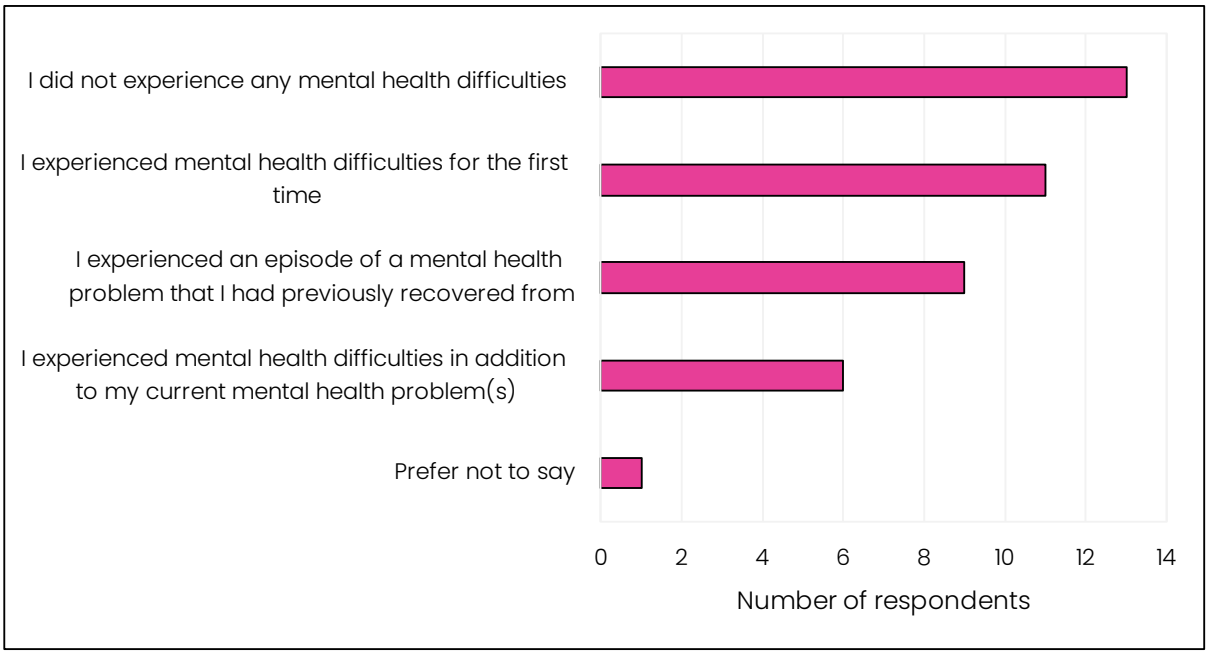


Figure 2. Responses from 26 people to the question 'which of the following best describes your experience whilst you were pregnant and after birth?'

Type of Mental Health Support Received

Of the 26 women who had experienced a mental health problem whilst they were pregnant and after birth, only 10 (38%) had been referred to a mental health support service. Three (12%) were given information about organisations to contact for mental health support and the remaining 13 (50%) shared that they were not offered a referral or any information about support organisations.

The 10 respondents who had been referred were asked about the type of mental health support they received. The most common support was a specialised maternal mental health service, with six (60%) of these respondents choosing this service. In addition to these four (40%) respondents said they had used psychological therapies service such as talking therapies, cognitive behavioural therapy, counselling, other therapies and guided self-help. Other services used included two mothers who had used a Mother and Baby Unit, one had used Adult mental health services (including community and in-patient services), one had

used voluntary or third sector support organisation, and one shared they had used their GP for support.

Waiting Times for Support

We heard that there was a mix of length of time that these respondents had to wait to get an appointment with a mental health support service after being referred:

- One had an appointment within a week but their symptoms got worse in this time,
- Two waited three to four weeks and their symptoms remained the same,
- Two waited five to six weeks, one of these people said their symptoms improved in this time and the other stayed the same,
- Three waited over six weeks, two of these said their symptoms got worse and one that they remained the same,
- One was unable to recall, their symptoms got worse during their wait,
- One had their referral rejected and their symptoms stayed the same.

Making Informed Choices

The 13 women who shared that they had a diagnosed mental health condition prior to becoming pregnant were asked about the support they were offered during their pregnancy. When asked if they 'knew how to access mental health support if I needed it', four (31%) of these women strongly disagreed with the statement, while three (23%) strongly agreed and five (38%) agreed.

These respondents were also asked how they felt about making informed choices. There were mixed responses around how informed they felt. Seven (54%) shared that they agreed or strongly agreed with the statement 'the support offered allowed me to make informed choices about managing my mental health during pregnancy', while the remaining six (46%) disagreed or strongly disagreed with the statement.

This mixed response was similar for the statements 'I was informed about the risks of taking medication for my mental health through pregnancy' and 'I was informed about the risks of stopping medication for my mental health during pregnancy' as displayed in Figure 3.

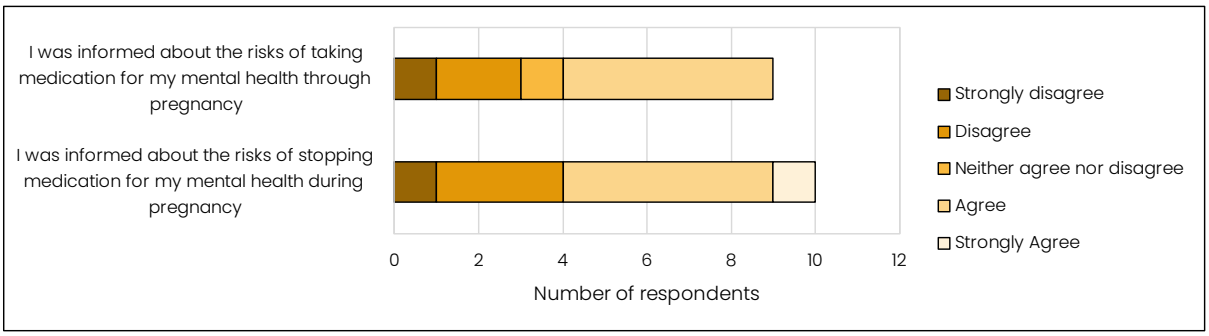


Figure 3. Responses to the statements 'I was informed about the risks of taking medication for my mental health through pregnancy' and 'I was informed about the risks of stopping medication for my mental health during pregnancy'.

In addition to these questions for those who had a diagnosed mental health condition prior to pregnancy, all respondents were asked about how informed they felt during their treatment and care. Most women shared that they 'felt well informed about my care, including any procedures or interventions that took place during labour and childbirth' with 17 (43%) agreeing with the statement and eight (20%) strongly agreeing.

Similarly, 19 (48%) agreed with the statement 'staff communicated things to me in a way I could understand' and seven (18%) shared that they strongly agreed.

Involvement in own care

When asked how involved they felt in their care, most respondents either agreed or strongly agreed with the statement 'I felt involved in decisions about my care' (22, 55%), while 13 (33%) either disagreed or strongly disagreed.

Impact of Support on Mental Health

Respondents were asked 'thinking about the care and support you received during labour and childbirth, what impact did it have on your mental health?'; there was a mix of responses to this question. Nearly half of respondents (19, 48%) said that it had a negative impact on their mental health, 13 (33%) said it had a positive impact, and the remaining eight (20%) said it had no impact.

In addition to the survey data, Healthwatch Norfolk conducted three one-to-one interviews with new mothers that received support from Norfolk based perinatal mental health services within the last 12 months. We have turned their stories into two case studies to highlight two quite different experiences. All identifying information has been removed from these case studies and pseudonyms given to protect the anonymity of the mothers we spoke to.

Ellen's* Story

Ellen recently moved to Norfolk and had trouble bonding with her baby, episodes of anxiety and low mood. Ellen described her worry as she felt *'disengaged'* from her baby and that it was *"very apparent that I was getting really, really low".*

After not knowing where to turn due to a lack of *"sign posting for help with perinatal mental health. I started googling and found out about the MBU [Mother and Baby Unit].* As a result, Ellen reached out to the Perinatal Mental Health Services and her Health Visitor, *"I made the inquiry. I called them directly, but I think that my health visitor facilitated that or fast tracked it to get me in because I was really desperate."*

Ellen had been receiving *"ad hoc"* visits from the Early Childhood and Family Service to engage in baby massage to help bond with her child. Despite this, Ellen felt that she needed *"more constant support at that time"*, especially since only recently moving to Norfolk with her husband and having no local family support. After a short period of time, Perinatal Mental Health Services contacted Ellen and offered her a bed at the Mother and Baby Unit for a six-week period of treatment.

"I had a lot of regular contact. There was a, a good plan put in place for peer support and regular mental health nurse visits and conversations with a psychiatrist. All of that was super helpful to get me acclimatized back to home life."

With intensive support from staff, Ellen was supported to bond with her baby in a safe environment.

"The nursery nurses would invite me to sensory sessions, different activities with my baby. It was just an opportunity to give pointers in real time… to look at what my baby is doing, what is being displayed and what it means, so that I could start to familiarise myself with what my baby needed. I threw myself into it."

The Nursery Nurses also provided Ellen with video footage of her interactions with her baby *"showing me the bond… that was kind of*

tangible", a process that Ellen described as *"invaluable"* and a *"great opportunity".*

Ellen explained that having round the clock support was vital and if she was *"struggling to settle [her baby] overnight as there was somebody always there on duty,"* and it's the type of support that isn't always available to new parents.

During her stay on the MBU, Ellen felt included and involved with her treatment and care. Ellen attended weekly meetings with perinatal mental health staff and one-to-one meetings with the psychologist as well to "*discuss my progress and how to alter any medication that would've been appropriate".* Ellen's husband was invited to *"have a one-to-one talk to the psychologist about his perspective on the circumstances"* and he was updated about Ellen's progress after the weekly group meetings, even when he was not able to attend. Ellen's husband and parents could have been involved in her treatment options and care, *"but it was normally relayed to them as they were looking after my baby while I attended independently to allow me to give full focus to the meeting".*

There was an initial offer of mental health support offered to Ellen's husband, but "*it was never followed up by the psychologist or, anybody else"* and he was never given any subsequent support after that initial meeting.

After a six week stay on the Mother and Baby unit, Ellen was allocated a Mental Health Nurse and Peer Support Worker to provide support at home.

"There was either a Mental Health Nurse or a Peer Support Worker or a Nursery Nurse that I had to come out and see me. There was normally at least a visit, if not two visits from different people each week."

Ellen reflected on her experience of community mental health aftercare, provided after being discharged from the Unit*, "it was a good follow on to have the community support afterwards. I didn't feel that I was left to my own devices to try and make such a vast improvement with only a short period of time in the MBU".*

Ellen rated the Peer Support Worker's involvement highly and remarked that their involvement was person centred *and "based on what my*

needs were… what I wanted to do." Ellen appreciated the Peer Support Worker's company, conversation and shared lived experience and said that it created *"a very safe space when we spent time together".*

The Peer Support Worker remained in regular contact with Ellen and "*reached out to ask "do you want an appointment this week? What would you like to do?" and they would always give me praise if there were positives in the conversation".*

The Mental Health Nurse allocated to Ellen was clear about the treatment plan and informed her *"what the expectations were and what the plan was"*, keeping Ellen regularly updated.

Healthwatch Norfolk asked Ellen if she thought there were any improvements that could have been made to her treatment and care. Ellen responded with two suggestions, including better signposting for Perinatal Mental Health support services available in Norfolk.

"I think that's the biggest thing I think that a lot of mums struggle with is when something like this happens, how do you know who to reach out to? I don't think that it's apparent… sign posting isn't very clear. It's not something that's a leaflet's given out to you when you've had a baby, because it seems to happen out of the blue. It's not something I expected. I didn't know who to turn to."

The other suggestion Ellen made was to include more craft or structured activities available to parents staying on the Unit, *"the only thing I could probably say [that could be improved] was a little bit more structure would've been helpful. More events throughout the course of the day. I did feel at a loose end going around the courtyard quite a bit. There could have been more activities"*. Ellen explained that the craft activities were *"good",* and they helped by enabling her *"to do something and distract myself from how I was feeling and have a few minutes for me."*

Ellen valued the support given to her by staff at the Mother and Baby Unit and from community perinatal mental health services.

"I think that it was enough the service for me and I'm glad that there was an opportunity to be able to have that service... I was definitely lucky that that was on my doorstep. It was something that was a of a great benefit for me to have been able to have that chance to be a resident for a while for that quite daunting experience."

* All identifying information has been removed.

Alysa's* Story

Alysa lives in Norfolk with her 10-month-old baby and husband and during pregnancy, she *"struggled with quite extreme anxiety"* and was referred to the Wellbeing Service to receive Cognitive Behavioural Therapy. Alysa had asked to be referred to perinatal mental health services during her pregnancy, but was told, *"No, you have to go to well-being first before… So I did wellbeing and had my last session of CBT days before my baby was born".*

After a traumatic birth experience and being treated for Sepsis, Alysa spoke to the perinatal mental health team at the hospital and asked for a referral, but this was instantly *rejected "because it was too soon to tell whether or not I'd had PTSD after the birth".*

Alysa's midwife also referred her for perinatal mental health support and the referral was also chased by her Peer Support Worker, her health visitor and her doctor. Despite all this support, it still took eight weeks for Alysa to see someone from the perinatal mental health team which meant *"quite a long time of waiting and not really knowing what was happening and not really hearing much".*

There was only a week in between seeing the perinatal mental health worker and being allocated a bed in the Mother and Baby Unit, "it was very quick… they *said "you need to go… we would like you to go to the MBU. We've got a bed now. Off you go."* A Mental Health Nurse called Alysa to let her know about her space at the MBU and visited her that afternoon to go *"through any questions that I had on anything like that, which was really good and really useful".*

It was difficult for Alysa's husband to be involved in her treatment and care due to work, which meant that Alysa needed to explain what was happening and make decisions about her treatment by herself.

"Staff were coming round when he was at work a lot of the time… so I then had to relay that all back to my husband and he was at

work when the nurse came around my house and he couldn't take any time off, unfortunately. A lot of the time I was being seen on my own and sort of making the decision on my own".

Work commitments meant that Alysa's husband couldn't be there during ward rounds and because *"dads weren't allowed in the communal areas or on the wards".* Alysa explained that there were no bonding sessions set up for her husband to be part of, *"it was never offered to do a session with the three of us in my room".* Alysa's husband was able to attend some infant-parent therapy sessions, which he *"didn't find particularly useful".*

During her experience of the MBU, Alysa's husband was offered very little support for his mental health.

"They told me once on the unit that they were going to call him and do a welfare call on him just to see how he was doing. He didn't receive a call. He hasn't been offered any additional support. He hasn't been offered to speak to anyone at all."

Alysa felt that she *"wasn't necessarily a priority because I wasn't suffering with psychosis or bipolar disorder"* during her stay at the MBU *and "often just felt like I was just being left to get on with it. So I was quite frustrated a lot of the time when I was on the unit".*

Communication about her treatment and care was another issue that Alysa struggled with because *"things weren't communicated very well about what the plan was… ward rounds were awful because they were always late."* Alysa was left unsure about the support she needed and the progress she has made during her time at the MBU, including when she might be ready for discharge.

"Every ward round, I would say, "okay, when's the plan? How long am I going to be here?" For the first couple of weeks, I was told the plan is to wait. "We're just waiting to see how everything settles down with you." And then it was one week, I said, "Okay, we need a date because I'm just wandering around kind of aimlessly here. We need something to work towards." And it was that ward round that I asked that we came up with a discharge date".

Alysa recognised that the *"staff tried really hard"* but had the impression *"that there wasn't enough of them, which I know is the*

case all across the NHS." Alysa described the mental health staff based on the MBU as *"lovely and amazing and trying their hardest"*, despite *"staffing and funding being an issue".*

Once Alysa left the Mother and Baby Unit, her experience of community mental health support didn't improve. Alysa's care-coordinator whilst on the Unit left their post and when she arrived home, she went back to her previous care coordinator who she *"had met once".* As a result of still receiving support from the infant-parent therapist once a week, the perinatal team said that *"you don't need to see your care coordinator now… your care coordinator is going to step back."* Alysa felt like she missed out on having communication with someone about what was going on with her care. Since finishing treatment with the infant-parent therapist Alysa only hears from her care-coordinator if she *"asks them to text me and ask her to call me, otherwise I don't see her. I don't hear from her".*

Alysa was assigned a Peer Support Worker and this is someone with lived experience of perinatal mental health issues who Alysa described as *"amazing"* and who visited her every week she spent on the Unit. When Alysa felt upset and alone during her stay on the Unit, the Peer Support Worker *"called the unit on my behalf and said, "Someone needs to go and talk to her. I am concerned that she hasn't spoken to someone all day."* Their input extended to *"emailing my care coordinator and saying, "Right, what's going on? What's the plan?" She arranged a professionals meeting with all of us".* Another professional that Alysa described as *"amazing"* was her Health Visitor. After Alysa was discharged by her midwife, the Health Visitor came round *"every day that she was in the community, she would pop round and see me, even if I hadn't booked an appointment".*

Healthwatch Norfolk asked Alysa what she thinks needs to be improved within perinatal mental health services. Alysa reported that communication needs to be improved to include weekly meetings with her care coordinator that do not put the *"onus on me to say that I need help as I'm not very good at asking for help".* The second thing that Alysa thinks needs to be addressed is involving partners and co-parents to be involved with the

recovery process on the MBU and offering them sufficient mental health support.

"I know it's not necessarily ideal. I do get worried about my husband and the fact that he's not been offered any additional support and I know it was obviously very hard for him as well."

Alysa is now waiting for the perinatal mental health team to give her extra trauma stabilisation therapy and potentially a referral for Eye Movement Desensitisation and Reprocessing (EMDR) therapy. Alysa was concerned that she would be due for discharge from perinatal mental health services due to her baby nearly turning one, *"but they have said, because I was on the unit, I can stay with perinatal a little bit after she's turned one… which is good. That's something I was concerned about".*

* All identifying information has been removed.

Eating Disorder Workstream

Within Norfolk and Waveney, the Norfolk Community Eating Disorder Service (NCEDS) is for people aged 18 or over who present with moderate to severe symptoms of an eating disorder. These are diagnosed conditions that cannot be solely managed within Primary Care, including: Anorexia Nervosa, Bulimia Nervosa and an Eating Disorder Not Otherwise Specified (EDNOS). The NCEDS service offers assessment and treatment plans based on a *"clinical, evidence-based approach"* (CPFT, 2023) which should be compliant with NICE guidelines and advice. The NCEDS service is made up of a multi-disciplinary team of specialist psychiatrists, psychologists, occupational therapists, dieticians, support workers, and nurses.

The team also offers a FREED pathway (First Episode and Rapid Early Intervention for Eating Disorders) for young people aged between 18 and 25 who have been diagnosed with an eating disorder less than three years ago.

Who we heard from

Healthwatch Norfolk interviewed one person diagnosed with an Eating Disorder to find out more about their recent experiences of community mental health services.

Progress made by the Community Transformation Steering Group

Healthwatch Norfolk interviewed members of the Community Transformation Steering Group and Transformation Leads to find out how they have been trying to improve the service provision for people living with an eating disorder over the past 12 months. The Transformation Lead started by explaining that this workstream focuses on eating disorders and does not include "disordered eating".

> "There is a difference between eating disorders and disordered eating... I think the main area around that is that it is about the diagnosis, which unfortunately is a bit of a blunt instrument, but when you are commissioning a service, there does need to be inclusion/exclusion, otherwise, it just wouldn't be possible to manage."

Eating disorders can be related to a person having extreme behaviours related to their eating, body weight, and body image. An eating disorder is a serious mental illness that needs intensive treatment and support for recovery. An eating disorder is a clinical diagnosis, whereas disordered eating is not. Disordered eating is a broader term that includes disordered relationships with food, exercise, and a person's body. It is a term used to describe the behaviour patterns seen in someone who does not fit within the specific criteria for an eating disorder (Tastelife, 2020)

We also wanted to find out more about the transformation work that has taken place over the past 12 months. The Transformation Lead explained that the Eating Disorder Team has a VCSE "*partner within the system*" that helps to meet the requirements for the statutory NHS Adult Community provision. Eating Matters is for people with a mild presentation of an eating disorder, they provide counselling to people with mild symptoms and *"fill in that gap up to the moderate to severe which are picked up within the statutory services."*. The Lead described Eating Matters as *"fantastic at what they do".*

Intensive Community Support Pathway

In early 2022 the Intensive Community Support Pathway *"went live"* with two key functions. It has been created *as "a step-down and a step-up service"*, with admission prevention as one of its key purposes. The aim of the service is to provide "*more intensive support for a moderately short period of weeks."* In the past, if a person's situation escalated, it might have meant they required either admission as an inpatient in an acute setting or as an inpatient to a specialist eating disorder unit. The Transformation Lead explained how intensive support should work.

"Intensive support basically bridges that gap from the community to inpatient by providing support several times a day in person or virtually to support people through that period with a view, to preventing an admission at the end of that. There is a flexibility around that time period."

The Intensive Community Support Pathway can be used for people coming from an inpatient environment, who, without support, wouldn't be able to go back to support from a community service. Through the Intensive Community Support Pathway the individual can be offered the same level of service, but it's used to support a step down from the inpatient environment.

"The beauty of it is that the Intensive Community Support is that it is a team within the Community Eating Disorders team. So basically, it's all there. They are the same people working together side by side, so they are able to assess when somebody is suitable for it, assess when somebody is able to go back into the community team and that they're actually having the conversations, in essence, in the same team."

Within the Community Eating Disorder Service there are a variety of staff members, including nursing staff, dietitians, psychologists, support workers, and administration staff.

Eating Disorders Strategy Oversight Group

The Transformation Lead reported that they have partners that sit on the Eating Disorders Strategy Oversight Group, including Eating Matters, Experts by Experience and the statutory providers. There are representatives present on the group that are *"external to the health system"* including Family Choice and Norfolk County Council.

"There is a great deal of input coming at the system from lots of different angles to make sure that everything is considered and it isn't NHS-centric or anything along those lines."

A key piece of work undertaken by the Oversight Group is an all-age strategy document for eating disorders in Norfolk and Waveney. It's due to be published imminently on the Norfolk and Waveney ICB website.

"That's probably one of the key areas where we were able to lay out what our vision is, the pillars of how we will achieve that vision...to some of the specific things that we will actually do and produce."

Rethink Mental Illness were asked to co-produce and host a survey that asked service users what they would like to see from the service and their priorities. The results were used to inform and check that the strategy is *"representative of what people wanted."* The strategy is due to be publicised by the Communication Team at Norfolk and Waveney ICB and representatives from the Oversight Group *"so that people are picking that up to be aware, and then obviously it will just direct them into where the [strategy]document is."* The Transformation Lead explained that it's intended for the strategy document to be made accessible to enable *"anybody with an interest or knowledge of eating disorders to pick up and read and understand what the direction of the services are going to be".*

Future plans and priorities

Healthwatch Norfolk asked the Transformation Lead what the workstream priorities are for the next 12 months. They reported that the workstream will be focussing on reduced admissions, developing the Intensive Community Support Team (both in the acute and specialist eating disorder environments) and the FREED (First Episode and Rapid Early intervention for Eating Disorders (FREED) pathway. The two key focuses within the Eating Disorder Pathway will be developing the Avoidant Restrictive Food Intake Disorder (ARFID) pathway and a single point of access. Both pathways are in the early stages of being scoped out, but it's hoped that early on within the next financial year they will be *"up and running to a certain degree."* The Transformation Lead explained that they are

awaiting information from the commissioners before they can move forward with the work.

"I think we are aware of the areas that need developing, and we are working in that direction. They're just not there yet. We're waiting on some key commissioning information from NHS England and also to do with finances as well, which will have a big bearing on what we can do."

The Transformation Lead reported that there are plans *to "work with the broader community transformation piece to develop an approach where the I Statements become integral to the process"* and consider how they will shape the eating disorder services. Healthwatch Norfolk asked the Transformation Lead what they thought the highlight of the eating disorder workstream has been over the past 12 months. They responded by explaining how extra funding has enabled them to increase service provision.

"I think it's around the expansion of the offer. Adult eating disorder services have always lagged behind children's services, traditionally in terms of funding and staffing resources… over the last 18 months, two years, there is an additional £1 million of recurrent funding that has gone in, including into the intensive support, so there is now parity."

The views of adults diagnosed with an eating disorder

Joined up services

Healthwatch Norfolk wanted to explore whether people experience joined up treatment and care from community mental health services. One person we interviewed explained how they had been allocated to the Eating Disorder Team.They were receiving support from a Psychologist, a Community Psychiatric Nurse (CPN), a Support Worker and a Specialist Psychiatrist. When they were discharged from the Eating Disorder team, *"I just received a letter in the post telling me"* and it was not something that was discussed beforehand. After this, their Psychologist and CPN left the service and they were placed on a waiting list for another CPN. Even though they regularly asked for updates about their CPN allocation and were "*repeatedly told I was on the list"* they eventually *"found out that I'm not on the list and I'm not getting a new CPN".* They found this *"difficult"* because the Community Mental Health team had not managed their expectations and *"if that had been communicated to me from the start, I still would have found it difficult, but not as much".* This person also described their treatment as *"inconsistent"* and that changes to staff were not communicated to them.

During the interview they acknowledged that there *"are some fantastic people who work within mental health services"*, but staff shortages will have an impact on patients' treatment and waiting times.

"I've had amazing people that have left due to it just becoming too much, which means the workforce then kind of crumbles upon itself because obviously if one person leaves, there's more work for everyone else… staff structure and everything is important; that staff are retained if they can be and if it's right for the staff, but also the impact that then has on the patient group."

Healthwatch Norfolk wanted to find out if adults being supported for an eating disorder are being included in the planning and completion of their care plan. We heard from one interview participant who described their care plan as *"very outdated" and "quite irrelevant"* and that their care plan had not been completed due to their CPN leaving. Another part of the care planning process involves a service user completing a Dialog+ form with their Care Coordinator. This is a new care planning approach that should enable care plans to be co-produced and personalised to the service user's needs. The form involves a service user completing 11 questions to rate their quality of life and the experience of care. One interviewee explained that they were asked to fill out a Dialog+ form with their psychologist, but this was not completed. They also don't believe that Dialog+ is relevant to everyone due to different people having different needs and priorities in life.

