healthwatch Norfolk

Community Based Mental Health Services in Norfolk and Waveney.

Year One Community Transformation Steering Group Evaluation

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

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 the Community Transformation Steering Group delivered with the transformation of community based mental health services.

How we did this

Healthwatch Norfolk created a five-outcome evaluation plan that involved engaging with adults severely affected by mental illness, their carers and support networks, Voluntary, Community and Social Enterprise (VCSE) organisations, primary care staff, Rethink Experts by Experience and members of the Community Transformation Steering Group to create this report.

What we found out

The results of the survey and follow-up interviews showed that adults seriously affected by mental health issues have not seen changes to their support and that the outcomes that they would like to see around involvement, trust, continuity, up to date care plans, involvement with family / carers and person-centred care are not yet being met.

The carers survey and interviews also showed that carers have not seen changes to the support for adults seriously affected by mental health issues. A lack of communication with carers makes it difficult for carers to provide appropriate support and adds to the pressure that they are under. Carers also reported that there is little support available to them, which has an impact on their own mental health.

The Transformation Steering Group have engaged well with Experts by Experience. This has been welcomed as a positive change. The Experts by Experience Reference Group has been established and have been engaged in a broad range of activities to support the transformation.

The voluntary, community and social enterprise (VCSE) sector have appreciated the regular information updates from the representatives of the steering group, particularly through the Mental Health Providers Forum. VCSE organisations believe

that the transformation plans are not co-produced and the role this sector could play, and the strength of their offer is not fully recognised or understood.

The early work to develop I Statements with adults seriously affected by mental health issues to identify the outcomes they want for themselves, has been overlooked in the transformation process. Keeping these outcomes at the heart of the transformation should ensure that the changes to community mental health services will help to achieve these outcomes.

The rehabilitation pilot is an excellent example of multi-agency working including the early planning stages. This is a good template for other transformation initiatives.

The Transformation Steering Group have not communicated their plans or successes well, particularly at an operational level and how the changes are expected to make a difference to adults seriously affected by mental health issues and their carers.

What this means

These findings reflect that although the transformation of community based mental health services are underway, the impact of any changes have yet to be recognised by adults seriously affected by mental health issues, their carers or stakeholders. There is more work to be done to achieve co-production around the transformation plans. Improved outcomes for adults seriously affected by mental health issues must remain at the heart of any transformation plan.

Recommendations

Outcome 1: The Community Mental Health Service Transformation Steering Group should use the I Statement outcomes as the benchmark for the transformation process.

Outcome 2: 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.

Outcome 3: The Community Transformation Steering Group must ensure that the plans are truly co-produced and that engagement with Experts by Experience and wider stakeholders is not just focussed on getting feedback on plans already made.

Outcome 4: Seek ways to incorporate wider VCSE support to adults with serious mental health issues into the transformation plans.

Outcome 5: Support the development and integration of the new roles (for example: Mental Health Practitioners and Recovery Workers) into the wider system.

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 with the transformation of community based mental health services in Norfolk and Waveney. Between April 2021 and March 2022 there were approximately 9124 people registered with doctors' surgeries as being severely affected by mental illness (NHS Digital Quality and Outcomes Framework, 2022) receiving or waiting for treatment and care in Norfolk and Waveney.

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.

This project is a three-year evaluation, which should be completed by the end of March 2024. This interim report covers the period from June 2021 - June 2022. This report is looking what happened within the first year of the programme. It should be noted that large-scale change can take years to achieve, therefore this can limit how much change will occur in the first year of the transformation.

In the first phase of the project, we focussed on five outcomes:

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 in community based services and support
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.

Due to a delay in rolling out the Rehabilitation Pilot part of the community mental health transformation, Healthwatch Norfolk will be evaluating its progress in year two of our work, after the pilot begins in August 2022.

Throughout this report, we have used some terms that are commonly used by members of the Community Transformation Steering Group, and they are explained below:

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.

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.

How we did this

We have engaged with the Community Transformation Steering Group throughout this project, with the Project Lead from Healthwatch Norfolk, Rachael Green, attending the steering group meetings. An evaluation plan was presented to the steering group in February 2022, which was agreed and approved by the steering group. A copy of the evaluation plan can be found as appendix 1.