"I don't really think it's relevant because… and I understand that obviously with any kind of population model, there needs to be a wide range of sort of subtopics… but I just think it's difficult because obviously, the subtopics will be relevant to someone somewhere, but then there's bits that are relevant to you that may then not appear. So we looked at that and started to fill it in, and then never got any further than that."

Another theme mentioned during the interviews was the availability of an allocated support worker during their treatment. One participant spoke about their support worker not being specially trained to work with someone diagnosed with Anorexia Nervosa because support workers need to *"be able to cover all diagnoses."* This meant the support worker did not have a "*helpful"* understanding of this person's experiences and symptoms. When the participant became unwell and struggled to maintain their weight, the support worker would ask what they had eaten and when they explained that their food intake had been minimal, they would rationalise and relate to the participant's answer.

"I remember when I was struggling to sort of maintain my weight and stuff and she'd ask what I'd eaten, and I'd sort of explain... and then she'd say things like, "*Oh, well, I'll sometimes have something for breakfast, but then won't have any dinner. I think everyone does that*." And whilst there was rational Me, who got where she was coming from, anorexic Me was very much like, see, I told you it's not necessary to eat."

One interview participant told us that their parents used to be involved in their treatment and care pathway, which created a *"joined up approach",* and they *"appreciated"* this because different parts of the mental health services *"work very separately."* Since their Psychologist left the Trust, their parents were no longer involved.

"We used to have regular team meetings with the Eating Disorder Team, my Psychologist, my CPN from the recovery team, my mum, or my dad, and me. And that worked really well because it's sort of from a joined-up approach... When my Psychologist moved on to a new role but since then, there's kind of no involvement with my mum and dad. It's kind of very separate."

Feeling in control

Healthwatch Norfolk wanted to discover whether adults diagnosed with an eating disorder feel in control of their treatment and care. One interview participant described how they felt involved in their treatment *"in some ways, yes. In some ways, no"*. This participant experienced 'refeeding' as part of their treatment programme. Refeeding is a treatment process that involves a person being given food and nutrition (either orally or through a feeding tube) with the intention of bringing their weight up to a healthier level and increase energy levels (Sachs et al., 2015). This can be a distressing process, especially if a person does not want to gain weight. During their refeeding treatment the participant managed *to "get back to some form of a meal plan...so I felt involved."* But the participant felt out of control when these appointments were frequently changed or cancelled because the mental health professional did not communicate to the participant that this may happen, *"it's not something that's kind of talked about... it would be nice to sort of feel like that was the decision that was made sort of together."*

Healthwatch Norfolk asked each interview participant to tell us about what's working well with community mental health services, and what needs to be improved. One service user described how there needs to be better communication between service users and mental health professionals about their treatment and care in the form *of "discussion around what is being done, what isn't being done."* They also suggested the better *"matching up of people"* between service users and their support workers to ensure that the appropriate support is given from a person with the right expertise.

"A support worker that I used to see years ago said that it used to be that they would see some people once every three months, but it was enough to keep them on the level. Whereas towards the latter part of when she was there, they weren't then being allowed to do that, which meant that people were then being discharged, but therefore becoming more unwell. I think ideally if there was sort of a step-down service if you like, where someone just had a phone call once every three months as a touchpoint… because to go from being in a team with access to multiple professionals and all of that to then being discharged back to a GP, which you can't get an appointment with even if your head has fallen off, it is difficult."

Personality Disorder and Complex Emotional Needs Workstream

Healthwatch Norfolk wanted to explore what adults diagnosed with a personality disorder think about community mental health services in Norfolk and Waveney. We spoke to 12 people (via five 1:1 interviews and a focus group with seven participants) to find out whether they believe the community mental health services available to them are joined up, consistent, person centred and whether they have seen any changes over the past 12 months.

Progress made by the Community Transformation Steering Group

Healthwatch Norfolk interviewed the Personality Disorder Transformation Lead to find out what has been happening in this area of the transformation over the past 12 months. Within the personality disorders strategy, one of the elements is embedding specialist personality disorder roles into the community mental health teams, establishing specially trained staff who have been "*upskilled*" to support a person with a personality disorder diagnosis.

Within NSFT, there is not a service that has been specifically set up to support people diagnosed with a personality disorder.

> "The reason for that is because the strategy looked at all the different models that were going on across the UK and looked at the best practice, the evidence base and discussed it with service users and carers, and that informed the decision to… instead of setting up a distinct and separate service, the decision was taken to embed the specialism within existing teams, so in the community mental health teams. And more recently, the idea is to do this into primary care as well, although there are some complicated issues around that."

Approximately one in 20 people are living in the UK has a personality disorder. Personality disorder can be hard to define and diagnose, so people with this often go unrecognised for a long time (MHF, 2022). The Transformation Lead explained that the decision was made to design the service like this to stop people that may *"fall through the gaps"* if a separate and distinct service is set up.

> "If you set up a distinct service, people fall through the gaps because they're not the right kind of ill. They're too ill for this. They're not ill enough for this. And they just end up getting bounced around, so. Yeah. So people didn't want that."

The Transformation Lead reported that recruitment for these specialist staff members is *"going really well and are nearly fully recruited."* There are several types of training available to NSFT staff to develop their knowledge, including the Knowledge and Understanding Framework (KUF) training which is also available to Enhanced Recovery Workers and Mental Health Practitioners. The Transformation Lead explained that it's a system-wide approach, *"so wherever we can upskill people to support people with a personality disorder, we will."*

Appropriately Trained Staff

In the early stages of this work, it was recognised by the Transformation Lead that mental health staff do not receive enough training in personality disorders. During an interview with the Transformation Lead, they told us that the average mental health nurse receives only half a day's training on personality disorders during their three years at university. This was also highlighted by mental health staff that were involved in a series of workshops at the beginning of the workstream development.

> "It's not a lot at all for such a complex condition. So they felt like they didn't have the tools, the correct tools in their boxes, and their education and training were the way forward."

As a result, the team set up a workshop with the aim of putting a package of training together, which included dialectical behavioural therapy and KUF training. They invited stakeholders from the *"third sector… staff, service users, carers, managers, you name it, we invited them"* to facilitate an "*open-ended*" and "*transparent*" discussion around training needs. The discussion focused on the "*lack of understanding and education and training, and ongoing training*" and the participants concluded that there wasn't enough highlight on good practice and too much emphasis on bad practice.

During the sessions, it was suggested that the team adopt the Knowledge and Understanding Framework (KUF) training. This is a learning programme for professionals working across health, social care, criminal justice and voluntary sectors to support people with complex emotional needs, often associated with a diagnosis of personality disorder'.

KUF training predates NSFT's personality disorder workstream and is a national initiative that's commissioned by Health Education England (HEE). HEE offered all Integrated Care Boards the opportunity to bid for a Band 7 KUF development lead in each area. Within the KUF team are two KUF development leads, one for Norfolk and Waveney and one for Suffolk. They have also recruited a team of

lived experience trainers to deliver the KUF training. It can be delivered as an introductory session or a taster session to educate people more about personality disorders.

The KUF training covers topics including:

- What is personality?
- What is a personality disorder?
- How does a personality disorder develop?
- What is the biopsychosocial Model?

The KUF training is available to anybody in Norfolk and Suffolk who is from a third-sector agency and all NSFT staff. There isn't currently funding available for the public to be part of the course. But there are *"things, like, bitesize training (that are more available to everyone) and the Living Well with Personality Disorder course, which is available through Recovery College."* Healthwatch Norfolk asked the KUF Development Lead what their priorities are for the next 12 months. They told us that it's important for their team to continue delivering the course and developing it. They will be recruiting more sessional trainers.

"There's five of us employed in the team, but the demand is there for more training, so we're developing the idea of sessional trainers, both with learned experience."

Other priorities for the KUF Development Leads will involve introducing mentoring by people with lived experience into the process, more clinical supervision for the session trainers and regular team reflections to *"make sure that everybody's okay to really sort of safeguard ourselves as much as possible."*

Peer Support Workers

Healthwatch Norfolk continued interviewing the Transformation Lead about the community offer available to people diagnosed with a personality disorder. This includes introducing Peer Support Workers within the remit *"to offer support themselves to people with a personality disorder, so they're there… if they need to meet up or go for a coffee or, you know, share their experience, they are there for that."* The Lead explained that the plan to originally recruit 15 Peer Support Workers to be embedded into community mental health has changed. After a review of the strategy and the pathway, it became apparent that Peer Support Workers require a certain level of psychological supervision to keep them safe and that a psychologist role would be needed to ensure that they had the supervision they required to remain safe and well.

"We've got a duty of care to everybody that we employ, to all staff, but I think because we're employing people specifically because of their lived experience, it's almost like we have a special duty of care to make sure that they are okay… because one day you might be okay with sharing a particular aspect of your experience and another day it just might be too much for that."

There are plans to start recruitment for a psychologist in October 2023. Instead of 15, there will be five Peer Support Workers recruited into each locality and they will link into the new mental health primary care roles. Mental Health Practitioners and Enhanced Recovery Workers will be able to refer into the Peer Support Worker. Peer Support Workers will also have *"links into a wider personality disorder offer,"* including the Waves programme, which is being expanded and currently has a waiting list of approximately 80 people. The Transformation Lead explained that there are plans to introduce Peer Led Groups which involves *"people with a personality disorder to coming together to support each other."*

Future plans and priorities

The Transformation Lead reported that the priorities for the personality disorder workstream over the next 12 months included developing the training programme further (including the DBT Intensive and DBT Foundational Plus upgrade), expanding the WAVES programme, continuing the training programme (including KUF and bitesize training) for enhanced recovery workers in Primary Care Networks and recruiting a jointly funded Band 8A Psychologist role to supervise the five Peer Support Workers.

The views of adults with personality disorder and complex emotional needs

For this evaluation, we spoke to 12 people to find out more about their experiences of community mental health services. This involved one to one interviews with five participants and a focus group with seven participants.

Joined up services

Every person that Healthwatch Norfolk spoke to reported that they had received inconsistent, often disjointed and sometimes unexplained treatment and care from their community mental health team, with people needing to chase appointments or receive follow up information.

> "There's been so many things where nothing has fitted. It's been very disjointed and very fragmented. Yeah. And as service users already in a period of confusion or distress, you always feel like you have to chase admin or you have to really be on your game. And that's, that's a horrible feeling."

There were several reports of care coordinators either cancelling or offering inconsistent, *"wide apart"* appointments or *"sporadic contact"* from their support workers. One participant explained that their appointments can *"be quite wide apart. It can be sometimes a month or two at a time"* and another interviewee reported that their support team's *"input has been a bit up and down… with quite long gaps between appointments."* Another service user highlighted that they haven't *"really seen her [their care coordinator] very regularly"* and due to appointments being *"spread out"* it has made it difficult develop trust or form *"a very close relationship with [the care coordinator] in terms of being able to kind of go to her with all my issues and stuff."*

One interviewee described their current relationship with their care coordinator *as "okay… they are better than the one I had at this time last year, who was just determined to discharge me."* A focus group participant explained how during a period of one to two months *"all I needed was an appointment with someone from my secondary care team to change my medication."* Despite reaching out seventeen times to community mental health staff to change their medication, they reached out and paid a private psychiatrist for help *"but they said I needed the care of a secondary team, so they couldn't help me."*

Another theme that arose from the interviews were people diagnosed with a personality disorder or another serious mental illness not being fully aware or sure of what their diagnosis is, whether it's the right one or what the implications and

symptoms for living with certain conditions could be, which can have a knock-on effect to the type of treatment and care offered.

"I've been diagnosed with EUPD (Emotionally Unstable Personality Disorder, also known as Borderline Personality Disorder). But I was also told I have a mild form of schizophrenia. But they've not really talked to me about my diagnosis and what it means. So they offered me CBT, which I took, and done it in group work. And I didn't get on with that. Then I asked if I could have CBT again, but by a face-to-face with local one on one, and they said "yeah". But that wasn't consistent. The woman kept cancelling on me. So it's like I didn't really get the full benefit of it."

This interview participant felt like they had a *"misdiagnosis"* of schizophrenia but even after contesting their original diagnosis, it took a while for their psychiatrist and other mental health staff to listen. This meant that they were originally regarded as *"difficult"* and were receiving inappropriate treatment and being threatened with discharge from services, until it was confirmed by another mental health professional that they had Emotionally Unstable Personality Disorder. The theme of not being listened to was echoed by another interview participant who explained that the only way they felt listened to was when they had reached crisis point.

"For community support, it feels like the only way anyone actually listens to you, or at least that's what I've found, is unless you've actually ended up in a crisis... that you're doing something dramatic, that nobody actually gives a toss. It's just like unless you're basically having a complete and utter breakdown and then crisis, nobody really cares. Yeah, not unless you're either in a crisis or in pain."

Care Plan

Healthwatch Norfolk wanted to find out the experience the interview and focus group participants had of care planning with their care coordinator. There were no positive responses and replies varied from not having a care plan in place to having an out-of-date care plan. One interviewee explained that they had a completed a care plan, two or three months previously that was *written "by my care coordinator",* but they had not seen a copy of it and only felt *"sort of"* involved with writing it. Another interviewee completed their care plan over the telephone with their care coordinator but felt rushed to get it finished.

"It was a meeting a bit like this and she wanted to get through it as quickly as possible. No, it wasn't a meeting like this, it was over the phone and she needed to get the call

done because she was clearly really busy. And to be perfectly honest, I have not a clue what it says on it."

One focus group attendee requested a copy of their care plan, but it did not appear on their community mental health record. They also found "*the new dialogue thing quite odd to be honest*." This participant also spoke about calling the duty line when they needed support and *"if you leave a message and they never get back to you."* Another interviewee explained how they called the duty during a crisis and didn't feel supported in the long term.

"Just over 12 months ago, and I had to call them a couple of times to get any response from them. And then it was a bit like putting a plaster on something. All they were doing was trying to keep me safe for that initial moment, that moment in time."

One interview participant spoke about how they called a duty worker to simply double check when their next appointment was and was asked to call First Response. The participant advised the duty worker that due to the call being made between 9am and 5pm they believed it was right to ring the duty worker. The duty worker *"kept urging me to hang up and speak to first response and I said that I didn't think that was the right practise."* Another interviewee mentioned that when they called the duty line, they didn't receive a reply and had to "*just manage at home, and just got on with it*." The interviewee explained that they were told their care coordinator would investigate the matter, but *"didn't hear anything back about it."* Another interviewee reflected upon a time when they called the Crisis Team at 11pm due to being in extreme distress, only to be told their call was *inconsiderate"* which left them feeling alone and confused, "w*ho else do you speak to at that time?".*

Discharge from Services

Another theme emerging from the interviews and focus group was the topic of discharge from community mental health services and how this was handled by staff. One interview participant described how they felt the mental health team "*were trying to get rid of people, discharge people too early. It's, "you've been in the service too long. We need to basically get rid of you." That's how it feels."* One participant reported how *"I've been threatened with discharge several times."* This is a theme that appeared in several of the interviews and led to service users feeling scared about having their support ended and unsure of what would happen next. Another interviewee discussed how they felt "*threatened*" with discharge earlier this year, despite experiencing a mental health crisis. Despite this information, their care coordinator advised that *"if I wasn't recovering, then I*

shouldn't be under a recovery-based team, and therefore, they should discharge me."

One interviewee disclosed that they believed their psychiatrist had been *"talking about discharging me from the first time I ever met him" and* a different interview participant voiced how they thought their previous care coordinator was just *"determined"* to discharge them. During the Waves focus group one participant explained that their care coordinator had advised that there was "*nothing else they can do for me*" and due to them having a place on the Waves course, they were going to be discharged. During the focus group discussion, one member explained that at their discharge meeting they had voiced concerns. They were worried about a risk assessment not being put in place after leaving services and reiterated that being discharged was not their decision.

"I'm concerned with the policy around discharges still that they are not safe because I would've not have been safe to have been discharged at that point… I absolutely wouldn't. I've also asked for my notes from my discharge meeting, of who made that decision and they said they've lost them. I'm still waiting for them."

Feeling in control

Within the evaluation framework, Healthwatch Norfolk aimed to explore how included, involved and in control adults severely affected by mental illness felt about their treatment and care. One interview participant spoke about how they felt that vital information about their treatment and care was withheld and decisions about their care were not directly discussed with them.

"Overall I have mainly felt included when it comes to making decisions regarding my care. However there has been a few incidences where I have felt professionals have withheld pertinent information from me. When I was hospitalised, I felt like decisions regarding my medication and overall care were made without my input. I was given medication without anyone explaining what it was for, or possible side effects. No-one told me what to expect while I was in hospital. "

Two members from the Waves focus group discussed how they do not feel included in their treatment and care and have been left feeling *"somewhat patronised"* and not listened to about their experiences of their medication or the dosage they take. An additional focus group member expressed how they felt that *"you can't ask for a visit unless you are in crisis."* Shortly after being admitted to A&E after a crisis, the same person was told to *"compose"*

themselves and to *"listen to music"* and *"watch furry cat and dog videos".* All the focus group participants reported that they would like to feel more involved in their treatment and care from community mental health services.

Stigma

During the Waves focus group, there were a several references to *"a lot of stigma"* that surrounds a personality disorder diagnosis and that *if "you've got the diagnosis of the personality disorder, it's kind of like you could be seen as just a bit difficult."* One interviewee believes that *"if you don't fit exactly to [a diagnosis] then you are just banged into the borderline personality disorder category."* Another interview participant spoke about how they experienced discrimination from their psychiatrist during an appointment, who insinuated that he assumed the participant might get violent after his comment.

"I think it was my second session with my psychiatrist. He told me I'd never work again. He said "*you've got this for life. You won't cope in life well.*" Then he raised his hands up and went, "*don't get mad at me and don't attack me.*"

Ongoing change

Healthwatch Norfolk were interested to find out about any perceived changes to community mental health services that people diagnosed with a personality disorder have recently observed. One interview participant remarked that they believe services are *"a lot more stretched than they were. My care coordinator couldn't fit me in for nearly a month this time when I'm supposed to be seeing them regularly. Trying to get through to them on the phone can take a long time, and nobody gets back to you."* Another interviewee reported that they believe that *"everything is being done well"* but that they perceive staff to be *"overworked"* and *"waiting times for people are just atrocious".*

One of the focus group attendees reported that they had noticed *"a lot more job openings and opportunities, giving people the opportunities to train and work in mental health."* Most interview participants and focus group members declared that they had not seen any changes to community mental health services or to the quality of care they receive, *"if anything quality of care has lessened."*

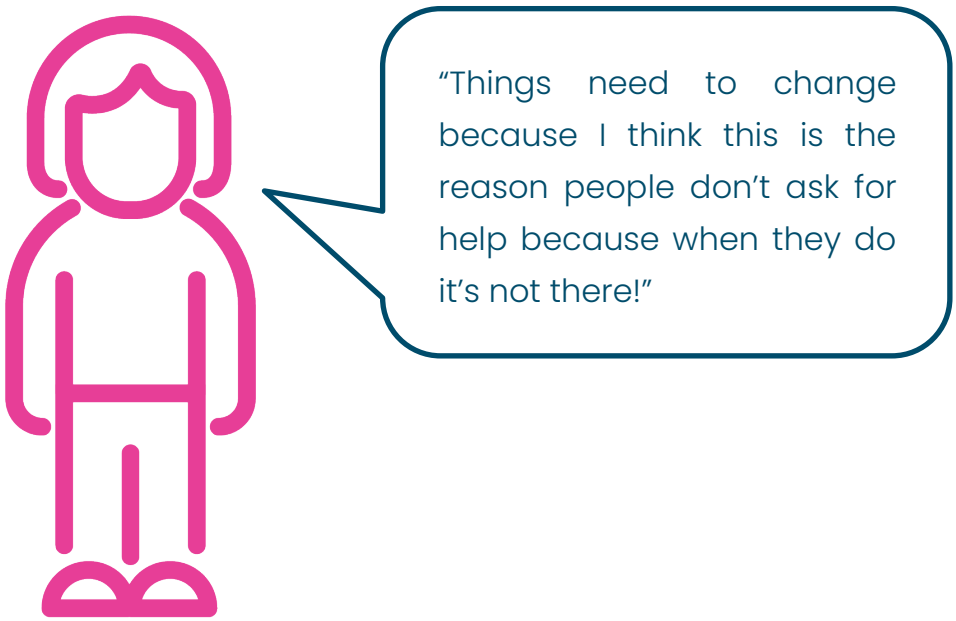
Service Improvements

Healthwatch Norfolk asked whether there were any improvements people living with a personality disorder felt were needed to community mental health services. Their responses included better communication with mental health staff, a change in staff attitude to discharging service users, ensuring that

mental health staff listen to service users, shorter waiting times and providing more support for carers and loved ones.

"Because I've got a partner, she was basically left to look after me. If that makes sense... But she didn't get any support looking after me... she had to go out and pay for her own therapy because she basically got told no one could help her."

One focus group member revealed that their *"mental health team will not include my partner in my treatment or care and dismissed it every time".*



At the Waves focus group, Healthwatch Norfolk asked the participants what improvements they would like to see in the community mental health transformation.

What improvements would you like to see due to the transformation of Community Mental Health Services?

"I would like to be listened to and not passed from pillar to post and not be treated like I'm stupid."

"Staff to have compassion, to listen, to actually give support and help and not to palm you off. The Waves Service needs to be expanded."

"When you're in a crisis – from my experience – it's usually because your treatment isn't working. So I think the best way to improve things is prioritising patients in crisis to be able to get prompt appointments for them. I had to see 17 people before I got in front of a prescribing nurse."

"There's not enough support or funding for the secondary care teams."

"Better, more consistent communication and more consideration of what the individual actually wants. I also believe some staff require more training on complex mental illness and trauma informed care."

"Mental health teams need to have a person-centred approach!"

"There needs to be increased access to long term therapy and support for people with complex and enduring mental illnesses."

"More advertising of different [community mental health] services available."

"Communication definitely needs to be improved. I don't feel like I should have to be chasing for appointments."

"More training on trauma-informed care."

"Better consideration into what I want my care to look like and actually show a desire to help and support, instead of palming off to other services."

Outcome two
What we found out

Families and Carers

Outcome Two

This outcome is focussed on the experience of families and carers of adults severely affected by mental illness (SMI) and that they report improvements.

Our recommendation for outcome two in our first report was that any changes to community based mental health services brought in by the Steering Group should ensure that carers of adults severely affected by mental illness are involved in the care of their loved one, offered support and that the value of their role is recognised. Specifically:

- To progress with the plans to develop I Statement outcomes for carers, working with VCSE organisations that work with carers of adults severely affected by mental illness.
- Ensure that transformation plans indicate which of the I Statement outcomes will be met as a result of any change.
- Consider forming a Carers Panel or a separate group of Experts by Experience to help co-produce and shape the community mental health service transformation process. This will strengthen the steering group's acknowledgment of the importance of families, carers and support networks and treat them as an integral part of their loved one's treatment and care.

Progress made by the Community Transformation Team

Following the publication of our year one report, the Steering Group developed a "Healthwatch Norfolk Recommendation Implementation Plan" to address the report recommendations. The Steering Group actions relevant to this outcome included:

- Hold a families and carers huddle.
- Produce an improvement plan based on the findings of the huddle.
- Implement the improvement plan.
- Hold a feedback session to the Steering group to present what actions have been taken and identify any changes in need.

We interviewed the Transformation Lead responsible for integrating support for carers of adults severely affected by mental illness into the transformation plans. The

Transformation Lead previously told us that there was a need to establish a workstream that involves carers of adults severely affected by mental illness and recognise the importance of their role for the service user's treatment and care. During the interview it became apparent that this subject is *"not a workstream in its own right"* and is *"more about embedding carer support and carers' views"* into transformation plans.

The Transformation Lead explained how they have focussed on trying to co-produce this work with carers by integrating the opinions and feedback from *"a group of carers and carers' leads in NSFT… after becoming increasingly aware that we weren't necessarily embedding their perspective into our proposals."* This has resulted in the Transformation Lead attending an NSFT based Carers Forum on a regular basis to discuss proposals that arise from the Community Transformation Steering Group work, *"ensuring that their views are captured and anything that might be useful for them arising."*

At the end of year one, the Transformation Lead hosted a "huddle" with carers. This explored carer's expressed needs, what potential gaps they perceive exist in carer support and services, and how community mental health services could better meet their needs. The Transformation Lead invited the huddle members to feedback their opinions, so they could be collated. *"I said to the group, "Okay, what are your needs? What do you need as a carer of mental health patients?"*

The main themes arising from the huddle included:

- Regular contact and updates from a nominated mental health team member.
- Educational support available to carers to enable best care.
- Structured psychological support to support their own wellbeing and resilience.
- Involvement in their loved one's care.
- Availability of peer-carer support and respite opportunities.
- Advice about crisis planning.
- Incorporating crisis planning into care plans.
- Signposting to the Carer's Passport.

The Transformation Lead highlighted that one of the biggest issues highlighted is that carers are *"not being sufficiently involved in the care of the person they support for most of the time"* which can leave them feeling frustrated. Carers expressed that they would like to be involved with the co-production, development and design of services and wanted to learn how they can be involved with crisis planning; learning about what they can do in a crisis involving their loved one, how can they de-escalate the situation, and what support might be available from their doctor. The huddle discussion also included conversations about how it would be useful for the Norfolk and Waveney Shared Care Record to link carers to their loved one's "service user assessments" and

whether respite care (for their loved one) could be included in their care package. The Transformation Lead admitted that it is still *"quite early days"* and that they *"haven't got anyone on the ICB yet aligned to this piece of work."*

"The various proposals that I am involved in I could ensure that their [carers] needs are heard and they're incorporated, and I can ensure that I bring them into discussions as appropriate. "

The Transformation Lead reported that they have been making sure that the carers voice is embedded within Rehabilitation Pilot Operations Policy, including the development of the operational specification.

"We've consulted with our carers to ensure that they're involved in the appropriate places in people's care. I think most of the people that are under the rehab team also have identified carers because of the nature of their ongoing condition. So that was an important place to ensure that their needs were met and accounted for."

The Transformation Lead explained that they were interested in setting up a separate Carer by Experience Reference Group. It was felt appropriate to have a separate group established to the existing Experts by Experience Group as hearing *"from both groups that mixing them doesn't necessarily work because there's differences of opinion as to how involved carers should be in the service users' care and that can lead to conflict."* The Lead has started to reach out to their existing NSFT Carers Forum as they can *"speak openly without worrying about upsetting service users."*

In July 2023 the Transformation Lead hosted a feedback session to the Steering Group to present the actions that have been taken because of the Carers huddle. There was also a project carried out to ensure that carers can obtain a direct referral route into the NHS Talking Therapies service and access to a fast-track referral following serious incidents involving their loved ones. In July 2023, Healthwatch Norfolk hosted an event inspired by the lived experience of carers and loved ones of adults severely affected by mental illness in collaboration with NSFT. There were multiple attendees present at the workshops from Norfolk and Waveney Integrated Care Board and the Steering Group. The event enables attendees to listen to the carers' lived experience and work together collaboratively to plan how support could be implemented for carers in health and social care services, including community mental health services.

Future Plans and priorities

Healthwatch Norfolk asked the Transformation Lead what the priorities are for supporting carers of adults severely affected by mental illness. The first priority

mentioned was further developing and making people aware of the Carer's Passport. The Transformation Lead acknowledged that they were working with Carers Matter to *"find money to support administering that scheme."* The Lead also has a vital role in giving the Carer's Passport meaning and importance within NSFT and community mental health services.

"The important part that I had to play was then to reach into NSFT and make those passports mean something. Because it's all very well issuing carer's passports, but unless that translates into operations, they're pointless, aren't they?"

The second priority that the Transformation Lead discussed was the "Stepping Back Safely" project. This is a piece of work lead by psychologists to design and help service users to *"step back from that intense care they may have had on a ward"* when they rejoin their community. This project also supports carers with how they can help their loved one *"step back safely"* because it can be *"daunting if the person you care for has been in a hospital that had lots of support and care, and then to be discharged can be a very scary prospect, and then carer feels like all the responsibility is on them."*

The third priority the Transformation Lead spoke about was how Carer's Assessments are conducted and embedded into clinical practice.

"As well as doing assessment and care plan for service user, I think we need a standard to start doing assessments in care planning for the carer."

A fourth priority will involve the CTSG setting up a 'Building on CPA' (Care Programme Approach) working group which will ensure Carers and Families have input into the planning and treatment of their loved ones, when the loved one gives permission and this is due to being in August 2023.

What carers told us

For year two of the Evaluation, Healthwatch Norfolk wanted to see if there have been any changes or improvements to carers' experiences since the year one report. Healthwatch Norfolk spoke individually to nine carers of adults severely affected by mental illness living in Norfolk to listen to their experience of community mental health services and asked whether their loved one's treatment and care was joined up.

Most of the carers we interviewed described how they had to fight for their loved one's treatment and care with many struggling to get them the right help at the right time. One carer described how they had to repeatedly act as an advocate and fight to get the right diagnosis for their brother through multiple visits to his psychiatrist.

"I've had to be his advocate. I've had to fight for everything he needs. He's a lot better now because he knows who to go to and who to talk to and he's dealing a lot better with that, but I still have to fight for him... I had to take on the fight for him... we're trying to get him tested now for either autism or Asperger's... It's not just the personality disorder."

Another carer explained how their Mum needs a lot of care and support after a dementia diagnosis. Despite having several family members looking after her, they still *"have to really fight"* for the right care package to be put in place and community mental health support to be set up. This carer expressed their concern about other adults severely affected by mental illness that don't have the same type of familial support in place, *"I feel that there's three capable adults looking after my mum; me, my sister, my daughter, as and when we can. Now, a lot of other people don't have that luxury."*

In conjunction with fighting for the right care and treatment, carers reported that the support their loved one received from community mental health services was not always joined up and became disjointed at times. *"I've always found that none of the [community mental health] teams and staff work together. Everything seems to be a separate identity and they don't talk to each other."*

Another theme that was mentioned by the carers was the continuity of care their loved one received. One carer explained if her daughter experiences short periods of good mental wellbeing and stabilisation, she becomes discharged from community mental health services but often her mental health begins to slowly decline again.

"As soon as she's discharged from the system, everything goes and then we have to start the process over again."

This is creating a cycle for the carer who must fight for her daughter to be reassessed by community mental health services. Another carer reported that continuity of specially trained mental health staff and social workers is the biggest problem their elderly mother faces. Quite often the carer's elderly mother receives different mental health workers to support her, leaving her mother confused and the family with no ongoing source of information about their loved one's condition or progress.

"The biggest problem is there's no proper allocated social worker, because a social worker needs to know the patient, needs to get to know their situation, needs to get to know the family, talk to them, see what they think. I've supported people with dementia. They need to know that's the same person. If a new person comes every day, they don't know what it's all about."

A third carer outlined how their daughter went into supported living for six months to provide them both with much needed respite and support. Despite this arrangement, the carer reported that every time their daughter experienced a crisis, they continually contacted the carer for help with the situation.

"She did the six months respite, then she went into supported living. That was rubbish, I have to say because every time she went into crisis, they phoned me and said, "*we need help come and help her*", so I didn't find that very helpful."

A fourth carer described how their mother had been left to take full time care of their brother because they received such little support from community mental health services. Their mother felt like she had to become their son's carer as no-one else could provide the support her son desperately needed and after a while it eventually became too much.

"She had to make sure that she could meet his needs because nobody else could do it. But recently she said that this wasn't something that she could continue with because it was all too much and that she was actually left with the whole weight of everything, all on her shoulders."

Being Involved

Healthwatch Norfolk asked each of the carers how involved and included they felt in decisions about their loved one's treatment and care. All the carers we interviewed reported issues with being included in discussions about the planning and provision of community based mental health services for their loved one. Several carers highlighted that they had no idea what their loved one's official mental health diagnosis is or the potential severity of their symptoms. *"I didn't know how severe his mental health was which was horrendous for him. Bad for me because I hadn't got a clue. I thought, "What the heck do I do?"*

A second carer described how they don't fully understand their loved one's diagnosis or what it means for their long-term prognosis. *"What it actually means, I haven't got a clue. No-one's ever told me… I know how to live with it, but I don't know what the diagnosis is or anything."* Another carer explained how they weren't made aware of the type of medication their loved one was taking when their treatment started, *"the doctors tell me nothing".* The carer was left uninformed about what the medication was for or the potential side effects for both their loved one and their immediate family.

"He's zonked out half the time. And the Mental Health Practitioner says, "well, I'm not surprised. Most of your tablets will have that effect on you," but he didn't know that. I didn't know that… I get told nothing."

Even after caring for their loved one for several years, this same carer felt that they are *"still in the dark as to his condition in some respects and also the medications"* and are left unsure whether he is on the right medication or the most effective dose, *"should he be taking these? But I know he needs them, you see, to keep him sane".*

One carer explained that even though they have their loved one's consent to be involved in their treatment, they still have to track down the mental health staff treating their family member to find out what's going on with their treatment plan.

"We've had to find out things for ourselves. We've tried ringing [the community mental health team] and unfortunately whenever we have, you know, it's been hard to find things out."

Another carer described how they felt overlooked and frustrated by their wife's psychiatrist. The psychiatrist did not wait to include them during a routine ward round during their wife's recent hospital stay. *"I remember feeling when she [the psychiatrist] went, I was like, "so what's happening here? What's the treatment plan? How can I help?"* The carer was left not knowing how they could support their wife, any updates on her condition, when she might be ready to be discharged or the mental health support that might be put in place once their wife was home. This lack of information and update meant that the carer couldn't plan for their wife's eventual release and consider how this might affect their homelife or impact upon their children.

"If I'm trying to support my wife the best way I can and try and support home life and the children the best way I can, there are some bits I feel I should know. The psychiatrist literally came, spoke to my wife, and left."

A different carer expressed that they weren't sure if their loved one had an up-to-date care plan or what might be included within it. *"I'm sure there must be one because there is a general plan about how things go… but a formal document, no, I haven't seen one. I would guess there is one."* If their loved one wants their family member to be involved in their care, they are left to remember to pass on a copy of their care plan, *"usually she gives it to me… they just send her two copies and she'll pass one on".*

Despite not being involved with or having access to their loved one's care plan, another carer suggested that the care plan could include a specific question that asks, "would

you like your family to be involved in your [care] planning?" They reported that *"the psychiatrist did say lots of family ask for that… so I don't know if there is anything like that on the plan".* This carer believes that (with informed consent) carers *"should be involved in this support plan… they should be involved in support planning and they're not always involved in that."*

Not Being Heard

All the carers that Healthwatch Norfolk interviewed felt that the voice of the carer is not always being heard and their opinions and feelings are often disregarded.

"You're dismissed because you're not the patient. You're completely dismissed… I am largely treated as the taxi driver who brings her to the clinic."

One of the carers recounted how they have supported their loved one through *"fifteen years of illness"* and when their loved one reached crisis point, they felt *"ignored"* by mental health services, despite repeatedly asking for help. *"I tried to open every possible door and really say, "come on, do something. He's really unwell." And I've just been shut out completely."* An additional problem raised by a carer, involved their loved one revoking consent during an episode of acute mental illness that allows their partner to be consulted about their treatment and care.

"When things are bad for her, she doesn't want me to know. So, she will use the confidentiality thing. So, whereas I might want to know, one for being husband, but two, just to know what's going on and what the treatment plan is, then she might refuse it. "

One carer spoke about their loved one's stay on a psychiatric ward and the difficulty they had receiving updates from staff about their partner's condition, despite having their permission. In the end the carer resorted to speaking to acquaintances based within mental health services that were unrelated to his partner's care, to understand what was going on.

"When things are acute and when she's been at hospital, it becomes a nightmare to actually find out anything… to get any information out around treatment or plans; it's even harder than it is normally. I have felt very frustrated there. Some of it I just had to find out by speaking to other people in the know. "

Use of the Carers Assessment

Healthwatch Norfolk asked each carer about the type of support they had been offered since becoming a carer for their loved one. In Norfolk, Carers Assessments should be

made available to adults (aged 18 plus) who provide unpaid care and support to someone living in Norfolk who is elderly, affected by a disability or a long-term health condition, (Norfolk County Council, 2023) An assessment should involve a conversation about a carer's wellbeing and is not intended to be a test of someone's ability to be a carer. It should be an opportunity for a carer to reflect upon the type of support they feel is needed, by exploring their feelings, their physical, mental and emotional wellbeing, whether caring for a loved one is suitable for them as a long-term option and how caring might affect their employment, finances, leisure activities, education, wider family and relationships.

To be referred for an assessment, a carer can contact Carers Matter Norfolk who will carry out the assessment or they can be signposted via community mental health staff. But this is only viable if a carer is aware of their options. Several carers reported that they had been offered a Carers Assessment, but either they didn't receive one or that nothing became of the assessment they did receive. *"I was offered a carers assessment but don't think anything came of it."*

"I got called in and it was to assess how I was coping looking after [my loved one]. It was a carer's assessment. They said, "we'll be doing this every year to see how you get on." I went, "Okay." That's 5 years ago and I'm still waiting. I've had nothing."

Carer's Identity Passport

Carers in Norfolk, are entitled to a free identity card supplied by Carers Voice Norfolk and Waveney. This card identifies that someone is a carer and can be used in a hospital setting, as an outpatient, within the emergency department or on the ward. It enables carers, the people they care for and staff to work together as a team. The Carer's Identity Passport should be recognised within East Coast Community Healthcare, James Paget University Hospitals, Queen Elizabeth Hospital King's Lynn, Norfolk and Norwich University Hospitals, Norfolk and Suffolk Foundation Trust and Norfolk Community Health and Care Trust, (Carers Voice, 2023).

One of the carers we spoke to mentioned they had heard about the new carer's identity passport but thought that the scheme was still being developed.

"I heard there is a Carer's Passport and read the information. At the moment, what I understand about it, it says that it will have a meaning, but it seems like they're still working on that meaning, and what exactly Carer's Passport would mean."

Healthwatch Norfolk interviewed the Transformation Lead delivering on including carers in the development of the Transformation and asked if they had been involved with the Carer's Passport. During the Carers Huddle the group facilitators asked the attendees what their needs were *as "a carer of mental health patients".* The carers identified a need for Carer's Passports as one way to support them and make them feel recognised in their loved one's treatment. This is something the Transformation Lead recognised that the Community Transformation Steering Group will be more involved with over the next 12 months.

Wider Support

Most of the carers reported that they have received little to no support from community mental health services to help facilitate their role as a carer, *"nobody's contacted me, saying, "How are you getting on?".* One carer suggested that *"some kind of talking therapy"* might have helped during one particularly *"traumatic episode"* with their loved one, but they were offered no support or guidance leading to a "*very stressful time".* Another carer spoke about the *"non-existent"* help they received from mental health staff, "*I never had any help from any mental health staff, none… Nothing's been good… the lack of help given to carers… no info back up, nothing."*

A different carer explained that being a carer for their partner had triggered a crisis for themselves and their mental wellbeing. This carer was told they would have to wait six weeks for any help. This left the carer feeling like they *"have to keep fighting for myself"*

and lead to them *"to go outside and find somebody to help me"* through private healthcare because they could feel their *"mental health is going downhill"*. This particularly difficult time impacted on the carers ability to not only support themselves, but their partner too.

"What they [community mental health services] don't understand is because I'm not getting help or we're not getting help, the amount of times we have nearly split up, what's going to happen to my partner then?"

Another theme that emerged from the interviews with the nine carers was the effect that caring for an adult severely affected by mental illness not only has on the carer, but on the wider family and support network, *"it interrupts all of our family time and it's very frustrating"*. Healthwatch Norfolk asked one carer what has been good about their experience as a carer and they replied with *"nothing"*. They were left feeling unsupported and that they *"couldn't cope"* due to a lack of support for themselves and their family. A different carer suggested that *"even if members of the family are paid carers, they should still be supported as people"*. Another carer described how she now feels *"very protective over my mother"* due to her brother *"verbally abusing"* her regularly during periods of ill health. One carer highlighted that they don't think some mental health staff understand the impact an adult severely affected by mental illness can have during particularly acute periods of ill health and how it ripples through their entire support network.

"They don't understand what he's going through. They don't understand the knock-on effect it has with the carers, the carer's family. It has a knock-on effect on everybody."

There were a few ways that carers mentioned that helped them to feel supported within their role. One carer mentioned how her mum had *"connected to a carers group"* after years of supporting her son being re-admitted into hospital and through this, *"she can get help if she needs anything"* from other carers. Another carer mentioned that they had adopted their own coping mechanism, *"when things do get bad, I have written down …a three or four page thing that tells me what's worked before and what hasn't worked."*

Healthwatch Norfolk wanted to know what the carers thought might help their experience of supporting their loved one. Collectively, they discussed ideas that they believe would improve their situations, including making sure carers are well informed, asking carers how they would like to be involved and ensuring that carer's voices are heard.

Four carers mentioned that they believe that carers should be given more information about their loved one's diagnosis, the potential implications for them and their family and the types of medication their loved one might be prescribed. This would include their loved one being given a physical copy of their care plan that could be shared with their carer (should they choose to).

> "What do I think would help? We [carers] need more information. We need more information to help deal with severe mental health."
>
> "We need to understand the drugs and the effect that it has on them because nobody tells us. It has an effect on us as well, you see. The effect that drugs have on him is having an effect on me."
>
> "Help carers to understand the signs to look out for… which is to look out when they're cutting themselves off from the rest of the family, isolating themselves, , and not really coping in general… knowing where to go for the help."
>
> "He doesn't get a copy of anything… but it would be really good if he did have copies of the care plans or the assessments…. So if that's something that can ever be introduced so the nearest relative could really understand what he's actually getting and why he's getting it."

All nine carers indicated that they would like to be invited to be involved in their loved one's treatment and care (with consent) and to feel like they are being listened to and included in the planning of services.

> "There are times when if I could be told in very general terms, "This is the treatment plan for her. This is what we plan to do and this is how you can help or not help," as in not do these things."
>
> "Being listened is the number one for me. Being involved in planning the care is the number one as well."
>
> "Just being involved, being heard, being communicated with."

Another carer suggested that carers and relatives of adults severely affected by mental illness could be given a form that invites them to state what type of involvement they would like in their loved one's care, how they feel about their caring role, what support they need and how community mental health services could be improved.

> "Invite the carers and invite the relatives. Give them a form and say "we would like to understand how you're feeling about this and is there anything you think can be improved?"

Outcome three
What we found out

Community transformation steering group

Outcome Three

For outcome three of the Evaluation report Healthwatch Norfolk we wanted the Community Transformation Steering Group to evidence that they have made changes that positively impacted on community mental health services in Norfolk and Waveney. Some of the evidence of changes are shown in Outcome One.

Our recommendations in Year One that relate to this outcome were that the Community Transformation Steering Group must ensure that the plans are truly coproduced and that engagement with Experts by Experience and wider stakeholders is not just focussed on getting feedback on plans already made. Specifically to:

- Continue to develop the role of the Experts by Experience and seek opportunities for full coproduction.
- Seek broader opportunities to engage with wider groups of Experts by Experience through other VCSE partners.
- Review the membership of the Steering Group, Operational Group, and Working Groups to ensure broader VCSE representation.
- Ensure that the I Statements outcomes are at the heart of the evaluation framework for the Community Transformation Steering Group.

In this section we have focussed on co-production and partnerships, and the development of a VCSE strategy.

We have also looked at the first recommendation from outcome four in the first year report that the Community Transformation Steering Group seek ways to incorporate wider VCSE support to adults with serious mental health issues into the transformation plans. Specifically that they:

- Recognise the value, unique qualities, and professionalism of VCSE organisations and how they can help to meet the wider needs, such as advocacy, of adults with serious mental health issues and incorporate these services into the transformation plans.
- Explore how these services can be funded to ensure their sustainability.

- Work with the Norfolk and Waveney VCSE Assembly to develop the VCSE strategy, thereby ensuring wider representation and develop opportunities for coproduction with the VCSE sector, and involving them at the beginning of service design, not part way through.
- Seek alternative means of engaging with smaller VCSE providers that allow them to contribute more fully without always having to attend meetings organised by the steering group.

Progress made by the Community Transformation Steering Group

Following the publication of our year one report, the Steering Group developed a "Healthwatch Norfolk Recommendation Implementation Plan" to address the report recommendations. The Steering Group actions relevant to this outcome included:

- Developing a VCSE strategy within the system to outline how the Steering Group can work collaboratively with VCSE providers to support adults with serious mental health issues.
- Ensuring there is a range of VCSE membership at the Community Transformation Steering Group.
- Patients having access to a wider range of place-based support that is bespoke to their needs. VCSE sector will become an empowered part of the system with a voice in strategic planning.
- Strengthening co-production by co-producing plans from the beginning, embedding learning from the Rethink first year report and involving a wider range of stakeholders.
- Involve an Expert by Experience with the co-chairing of the meeting to allow co-production to take place earlier, ensure the voice of lived experience is heard at a strategic planning level and facilitate the separate groups of people with lived experience to come together into a collaborative forum.
- Re-launch CT Steering group with an Expert by Experience co-chairing.
- Embed recommendations from Rethink report into CT plans.
- Facilitate Experts by Experience and other stakeholders to join together to work collaboratively.
- Ensure co-production occurs from the beginning.

Healthwatch Norfolk wanted to understand the level of co-production within the eating disorders, and personality disorders and complex emotional needs workstreams. We spoke to the relevant Transformation Leads.

The Transformation Lead for the eating disorder workstream explained that: "*they had "Experts by Experience representation on the task and finish groups"* and that the workstream strategy had been coproduced with the Experts by Experience reference group.

> "The information that has gone in there [the strategy] has been looked at. The document, the final review was done by an Expert by Experience of the document. So I think that's probably almost the best way that the final check is, "This is the thing that's going to go out. We want you to be the last set of eyes on that, and obviously, then take the feedback and make the amendments as appropriate within there."

The Transformation Lead reflected upon how in few select parts of the transformation the ICB will *"understand the mechanics of commissioning better"* and highlighted a potential barrier to co-producing the eating disorder workstream exists if a person with lived experience *"predominates".*

> "There can be situations where an individual Expert by Experience's view predominates … because eating disorders is quite a broad topic. There can be a very specific area that the particular Expert by Experience is interested in, that is focused upon, where maybe the whole needs to be looked at rather than a specific area."

The Transformation lead acknowledged the value and wealth of experience that the Experts by Experience and commissioning knowledge of the ICB bring and explained how *"it is about blending all of those things together*".

Healthwatch Norfolk interviewed the Perinatal Mental Health Transformation Lead and asked whether the perinatal pathways have been co-produced. They informed us that they have worked with people who have lived experience to shape the pathway, but that the integration of the pathways has been and is a gap that they *"have recognised".*

> "The pathways have service users by experience that inform the delivery of those respective pathways. Lotus has a user participation group, the maternal mental health service. Perinatal services have a user participation group. The perinatal pathway has used lived experience and peer support workers that designed that bit of the service. So they all were co-produced."

The Transformation Lead also spoke about the importance of VCSE Sector Involvement within the Perinatal Mental Health pathway. This has been recognised in the steering group's terms of references and they have started to bring in representation from voluntary sector organisations onto the steering group. The Transformation Lead explained that this would involve liaising with specialist voluntary sector organisations that have a particular interest in "*protecting characteristic groups like LGBTQ and BAME communities"* to hear what it's like to be part of their community and how services could be transformed to support their needs.

We spoke to the Transformation Lead for the Rehab Pilot workstream. They told Healthwatch Norfolk that Experts by Experience co-designed the Rehab Pilot Launch Event and every interview for Rehab Pilot staff *"had an expert by experience in it, so they did all our interviews with either me [the Transformation Lead] or the other shared leadership team members".*

During the interview with the Transformation Lead, Healthwatch Norfolk asked how the Rehab Pilot workstream had been co-produced with Experts by Experience and local voluntary (VCSE) organisations. The Transformation Lead reported that the Experts by Experience had advocated for VCSE sector involvement: *"the work stream meetings had experts by experience on them, and they helped to determine things like the amount of VCSE partners that we had".* The Transformation Lead explained that the Rehab Pilot could have easily provided support workers and peer support workers to make up the workforce, "*but the experts by experience really wanted it to be a multi-partnership kind of team."* Norfolk and Waveney Integrated Care Board then the ICB then gave the Steering Group direction steer on making sure that enough of the Rehab Pilot staff came from different organisations, which the Transformation lead describes as "*really powerful".*

In January 2023 we interviewed a Senior Transformation Programmes Lead from Norfolk and Suffolk Foundation Trust (NSFT) who has been leading on the transformation on behalf of NSFT across the Norfolk and Waveney system. They told us about the work they had done to widen the range of VCSE membership at the steering group. The ambition was to find a way to reach out to a broad cross section of providers. The Transformation Team attempted to use two mechanisms for engaging with the VCSE sector – the Mental Health Providers Forum and the Norfolk and Waveney VCSE Assembly. The Transformation Lead felt that by inviting the Chairs of both these Forums to join the Community Transformation Steering Group, it would ensure that there was communication back to the sector and would be the best way to

"Because the idea was that those two as chairs had to come to our VCSE workstream, that had a number of their members on anyway, but then they can also take the findings of that work back to the assembly and the Provider Forum who had an even broader group of VCSE sector."

The Mental Health Providers Forum is a VCSE sector-led Forum, which is currently chaired and administered by Together UK. The Forum does not receive any funding. Membership is open to any organisation that is involved in mental health in Norfolk and Waveney

In 2019 a Health and Social Care Assembly for Norfolk and Waveney was being developed by Norfolk and Waveney's Sustainability and Transformation Partnership in partnership with Voluntary Norfolk, Momentum, Community Action Norfolk, and Community Action Suffolk. This was funded until March 2021. A Chair for the Assembly was appointed in May 2021. Following the requirement in the Health and Care Act (2022) for formal engagement of the VCSE as part of the Integrated Care System, the VCSE Assembly for Norfolk & Waveney, became part of the ICS and was relaunched on 1st July 2022.

The Transformation Lead attempted to engage with the chairs of both the Mental Health Providers Forum and the Norfolk VCSE Assembly.

"I tried reaching out to (the Chair of the Assembly) and didn't really get much of a response. She's difficult to get a hold of, but I must say that (the Chair of the Mental Health Provider's Forum is) brilliant."

The Transformation Lead also told us that despite having an invitation to attend the Steering Group and the VCSE workstream, the Chair of the Norfolk and Waveney Assembly did not attend the meetings.

The Transformation Lead expressed the importance of the role of the representatives and their responsibility.

"Because we couldn't invite (someone) from every VCSE sector organisation into the steering group because it would be ridiculous. So you've got to find ways of identifying representation, haven't you, for a larger group. And I don't think we make that role clear enough...I think we need to do a bit of work as a system making it clear that people on those groups are-- what capacity they're sitting on those groups. So for example, (a VCSE CEO) is on our steering group, but in my mind, they're on that steering group as the Chair of the Provider Forum. Because that way, she's reaching out to the whole

group of VCSE sector…. we need to better communicate what it means to be a member of a group. And if we did that …. then we could make it clear that if you can't attend…then perhaps you can send someone in your place."

The Transformation Lead identified that there are challenges to working with the VCSE sector due to potential conflicts of interest creating an unwillingness to collaborate with one another.

"We have clear roles to play, don't we, in the system, and it makes sense to work collaboratively. But for some VCSE sector (organisations), they are directly in competition with others."

The other challenge the Transformation Lead expressed is the varied nature of VCSE sector organisations in respect of size and the services that they provide. Their preference is to engage with the larger organisations that have a broad range of services, as the preference for statutory partners is to focus more broadly.

"The other issue with VCSE is that they are very often very focused on a specific piece of service delivery and we tend to be talking quite broadly all the time. So capturing everybody's contribution to the system becomes very hard because you've got some real specific pieces of work that these CICs might deliver wrong. And as a result, we need to be guard against always using the same providers because they're generalists."

The Transformation Lead also told us that this workstream, particularly the development of the VCSE strategy, had been delayed as it was reprioritised as other work had to take priority such as the care pathways development, etc. and would be picked up in April 2023.