Early in the transformation process eleven "I Statements" were developed by Norfolk and Suffolk Foundation Trust (NSFT) in consultation with service users and carers through a series of engagement events across Norfolk and Waveney. They were created through discussion during the Autumn 2020 and Spring 2021, involving:

- Access Community Trust's LEAF Group (Lived Experience Advisory Group)
- Carers of adults severely affected by mental illness
- The Community Transformation Steering Group
- Workshops held in January 2021 with adults severely affected by mental illness

The statements were drafted to show the outcomes that people severely affected by mental illness wanted to achieve. The I Statements informed the development of the Community Mental Health Transformation Strategy and are the basis of Healthwatch Norfolk's evaluative framework.

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.

Feedback for the five Healthwatch Norfolk evaluation outcomes was collected via two qualitative methods: surveys and interviews.

Outcome	Qualitative Research Method
One Adults severely affected my mental illness	Survey (n= 221) 1:1 Interviews (n= 10)
Two Carers of Adults severely affected my mental illness	Survey (n= 58) 1:1 Interviews (n= 3)
Three Steering Group and Co-production	Survey (n= 5) Joint Interview (n=2) 1:1 Interview (n=1)
Four VCSE and 3rd Sector Organisations	1:1 Interviews (n=9)
Five Mental Health and Primary Care Workforce	1:1 Interviews (n=3)

Outcome One and Two

Surveys for Outcome One and Outcome Two

Healthwatch Norfolk compiled two surveys with a series of questions to get feedback from adults severely affected by mental illness and carers of adults severely affected by mental illness. Online surveys were deemed the best way to collect information to allow for as wide a reach as possible, and to ensure consistency and ease of analysis. The survey was co-designed with Rethink Mental Illness and members of their Expert by Experience Reference Group. This was to ensure that we asked the right type of questions, covered relevant themes and topics, and used the correct language in our surveys. The survey was based on themes from the I Statements.

We ensured that we reached each of the Community Transformation Steering Group's priority cohorts for their year one work (Eating Disorders, Personality Disorders and Rehabilitation) by gathering information about the type of mental illness each survey respondent reported living with, in the demographic section. This information was given voluntarily, and it was not compulsory to fill in this information.

Both surveys were available online through SmartSurvey, in paper form and easy read. There was also the option to call Healthwatch Norfolk so that either survey could be

completed over the telephone. This was to ensure that those who may be digitally excluded had the chance to take part.

The survey related to adults severely affected by mental illness ran from 1st February to 31st May 2022, totalling 221 responses, which were mostly received online.

The survey related to carers of adults severely affected by mental illness ran from 1st February to 31st May 2022, totalling 58 responses, which were mostly received online.

Both surveys were promoted via Healthwatch Norfolk's social media channels (LinkedIn, Facebook, Instagram, and Twitter), Healthwatch Norfolk website and newsletter, via Community Development Officers, through local charities and third sector organisations, the Mental Health Providers Forum and via a survey link on Footfall.

Public involvement and Consent

Participation in both surveys was entirely voluntary and anonymous, however, to complete the survey participants had to give their consent for their answers and feedback to be shared. If participants wanted to leave more in-depth feedback or leave any comments on the survey itself, they were advised to contact Healthwatch Norfolk at: enquiries@healthwatchnorfolk.co.uk

Respondents were also asked if they wished to give their consent for us to contact them for an interview.

Survey Data Analysis

Both surveys comprised of a range of question types (including multiple choice, closed-ended, and open ended), so analysis was broad to reflect this spectrum. Answers where respondents could type their own comments, were analysed thematically in NViVO. This enabled participants' free text responses to be coded to establish themes, which are reflected in this report. Comments in this report are direct quotes from survey respondents and these have been left unchanged to ensure originality. Percentages in this report are rounded to the nearest whole number. A copy of the survey questions can be found as appendices 4 and 6.

Interviews for Outcome One and Outcome Two

Outcome One - Adults Severely Affected by Mental Illness

To obtain more in-depth information and opinions regarding the experiences of community based mental health services by adults severely affected by mental illness and carers, Healthwatch Norfolk conducted ten one to one, semi structured interviews

with the adults severely affected by mental illness and three one to one interviews with carers online via MS Teams.

Healthwatch Norfolk contacted adults severely affected by mental illness and carers that indicated in the survey that they were willing to be contacted, offering the opportunity to be interviewed. A total of thirty adults severely affected by mental illness and ten carers were contacted for interview. Those who did not respond to the email were not followed up as we assumed that they no longer wished to be interviewed.

This method enabled more detailed data to be collated through open-ended responses from participants and provided an opportunity for Healthwatch Norfolk to learn about local experiences of community based mental health services in more depth. The interviewer had a list of broad topic areas and questions that mirrored the contents of the relevant online survey, to cover during the interview process.