The Lead was confident that the previous work undertaken around the development of the strategy hadn't been lost and would continue in April. The original plan had been to establish working groups, which reflected four workstreams and would include the most relevant VCSE sector partners for each area of focus. These working groups would help to develop the strategy. The Transformation Lead told us that the task of the working groups had been completed and that from April they would draft the strategy along with an ICB representative.

Future Plans

We spoke to the Transformation Lead again in June 2023. They told us that they had all the information that had been collated from the working groups and they had a draft

VCSE Strategy. The Lead shared her plan to incorporate the key principles of the strategy across the workstreams to support the working relationships with the VCSE, especially with those organisations which are smaller.

"[We are] trying to better partner with our VCSE sector. Yeah. Around, around those sort of collaborative partnerships rather than transactional commissioning. That, that was one of the themes that definitely came through from the work that I did with VCSE sector is, you know, sometimes the contracts are just too onerous for them, for their, for the size of them or the, um, you know, that that's just not in a position to put in, put in huge bids. They can't compete basically with the big, with the big VCSE. Yeah. And yet they often provide some really important, um, niche services that, that will support those that we've already acknowledge, um, suffer from health inequalities."

The next step was to take the draft strategy to the Mental Health Providers Forum for approval.

What Key Stakeholders Told Us

Plans should be truly coproduced

Our recommendation was that plans should be truly coproduced and not just focussed on getting feedback on plans already made. We spoke to representatives from the Experts by Experience Reference Group and a range of VCSE sector providers to see what steps had been taken to meet this recommendation.

Strategy for Co-production

One key piece of work that the Experts by Experience are currently working on is a Co-Production Strategy for Norfolk and Waveney ICB and this work will be facilitated by Rethink. One Expert by Experience commented that *"one thing that is quite good is the co-production strategy. Rethink is facilitating that. So I mean, I've only been to a couple of those meetings, but I think that's quite promising, really."* This work will also involve People Participation Leads employed by NSFT, Community Voice Champions and local voluntary organisations. The Experts by Experience will be looking at the framework behind the Co-production Strategy to create a toolkit for people to use. *"So not only telling them what the strategy is, just a document, but actually giving them the tools to make sure that they can carry it out and also measure the effectiveness as well."*

An Expert by Experience posited that this strategy will be important to get across the true meaning and values of co-production, when *"you sit down and you share power,*

make decisions together, a meeting of minds and innovation; that's co production. Not just advisory to a meeting." They viewed the Strategy as a "system wide, five-year document that's going to be kind of our legacy… something that we're leaving something behind about co-production and best practice.

Coproduction with Experts by Experience

For Healthwatch Norfolk the involvement of people with lived experience of serious mental illness in the coproduction of services is a key factor in the success or otherwise of the community mental health services transformation.

We interviewed three Experts by Experience to explore whether they believe co-production has been implemented and improved over the last 12 months during the transformation process. One Expert by Experience reported that they believe that there is co-production taking place because if *"we didn't have a voice there [at the CTSG] and the messages were getting cut back, then we probably wouldn't hear half the stuff that went on."* Another Expert expressed that they believe co-production processes *"are getting there… definitely getting there."* They reasoned that there's always *"room for improvement with communication"* between the Steering Group and the Reference Group, but that overall the Experts by Experience *"are doing a really great job and definitely have quite a strong table now in regard to the Transformation."* The Expert added that they are always encouraged to question whether Experts by Experience were involved at the start of a workstream and encouraged by Co-production Officers to *"question what the steering group is doing in a positive way, to see if there is anything where co-production is missing… so our voice is heard.*

When asked if they believe true co-production is happening within the Transformation, a third Expert by Experience said that *"it's a bit of both because some meetings I feel really positive and then sometimes I'll come out [of Steering Group meetings] and think, "Well, really?" so it's a mixture."* Another Expert by Experience added that they believe it's difficult to have a consistent understanding of co-production across the Steering Group because *"everybody has a different breadth of knowledge and understanding of what co-production is, so there's no kind of consistency across the group."* This Expert reported that they believe that there are *"some absolutely fantastic people [on the Steering Group] who understand totally and are really engaged and enthusiastic"* with co-production and how it should operate within the transformation. This will be complimented by the Co-production Strategy.

One Expert by Experience explained that their involvement with the Personality Disorder and Complex Emotional Needs Workstream had unexpectantly come to

an end. After working with a dedicated NSFT staff member to devise a training course, the staff member left and the work was transferred over to the Knowledge and Understanding Framework Team. They advised the Expert by Experience that *"they didn't need anybody else with lived experience. They've got enough."* The Expert by Experience reported that the Senior Co-production Officer tried to find an explanation for this and has *"been trying to get answers but they're not getting any."*

Another Expert by Experience described how the Reference Group "*were never in the strategic work stream meetings"* for this workstream. The end of the Experts by Experience involvement with this workstream coincided with the former Rethink Co-production Manager leaving. Due to *"changes within the personality disorder team"* and not having a direct contact within the Workstream, the Experts by Experience *"didn't know what was going on."*

There has been Expert by Experience involvement within the Physical Health Workstream, particularly on one online form which (according to the Reference Group) contained *"judgmental language."*

> "We were trying to change it to make it a bit more accessible. And then there was a question about gender because it was "male, female, other," and it's like, "that's not the best."

Another Expert by Experience reported that the Reference Group involvement *"within some work streams are better than others."* They described the support given to the rehab team which provides *"wrap-around care for people with mostly complex psychosis who are kind of in and out of the hospital"* as *"quite good… particularly the task and finish group leading up to the launch event."* As a result, another Expert by Experience is now involved *"in running a kind of drop-in craft session once a week as part of that project." And really involved in delivering the service."*

Healthwatch Norfolk asked the Experts by Experience if one or more of them have been involved in the Primary Care Workstream since it began. One Expert by Experience responded that the Reference Group have only recently been included within this workstream.

> "We only got invited… so [the PCN Steering Group] only meets quarterly in the first place, which is strange because it's such an important thing and I think we were invited to the last one, which would have been three months ago, obviously, but we

couldn't attend, I think because we had training at the same time. So this was the first one that we've attended. So we haven't been involved from the start."

During this meeting, Experts by Experience voiced their confusion about the new mental health roles, including their remit, *"who's doing what and who's employed by who and who's going to be physically sitting where."* During the meeting, a Google Jamboard (a collaborative, digital whiteboard) was brought in so that participants could conduct a SWOT analysis and consider the strengths, weaknesses, opportunities, and threats facing this workstream. These themes were used to shape the next phase of the workstream.

Healthwatch Norfolk asked the Experts by Experience what improvements they would like to see regarding their involvement and co-production practices within the Transformation process. One Expert by Experience would like to be informed "*straight away*" if the Steering Group are considering a new piece of work. This Expert used the Carer's Passport work as an example and said that they "*weren't aware that they were planning this and what it really is… if they are planning something in certain area, it would be lovely to know beforehand, that this is what is happening*." A third Expert by experience expressed similar concerns and reported that when "*there are loads of new pilots… it would be good to really understand the ins and out better, like when they presenting something, and then you don't want to ask while you're in the meeting*." They would like a clearer explanation of what each new pilot is, the purpose behind it and what the intended impact on community mental services could be.

One Expert by Experience suggested that they would like the Steering Group to *"allow us to share our story … our personal story and experience… I think it could be very powerful for people to understand … a real story, I think, is always very helpful. And that makes it real as well. They're real people's lives and your experiences. And that's the whole kind of essence of having Experts by Experience."*

All three of the Experts by Experience that Healthwatch Norfolk interviewed spoke with commitment and passion behind their role as Experts and valued how their life experience is helping to shape the community mental health transformation.

"I love the reference group. I felt like there is lots of experience and passion and it's always… every topic is we're looking from different angle and from different kind of personal experience. And it's wonderful because everyone has room to talk. Everyone is kind of really encouraged to have a voice. "

Coproduction with wider stakeholders

Healthwatch Norfolk asked the VCSE representatives about was the level of co-production they believed took place through each stage of the Rehab Pilot development and for the transformation in general. One VCSE representative reported that "*throughout the production of it, there was always opportunities for people to be involved. I guess in terms of service user input. We could have probably done with more than what we had".*

Another VCSE representative commented that "*if I was the one that was looking at the co-production of it, what I would have done from NSFT's point of view is I'd have had probably an entirely separate group where there wasn't any senior management input… I think there should have been more opportunity for Experts by Experience, those with lived experience to go off on their own looking at what we were trying to achieve and coming up with their own ideas, rather than be very much constrained by the senior managers*". A third VCSE representative recognised that there have been "*great improvements*" with implementing co-production throughout the entire transformation process and design of services but reflected that they think *"it's still being navigated".*

Review the membership of the Steering Group

The Community Transformation Steering Group was revised and relaunched in January 2023. Membership of the steering group includes representation from Norfolk and Waveney Integrated Care Board, Norfolk and Suffolk Foundation Trust, Norfolk County Council, Suffolk County Council, the VCSE representative from the Mental Health Providers Forum and NCAN, VCSE provider organisations (Mind, Change Grow Live, Rethink), Norfolk Police, Primary Care and East Anglian Ambulance Service.

Increased Involvement of Experts by Experience in the Community Transformation Steering Group

The Steering Group is now co-chaired by an Expert by Experience, a Clinical NSFT Lead and a Senior ICB Programme Manager.

This has been *"really welcomed"* by the Experts by Experience Reference Group. One Expert by Experience reported that *"I feel that we're getting our voice heard and we're actually influencing just by the fact that we're now getting involved…I suppose we could have done it before, actually. But we do put things on the agenda. We do seem to have a higher profile."* Another Expert by Experience stated that they do not feel that the co-chairing role is "equal" yet because *"the chair should be a rolling chair, so they should change every four months"* and noted that the Clinical Lead and Senior Programme

Manager co-chairing the Steering Group are *"a permanent fixture"* of the Transformation process with *"more experience."*

One Expert by Experience expressed that they believe the Steering Group are now *"taking into consideration our feelings and our experiences" when* planning new projects within the Transformation and are mindful and *"really careful to kind of come in and ask as our opinion in regard to the potential changes."* The Expert elaborated further and noted that the Reference Group can access more training opportunities that are available to NSFT staff. This type of Expert by Experience involvement means that *"people are aware that we exist and we kind of have a voice. So that's definitely the change."* Another Expert by Experience believes that the Reference Group has *"made some changes within the whole programme especially when we got the rehab group going."* The Expert explained that some of the reference Group members were *"heavily"* involved with the Rehab Pilot. They also mentioned the Physical Health Check Forms and after voicing their concerns, they felt listened to.

"I actually come away feeling proud. Because that form was just set up to fail people. And then with the changes we've made, I think that that could be a proper success."

Another Expert by Experience stated that the Reference Group are *"changing language"* by challenging the Steering Group on their use of acronyms, suggesting that members use the term "under-served" instead of "heard to reach" and explaining the difference between the terms "complex emotional needs" and "personality disorder".

One Expert by Experience told us that it would be helpful if the Steering Group agendas were sent earlier, something that was noted during year one of our Evaluation, although they felt there had been a slight improvement: *"Sometimes it's just, let's say day before, and there is a lot of documents and lots of reading. So they are getting better. So again, it's definitely they listen and they try."*

"In the steering group, we all have a chance to contribute. I guess we don't often get the papers very far in advance, so that's quite hard. For us to gather our thoughts or have any sort of pre-meeting is impossible really."

VCSE Sector Membership at the Steering Group

The Chair of the Mental Health Providers Forum continues to sit on the Community Transformation Steering Group. We interviewed them about their role in representing and feeding back to the sector.

"I feel I have a responsibility to kind of be there for the grassroots ones and the ones that don't have the resource to be able to attend things and feed that message back."

But they also recognise the limitations of smaller organisations in participating in groups or meetings.

"Sometimes I'll go out and I'll share things and I'll be like, "Oh, please, expressions of interest. Would you like to be involved in this task or finish groups?" But they have such limited resource to be able to get involved, that it's almost like a thankless task for the commissioners and staff too-- they come in and they're giving and they don't get a lot back, but I don't think that's-- as I said, it's no fault other than the fact that they're so under-resourced and they're struggling at the moment in terms of oversubscribed wait lists that have doubled and lack of funding to support that."

Several of the VCSE sector organisations we spoke to still felt that the Transformation Team used the Mental Health Provider's Forum to update the sector on what was happening, but there was still not a way of influencing the transformation plans.

"I think that they need to include the VCSE more in those leadership type (roles) and those discussions than they do at the moment because even though they talk about supply collaboratives and partnership work and everything, it's very much, "We've had a meeting. We've decided this. This is what we're going to do."

There was also some criticism about the format of the updates provided and VCSE representatives reported that they can be difficult to understand.

"The one thing I will say from my experience of those, there still feels to me like work to be done when they come and deliver updates on making that really accessible and easy to follow. Very heavy PowerPoint slides filled with information, and what we are trying to move towards is creating these spaces that are accessible to everyone." and one person told us "I guess it's about getting accessible information out regularly. And maybe I'm missing that, but I'm not seeing it. So yeah, accessible information regularly, not great weighty tomes that busy people have to kind of fight their way through to get to the person and points."

One of the stakeholders was positive about the communication between the Transformation Steering Group and the VCSE sector.

"I would say, kind of, the flow of communication back to VCSE providers, certainly using the forums like the Mental Health Providers Forum as a conduit for that, has been really

effective, and I think it's consistent. In the past, what I've seen, maybe if I'd go back two years ago, a year ago would be kind of sporadic attendance, not many updates, whereas I think communication flow is certainly improved."

Another felt frustrated that there were insufficient timescales given for some key issues or around engagement, which made it difficult for providers to respond.

"But for instance, they are looking at recommissioning some advocacy or looking at commissioning some more advocacy and we had a two-week turnaround to submit a bid for it. My calendar is full two weeks in advance. And I don't think there are very many people whose aren't at this point. And I think the attitude very much from people is, "No, I'm not going to-- why would I change my calendar to suit your calendar when you couldn't be bothered to give me notice." And that just seems to be-- so a lot of these events, I just think, "Well, if they'd really wanted me there, they'd have given me a month or two months or whatever."

One provider talked about engagement with NSFT staff and Transformation Steering Group, but also pointed out that the engagement with both appears to have tailed off:

"The NSFT have got some pretty good voluntary sector engagement workers, but I haven't seen them about for a while, actually. And I do try and get myself to the mental health providers group. But they used to be pretty good at flashing in and giving a quick update, but I haven't seen so much of that. And I know that there's also, I think, a partnership engagement director over at NSFT and (they) started with great promise of wanting to engage, but for whatever reason - and I suspect it's resources and firefighting - hasn't necessarily been able to kind of carry that through."

Experts by Experience

We were keen that the role of the Experts by Experience was developed, but also that opportunities were sought to engage with a broader range of experts by experience through VCSE organisations.

We spoke to three Experts by Experience, the Co-Production Practice Manager from Rethink and Senior Programme Managers from the Community Transformation Steering Group.

There have been some changes in the staff supporting the Experts by Experience group and in the group itself. The group is still hosted by Rethink, but there is a new Co-Production Practice Manager supporting the group. The group has increased in size to sixteen members.

Since the previous Healthwatch Norfolk evaluation report, the Reference group have been continually involved in supporting the community mental health transformation. Highlights of their involvement include:

- Bringing lived experience into the development of the Joint Forward Plan and plans to engage in the next iteration by partaking in three workshops.
- Three Experts by Experience are members of the new Urgent and Emergency Care Steering Group and are engaged in the strategic oversight of activity and outcomes.
- Co-producing the Norfolk and Waveney Integrated Care System Mental Health Co-production Strategy and Framework. Rethink is facilitating the development of the strategy.
- Engaging with the Mental Health Liaison Team service specification as part of their review workstream.
- Being part of the new Primary Care Network Community Transformation Workstream.
- Reviewing the Section 136 patient leaflets.
- Presenting at the NSFT Interactive Workshop 'Mapping the Mental Health Offer for Norfolk and Waveney'.
- Advising on the format of the form for Section 117 personal budget monies.
- Supporting the process of involvement for the Right Care Right Person initiative, including "Concern for Welfare", "AWOL" and 'Building on a CPA initiative." Experts by Experience are involved with the Complex Design Panel and attend weekly meetings about the Supported Living workstream.
- Supporting the Talking Therapies service specification review.
- Setting up a working group of Experts by Experience, Experts by Training VCSE representatives and other relevant stakeholders to evaluate the development and delivery of the Experts by Training course.
- Attending the Personality Disorder strategy.
- Regularly attending transformation workstream meetings.
- Regularly attending and co-chairing Community Transformation Steering Group meetings.

Training and Support

The Expert by Experience Reference group has received the following training and support over the past 12 months to undertake their role:

- Equality and Diversity, Attending and Chairing Meetings, Coproduction, Communication, Influencing and Questioning Skills and Community Engagement training.

- Monthly one to one support meetings with Rethink staff.
- Attending and engaging a workshop that analysed and developed priority areas for Expert by Experience involvement. This workshop also incorporated community listening data.

During our interviews with the Experts by Experience, it was revealed that at least one Expert *"takes part when there is any training, face-to-face training,"* so they can talk about and share their own lived experience and feedback on the training to the rest of the Reference Group. All three of the Experts by Experience spoke about how they have "done lots of training" through Rethink and NSFT, *including "skills to be able to become stronger, how we communicate…how to ask a question, etc…"* One Expert by Experience described the Equality and Diversity and training session they attended with Rethink as *"one of the best I've been on because they went into detail on stuff… that's how I get my head around from going into detail like give examples."* Another Expert by Experience said they enjoyed their induction training because "sometimes you sit at the computer and think, *"oh, it's going to be PowerPoint-heavy. And it wasn't that bad."*

Experts by Experience from the wider sector

We are not aware of any work to engage with wider groups of Experts by Experience through other VCSE partners, which we had recommended in year one.

Incorporating the wider VCSE Sector

We wanted to understand what progress the Transformation Steering Group had made in finding ways to incorporate wider VCSE support to adults with serious mental health issues into the transformation plans.

Development of a VCSE Strategy

We spoke to a range of VCSE providers who were involved in the initial work to develop the VCSE strategy.

One VCSE provider told us that early work had started but not progressed.

> "Part of the community transformation steering group, and as part of the Mental Health Providers Forum, we did have a breakout group. And I know [that a number of VCSE organisations] were all involved in that. But we had a few meetings and then it kind of just died a death and it wasn't picked back up again."

The delay on this workstream or that the task of the working groups had been completed does not appear to have been clearly communicated to the VCSE sector, apart from communication to two of the partners who were on the steering group, one

of which had emailed the Transformation Lead to find out what was happening. We spoke to representatives from VCSE sector organisations who expressed their frustration that this workstream had been delayed:

"The VCSE workstream was the kind of key… that was the one I chased. If you're going to make so much noise about how much you want to work with the voluntary organisations and with the third sector, that is a really basic and really simple way to show that you're serious about doing it. And so when it's looking at things that go on the back burner, it makes no sense to me that someone thought that's the thing to put on the back burner when these are your allies."

One local VCSE Service Provider *commented, "I think my only statement, to be quite honest, is it needs to get back up and running because I think it's taken a backward step. I think with the CQC and the ICB implementation, it's probably lost a year, and I'm thinking that we need to have-- we need to catch up. And I'd love to be a part of it, but yeah, let's see it in another year's time."*

The Transformation Leads have continued to attend the Mental Health Providers Forum to give updates on the progress they have been making, however the minutes of the meetings do not reflect any discussions about the delay of this workstream.

Another VCSE provider suggested that there must be more transparency around funding when asked about what needs to happen in the future.

"I guess a little bit more transparency around what's coming through, how that's being spent."

VCSE Sector Involvement

We had recommended that the CT Transformation Group engage with the VCSE sector through the Norfolk and Waveney VCSE Assembly and we wanted to talk to the Chair of the Assembly to see what engagement there had been, however we were unable to get a response to our requests for interview from the Chair, which reflects the experience of the Transformation Lead.

We spoke to several representatives from the VCSE sector about their involvement in the transformation plans and work. A Chief Executive from a larger VCSE organisation told us about their involvement.

"I also act as the SRO [Senior Reporting Officer] on the prevention and well-being-- suicide prevention and well-being programme. So I've been leading that. And part of that is to look at the IAPT service or, as they say, talking therapies nowadays, putting the

well-being hubs and suicide prevention. So I've been really actively involved in the whole transformation from day one to where we are today."

We spoke to other CEOs of VCSE sector organisations who said that they were not involved in the Steering Group or Transformation Plans.

"None...I pretty much get my information from the mental health providers forum. So yeah, I'm probably having it second-hand".

One provider we spoke to was complementary about information being circulated, but also warned about the risks of duplication of effort.

"What's come across from a lot of the people that attend is that there's a lot of duplication. There's sort of other groups that are going on, that are doing similar things. So it's about linking those together to make sure that they're not reinventing the wheel. If you've got something that's already there, to tap into that. That's one of the things that immediately comes to mind from recent meetings that people have raised."

The challenges of smaller charities engaging with the statutory sector was also recognised by VCSE providers.

"The problem with NHS and strategy is they have lots and lots of metrics and they also have the MHSDS system, which is quite complicated. When you talk to VCSE now, I'm not too bad because we're big enough and bad enough and we've got people who can use the system. The smaller charities, so by default, the way they go through and use their system, they're disadvantaging the smaller charities because they can't report the metrics in the same format that NHS wants."

However, the CEO of a larger provider also told us that they struggled to find the time to engage.

"We've got a really big service. We're supporting 300 people. I can't spend oodles and oodles of time sitting on endless mental-health-type meetings. So I need the information passed over to me in the right kind of format. And somewhere along the line, that's not happening. And I don't think it's about me not putting my time where it's needed."

One of the other larger VCSE organisations suggested that the Transformation Steering Group should try to use the larger organisations as an intermediary for engaging with those smaller organisations:

"It would be far better if they were to engage with (our organisation) and we were to work with the smaller charities because we understand their culture and their community, rather than somebody like NSFT trying to communicate that, who are totally different cultures. So I think that is still not understood."

One stakeholder felt positive changes had been made and that there was a broader involvement of VCSE sector organisations.

"Now, sort of through the past year, year and a half, that involvement has broadened to a number of providers. And that I think is very welcome as well because it gives a much wider range of voices and views in the process, really."

One VCSE organisation that provides employment support to people with SMI was positive about how the Community Mental Health Team engaged with them but recognised that the team are not always able to focus on wider support.

"Although the community mental health has been amazing in working with us, they're putting out a lot of fires at the moment and not really thinking about employment as an aspect. They're thinking, "Let's keep these people safe." Rightly so."

Moving forward, one provider told us that the Steering Group should focus on "*some input from the VCSE to talk about local priorities on the ground. And I keep banging the drum about advocacy and prevention.*"

Outcome four

Community based services experience change

Outcome Four

Within the Healthwatch Norfolk evaluation plan, outcome four was designed to investigate whether community-based services report ongoing change and improvements to joined up services and waiting times.

Some of the Year One Report recommendations for outcome four have been addressed earlier in of this report (see outcome three). Our focus is on whether VCSE organisations and other community based services report that they are seeing the impact of the transformation on the adults they support.

Our findings for Year One identified that the Community Transformation Team had not communicated their successes widely enough and we recommended that the Steering Group Update the Community Transformation Steering Group Communication and Engagement plan for 2022 – 2023. Specifically that they:

- Work in collaboration with Integrated Care Board (ICB), NSFT, partner VCSE organisations and Experts by Experience to refresh the Communication and Engagement Plan.
- Identify the Community Transformation Steering Group priorities for 2022-2023 and communicate these to adults severely affected by mental illness, their carers and frontline staff in a context that explains what the changes to services and staff personally means for them. This will help reduce any culture clashes between different mental health service providers.
- Communicate the Community Transformation Steering Group successes with wider audiences, particularly the Rehabilitation Pilot and when co-producing with external VCSE partners. This will evidence the positive impact the steering group make on community mental health provision for adults.

Progress made by the Community Transformation Team

The Community Transformation Team did not identify any specific actions in their "Healthwatch Norfolk Recommendation Implementation Plan" to address our report recommendations. However, the launch event for the Rehab Pilot is evidence of communicating success with a wider audience.

Launch Event

On Thursday 22nd 2022 September a Launch Event was held for the Rehab Pilot at The Space, Norwich, and was attended by over 110 people. The event openly invited anyone living in Norfolk to join NSFT to celebrate the launch of their new integrated, multi-agency community mental health team.

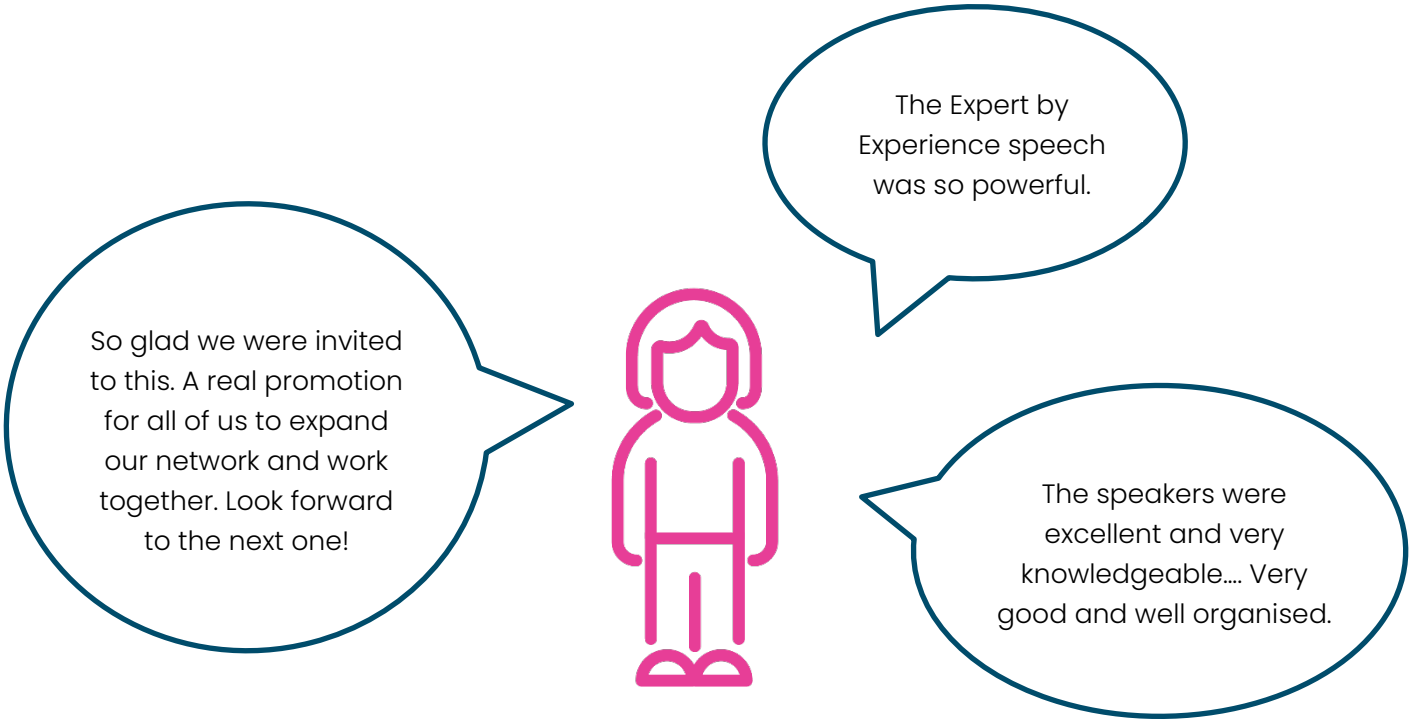
Figure 4: An Invite to the Rehab Pilot Launch Event

At the launch event 14 stalls formed a 'marketplace' of partner agencies (from various Norfolk health and social care providers, local voluntary organisations and representatives from Norfolk and Waveney ICB and NSFT) who offer invaluable rehabilitative support across Norfolk. The launch event was attended by a leading expert (a Consultant Rehabilitation Psychiatrist) and an Expert by Experience from the Reference Group who *"delivered really powerful speeches"* to the attendees about the importance of community-based rehabilitation.

The Rehab Pilot Transformation lead reported that this event was *"very well received, and we had a lot of positive feedback about the scope of the team, the setup of the team, and how people thought that we could help this group of people that really have faced so many multiple barriers".*

Another senior member of the Rehab Pilot described how they felt 'overwhelmed with the positivity in the room" at the launch event and that hearing directly from Experts by Experience made it a *"real positive event that really helped open my eyes to understand just how far-spread rehabilitation is and needs to be".*

As part of the Launch Event, feedback was obtained by the attendees. Some of the feedback received by the Launch Event organisers includes:



There was also a Press Release issued that highlighted the positive feedback from the Launch Event titled "Pioneering new Complex Psychosis Rehabilitation Team is launched". The Transformation Lead added that the Rehab Pilot team have *"been in the paper a few times (for the launch and pre-launch)"*, have a service leaflet, facilitate drop-in sessions at the REST Hub and use Twitter, *"to keep people up to date about the team"*.

Communicating Success

During the interview with the Transformation Lead, Healthwatch Norfolk asked how the Rehab Pilot team communicate and celebrate successes. The Transformation Lead acknowledged that they *"meet with our communication lead once a week and we also have internal comms who are constantly asking us for good news stories and there are definitely plans to share good stories"*.

It is also hoped that the work around the I Statements will provide "*evidential assurance to the people needing support for their mental health that services are meeting their needs as described by them. Periodical review of I Statements and self-assessment across the system will address any developing needs"*. However, how this will be communicated to adults severely affected by mental illness and their carers is not clear.

What Key Stakeholders Told Us

Healthwatch Norfolk conducted interviews with relevant local VCSE providers and staff from Norfolk County Council, including housing and employment support services. These interviews questioned the respondent's views about the impact of changes by the Transformation work to community-based services. The questions focussed on improvements to joined up working and waiting times and whether adults severely affected by mental illness feel in control of their care.

Ongoing Change

At the beginning of each interview, each provider was asked whether they have seen ongoing change to community mental services since the transformation began. One provider explained that system pressures has meant *"it's difficult from our workload to actually identify whether there has been any change due to any of this work."* A second organisation representative said that they have not witnessed any noticeable changes.

> "I don't think it has…I don't think anything in particular has improved or developed, certainly not from what I'm seeing. We're still seeing an incredible shortage of mental health services for the people that we support in both directorates."

A third provider explained that they have seen *"great improvements"* to services that are still being navigated and worked upon. A fourth VCSE organisation reported that the Steering Group should be recognised for the good work taking place, but that services have been waiting *"about 12 years for this change to happen."*

> "It's really important to recognise that although there is clearly some good work happening and some great intent and some good changes that are happening… is that I can hear people talking about that… the next day I can go and sit in a space with people with a diagnosis of severe complex mental illness and hear them saying that they are having a really poor quality of care, that they aren't being listened to, that they don't know how to access services."

Joined up services

Healthwatch Norfolk asked the community service providers whether they have seen improvements or changes to the standard of community mental health services. One voluntary sector organisation reflected that they believe the 'intent' to improve mental health services is in place and that it needs to be *a "cultural change within statutory services"* to see any effective change. This organisation felt that there is *"innovation"* present within the transformation process with

"amazing, fresh ideas" which can *"really make a difference to people,"* but had concerns that this could be a short-term solution.

"New ideas are great, but that is like a plaster over a great big gaping wound if you are not going to change the culture within an organisation that really genuinely needs to change."

A second organisation posited that to improve joined up working within community mental health, the Steering Group *"need to include the VCSE more in those leadership type roles and those discussions more than they do at the moment because even though they talk about supply collaboratives and partnership work and everything, it's very much predetermined.* This organisation believes the process is at times too prescriptive and that a VCSE workstream within the Transformation should be run by a VCSE providers because it *"would really wipe the floor, I think, with a statutory service. I think they'd be shocked at how fast things can be put into place."*

A third VCSE organisation commented that they have not seen changes or improvements to joined up working. *"I don't see that. No, I've not seen that. I think we're still really struggling with kind of accessing services and the flow of communication*." This organisation hasn't seen any improvement around discharge and the "*safe planning*" to implement this and that "*remains a real concern*" for them. They did add a caveat to this by saying that they are "*super aware that it's staff and resource issues*" that can affect changes and improvements to mental health services.

A fourth service provider recognised that they work with *"people who are marginalised with multiple complex needs"* and that these areas have been *"a poor focus for us as a system in the past."* They commented that they "*value*" Norfolk and Waveney ICB's commitment to concentrating on marginalised communities by bringing in a focus on *"housing, and bringing in partners who are going to be helpful in taking those agendas forward to create more housing access and specialists in supported living"* into Transformation plans. This representative felt that it was important that the Steering Group were also focussing on people with dual diagnosis and complex needs, not just within the Rehab pilot, but as one of the four main priorities going forward for the next year of the Transformation.

"It feels like, as a system, we've neglected people with dual diagnosis and complex needs probably too much over the last 10 years. COVID didn't help, but it feels kind of really important that we're going to focus on them."

The fourth organisation also praised the development of the clinical team within the Transformation for people with a serious mental illness. They spoke positively about the Steering Group incorporating *"a very holistic model including welfare rights advice and housing sort of in that team".* A fifth organisation described how involving people with lived experience within the transformation work is *"really effective".* They explained that their involvement of Experts by Experience has broadened to several providers, *which "gives a much wider range of voices and views in the process,"* enabling gaps in joined up working and service provision to be explored and identified within the workstreams.

One of the biggest successes reported by the VSCE representatives was the formation the multidisciplinary, multi-agency Rehab team, "*I think it was a bit of a slow start, but I think now everybody's in place and working together and feedback is really positive."*

All the VCSE partners agreed that providing a collaborative, joined up approach to providing rehabilitative services for people with complex psychosis is vital.

"If you don't work together, then you're working against each other. And it's not fair on them (adults severely affected by mental illness) because if they're with us because they've got enduring mental health problems, then they need the consistency of a combined approach… it's really important to have a combined approach".

VCSE sector involvement within the Rehab Pilot is a crucial part of the model. VCSE organisations provide opportunities for members of the public to engage with their community, help shape and design services and enable the voices of users, patients and carers to be heard. Multidisciplinary working and strong organisational partnerships formed within the Pilot were credited by VCSE partners as preserving their unique nature and role within the community.

"I think the way that the rehab team has been structured, that's been a real benefit … we've not lost our key values, which is what really we should be bringing to that team, is a different perspective. So keeping that kind of value base because ultimately, we can connect easier sometimes with the service users that are disengaged from services and stuff and be that pathway into engagement."

> "As an outside organisation, I couldn't be more positive about the pilot and about the support that people using the pilot are getting. I think, other than minor teething problems as the group sets up, I can already see that the service that's being provided to the people that are under the rehab team is so much better than the service they were getting from the community mental health teams, particularly because we've got people that can be quite sort of paranoid and distrusting of services. And in the community mental health team, it's quite likely that someone would be turning up to give them their depot medication every two weeks, and it would be a completely different person every time."

Healthwatch Norfolk spoke to one of the Social Workers involved in the Rehab Pilot and asked what they thought about so many agencies being involved.

> "The multi-agency arrangements are brilliant. I think the fact that we've got CGL working there where many of our social users have drug and alcohol issues in conjunction with serious mental illness. Many of them have issues around aspects of housing or benefits. We've obviously got the law advisor there, so I think that works really well. So, I think that multi-agency working is quite unusual for Norfolk. We don't really have many other teams working like that. That's kind of a stand-out example."

One VCSE representative spoke about the good communication that exists between all the teams involved in the Rehab pilot and *"regular steering group meetings"* that keep the whole team updated. One VCSE representative spoke about other projects their organisation has been involved with as being "*quite insular and closed off from everybody"* but explained that it "*is not the case with this [the Rehab Pilot team] … I've got no qualms at all about the communication. It's refreshing".* Each VCSE organisation described the communication between partners as being consistent, regular and informative, which can only be of benefit to those who are being supported.

"We all communicate with every member of the team every day. We all know what each other's doing. We have a meeting every morning that we're all involved with to discuss that."

Training organisations together can help to improve joined up working. Specialist NSFT training made available to staff was another strength reported by VCSE sector representatives involved with the Rehab pilot: *"we have access to NSFT*

training… so we've all done quite a comprehensive psychosis and bipolar training as part of the team."

Waiting times

Healthwatch Norfolk approached each of the voluntary and third sector providers to ask whether they have seen any improvements in service waiting times. Two organisations responded "*no*" straight away, with one organisation commenting *"not for us… We are still literally beating our head against the wall trying to get support services for the people who use our services."* A third organisation reported that they believe waiting times have reduced on a *"low level*" where *"soft skills*" are involved, including access to support from Mental Health Practitioners and Enhanced Recovery Workers, but noted that waiting times for Talking Therapies have increased. A fourth organisation reported that they think waiting times have reduced but that they are unaware of exact current waiting times but added that *"Community Mental Health Team need more to be able to make a difference."*

Feeling in control

Part of the Healthwatch Norfolk evaluation explored whether VCSE sector organisation believe that adults with a serious mental illness are involved in their treatment and care. One organisation explained that they believe a person's involvement can be compromised when they are sent out of area for treatment, "*because they're out [of area], it's out of mind, out of sight. They highlighted that this still happens "a lot*".

A second charity representative replied that it depends whether they can get mental health treatment and care in the first instance. *"A lot of the time, the answer is no. What we tend to find is that people get ping-ponged from one end of the spectrum to the other."* They explained that their organisation has a designated professional who can help *"people to engage, not just in their mental health provision, but in physical care as well".* They continued to explain that people experiencing poor mental health, particularly those with a dual diagnosis or severe mental illness may be experiencing paranoia. This can make it even more difficult to engage them in their own treatment and care, but that people should always be "*supported to engage as far as they're able."*

Support for Carers

Healthwatch Norfolk asked the VCSE partners about the support given to carers and loved ones of people being supported by the Rehab Pilot. One VCSE representative explained that there is a designated Occupational Therapist within the team to lead on carer support. There has been a lot of support from the Carers Lead at NSFT who "*plays*

a role within supporting carers sort of outside of our team and within NSFT". Another VCSE representative explained that there is a system being developed within the Rehab Pilot so that *"each relative would be designated another person within the team, outside of the original care coordinator for the family member".*

The Rehab Pilot team have recently received having training regarding informed consent. This training was to clarify *"what we may have originally thought of as consent, what can be shared, what can't be shared, and how we can interpret that to sort of try and support the family members"* to try and keep carers and loved ones as informed and involved as legally possible. All VCSE representatives agreed that this was a key focus for the team and something that everyone should be aware of.

"When there is a phone call [from a carer], we all sort of go out of our way to try and support as much as we can. Even if we don't have consent, we understand what things we can do, and whether we can listen, even if we can't share."

One VCSE representative admitted that *"there's a lot that we could do more"* in terms of how VCSE organisations can help with supporting carers of adults severely affected by mental illness to achieve this, one VCSE representative suggesting bringing in more carer Expert by Experience representation into the community mental health transformation.

"I think it's important to have a cross-section of different carers [as Experts by Experience] because it could be a brother, it could be a friend.... I think you could fall into the trap of only having one perspective on what it is to be a carer."

Challenges

The focus of the interviews moved on to looking at challenges faced by creating the multidisciplinary team. There were initial challenges that could be expected when joining multiple health and social care providers from different sectors. This became evident during the hiring of team members for the Rehab Pilot when the recruitment processes are different between VCSE and Public sector organisations.

"When you amalgamate the two sectors in any sort of initiative, there's very different practices in the way we do things. Within the third sector system, we're not bound by lots of bureaucracy and red tape. We're able to respond pretty quickly and we can adjust and change and adapt patterns, without having to go through a whole sort of series of governance" ... Our recruitment processes are fast. Our HR departments are responsive. We can recruit pretty quickly. We've got the people. They're here. They're

ready to go. And the challenge will often be NSFT, and their systems take quite a long time, so you may find that you're having to be quite patient in order for them to catch up a little bit. And that's not the fault of an individual. That is just a symptom of the system".

When Healthwatch Norfolk spoke to one of the Social Workers involved in the Rehab Pilot, they re-iterated that there has been a bit of a delay with recruitment, especially after one of the dedicated Social Workers left.

"One of the social workers is now leaving, and I think we are experiencing more issues with recruiting this time round. So that is going to be potentially a bit of an issue... getting qualified staff."

Another challenge facing the formation of a multiagency team is ensuring that each organisation and its staff have access to a person's the health and social care records. Each partnership organisation uses a different IT system to record and access client information, which can make it difficult or even impossible for other organisational staff members to access, slowing down the support process.

"I think one thing that is taking a while is for all of us to have access to the NSFT IT system, which is Lorenzo. ... The process has been so slow that I'm still waiting for the other staff members to have access to the same system... I think that is something that's been a bit tricky. I think social services, again, have opted not to access that system. So again, that can make things a little bit difficult. It's a little bit disjointed. There's still a little bit of, if you wanted to find out something, you then need to rely on that agency to look on their systems for you".

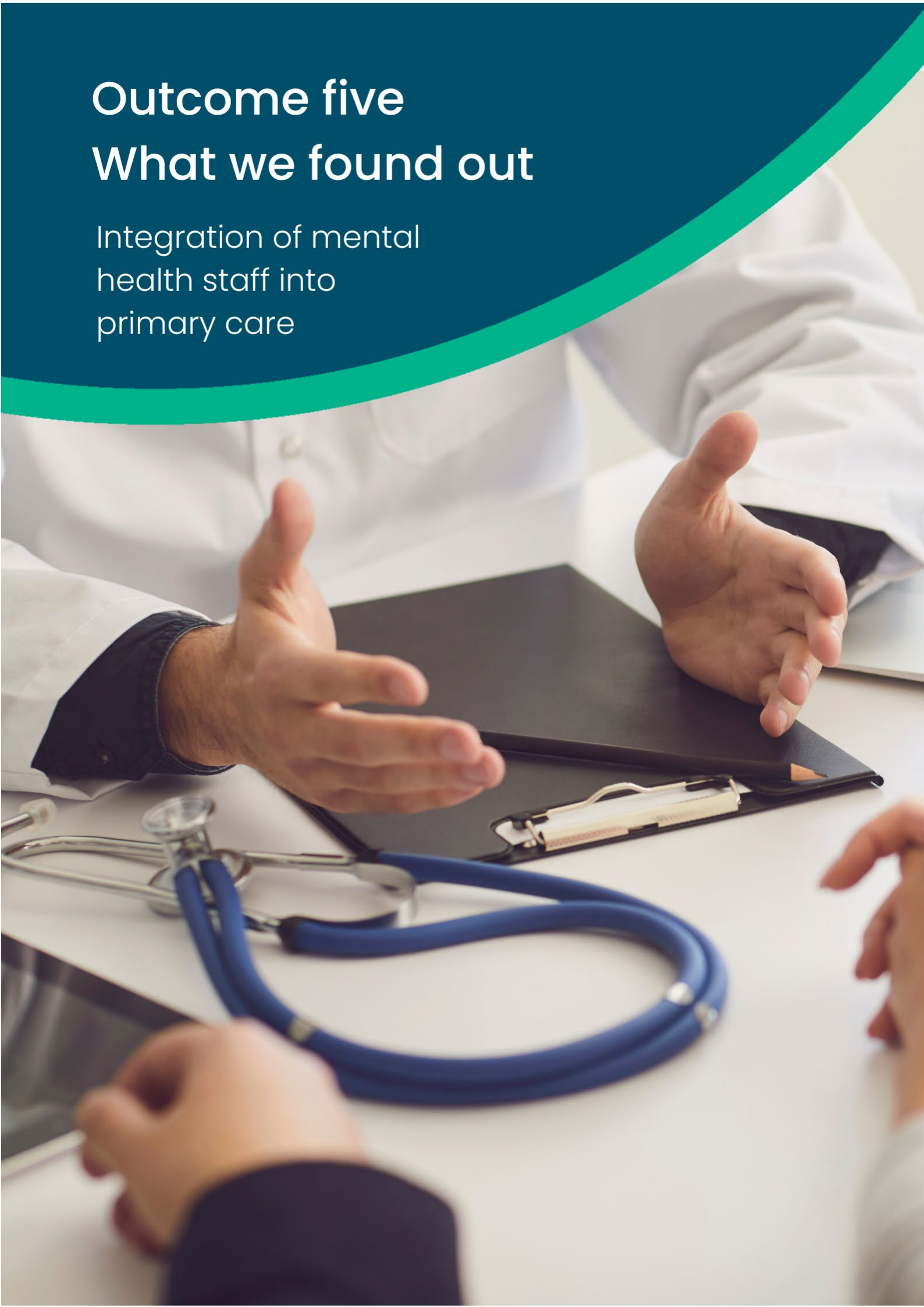
One VCSE organisation reported that there had been initial delays in issuing contracts and payments meant that they were unable to start providing services for people being supported by the Rehab Pilot.

"I think from VCSE perspective, contracts issues have been the most challenging hurdles for us. So, my contracts team is only contacting them because we still haven't received any payment, even though we've got staff in place."

We asked the VCSE partners what they thought the priorities should be, moving forward with the Rehab Pilot. They replied with two main focuses, including forging stronger relationships with NSFT and for the Rehab model *"to be expanded across the county".*

Outcome five
What we found out

Integration of mental health staff into primary care



Outcome Five

This outcome is focused on whether mental health workforces report improvements in community-based services for adults severely affected by mental illness. Healthwatch Norfolk were particularly interested in the integration of new mental health staff roles into primary care settings.

Our recommendation for outcome five in in our first report was support the development and integration of the new roles into the wider system and ensure the most effective use of existing and new staff to best meet the needs of adults severely affected by mental illness. Specifically:

- Provide clear, concise role descriptions, responsibilities and treatment criteria for the new mental health staff roles (for example: Mental Health Practitioners and Recovery Workers) for the public and front-line staff within the blended workforces. Consider creating videos of a 'day in the life' of the new roles to help understanding and for recruitment.
- Communicate changes to job roles and employing organisations in a timely way, ensuring that applicants are properly informed of any changes. Ensure the most effective use of existing and new staff to best meet the needs of adults severely affected by mental illness.
- Support the development and integration of the new roles into the wider system.
- Ensure that the transformation plans include the opportunity to review how existing staff are utilised so that adults severely affected by mental illness get the best possible support.

Progress made by the Community Transformation Steering Group

Following our report recommendations, the Community Transformation Steering Group devised a “Healthwatch Norfolk Recommendation Implementation Plan” to ensure that the recommendations were acted upon.

The actions they identified were:

- A soft launch of the Mental Health Integrated Community Interface (MHICI) to test the model.
- Develop a plan to address the psychological 'missing middle'.

- Develop a streaming process for Mental Health Primary Care Network (PCN) roles (to ensure people are receiving the right support from the right practitioner).

The Healthwatch Norfolk Recommendation Implementation Plan" stated that for year two of the Transformation, the new mental health roles should be integrated further into the wider primary care system. This would involve the Steering Group working on their communication of the pathways into these new roles (particularly in primary care) and developing a multi-disciplinary, "Mental Health Integrated Community Interface" (MHICI) to bridge the gap between primary and secondary care.

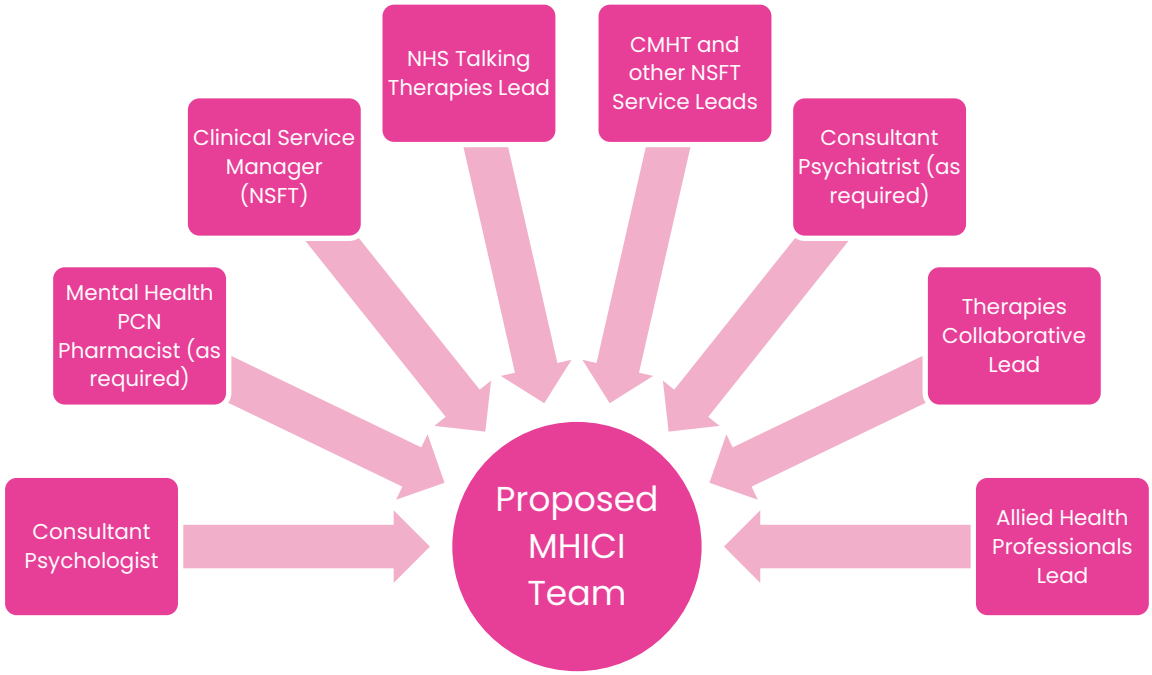


Figure 5: The Proposed MHICI Team

The Mental Health Integrated Community Interface (MHICI) is a locality-based team for people that have complex needs (for example: for people with post-traumatic stress disorder or a brain injury) who cannot be neatly placed within primary or secondary care. The MHICI team will *"put a plan in place"* for treatment to ensure their needs are met via a collaborative therapy approach. It is still unclear where this team will *"physically sit"* and whether is separate to or a function of community mental health services. There will be various entry points to the MHICI team, including through primary care, the Wellbeing service, the Integrated Front Door and via the youth services for people aged 18 and over.

"It's a virtual collaboration. So they'd be commissioned as a whole, and they would be able to say that they are a member of the collaborative, and that would enable the MHICI to refer into them."

The plan also stated that patients should have access to mental health support within primary care with reduced waiting times, an assurance that people will be seen by the most appropriate clinician the first time and access to wider ranges of support.

Recruiting, Developing and Integrating a Skilled Workforce

For year two of this Evaluation, the first part of this outcome explored whether the Community Transformation Steering Group had recruited, developed and integrated a skilled workforce into primary care networks.

Primary Care Networks have access to special funding through the Additional Roles Reimbursement Scheme (ARRS) which has been created to help fund new roles. Through this scheme, GP surgeries can claim reimbursement for the salaries of additional staff to create a multidisciplinary team within their practice. These new staff roles would have been selected to specifically meet the needs of the population within the local primary care network. The types of roles the ARRS funding can be used for to recruit Mental Health Practitioners include:

- Assistant Practitioners (band 4)
- Mental Health Social Workers (band 5)
- Mental Health Occupational Therapists (band 5-7)
- Qualified Clinical Associate Psychologists (band 6)
- Mental Health Nurses (band 6-7)
- Psychological Therapists (band 7-8a)
- Advanced (Mental Health) Nurse Practitioners (band 8a)

Challenges

According to the Transformation Lead, there have been several barriers to implementing the new mental health roles into primary care. These barriers include the physical difficulties experienced by Mental Health Practitioners that are based at more than one surgery, who are "stretched across a number of surgeries," and spending time travelling around their designated Primary Care Network, which is "wasting time sometimes on travel when they could be seeing patients". There have also been reports of "confusion around allocation of appointments" whereby primary care staff may allocate "inappropriate" patients to Mental Health Practitioners.

"They're using [mental health] nurses to sort of do first contact meetings with patients when they could be carrying out some higher level intervention work and really properly proactively supporting patients. But we can see why that's happened is because we

haven't been able to recruit all of the posts in one go. We were asked by the NHS to spread it out over three years."

Recruitment and retention issues are another challenge facing the integration of these new roles, but this is a system wide problem. The Transformation Lead speculated that these challenges are due to geographical restraints and remote working locations, "t*he more west of Norfolk we get, the harder it is to recruit to those roles,"* new mental health staff thinking *"the job was not what they thought it would be"* and cultural differences between primary and secondary healthcare.

The Transformation Lead explained that the expectation of how these new mental health roles would integrate differed for primary and mental healthcare professionals. This has highlighted a cultural difference in working patterns and style. As this integration is relatively new, it's not surprising that confusion will exist about how the new mental health roles will integrate, develop and adapt within primary care.

"I think there's also some challenges with a mix of culture. So bringing a mental health resource into primary care. The culture's a different, they spend longer with patients, you know, they have longer, time allocated. Whereas for physical health it's sort of 10 minutes appointment one."

Future plans and priorities

The Transformation Lead and steering group responsible for implementing these new roles have been proactive in their approach to trying to resolve the recruitment and retention problems, "*we are looking at ways to try and make some of the roles seem more attractive."* During phase three of this project, the steering group have been meeting with either Primary Care Networks or locality teams to discuss their region's specific mental health needs. This includes discussions about what roles are available under the ARRS funding and asking if "they want to do something different" regarding the integration of these roles to "help reduce the destabilisation".

The Transformation Lead declared that Primary Care Staff and Practice Managers are requesting access to more Mental Health Practitioners, which *"goes to show that they see the value in the roles. I believe they are seeing some impact of having the mental health practitioners in their GP practices, both with their time and appointments."* The Transformation Lead has received positive feedback from GPs and patients to say that they've made a positive difference. There are also plans from the Steering Group to secure funding from Norfolk and Waveney ICB to create videos that clarify what each of the mental health roles is and their remit for patients, GP managers and primary care staff.

The full cohort of 25 Clinical Associate Psychologists recruited 18 months ago completed their training in June 2023 and will be due to start their new locality based roles as Band 6 professionals. These roles are new to community mental health services and each candidate was required to have a psychology degree which prepared them for the 18-month master's level apprenticeship.

Healthwatch Norfolk asked the Transformation Lead to discuss the priorities for this workstream over the next 12 months.

"Our immediate priority is to map the resources that each Primary Care Network has access to in the mental health space, so we [the Steering Group] can work with them and mix their skills to meet their patients' needs and so we can work with them on developing the skills of their current staff."

The Lead informed us that the first priority is completing the recruitment of primary care based staff, including Enhanced Recovery Workers. The second priority is to integrate these mental health roles into "a cohesive team and not in silo… as a team on a neighbourhood level, PCN level." The Transformation Lead described a "streaming model" which they are piloting which allows patients to be added to a task list on the GP surgery's clinical system each morning to enable them to be allocated to the correct mental health professional. This would involve a Mental Health Practitioner setting aside some time in the morning to review each potential patient with an Enhanced Recovery Worker, Peer Support Worker or a Social Prescriber to "decide where this patient would be best to sit."

What Key Stakeholders Told Us

Healthwatch Norfolk interviewed a selection of Mental Health Practitioners, Enhanced Recovery Workers and Social Prescribers to get feedback on their roles, how they feel they are contributing to transformation of community-based services and how integrated they feel with the wider workforce.

Mental Health Practitioners

At the time of writing this report, 44 of 46 of the Mental Health Practitioner posts have been recruited. Healthwatch Norfolk interviewed five Mental Health Practitioners (including Mental Health and Wellbeing Coaches) from across the county to find out about their experiences of being based within primary care. Mental health practitioners support adults whose needs cannot be met by talking therapies provided by the Wellbeing service, but who may not meet the criteria for receiving ongoing care from

secondary mental health services. *"I work with people generally with mild to moderate anxiety and depression."*

Mental Health Practitioners can be employed from a wide range of clinical and non-clinical roles with mental health expertise (ranging from Band 4-8a). These roles include qualified mental health nurses, occupational therapists, health and wellbeing coaches or social workers. *"Some mental health practitioners come from mental health nursing, whereas the coaches, we all seem to come from a counselling background."* Patients can be referred to Mental Health Practitioners through various routes within and externally to their GP practice.

> "The practices refer to me directly as I'm part of the team in the practice and the referrals can come from reception. They can also come from GPs, nurses, medical students. Just basically anyone who works in the surgery can refer to me. I also get referred to by my social prescriber as well from time to time."

A recent introduction to the Mental Health Practitioner role is their ability to refer patients to the Wellbeing Service and one Practitioner remarked that "*it's really helpful that the wellbeing service recently has created something on the GP system… we can just create a task then they can take a referral from us."*

Mental Health Practitioners are allotted approximately 40 minutes with each patient to *"assess them and signpost them to the organisations that can give them the help that they need"* and some can offer interventions like stabilisation work by using a Dialectical Behaviour Therapy (DBT) skills handbook.

Healthwatch Norfolk asked each of the Mental Health Practitioners what they thought the benefits are to having their role brought into primary care. These included shorter waiting times for patients to be seen with mental health related issues, *"we can see them a little bit quicker than some of the other services"*, providing flexible, person-centred support, *"I normally do six sessions… but I have got a little bit of flexibility within that so if we're working with someone and they do need more than the six, I can kind of extend that out"* and helping GPs by lowering their caseload, *"we get to see a wide variety of people presenting issues and problems… I think it helps with the GPs as well, because obviously it cuts down all the time that they might have to spend supporting someone with mental health problems, because they can come and see us".*

Recruiting Skilled Workers

Healthwatch Norfolk were interested to learn whether Mental Health Practitioners were being offered adequate training and development opportunities to be able to thrive in their new roles. All the Practitioners that we spoke to mentioned that most of the training they receive comes from NSFT with a mandatory training programme including *"Child Protection and Mental Health Act training… the things you need to keep up to date with".* There are extra courses that Mental Health Practitioners can undertake including "Mentalizing Skills and the KUF [Knowledge and Understanding Framework] training." One Practitioner praised the KUF training and described it as *"really good…really well put together"* and remarked that even after working in mental health with people presenting with *"quite severe big personality issues in secondary care"* that there was *"still a lot of stuff I could get out of the training".*

All the Practitioners mentioned that they cover multiple GP surgeries within their role during the week. One Practitioner explained how they shadowed another Mental Health Practitioner for two weeks and learned a lot about the GP practice during this time, including how to use SystmOne as part of an informal induction process.

> "My patch is one of six… so my training, if you like, was two weeks shadowing her for everything, and that was it. And I mean, it was great. We saw lots of patients together. She showed me how to look at my appointments, my ledgers on SystmOne, how to call people, and how to document on SystmOne, which was brilliant because it's the most important thing, and be able to obviously look at their notes and medication and things and task a doctor, which was brilliant. But that was kind of it. But that's all she could do in a couple of weeks."

Another Mental Health Practitioner reported that they are unaware what other GP surgeries do to induct and train new Practitioners and that a more formalised and varied induction would have been useful. *"There's perhaps no consistency [in the training] because I guess it would have been great to have a week with not a practice manager as such but somebody who knows the ins and outs of SystmOne, recording, just who the doctors are even… I think it needs a proper induction because I guess mine was an NSFT induction with NSFT. It needs to be done as a whole really. The surgeries need to be much more involved in welcoming people".* The same Practitioner expressed concern that they *"don't think half of them [primary care staff] know who I am if they passed me in a corridor."* This type of situation has the potential to leave Mental Health Practitioners feeling cut off and lonely within their workplace.

> "It's quite an isolative role, really. Like I say, you get there, and it's sort of back-to-back appointments. But when I do need to communicate with others, it's always been quite positive and quite productive. But yeah, unfortunately, because the nature of it, you don't really get to see that many people that often."

Another Practitioner explained that because it's *"quite a unique and new role … at times, it can feel isolating."* This can be due to the Practitioners being spread over the county and covering multiple GP practices during their working week. This Practitioner did emphasise that they have *"good contact"* with other Mental Health Practitioners around them *"to kind of keep that support for each other going as well because we're just kind of finding our feet at the moment".*

One Practitioner described how they actively book out time with a doctor or other primary health care worker if they need to ask a question or talk about something otherwise they *"don't get that opportunity and neither do the GPs because when you look at their appointments, they are booked all day as well… so it's not quite the multidisciplinary team I thought it might be."* Another Mental Health Practitioner explained that they turn up to their role in the morning, find their allocated room but feel like *"a bit of a travelling salesman because you have to bring everything with you"* and how it's difficult to connect with fellow Practitioners because *"we're never in one place at the same time."*

Staff Integration and Understanding of Role

Healthwatch Norfolk aimed to gauge how integrated and settled Mental Health Practitioners feel within their GP practices, especially as these roles are still a relatively new introduction into primary care. All the Practitioners reported that their respective GP surgeries had been welcoming, approachable and included them within the team.

> "I'm included sort of in practice that I've been established in for over a year. I'm included in their regular daily coffee breaks and meets and things like that. I feel very much part of it because I'm able to go and talk to sort of any of the colleagues there about anything really that is impacting on the role… Quarterly we all meet as a mental health team as well to talk about sort of anything that's challenging, but also the successes in the team."

One Practitioner commented that even if their primary care colleagues are busy, they can set up a task through the SystmOne computer system *"so if you need help, they are there".* Another Mental Health Practitioner reported that they feel that *"the GPs in the surgery are really supportive"* of their role and they believe the integration of these mental health roles within primary care allows them to *"work quite well as a team."*

In year one of the Community Transformation Steering Group Evaluation, there was confusion regarding what a Mental Health Practitioner role involves, how they work and what they can bring to primary care. To follow up this original finding, Healthwatch Norfolk asked each Mental Health Practitioner whether they believed doctors and other primary care colleagues were any clearer about their roles.

From the feedback given from all five of the Mental Health Practitioners reported improvements in primary care colleague's understanding of their role. One Practitioner explained how their team are *"always asking questions if they're not sure"* about something related to their job. They added how they are working to *"refine [their remit] with them by saying that this is what I can and can't do"* to aid a colleague's understanding. Another Mental Health Practitioner described how the clarity around their role was mixed within their primary care team.

> "For some is the answer is yes and for other GP surgeries, the answer is probably no. What we're not is counsellors/therapists… Some of the GP surgeries do refer [patients] to us for counselling and so it's explaining straight away that, no, we're not counsellors or therapists. We use therapeutic skills. Of course, we do. But we're not therapists, per se. "

A second Practitioner explained that a lot of their initial referrals have been for bereavement counselling and "a mental health nurse isn't a counsellor. They're not psychologically trained… they're not counselling trained." This Practitioner was concerned about the initial misunderstanding of their role and how it has become a bit of a *"jumble".*

> "There's a big gap in the knowledge of who provides and can do what really in terms of the other people such as the Mind Enhanced Recovery Support Workers, myself, the qualified counsellor that we do have here, and the social prescribers."

A third Mental Health Practitioner detailed how their doctors' surgery are keen to ensure that the appointments they are referring over to the Practitioner are *"appropriate"* but that there have been *"a couple of instances where things haven't really been appropriate."* The Practitioner explained that they were able to sort out these situations "quite well" and that they had not experienced a repeat of being assigned a patient they cannot treat. They also told us that one of their neighbouring GP practices have requested a presentation outlining the new mental health roles and how they work within primary care. An initiative that the Practitioner predicted *"might become the norm within other practices as well."*

A fourth Practitioner explained that they proactively spent the past year *"establishing the role and establishing what I can do and kind of getting to know the surgeries"* to ensure they integrated successfully into their new primary care based workplace. This Practitioner highlighted that they are proactive within their role to ensure that patients *"are directed to the right person first time, rather than having to keep on re-explaining their story to lots of different individuals".* Another Practitioner detailed how coming into this new role based in primary care was *"quite different to what I'd been used to."* It took time to get *"used to the expectations and what to provide and being more of a signpost in role"* compared to their previous roles based in the community mental health and mental health facilities.

Public Awareness

Healthwatch Norfolk asked each of the Mental Health Practitioners if they thought the public were aware of their role and how to access support. One Practitioner disclosed that they believe these new roles are clearer for *"people who have already had input from mental health services"*. This Practitioner also believes that a lot of patients are grateful that "*there is somebody now in the primary care in their own GP surgery where they can come, rather than have to go through the CMHT team"* once they learn about the new role.

A second Practitioner replied that they don't think the public know as much as they could about their role and that they are *"really trying to work on that… getting some information the surgeries to promote the roles that we have"*. The Practitioner reported that they thought there are "*a couple of projects kind of going on at the moment*

[within the Steering Group] with producing more documents, like leaflets and things for the TV screens in the surgeries and that sort of thing with more about our roles and what we do". Another Mental Health Practitioner declared that their doctors' surgery was working on clarifying the types of roles available to patients within primary care by creating a poster to display.

> "We are working on a poster to talk about what the primary network is and who's in the primary network, what we do, that you can self-refer, and you do not need to see a GP to go to Wellbeing or access psychological therapy and hopefully have it in our patch of six so it's all the same, so there's some consistency."

The poster will describe what each of the mental health professionals based in primary care can do because *"people don't necessarily understand what a mental health nurse is and why is that different to a mental health and well-being coach."* Another Mental Health Practitioner expressed concerns that they don't think people are fully informed about their role and *providing "solution-focused treatment with people and problem-solving".* They were concerned that *"sometimes people can be quite disappointed, perhaps, if they feel they're coming for counselling",* which is not within a Practitioner's remit.

Patient Feedback and Waiting Times

Overall, all the Practitioners reported that the response to them coming into post has been *"really, really positive"* and that both staff and patients have *been "really welcoming and about the role and the change to things."* One Mental Health Practitioner recounted how they perceive patients being "*grateful"* of their support. They remembered how one patient told them *"you made me laugh. I feel just better having seen you".* Another Practitioner mentioned the feedback forms that their surgery hands out to patients and this feedback has also been mostly positive.

> "A lot of [the feedback forms] are compliments …. "We should have sought help around these ages ago" or "it's been really helpful." I'll get some people come in that are absolutely fuming because they had requested a GP appointment. However, by the end of the appointment, they actually felt quite a lot better about the appointment and sort of happy to see me again if that's the case."

Healthwatch Norfolk asked each of the Mental Health Practitioners about their caseload and waiting time for their appointments. Their waiting lists varied from two weeks to six weeks for an appointment. One Practitioner described how busy they are over the course of a week due to covering different doctors' surgeries in their patch.

> "I'm finding that I am busy a lot of the time. In one surgery, I'm in three days a week, and I'm working about two weeks in front, continually. And the other one I'm working sort of five or six weeks in front. I'm only there for one day a week, and I share that practice with another coach as well."

A second Practitioner explained that after an initial appointment, if they need to book a follow up appointment, their wait is around four weeks *"because that's how full my diary is"* but it also enables them to form *"a relationship and trust over time" with* their patient. A third Practitioner told us *that "very rarely do I have an empty appointment slot", so patients are being booked in for their support.*

A fourth Practitioner spoke about their colleagues who are *"booked up weeks in advance"* creating longer appointment waiting times but that *it's "it's working for me quite well at the moment to be able to offer those brief intervention sessions."* They described how their workdays can be *"quite full on"* and then they usually have *"almost back-to-back appointments with a short lunch break."* Another Practitioner noticed an immediate cultural difference between working within primary and secondary care and they are *"very aware that my appointment times are longer than theirs [other primary care roles"*. This Practitioner explained that these longer appointments are necessary because patients "need that space to feel confident and comfortable before they open up". If they were booked in with a doctor to talk about their mental health, they may feel *"rushed"* in the ten-minute time slot they are given.

Several of the Mental Health Practitioners mentioned the interoperability of systems that store patient records and the difference between primary and secondary care. Within primary care settings, healthcare staff have access to SystmOne or EMIS to record patient information and mental health services use a system called Lorenzo.

> "I've got access to SystmOne. And that's the system that we use within the primary care. So that's great. But yeah, I can't be on SystmOne and Lorenzo at the same time. So that can get a bit tricky if there's patients that are on both systems. Sometimes there's information on one that's not on the other, which would be quite handy, but also getting a bit of history about their mental health as well."

This can cause confusion for the Practitioners who might start offering treatment or interventions that a patient has already received. One Practitioner thought that it would be *"easier if you could access either the same information on both systems and just [have it] on one system."* The Practitioner did talk about GP connect being present in their surgery that enables allows clinical staff to share and view patient records between different IT systems, but that they still felt *"a bit lost"* with learning *"all the lovely tricks and how to send letters and onward referrals."*

Healthwatch Norfolk asked each Mental Health Practitioner how their role could be improved over time. One Practitioner reported that they believe longer appointments would help them within their role.

> "I would prefer slightly longer appointments. When I was doing assessments in secondary care, you'd usually need a good two hours to sort of see the person going through everything and then paperwork and any referrals or ongoing measures from there. And that's almost a minimum amount of time."

The Practitioner acknowledged that there is more pressure within primary care to provide *"shorter appointments"* but felt that it can be difficult *to "get a bit of a feel for the person"* in a 10-minute appointment. Another Practitioner recommended that people's understanding *of their "appointments, the role, and what they can benefit from it can definitely be improved."* The last recommendation involved longer training sessions on SystmOne as they are *"still not as confident with it as what"* they would like to be.

Enhanced Recovery Worker

Enhanced Recovery Workers (ERWs) are part of the new initiative brought in by the Community Transformation to diversify the type of mental health support available to patients within primary care. They are recruited and managed by Norfolk and Waveney

Mind. There are currently 24 out of 25 Enhanced Recovery Workers employed throughout the 17Primary Care Networks located in Norfolk which the Transformation Lead described as *"a real success story over the last few months,"* despite some initial recruitment and communication challenges.

"There've been some challenges around communication with primary care about the roles and some initial confusion as to what they do, when are they coming on board and challenges around access to clinical systems. So we have, taken a lot of learning from the mobilisation of phase one to apply to phase two."

There are plans to recruit another 15 Enhanced Recovery Workers and discussions are under way about where to place them: either by an Expression of Interest from PCNs or via a *"blanket approach"*. These discussions will include Experts by Experience and primary care representatives and will also examine the delivery model in closer detail.

Healthwatch Norfolk interviewed an Enhanced Recovery Worker and Mind representative to find out more about the role and how they are being embedded into primary care across Norfolk.

ERWs can support *"patients presenting with a low complexity mental health condition for the first time… to provide non-urgent mental health support by working with patients to identify their support needs and plan their mental health recovery."* (Mind Leaflet, 2023). An ERW can see six patients a day and are *"people that the surgery, mental health nurses or GPs themselves can book in."* Each patient can receive up to six sessions but can decide to stop after a few sessions if they no longer feel the need for support. An Enhanced Recovery Worker will conduct a first contact assessment, undertake personal goal setting with a patient and use a psychologically informed environment (PIE) approach to provide practical support to help *"prevent and reduce the number of patients falling through the "gap" due to the complexities of their need"*. An ERW will also *"do an initial DIALOG+ assessment"* with each patient and at the point of discharge *"to see if there's been improvements."* The Recovery Support Worker described how they can support patients within their GP surgery.

"I deal with the mild end of mental health issues, so your low mood, your anxiety… we can discuss grounding techniques and such. And we have a lot of signposting. We signpost a lot of people to either Mind services or other local services that we're aware of."

Each Enhanced Recovery Worker attends an extensive list of core training courses including Safeguarding Adults and Young People, Equality and Unconscious Bias, Professional Boundaries, Suicide Awareness, Recording and Reporting, Basic Recovery Workers Training, Mental Health First Aid and Knowledge and Understanding Framework training.

During the first stage of recruitment, Mind recruited five Team Leaders to cover the whole of Norfolk and five Enhanced Recovery Workers (ERWs) in each Primary Care Network area (North, East, South, West and Central Norfolk). Healthwatch Norfolk spoke to a Mind representative who explained that they are "*still filling a few places, but most of the areas are full now for recruitment.*" Recruiting an ERW into each Primary Care Network was a *"priority"* to ensure that they can tailor the services and support given by an ERW to the patient need in that area.

The second stage of recruiting ERWs will involve Mind evaluating *and "looking at actually where are these extra people needed? Where's the need?"* Regular discussions between Mind and Norfolk and Waveney Integrated Care Board will be essential to *"make decisions together because they* [NWICB] *often have the voice of the Primary Care Managers and Mind often have the voice of the team leaders and the Enhanced Recovery Workers, so that we meet together to make a decision that works for everyone involved."* The Mind representative emphasised that *"we are also very much led on the GP practice because different surgeries prefer to do things in a different way and it's important that we are accommodating to that".*

Healthwatch Norfolk asked the Mind representative to explain the difference between Mental Health Practitioner and an Enhanced Recovery Worker.

> "Enhanced Recovery Workers aren't mental health nurses, they're not counsellors, they're not psychologists. They will deal with the more lower level mental health, the more the mild to moderate end and they're [Mental Health Practitioners] more severe."

After an Enhanced Recovery Worker has been recruited, it's important to ensure that they are fully integrated into their primary care team. A Mind representative acknowledged that GP surgeries *"all work slightly differently"* but *"on the whole they've [GP surgeries] been very welcoming, as it's a service that they really want."* To ensure that *"no major problems"* exist when a new ERW starts in a primary care team, the ERW Team Lead and newly appointed Enhanced Recovery Worker can visit the new GP surgery to meet with the Practice Manager so that *"everyone's on the same page"* with

the services that the ERW can and cannot offer patients. The Practice Manager will then be asked when they would like a regular review of the ERW role.

> "I've asked them, when would you like us to review this? … Sometimes people don't always want a meeting because they're very busy. So I said, "Do you want to just email me if you've got any concerns or do you want us to catch up in two, three months' time?"

Recruiting Skilled Workers

Healthwatch Norfolk interviewed an Enhanced Recovery Worker (ERW) to find out what is working well with the integration of mental health workers in primary care. During the recruitment process, Norfolk and Waveney Mind were seeking candidates with *"mental health experience, either personally or with a family member"* or relevant roles relating to support work and a lot of their staff *"come from a background of being counsellors."*

We spoke to an ERW about the type of training that they have received to undertake their role. The ERW explained that in addition to the extensive list of core training they receive, *"Mind is also open to us highlighting any further training we feel we may need following our interactions with patients and noticing common problems/themes occurring that may be helpful to assist us in carrying out the role."* Each ERW also has access to an e-learning hub provided by NHS England.

Staff Integration and Understanding of Role

The ERW described their relationship with the GP Surgery as *"really good"* due to the great communication between staff members and patients and the need for a service that the Enhanced Recovery Workers provide.

> "There's open dialogue, open conversations. What's working well is my support with the mental health practitioners. And I think also, because we've had quite a lot of uptake, we are very, very busy. So it shows that there's a need for it and people are coming back."

The integration of this new role within primary care has been a *"learning curve"*. Initially a few of the Enhanced Recovery Workers were receiving *"inappropriate referrals"* from primary care colleagues because ERWs do not prescribe medication, diagnose mental health conditions, or complete sickness certificates. This means that the ERW we

interviewed is always mindful of explaining their role and clarifying their remit when they meet a new patient.

> "We were getting people coming in expecting… they were like, "Oh, I need a new script from the surgery." And I'm like, "Well, sorry." But I always say, as soon as they come in, and I explain who I am, what I can do. So we cross that bridge as they walk through the door because you don't want them coming in with an expectation and then you turn around after 45 minutes and go, "Well, actually no, I can't do that."

The ERW explained that if they do receive an inappropriate referral through, they can send a task through the clinical system to the doctor to explain why they cannot see a particular patient. This information has then been passed on by doctors and healthcare staff during their regular meetings. The ERW believes that once they are *"embedded more in the surgeries"* they will be able to integrate better and join the team meetings with *"the GPs, the med students and everyone"* to provide feedback and *"bounce off each other."* The ERW described how they are enjoying their new role but felt a *"bit unsure to start off with"* because it's a new role and *"you don't know how you're going to be received into the GP surgery."* Their surgery already had a mental health nurse in place leading to *"a few prickly receptions, but once they realised who we were and what we were doing, then it was fine."* Since that initial experience, the ERW has felt more positive within their role.

Public Awareness and Waiting Times

The Enhanced Recovery Worker reported that patients seem to be engaging really well with them and that Mind produced a leaflet outlining their role that *was "distributed to our surgeries so that they could look, put it in reception for patients to see and also for the GPs to use".* One of the biggest initial challenges faced by the introduction of ERWs is the DNA (did not attend) rate. The ERW thinks that being based in a doctors' surgery could be off-putting due to *"white coat syndrome"* and being based in *"a community hub like in Norwich, they've got Churchman House and places like that… which takes away the expectation of medication."* The waiting time for an appointment with the Enhanced Recovery Worker we interviewed is approximately between one to two weeks. This allows the ERW some flexibility with their time and ability to see patients and provide *"patient centred care."*

> "Last week I had an urgent call come through, reception didn't know how to deal with it so they triaged it to me so I could spend half an hour with this lady on the phone. And they got her in, literally, the Tuesday of the following week."

This patient was *"so thankful"* for being seen so quickly and remarked how she was given *"plenty of time"* during her appointment and appreciated the opportunity to see the ERW face to face and not just talking over the phone.

Social Prescriber

Healthwatch Norfolk interviewed to a Social Prescriber to explore what they thought about the introduction of these new mental health roles in primary care. The Social Prescriber that we spoke to exclaimed that they feel that *"clients have more options for different stages of mental health"* and mentioned that *"clients have more options for care within surgeries like health and wellbeing coaches and social prescribers and Mental health advisors"* and that being based within in primary care as a *"first point of contact"* has been very helpful *"for knowing where to sign post clients to and having the doctors at hand if I feel clients need professional help too."*

GP Practice Managers

For the second part of Outcome 5 Healthwatch Norfolk aimed to speak to Primary Care Practice Mangers to discover what they thought about the introduction of the new mental health roles rolled out in primary care. Healthwatch Norfolk to spoke to three Practice Managers to find out if primary care staff report that the blended mental health and primary care teams are working effectively and what benefits these new roles bring to primary care.

> "They're really, really valuable. They bridge a gap between secondary care and primary care… if a patient is known to secondary care, then that is where they're directed. But if they're not and they're too advanced for wellbeing, then we will book them in straight away with our mental health practitioner within the practise, so it avoids any sort of delays or referrals."

Another Practice Manager described the roles as invaluable and explained that the appointments offered by Mental Health Practitioners are *"in depth"* and

"comprehensive" enabling the Practitioner to go through a lot of information with the patient so they can *"directs them to all the other services that are available"* to the patient. They were very pleased that there *are "lots of mental health avenues coming into primary care"* and that their ability to refer patients into the Wellbeing Service is a benefit to the surgery.

> "That's another sort of service that we've just adopted around Wellbeing and a direct route into Wellbeing. We've had an initial kick-off meeting and all of our reception staff and our doctors were present and they can refer immediately."

One of the Practice Managers explained that their surgery holds regular Mental Health Practitioner reviews with primary care staff. The manager asked the doctors about the value they perceive that this role brings to the practice, and they *"did say it's really helpful"* and that they are *"real asset to the team".* One Practice Manager praised how quickly Practitioners can book patients in to see them for an appointment.

> "I think the fact that [patients] can access the help they need a lot quicker because the referral process... we can generally get someone booked in with the MHP within two weeks and then she'll follow up and be the support and she knows that she can come through and speak to any of the doctors or ask the doctors about any concerns."

One Practice Manager commented on the 45-minute length of the appointment between a Practitioner and Patient as a *"long time... which is great for the patient"* and that they can *"make an impact"* on the patients they see and can *"either refer them on or they deal with them and bring them back and kind of treat them".* Healthwatch Norfolk asked each of the Practice Managers whether they thought it was clear to primary care staff what the role and purpose of a Mental Health Practitioner is.

> I do think that role's now been embedded enough that they know what it is. I think the issue you've got is that we [practice managers] wouldn't book them, so it would be more doctor led, but I think it's a service that very much supports the doctor. Therefore, you know that that Mental Health Practitioner is available for the doctor to say, "yeah, I've got this patient, should I put you in?" So I think it is, that role is known enough to us now."

Healthwatch Norfolk also asked each Practice Manager whether they thought it is clear to the public that there are Mental Health Practitioners are in place and what their role is. One Practice Manager was unsure and was not confident that their Mental Health Practitioner was on their website.

> "Possibly not. I'm not actually sure whether the MHP is mentioned on our website… Maybe we need to promote that a bit more that they are here, an additional person the same as we have the physios as well. It might not [be clear] unless they're engaging already in seeing a GP then no, potentially it might not be that well known that there is a MHP here."

The next part of the interview focused on the potential challenges faced by doctors' surgeries since the new mental health roles were introduced. One Practice Manager mentioned that their Practitioner was experiencing a high rate of DNA (did not attend) appointments, which was a little concerning to them considering the length of each appointment is 40-45 minutes face-to-face with a patient.

> "There's quite a high DNA rate with those and obviously they're quite lengthy appointments. I think sometimes if the MHPs just done a phone call they might break it down to 20 minutes… but I mean, for example yesterday they saw five patients and three did not attend."

The Practice Manager was unsure why the DNA rate was so high as each patient receives a text reminder about their appointment. This is a process that is meant to help *"vulnerable and struggling"* patients remember that they are booked in, but despite this there are still *"consistent"* appointments that are not attended. The Practice Manager explained that if a patient fails to attend their

appointment, the Practitioner will alert primary care staff who will *"try and make contact and get them rebooked in."* The Practice Manager believes that despite the DNA rate for the Practitioner being high, patients "*prefer to come here to a GP practice that they know and familiar surroundings than worry about having to find somewhere they don't know where it is or it's in the city and they don't know how to get there."*

The doctors' surgery that this Practice Manager oversees have signed up to a "DNA probability pilot". This system allows them to search and analyse the appointments booked for the next day and the software will flag patients as red or amber as potential no-shows and enable staff to *"make contact with them the day before, remind them about the appointment."*

Another challenge face by two of the Practice Managers interviewed is that they would like to increase the number of Mental Health Practitioners available to their surgery.

> "We all need them, we probably all need more of them because that [mental health problems] are a lot of what's coming through for the GPs and obviously that's what MHPs specialise in and they know where to signpost, they know what help is out there for these people and they can get them to that a lot quicker than seeing a GP."

One of the Practice Manager expressed concern and curiosity about the length of the appointments required by the Practitioners and wondered *"whether they need that long… because they have got these 40 minutes and we're not going to get through many patients"* but also added that they were in no way questioning their professionalism. This Practice Manager questioned their Mental Health Practitioners about their need for such long appointments *when "primary care has to see the same patient with the same mental health problem in 10 minutes".* The Mental Health Practitioners responded by explaining that *"this is a very unique role where you do need this kind of time with these patients."* The Practice Manager rationalised the appointment length by concluding that *"they [MHPs] are obviously doing something much more holistic and longer."*

The other issue being addressed at the time of the interviews was the complaints handling procedure around Mental Health Practitioner appointments and who should be handling these.

> "There's quite a big gripe around complaints within primary care where if a complaint comes in from a patient against their consultation or anything that's happened with a Practitioner, NSFT will say the practice has got to deal with it, but we'll say "no, you've got to deal with it because it's your staff member staff", so there's lots of confliction against that at the moment. I think it's a bit of a misunderstanding in terms of the Memorandum of Understanding (MOU) and I think it wasn't clear. So that's definitely a little bit contentious at the moment."

One of the Practice Managers questioned who should be checking the Mental Health Practitioners work because *"our doctor cannot read every single consultation and just double check and then feed back to them that it's appropriate or not appropriate because they're autonomous practitioners."* The Practice Manager acknowledged that somebody should be *"reviewing or monitoring their competency"* by checking their consultations like their surgery's doctors experience. They suggested this *"was something that should be thought about in the future."*

Another Practice manager reflected on how they had been asked to sit on the interview panel for some of the Mental Health Practitioner interviews which they perceived as a positive and interesting opportunity.

> "The great thing is I get asked to be on the interviews from the mental health team… from NSFT who are recruiting these roles, they often ask me to sit as a practice manager on their interviews. I get to see some of the people that apply."

Healthwatch Norfolk first interviewed the Primary Care Network Mental Health Integration Lead in January 2023, where they reported that the workstream has been working towards developing a more *"psychologically informed workforce."* The aim was to develop their psychological resource and provide more psychological and evidence-based therapy across primary care. This was followed up with an additional interview in July 2023. The key milestones for this workstream include:

- Locality & PCN meetings have continued in order to map the current mental health (MH) workforce in PCNs and establish which mental health roles to recruit in the final wave of Mental Health Practitioner (MHP) recruitment.

- A continuation of working with ICB leads and Primary Care on the roll out of Enhanced Recovery Workers (ERWS) with 6 ERWs assigned to each locality area.
- Exploring the roll out of streaming model in PCNS where PCNs are signed up to the talking therapies direct tasking model. This will ensure the patient accesses the correct level of support for their needs.
- The Community Personality Disorder model was agreed on the 1st June 2023 with 23.5 Peer Support Workers, 1 per locality, to link in with the Primary Care Network Mental Health roles to offer peer support and link people in the wider Personality Disorder workstream offer.
- The new Community Mental Health Pathways Integration Oversight Group has been set up to bring together the work within community transformation to ensure there is a clear pathway from primary care through to secondary care for people with differing levels of mental health complexity.

What this means

The transformation of community based mental health services is an enormous task and we were not expecting to see radical change within this second year but hoped for continuing evidence of progress. There is evidence of change in some areas, but not in others. The Community Transformation Steering Group has made positive steps to address our recommendations from the Year One report.

This second year evaluation report has found evidence within each of the workstreams of a commitment to introduce multiagency working and working in partnership with wider stakeholders. The amount of multiagency working differs between the workstreams, but the Rehab Pilot is an excellent example of multidisciplinary working and a holistic approach. The work on physical health checks shows evidence of co-production with Experts by Experience and partnership working with wider stakeholders.

We found it difficult to access many adults severely affected by mental illness, but those we interviewed and those who participated in focus groups revealed variable experiences with community mental health services. Their feedback depended on their experience of a particular community mental health service at the time the interview was conducted. People diagnosed with a personality disorder or living with complex emotional needs were the least satisfied with the community service they received and did not believe there had been any positive change. Poor communication was an issue for many adults we spoke to severely affected by mental illness.

The progress made with integrating the I Statements into system measures is promising. However, there does not appear to be a process to seek ongoing feedback from adults severely affected by mental illness to see if they believe that these outcomes are being met for them, which should be the true test of the I-Statements.

The experience of carers and loved ones of adults severely affected by mental ill health does not appear to have improved and they are still struggling to get their voices heard and to be involved in the care of their loved one. The use of the Carers Assessment and the Carers Passport is not widespread and does not appear to have a positive impact for carers yet. There has been a lack of continuity of involving carers and loved ones in the community mental health transformation since it began. Carers involvement does form a separate, designated workstream. By not creating a separate workstream for carer involvement there is a risk that their lived experiences and voice are not championed and therefore end up being omitted from the transformation process. We recognise that carers lived experience is being incorporated into the Care Planning

Approach workstream and it's important to ensure that carer involvement and co-production remains consistent.

Efforts have continued to engage with the VCSE sector through the Mental Health Providers Forum and the Norfolk and Waveney VCSE Assembly, however we identified in our previous report that the VCSE Assembly was still developing, and it is difficult to see what progress has been made in getting this running as a proficient mechanism for bringing together the VCSE sector and representing their views. Given the lack of engagement from the VCSE Assembly, we cannot criticise the Community Transformation Steering Group for not meeting this recommendation.

There is evidence of Experts by Experience being involved with many of the workstreams in different capacities, but very little evidence of any Steering Group engagement with wider groups of Experts by Experience through other VCSE partners, which we had recommended in year one. There is a risk that by focussing on feedback from a small group of individuals, the opportunities for wider learning and co-production are missed.

There is evidence that some larger VCSE organisations are involved in the workstreams and the delivery of services. However, smaller VCSE organisations are still not being involved in the transformation process or Steering Group / workstream membership. The lack of progress with the VCSE strategy has not helped with this and does not reassure the sector that they are a valued partner. VCSE organisations have a critical role in building trust and facilitating connections and relationships at a neighbourhood level. Therefore, it is incredibly important that local VCSE organisations (big and small) are involved in the community transformation process.

The Steering Group and Transformation Leads have made progress with communicating positive and successful aspects of the transformation through the Rehab Pilot launch event and Physical Health Check Roadshow, which were well received by the public, especially for the Rehab Pilot. Showcasing these successes means that members of the public, and more importantly, those adults severely affected by mental ill health and their carers / loved ones, are more aware of how community mental health services are being transformed and that progress is being made.

The VCSE organisations that we interviewed recognised the efforts that were being made to transform services but could also see the enormity of the task. They reported that there has been an improvement in the holistic approach taken by the Community Transformation Team within the rehab pilot and saw this as a success. But they have not experienced changes to joined up services, waiting times for community mental health services and state that people diagnosed with a serious mental illness are still

not feeling in control. They also identified that support for carers is variable, but there is some work being undertaken to address this.

The integration of the new mental health roles into primary care has been a successful process. Both mental health staff and primary care managers are reporting that they are becoming more aware of each other and their cultural working differences. Mental health staff have explained that they are feeling welcomed into primary care settings and even though it can be an isolative role, many GP practices are doing their best to ensure they feel like part of the team. Primary care staff are realising the value of these new roles and would even welcome more mental health staff being brought into their practices and funded through the Additional Roles Reimbursement Scheme (ARRS).

Change is happening, but many adults severely affected by mental illness and their carers are not yet experiencing this. There are still issues about services not been joined up, waiting times to access services and people feeling in control of their care. Where there has been significant progress with the Rehab pilot, the success of this is due to a holistic approach, proper partnership working with a range of stakeholders and embedding the views of Experts by Experience in the design of the service. For continued success with the transformation of all community based mental health services these elements must be at the heart of the process.

Recommendations

Healthwatch Norfolk identified recommendations for each of the five outcomes in the year one evaluation report. For the year two report, when looking at what the data and feedback have told us, we felt that the recommendations for outcomes one, two and three would also cover any improvements needed for outcome 4 and 5. Outcomes four and five explore whether wider stakeholders are seeing any differences to community-based services and is effectively additional evidence to support (or otherwise) what adults severely affected by mental illness were telling us in this year's report.

Healthwatch Norfolk are also mindful that this is year two of a three-year project, which is due to finish next year and that the recommendations need to be proportionate and realistic.

Outcome One

The Community Transformation Steering Group continue to use the I Statement outcomes as a benchmark.

- Ensure there is a process so that adults severely affected by mental illness and their carers or loved ones can feedback on whether they believe the I Statements have been met for them and use this feedback to see what changes need to be made.

Outcome Two

The Community Transformation Steering Group ensure that the previous recommendations for this outcome are met:

Any changes to community based mental health services brought in by the Steering Group should ensure that carers of adults severely affected by mental illness are involved in the care of their loved one, offered support and that the value of their role is recognised. The involvement of carers should be a core focus for each care pathway and priority cohort for the community mental health service transformation.

- To progress with the plans to develop I-statement outcomes for carers, working with VCSE organisations that work with carers of adults severely affected by mental illness.
- Ensure that transformation plans indicate which of the I Statement outcomes will be met as a result of any change.

- Consider forming a Carers Panel or a separate group of Experts by Experience to help co-produce and shape the community mental health service transformation process. This will strengthen the steering group's acknowledgment of the importance of families, carers and support networks and treat them as an integral part of their loved one's treatment and care.

Ensure that the focus on carers is not lost because it is classed as an enabler for the other workstreams.

Link in with HWN project exploring the experiences of carers of loved ones of adults severely affected by mental illness.

Outcome Three

The Community Transformation Steering Group seek broader opportunities to engage with wider groups of Experts by Experience through other VCSE partners.

The Community Transformation Steering Group ensure that the VCSE are facilitated to become equal partners in the transformation plans and process.

- Make the development of the VCSE strategy a priority, ensuring wider representation and develop opportunities for coproduction with the VCSE sector, and involving them at the beginning of service design, not part way through.
- Seek alternative means of engaging with smaller VCSE providers that allow them to contribute more fully without always having to attend meetings organised by the steering group.
- Explore how VCSE services can be funded to ensure their sustainability.

Commissioner Response: Norfolk and Waveney Integrated Care Board (ICB)

Norfolk and Waveney ICB would like to begin by expressing our gratitude to Healthwatch Norfolk for providing a detailed and independent evaluation report on Year 2 of the Community Mental Health Transformation Programme. The insights and feedback are greatly appreciated.

We are pleased that the report highlighted progress in the following areas:

- Each Community Transformation workstream is now benchmarked against the relevant "I Statement" outcomes.
- There is clear evidence of continued engagement with the VCSE sector, and involvement of Experts by Experience in many workstreams.
- There has been a notable improvement in the holistic approach to the programme.
- The integration of community-based mental health roles has been successful, with these roles and stakeholders increasingly aware of each other and adjusting to cultural working differences.

These achievements demonstrate that, although transformation is ongoing and we recognise that it is a long-term process, our community mental health services and pathways are beginning to transform, ultimately leading to better outcomes for our service users in Norfolk and Waveney.

Moving forward, we will continue to focus on enhancing experiences for carers and loved ones, reducing inequity across the system, and improving waiting times. We will achieve this by ensuring that plans are co-produced and by strengthening our collaborative efforts with our system partners.

We highly value the feedback and recommendations provided in the evaluation and are committed to continuous improvement. We appreciate the independent perspective of Healthwatch Norfolk and the contributions of all those involved in the evaluation process. We look forward to implementing these recommendations and achieving better results for our local population.

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Appendix

Appendix 1: Evaluation Plan

Goals
Healthwatch Norfolk (HWN) aim to evaluate whether community mental health provision for people with severely affected by mental illness (SMI) has improved in Norfolk and Waveney: • The Community Transformation Steering Group has done what it set out to do. • Adults severely affected by mental illness (SMI) have experienced positive change. • Families and carers of severely affected by mental illness (SMI) have experienced positive change.

Outcomes	Steering Group Focus and Actions	What HWN Aim to Show	Tasks
Outcome 1 Adults severely affected by mental illness (SMI) report improvements in and access to community-based services.	<u>Existing Workstreams from Year 1:</u> **Complex Emotional Needs / Personality Disorder** 1. Embed the CEN/PD strategy 2. Embed training internally and to system partners **Eating Disorders** 1. ARFID pathway 2. Single point of access 3. Training and upskilling for non-eating disorder professionals <u>Workstreams Introduced in Year 2:</u> **Rehab Pilot** 1. Recruit to full team 2. Mobilise pilot July 22 3. Identify cohort/ develop ops policy/service spec 4. Develop metrics and measure impact of pilot 5. Evaluation report to steering group Jan 23 **Physical Health Checks** 1. National target number (from the analytical toolkit) of 5,939 and a	**Joined up services** Community-based services are providing care that is joined up. **Waiting times** Adults with SMI receive specialist interventions, in a timely and appropriate way. **Rehabilitation** Adults with SMI experience an appropriate period of rehabilitation to enable recovery and ensure an optimum level of independence. **Feeling in control** Adults with SMI feel included in decisions and in control of their care.	Focus Groups and 1:1 Interviews to be conducted with adults severely affected by mental illness. Focus to be on: *Joined up services *Waiting times *Period of rehabilitation support *Feeling in control *Changes from previous experiences *Experience of physical health checks Provide Rehab Pilot Case Study for report.

	local trajectory for end of this year is 4,748 2. Establishing the Physical Health group to pull together for mental health and LD&A physical health monitoring 3. Ensuring all system data (for SMI physical health checks) is reflected in primary care systems to enable accurate data extraction via GPES national team. **Perinatal and Parents of Infants** 1. Extending the offer to 24 months after birth 2. Keeping in line with the access rate (goes up to 10% this year) 3. Having a process in place to sign-post partners of pregnant people to support for them	**Ongoing change** Adults with SMI have seen changes in community-based services.	
Outcome 2 Families and carers of adults severely affected by mental illness (SMI) report improvements in and access to community-based services.	Involving and providing support for carers, loved ones and advocates of adults Severely affected by mental illness within each CTSG Workstream.	**Joined up services** Carers, loved ones and advocates of adults severely affected by mental illness are aware of wider support services for them and their loved one and how to access these services. **Feeling in control** Carers, loved ones and advocates of adults severely affected by mental illness feel included in decisions about the care of their loved one. **Support** Support is made available to Carers, loved ones and advocates of adults	1:1 Interviews to be conducted with carers of adults severely affected by mental illness. Focus to be on: *If they feel included in decisions about the care of their loved one. *The support they have received themselves. *Changes they have seen in community-based services

		severely affected by mental illness.	
Outcome 3 The Community Transformation Steering Group can evidence that they have made changes that have positively impacted on community health provision for adults severely affected by mental illness (SMI).	Rehab pilot Eating Disorders Complex emotional needs Physical health checks Perinatal support Parents and carers Workforce Development of VCSE Strategy	**Co-production and Partnerships** The transformation work has been coproduced with people with lived experience and meets the I Statements outcomes. Steering group can evidence that partnerships have been formed and bring value. The CTSG has developed their VCSE strategy and is successfully engaging with the VCSE sector and forming partnerships.	Interviews/Focus group with Rethink Experts by Experience Identify where the steering group has engaged with other experts by experience from different organisations and get feedback. Identify and involve organisations that are engaged with the key priority cohorts and get feedback on whether they have coproduced the plans. Interviews with partnership organisations (NCC, VCSE, District Councils) to obtain feedback on whether they have been involved in the design of services. Seek feedback on VCSE coproduction in the transformation plans.
Outcome 3 The Community Transformation Steering Group can evidence that they have made changes that have positively impacted on community	Rehab pilot Eating Disorders Complex emotional needs Physical health checks Perinatal support Parents and carers Workforce	**Joined up services** The actions taken by the CTSG ensure community-based services are providing care that is joined up.	**Transformation Leads** Interview transformation leads for each area to ask: *What the key actions are for each priority cohorts

health provision for adults severely affected by mental illness (SMI).		**Waiting times** The actions taken by the CTSG ensure that adults with SMI receive specialist interventions, in a timely and appropriate way. **Rehabilitation** The actions taken by the CTSG ensure adults with SMI experience an appropriate period of rehabilitation to enable recovery and ensure an optimum level of independence. **Feeling in control** The actions taken by the CTSG ensure that adults with SMI feel included in decisions and in control of their care. **Ongoing change** The CTSG have measures in place to show the impact of their actions. **Physical Health Checks** That there has been an increase in the numbers of physical health checks being undertaken.	*What improvements they expect to see as a result of the changes they are planning / have made? *What impact do they expect on joined up services and waiting times? *How has the work been co-produced - experts by experience/ other sectors including VCSE? *How are the changes linked to the outcomes that people with SMI want for themselves (I Statements)? Interview transformation leads 10-12 months after first interviews to ask them how successful they feel they have been in their plans, what the impact has been on adults with SMI. Review the CTSG evaluation results and the impact identified from their own evaluation. Request data of number of physical health checks being offered vs. being attended by adults with SMI and monitor change.

			Engage with Steering Group members about the progress of the Physical Health Group and how they are ensuring all system data (for SMI physical health checks) is reflected in primary care systems.
Outcome 4 Community based services (NCC, district Councils and VCSE sector organisations supporting adults with SMI) report improvements to joined up services and waiting times.	Rehab pilot Eating Disorders Complex emotional needs Physical health checks Perinatal support Parents and carers Workforce	**Joined up services** Community-based services report improvements in joined up working. **Waiting times** Community-based services report that adults with SMI receive specialist interventions, in a timely and appropriate way. **Rehabilitation** Community-based services report improvements in rehabilitation services. **Feeling in control** Community-based services report improvements in adults with SMI feeling included in decisions and in control of their care. **Ongoing change** Community-based services report that they can see ongoing change in community based services.	

Outcome 5 Mental Health Workforces will report improvements in community-based services for adults severely affected by mental illness (SMI).	1. The workstreams set-up in June 22: New opportunities; Upskilling; Health and Wellbeing; Culture and Leadership 2. The workforce strategy launching June 22. 3. Delivery of the workforce implementation plan in March 2024 1. Recruit 20 MHPs to PCNs 2. Recruit 25 recovery workers to PCNs 3. Recruit 10 PSWs to PCNs	**Skilled Workforce** Development of a skilled workforce through delivery of a mental health workforce & training strategy. **Integration** Mental health services are integrated into Primary Care; developing blended primary care and community mental health teams. **Primary Care staff** Report that the blended mental health/primary care teams are working effectively.	Interview workstream lead to find out progress since last year, the priority actions for 22/23 for: *New Opportunities *Upskilling *Health and Wellbeing *Culture and Leadership and the expected impact of these actions. Confirm the workforce strategy has been launched and the intended impact of this. Find out about the recruitment and the intended impact of the following posts: *Clinical Associate Psychologists *Specialist Pharmacists in Primary Care Interview a selection of Mental Health Practitioners, Recovery Workers and Peer Support Workers to get feedback on their roles, how they feel they are contributing to transformation of community based services and how integrated they feel with the wider workforce.

			Continue to engage with GP Practices and PCNs about the integration of the new roles and the impact it is having.

Appendix 2: Report Glossary

Glossary	
Critical Friend	A person or organisation who offers encouragement and support to another person or an organisation, but who also provides honest and often candid feedback that may be uncomfortable or difficult to hear.
Co-Production	The active involvement of people with lived experience of mental illness in service design to increase the quality and efficiency of services and improve clinical outcomes (McKeown, 2014; Nesta, 2012).
Community Transformation Steering Group	This group oversees managing the transformation of community based mental health services across Norfolk and Waveney. It is made up of representatives from local health and social care providers, people with lived experience, voluntary and third sector organisations and staff from local mental health services.
Complex Emotional Needs	People who are experiencing difficulties with emotional regulation
Disordered Eating	Disordered Eating is clinically defined as irregular eating behaviours that do not meet the diagnostic criteria of a specific eating disorder.
Dual Diagnosis	Within this report, if a person has a dual diagnosis it means they have been diagnosed with a severe mental illness and experience drug or and / or alcohol addiction.
Eating Disorder	An Eating Disorder is a serious psychiatric conditions driven by the extreme over-evaluation

	of a person's weight and shape. They are experienced by a minority of people and are assessed on specific diagnostic criteria. Examples of Eating Disorder diagnoses include: Anorexia Nervosa, Bulimia Nervosa, a Binge Eating Disorder and Avoidant Restrictive Food Intake Disorder.
Enhanced Recovery Worker	Enhanced Recovery Workers (ERWs) are specific members of staff based in a Doctors' Surgery. They can support patients presenting with a low complexity mental health condition for the first time to provide non-urgent mental health support by working with patients to identify their support needs and plan their mental health recovery. The main difference between this role and a Mental Health Practitioner is that ERWs do not need to be registered professional working within Mental Health services.
Expert by Experience	A person who represents lived experience in considerations and decisions about how support in community mental health services can be best offered to meet people's needs. This input supports the co-production of personalised and holistic support that improves the experience and quality of treatment and support for service users, carers and families.
I Statements	Before the community mental health transformation started, eleven I Statements were formed through workshops and focus groups (hosted by Norfolk and Suffolk Foundation Trust) with adult severely affected by mental illness. These statements focus on their feelings and experiences of community health services and what they would like to see being delivered from the treatment and care they receive.
Mental Health Practitioner	In this report, a Mental Health Practitioner refers to a specific member of staff based in a Doctors' Surgery. A Mental Health Practitioner will already be trained as a

	Mental Health Nurse, Occupational Therapist, Social Worker, or registered professional working within Mental Health services and can provide support, treatment, and advice for patients that are experiencing challenges with their mental health.
Severe Mental Illness (SMI)	According to the NHS England Mental Health Implementation Plan (2019b) the term 'SMI' covers a range of needs and diagnoses, including but not limited to; psychosis, bipolar disorder, 'personality disorder' diagnosis, eating disorders, severe depression and mental health rehabilitation needs – some of which may be co-existing with other conditions such as frailty, cognitive impairment, neurodevelopmental conditions or substance use.

Appendix 3: Initial I Statements

Initial I Statements
I want services and support to be well advertised in my local community.
I want to have trust in services helping me to care for my mental health.
I want continuity in my care team.
I want to be part of my care.
I want my care plan to be up to date with my current mental health and my life.
It is time to move beyond engagement on vision and broad approach. I want to see change.
I don't want people to give up on me when my mental health does not fit services.
If I am unable to make my own decisions for myself, my prior wishes, and my family /carer views will be considered.
I want my loved ones and I to have an agreed care plan that is about me.
I want my carer/support worker to be interested in me. I expect professional carers to have an understanding of mental health needs.
I want to experience person-centred care, wherever I can - with, about and for me.

Appendix 4: Revised I Statements

1a. I have 24/7 access to community mental health services and support, which are engaging, accessible, embedded and localised.

1b. I am able to access the right care which ever "door" (referral route) I enter, I am not turned away when I need help.

2. I am empowered to access intervention and holistic wrap-around-care, which supports my long-term recovery and on-going health needs.

3. I trust services and will engage with my recovery journey and experience better outcomes, I am heard and able to influence my personalised care pathways.

4. I experience consistent relationships with those involved in my care, I feel listened to, validated and that my experience matters. This helps to build my wider capacity for trusting relationships, and this in turn promotes better health outcomes for me.

5. Everyone involved in my care knows my name, who I am, has read my history, and understands the care I am receiving. I do not have to keep retelling my story. My history is recorded in safe and clear way, it can be easily and quickly accessed, and my needs are understood.

6. I experience person-centred care, I am treated as an individual, rather than as a diagnosis. I am a person not just a problem. I have choice in how my care is delivered and my preferences are valued, people focus on "what matters to me", instead of "what's the matter with me". I am motivated and empowered and contribute to my care, I utilise additional resources that are personal to me, I am an expert in my own experience.

7. I have a plan for my care and recovery that is written in my own words and kept up to date, which includes the things in my life that matter to me, according to my choices. My care plan is my care plan.

8. Services communicate with me, and involve me, when changes need to be made to my care, I can prepare for this, and respond to any changes more effectively. My care team value my opinion and trust me.

9. Professionals are able to recognise the support that my carers require and are able to offer my carers support, their needs are met, and are more able to support me.

10 My diagnosis is only one part of me. My other physical or mental health conditions, as well as life events, might (or might not) be impacting on my current state.

11. My recovery journey is unique to me and its ok to have setbacks sometimes.

12. I am helped to gain perspective, address immediate stressors and life events, and receive holistic care.

13. I am validated and respected, staff consider and meet my communication needs.

14. I am treated as an equal in my care, and my lived expertise is recognised, I am motivated to take part in my care.

15. Carers and family members can be key protective factors in my recovery. They are fully involved (at my request only) alongside all relevant professionals, this provides the most effective care and promotes the best outcomes. When I experience crisis, these considerations are even more important.

Appendix 5: Interview Questions for Adults Severely Affected by Mental Illness

Thank you for agreeing to discuss your experiences of community based mental health services with us. If you would like to pause the interview at any moment, please let me know.

Anything mentioned within this discussion will be private and confidential unless there is a genuine and urgent concern for your safety or wellbeing. Any feedback from this discussion will be anonymised and any potential identifying information will be removed.

1. Please could you tell me a little bit about yourself and your experience of living with a mental health issue / a severe mental illness?

2. Please could you tell me about the community based mental health support have you received in the last 12 months?

3. Do you feel included when making decisions about your own treatment and care?

4. Are your family, someone close to you or an advocate included by community mental health staff in your treatment and care?

5. How would you rate your recent experience of community based mental health services?

6. What has been good about your experience of community based mental health services?

7. What changes have you seen to Community Mental Health Services within the last 12 months?

8. What changes to community mental health services could be made to make things better for you?

9. Is there anything else you would like to tell us about community mental health services in Norfolk and Waveney?

Thank you for your time!
Debrief

Appendix 6: Interview Questions for Carers, Supporters and Advocates of Adults Severely Affected by Mental Illness

Thank you for agreeing to discuss your experiences of community based mental health services with us. If you would like to pause the interview at any moment, please let me know.

Anything mentioned within this discussion will be private and confidential unless there is a genuine and urgent concern for your safety or wellbeing. Any feedback from this discussion will be anonymised and any potential identifying information will be removed.

1. Please could you tell me a little bit about yourself and your experience of supporting/caring for an adult severely affected by mental illness?

2. Do they have a diagnosis? / When were they diagnosed?

3. What has diagnosis meant for you as a carer?

4. Can you tell me a bit about your experience (and their experience, if relevant) of being supported by community mental health services in Norfolk and Waveney?

5. How would you describe your experiences (as a carer) of being supported by community mental health services?

6. What services have you received?

7. What about your experience has been good?

8. What about your experience has not been good?

9. Have you seen any recent changes to the community-based support you receive? If so, what are these?

10. What changes to community mental health services could be made to make things better for you?

Thank you for your time!
Debrief

Appendix 7: Interview Questions for Transformation Lead(s)

Name of Workstream:

Thank you for agreeing to discuss your role as the Transformation Lead for the Carers Workstream within the Community Mental Health Service Transformation

If you would like to pause the interview at any moment, please let me know.

The purpose of the interview is to understand from key members of the Community Transformation Steering Group:

- What the transformation process has delivered so far to improve the support for adults severely affected by mental illness and their loved ones / carers?
- What are the plans and actions for the next two years to continue improve support adults severely affected by mental illness and their loved ones / carers?

The outcomes that Healthwatch Norfolk would expect to see if transformation programme has been successful are:

- Adults severely affected by mental illness are being included in decisions about their own care.
- Support is made available to adults severely affected by mental illness and their carers.
- Adults severely affected by mental illness and their carers are being involved in the design of services.
- Changes to community-based services are being communicated to adults severely affected by mental illness and their carers.

This Interview will help us to understand the transformation plans and impact to services for adults severely affected by mental illness and their carers and to monitor the progress that you are making and the outcomes you expect to see.

Your responses will be used in Outcome 3 of our evaluation report:
"The Community Transformation Steering Group can evidence that they have made changes that have positively impacted on community health provision for adults severely affected by mental illness".

And towards our evaluation goals:
"Adults with SMI have experienced positive change".
"Families and carers of adults with SMI have experienced positive change".

We would like to record this interview and would like to ask your consent to proceed.

Please could you confirm the organisation you work for and your job role?

Please could you confirm your role in the Community Transformation Steering Group (CTSG) and your responsibilities?

Workstream Progress

Can you summarise what this workstream has achieved since it started? Please outline any changes to the support given to adults severely affected by mental illness and their carers that have occurred since the transformation process started.

How are community-based mental health services currently providing support adults severely affected by mental illness and their carers?

How are community-based mental health services currently involving adults severely affected by mental illness in their own treatment and care?

How are community-based mental health services currently involving carers of adults severely affected by mental illness in their treatment and care?

What work (within this workstream) are you most proud of?

What have been the challenges in implementing the plans for this workstream? What has been the result of these?

Have the findings from the clinical huddles influenced the work of this workstream? If so, how?

What outcomes would you expect to see for the adults severely affected by mental illness, and their carers due to the actions of this workstream? What do you have in place to measure improvements in the outcomes?

What are the priorities for the next 12 months for this workstream?

Can you tell me a little more about how this workstream has engaged with the VCSE sector (if applicable) or any plans you have to engage in the future?

Communication

How have the changes made to services in this workstream been communicated to adults affected mental illness, their families and carers and relevant VCSE organisations?

What are your plans for continued communication?

Co-Production

What work in this workstream has been co-produced with people with lived experience and with wider partners when transforming services (for example: VCSE organisations, Norfolk County Council and Experts by Experience)?

Can you tell me a little more about how you went about this?

What have you learnt and implemented as a result of co-producing the plans, (both with people with lived experience and wider stakeholders)?

Has there been any challenges?

I Statements

The refreshed I Statements that were co-produced by the Experts by Experience should be used as outcome measures. How will this workstream be monitoring whether the transformation plans meet these outcomes?

Feedback on the Overall Transformation Process

How will merging the Operational and Steering Group meetings affect the transformation process?

How has the CTSG communicated the changes made to services to VCSE organisations, adults severely affected by mental illness and their families and carers?

How successful has the CTSG been with implementing co-production practices – with people with lived experience and with wider partners (for example: VCSE organisations and Norfolk County Council)?

What do you think is working well with the changes to services the transformation process has delivered so far?

What do you think is not working well with the changes to services the transformation process has delivered so far? How could this be improved?

Are there particular issues or things that you think need addressing?

Do you think there have been improvements in joined up working? If so, please could you give an example of this?

Do you think there have been improvements in waiting times for adults severely affected by mental illness to get the support they need? Could you give an example of this?

Do you have any additional comments that you would like to make regarding the Community Mental Health transformation programme?

Thank you for your time!
Debrief

Appendix 8: Interview Questions for Experts by Experience

Thank you for agreeing to discuss your experiences of community based mental health services with us. If you would like to pause the interview at any moment, please let me know.

Anything mentioned within this discussion will be private and confidential unless there is a genuine and urgent concern for your safety or wellbeing. Any feedback from this discussion will be anonymised and any potential identifying information will be removed.

1. Can you tell me a bit about your experience of being an Expert by Experience as part of the transformation of community mental health services in Norfolk?]
2. What co-production work have you been involved in within the past 12 months as part of the Community Mental Health Transformation?
3. Do you think that bringing your lived experience to the transformation process has led to any changes so far?
4. In your role as an Expert by Experience, how would you rate your satisfaction with the support you receive from the Community Transformation Steering Group?
5. How often have you experienced barriers to taking part in this co-production work?
6. Do you think the Reference Group is as diverse or inclusive as it could be?
7. How would you rate your satisfaction with the communication you receive from: the Community Transformation Steering Group?
8. How would you rate the facilitation / running of the Community Transformation Steering Group?
9. What extra training have you received to support you in your role? / What training opportunities have been offered to you?
10. What extra training would you be interested in receiving to support you in your role?
11. What does true co-production mean to you?
12. What does the Community Transformation Steering Group do well and what could they do better to support you as an Expert by Experience?

13. Have you had enough support from the Community Transformation Steering Group to be an effective Expert by Experience?

14. Please use this time to tell us anything else you think it's important for us to know about your role as Expert by Experience.

Thank you for your time!
Debrief

Appendix 9: Interview Questions for VCSE Organisations Involved in the Rehab Pilot

Interview Questions for VCSE Organisations Involved in the Rehabilitation Pilot Workstream

Thank you for agreeing to discuss your role as a Voluntary, Community and Social Enterprise (VCSE) organisation supporting the Rehabilitation Pilot within the Community Mental Health Service Transformation

If you would like to pause the interview at any moment, please let me know.

The purpose of the interview is to understand from VCSE organisations involved with the Rehabilitation Pilot:

- how the transformation process has improved the support for adults severely affected by mental illness through the Rehab Pilot.
- what are the plans and actions relating to the rehab pilot for the next two years to continue improve support for adults severely affected by mental illness.
- How engaged you have been in the transformation process and to what extent you have been able to influence the plans.

The outcomes that Healthwatch Norfolk would expect to see if the Rehab Pilot has been successful are:

- VCSE Organisations report improvements in joined up working.
- VCSE Organisations report that adults severely affected by mental illness receive specialist interventions, in a timely and appropriate way.
- VCSE Organisations report improvements in rehabilitation services.
- VCSE Organisations report improvements in adults severely affected by mental illness feel included in decisions and in control of their care.
- VCSE Organisations report that they can see ongoing change in community-based services.

Your responses will be used in Outcome 4 of our evaluation report:

"Community based services (NCC, district Councils and VCSE sector organisations supporting adults with SMI) report improvements to joined up services and waiting times".

And towards our evaluation goals:

"Adults with SMI have experienced positive change".

We would like to record this interview and would like to ask your consent to proceed.

Introduction:

Please could you confirm the organisation you work for and your job role?

What experience does your organisation have with supporting adults with severely affected by mental illness?

Please could you tell me what involvement your organisation has had in the work around the rehab pilot? Is this involvement continuing?

Workstream Progress:

Can you summarise what you think the Rehab Pilot has achieved since it started? Please outline how the support for those adults severely affected by mental illness in the rehab pilot have been different to the experience they may have had previously.

What do you think is working well with the Rehab Pilot so far?

What work within the Rehab Pilot are you most proud of?

What have been the challenges in establishing and delivering the rehab pilot? How have these been addressed?

Is there anything that is not working well with the Rehab Pilot? How could this be improved?

Do you think there have been improvements in joined up working because of the Rehab Pilot? If so, please could you give an example of this?

How are the adults in the rehab pilot involved in their treatment and care?

Do you think there have been improvements in waiting times for adults with Severe Mental Illness (SMI) to get the support they need because of the Rehab Pilot? Could you give an example of this?

Are there particular issues or things that your organisation think need addressing regarding the Rehab Pilot?

What are the priorities for the next 12 months for the Rehab Pilot?

Communication

How has the introduction of the Rehab Pilot been communicated to adults severely affected mental illness, their families and carers and relevant VCSE organisations?

Do you think the Rehab Pilot Transformation Leads could improve communication? If yes, what do you think could be done differently?

Co-Production

How engaged and involved has your organisation and service users been in the planning and design of the Rehab Pilot?

Would you say that the rehab pilot has been co-produced with people with lived experience and wider partners? Why do you think this?

What have been the challenges/ barriers to co-production?

How do you think co-production could be improved within the wider community transformation programme?

Health Checks

Are you aware of whether those adults in the rehab pilot receive physical health checks as part of their care?

I Statements

The refreshed I Statements that were co-produced by the Experts by Experience should be used as outcome measures.

Are you aware of these I statements?

Do you think that the "success" of the rehab pilot will be measured against these statements? Can you tell me why you think this?

Feedback on the overall Transformation Process

Do you have any additional comments that you would like to make regarding the Community Mental Health transformation programme?

Appendix 10: Interview Questions for VCSE Organisations

Questions for Norfolk Waveney Based VCSE Organisations Affected by the Community Mental Health Transformation

Thank you for agreeing to discuss your role as a Voluntary, Community and Social Enterprise (VCSE) organisation supporting or affected by the Community Mental Health Service Transformation.

Healthwatch Norfolk are conducting a three-year evaluation on how the Community Transformation Steering Group deliver the transformation of community mental health services. If you would like to ask any questions, please email: rachael.green@healthwatchnorfolk.co.uk

Any answers that you provide may be used in the final report, but your personal details organisation name will not be identified.

The purpose of these questions is to understand from Norfolk and Waveney based VCSE organisations involved or affected by the Transformation:

- how the transformation process has improved the support for adults severely affected by mental illness.
- If your organisation is aware of the Community Transformation Steering Group plans and actions for the next two years to continue improve support for adults severely affected by mental illness.
- How engaged you have been in the transformation process and to what extent you have been able to influence the plans.

The outcomes that Healthwatch Norfolk would expect to see if the Transformation has been successful are:

- VCSE Organisations report improvements in joined up working.
- VCSE Organisations report improvements in Waiting times.
- VCSE Organisations report that they can see ongoing change in community-based services.

Your responses will be used in Outcome 4 of our evaluation report:

"Community based services (NCC, district Councils and VCSE sector organisations supporting adults with SMI) report improvements to joined up services and waiting times".

And towards our evaluation goals: *"Adults with SMI have experienced positive change".*

Introduction:

Please could you confirm the organisation you work for and your job role?

What experience does your organisation have with supporting adults with severely affected by mental illness?

Please could you tell me what involvement your organisation has had in the transformation work? Is this involvement continuing?

Workstream Progress:

Can you summarise what you think the community transformation has achieved since it started? Please outline how your organisation thinks support is different for those adults severely affected by mental illness different to the experience they may have had previously.

What do you think is working well with the Transformation so far?

Is there anything that is not working well with the Transformation? How could this be improved?

Do you think there have been improvements in joined up working because of the Transformation? If so, please could you give an example of this?

How are the adults severely affected by mental illness being involved in their treatment and care?

Do you think there have been improvements in waiting times for adults with Severe Mental Illness (SMI) to get the support they need because of the Transformation? Could you give an example of this?

Are there particular issues or things that your organisation think need addressing regarding the Transformation?

Communication

How has work being undertaken by the Community Transformation Steering Group been effectively communicated to adults severely affected mental illness, their families and carers and relevant VCSE organisations?

Do you think the Community Transformation Steering Group could improve communication? If yes, what do you think could be done differently?

Co-Production

How engaged and involved has your organisation and service users been in the planning and design of the Transformation?

Would you say that the Transformation workstreams have been co-produced with people with lived experience and wider partners? Why do you think this?

What have been the challenges/ barriers to co-production?

How do you think co-production could be improved within the wider community transformation programme?

Health Checks

Are you aware of whether adults severely affected by mental illness are receiving adequate physical health checks as part of their care?

I Statements

The refreshed I Statements that were co-produced by the Experts by Experience should be used as outcome measures for the Transformation.

Are you aware of these I statements?

Do you think that the "success" of the Transformation will be measured against these statements? Can you tell me why you think this?

Feedback on the overall Transformation Process

Do you have any additional comments that you would like to make regarding the Community Mental Health transformation programme?

Appendix 11: Interview Questions for Mental Health Professionals

Questions for Mental Health Professionals.

Thank you for agreeing to discuss your role as a Mental Health Professional based within Primary Care.

Healthwatch Norfolk are conducting a three-year evaluation on how the Community Transformation Steering Group deliver the transformation of community mental health services. If you would like to ask any questions, please email: rachael.green@healthwatchnorfolk.co.uk

Any answers that you provide may be used in the final report, but your personal details organisation name will not be identified.

The purpose of the interview is to understand how mental health workforce roles are currently being recruited and integrated into primary care as part of the wider transformation of community based mental health services.

Your responses will be used in Outcome 5 of our evaluation report:

"Mental health workforces will report improvements in Community based services for adults severely affected by mental illness."

And towards our evaluation goals:

"Skilled Workforce - The Community Transformation Steering Group implement the development of a skilled workforce through delivery of a mental health workforce & training strategy."

"Integration - Mental health services are integrated into Primary Care; developing blended primary care and community mental health teams."

"Primary Care staff report that the blended mental health/primary care teams are working effectively."

We would like to record this interview and would like to ask your consent to proceed.

Please could you confirm the organisation you work for and your job role?

Workstream Progress:

Can you summarise your role as a Mental Health Professional based within Primary Care?

What has worked well with the introduction of these new roles within Primary Care?

What hasn't worked well the introduction of these roles within Primary Care?

How do you think could this be improved?

How many Mental Health Practitioners, Recovery Workers and Peer Support Workers have been recruited to date in your PCN, and how many more posts are left to fill?

How will Recovery Workers be working with Mental Health Practitioners and Peer Support Workers to deliver mental health services within Primary Care for adults severely affected by mental illness?

What's working well with this model?

What's not working well with this model and how could it be improved?

What training and upskilling opportunities are being offered to these new roles? What training or upskilling do you think is needed for this role in the future?

Have these new roles evolved since the beginning of the Transformation, if so, how?

What are your PCN's priorities for the next 12 months regarding the recruitment, retention and management of these new roles?

Communication

Has the introduction of these new roles within Primary Care been widely communicated to the public, primary care staff and mental health staff?

Co-Production

Has the development and integration of these new roles been co-produced with people with lived experience and with wider partners when transforming services (for example: VCSE organisations, Norfolk County Council and Experts by Experience)?

Do you have any additional comments that you would like to make regarding the Community Mental Health transformation programme?

Appendix 12: Interview Questions for Primary Care Professionals

Questions for Primary Care Professionals.

Thank you for agreeing to discuss your role as a primary care professional.

Healthwatch Norfolk are conducting a three-year evaluation on how the Community Transformation Steering Group deliver the transformation of community mental health services. If you would like to ask any questions, please email: rachael.green@healthwatchnorfolk.co.uk

Any answers that you provide may be used in the final report, but your personal details organisation name will not be identified.

The purpose of the interview is to understand how mental health workforce roles are currently being recruited and integrated into primary care as part of the wider transformation of community based mental health services.

Your responses will be used in Outcome 5 of our evaluation report:

"Mental health workforces will report improvements in Community based services for adults severely affected by mental illness."

And towards our evaluation goals:

"Skilled Workforce - The Community Transformation Steering Group implement the development of a skilled workforce through delivery of a mental health workforce & training strategy."

"Integration - Mental health services are integrated into Primary Care; developing blended primary care and community mental health teams."

"Primary Care staff report that the blended mental health/primary care teams are working effectively."

We would like to record this interview and would like to ask your consent to proceed.

Please could you confirm the organisation you work for and your job role?

Workstream Progress:

Can you summarise how your Primary Care Network have been involved in the community based mental health transformation, regarding the recruitment of Mental Health Practitioners, Recovery Workers and Peer Support Workers into Primary Care?

What has worked well with the introduction of these new roles within Primary Care?

What hasn't worked well the introduction of these roles within Primary Care?

How do you think could this be improved?

How many Mental Health Practitioners, Recovery Workers and Peer Support Workers have been recruited to date in your PCN, and how many more posts are left to fill?

How will Recovery Workers be working with Mental Health Practitioners and Peer Support Workers to deliver mental health services within Primary Care for adults severely affected by mental illness?

What's working well with this model?

What's not working well with this model and how could it be improved?

What training and upskilling opportunities are being offered to these new roles? What training or upskilling do you think is needed for this role in the future?

Have these new roles evolved since the beginning of the Transformation, if so, how?

What are your PCN's priorities for the next 12 months regarding the recruitment, retention and management of these new roles?

Are there any plans to recruit a Clinical Associate Psychologist or Mental Health Specialist Pharmacist within your PCN?

Communication

Has the introduction of these new roles within Primary Care been widely communicated to the public, primary care staff and mental health staff?

Co-Production

Has the development and integration of these new roles been co-produced with people with lived experience and with wider partners when transforming services (for example: VCSE organisations, Norfolk County Council and Experts by Experience)?

Do you have any additional comments that you would like to make regarding the Community Mental Health transformation programme?

Appendix 13: Healthwatch Norfolk Recommendation Implementation Plan

Healthwatch Norfolk Recommendation Implementation plan					
Recommendation	**How will we implement this recommendation?**	**What will the outcome be?**	**Key deliverables**	**Time scale**	**RAG for progress**
Benchmarking progress using the **I Statements**	We will create a self-assessment toolkit which will be used for strategic planning and providers of services. The toolkit will benchmark how different parts of the system are meeting the I Statements and will identify where improvements are needed. The self-assessment will be repeated every six months to monitor progress and identify any ongoing gaps.	Evidential assurance to the people needing support for their mental health that services are meeting their needs as described by them. Periodical review of I Statements and self-assessment across the system will address any developing needs.	1. Have a refreshed set of I Statements for CT. 2. Strategic and operational leads to include which I Statements fit their work, as part of the monthly workstream updates. 3. Complete analysis of which I Statements fit to each workstreams and make recommendations where there are gaps. 4. Repeat the exercise six monthly.	1. November - Complete 2. Proposed deadline 31st March 2023. 3. Present findings to July CT Steering group. 4. Next self-assessment due July 2023.	
Ensure that **families and carers** are: 1. involved in the care of their loved one. 2. offered support 3. valued and their role is recognised.	We will hold a huddle focused on the needs of families and carers to identify how we can co-produce improvements, ensure the carers' voice is heard in strategic planning and the care of their loved one, and what support is needed and how their role can be more valued. We will also do a desktop exercise to explore what brief intervention initiatives are already in the system and whether this needs to be built on for people caring for people with SMI. This scoping exercise will need to take place first to help us form plans for improvement.	Carers will be empowered to provide appropriate support for adults seriously affected by mental health issues. There will be support available to them having an impact on their own mental health, and the value of their role will be recognised.	1. Hold a families and carers huddle. 2. Produce an improvement plan based on the findings of the huddle. 3. Implement the improvement plan. 4. Hold a feedback session to Steering group to present what actions have been taken and identify any changes in need.	1. Huddle to be held mid February 2023. 2. End of March 2023. 3. Working group to start implementation from March. 4. April Steering group - Complete.	

Strengthening **co-production** by: 1. co-producing plans from the beginning 2. embedding learning from the Rethink first year report 3. involving a wider range of stakeholders.	The CT Steering group will be re-launched in January 2023 with Experts by Experience co-chairing. This will allow co-production to take place earlier and ensure the voice of lived experience is heard at a strategic planning level. We will facilitate the separate groups of people with lived experience to come together into a collaborative forum.	Community Transformation plans will be truly co-produced and engagement with Experts by Experience and wider stakeholders will not just focus on getting feedback on plans already made.	1. Re-launch CT Steering group with EbyE co-chairing. 2. Embed recommendations from Rethink report into CT plans. 3. Facilitate Experts by Experience and other stakeholders to join together to work collaboratively. 4. Ensure co-production occurs from the beginning.	1. 10th January 2023 - Complete. 2. February 2023 - Complete. 3. February 2023. 4. Ongoing.	
Incorporating wider **VCSE** support into CT plans.	Develop a VCSE strategy within the system to outline how we can work collaboratively with VCSE providers to support adults with serious mental health issues. Ensure there is a range of VCSE membership at CT Steering group.	Patients will have access to a wider range of place-based support that is bespoke to their needs. VCSE sector will become an empowered part of the system with a voice in strategic planning.	1. Develop a strategy with system partners. 2. Widen range of VCSE membership at CT Steering group. 3. Identify funding to enable VCSE support within CT plans.	1. To be confirmed - Priority. 2. Complete 3. Complete.	
Integrating the **new mental health roles** with the wider system	New roles are in place with more being added. Work needs to be done to communicate the pathways into these new roles (particularly in primary care). We are developing a multi-disciplinary interface (Mental Health Integrated Community Interface - MHICI) to bridge the gap between primary and secondary care.	Patients will have access to mental health support at PCN level with reduced waiting times. There will be assurance that people will be seen by the most appropriate clinician the first time and access to wider ranges of support will be facilitated, meaning co-occuring issues can be addressed in a timely manner.	1. Soft launch of the MHICI to test the model. 2. Develop a plan to address the psychological 'missing middle'. 3. Develop a streaming process for MH PCN roles (to ensure people are receiving the right support from the right practitioner).	1. This is underway in each place. 2. This is underway as a workstream - Diane is leading. 3. This is in development with learning from the Suffolk model.	

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