Interview Data Analysis

The interview transcripts from outcome one and outcome two were analysed using thematic analysis in NViVO and the themes are reported in the 'What we found' section of this report. A copy of the interview questions for either outcome can be found as appendices 3 and 5.

Outcome Three

We sought to monitor progress of the Community Transformation Steering Group through attendance at the Steering Group meetings and by monitoring the minutes. Our evaluation plan also included holding a session with the Community Transformation Steering Group to link their actions and workstreams to outcomes for service users based on the I Statements. However, we were unable to hold this session as when we asked about the I Statements in January 2022, we found that these were in the process of being refreshed with the Experts by Experience.

Healthwatch Norfolk wanted to understand if partner organisations within the voluntary and community sector believed that they were involved in the community mental health transformation process and able to influence the plans. We did this through interviews with individual organisations and through attendance at the Mental Health Provider's Forum. 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 from them at the interviews.

We wanted to understand the level of co-production 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.

Co-production is a way of working that "involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation. Co-production acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality, and to maintain a person-centred perspective." (NHS England and NHS Improvement and Coalition for Personalised Care, 2022).

Survey (Co-Production)

Healthwatch Norfolk and Rethink created an online survey to find out what each of the Experts by Experience thought about:

- their involvement with co-producing the mental health transformation workstreams
- how valued they felt by the Steering Group
- how supported they felt by Rethink to be able to carry out this role
- any barriers they face to taking part in co-production work

Healthwatch Norfolk worked with Rethink to co-design this survey as they wished to get feedback on their own performance and it was not appropriate to ask the Experts by Experience to complete two separate surveys, which would have had similar themes. Healthwatch Norfolk posted the survey on SmartSurvey and it was available to the Experts by Experience for six weeks between April and May 2022.

The responses were anonymised, and any identifying data was removed by Healthwatch Norfolk, before sending it to Rethink. Rethink used the results to analyse their own performance.

Those Experts by Experience that completed the survey, expressed an interest in participating further with the project and consented to being contacted to talk about their experiences in more detail were contacted to be invited to an interview. In total, three Experts by Experience agreed to be interviewed.

Interview (Co-Production)

Healthwatch Norfolk conducted one joint interview with two Experts by Experience and one 1:1 interview to explore their experiences of co-production. Whilst the pre-set questions were asked in a particular order, their open-ended nature encouraged a conversation to develop amongst the interview participants. Participants were asked about their experiences of co-producing the plans for transformation of community based mental health services. The semi-structured interview questions can be found in appendix 8. Both interviews were held online and recorded using a Dictaphone, with prior consent from the participants.

Joint Interview Analysis

The interview transcripts were analysed using NVivo and through the thematic analysis of the responses. The interview themes are reported in the 'What we found out' section of this report. A copy of the interview questions can be found as appendix 9.

Outcome Four

Healthwatch Norfolk engaged with the voluntary, community and social enterprise sector (VCSE) through the Mental Health Providers Forum, which meets monthly. Healthwatch Norfolk gave a short presentation at the February meeting about the evaluation project and how the VCSE sector could get involved.

We identified and contacted key stakeholder organisations and invited them to an interview. Healthwatch Norfolk interviewed nine voluntary and community groups that support people severely affected by mental health issues. We have anonymised the organisation names in the report to encourage open and honest feedback from them at the interviews.

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 increasing Covid-19 rates, this was more difficult than anticipated. Healthwatch Norfolk attended three Primary Care Network meetings and interviewed two Primary Care Managers on a 1:1 basis. We will continue to connect with local Primary Care Networks (PCNs) in year 2 of the evaluation.

Limitations

There were some limitations in collecting data and feedback for this evaluation.

For outcome one and two, the recruitment of participants for interview meant that the sample were self-selecting because they responded to requests for interview through the online survey. The survey was available as a paper-based version, but all the participants who wanted to take part in interviews expressed this through the online survey. Whilst we ensured that our survey was available in paper form, all our responses were received online. This may mean that the results are biased towards more digitally confident members of the public.

Healthwatch Norfolk received a high response from adults severely affected by mental illness 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 when people who are severely affected by serious mental health issues may struggle to engage. We invited respondents that expressed an interest in talking to us and continued interviewing until we had sufficient feedback.

Within the survey, we invited respondents to tell us about any mental health diagnoses they have been given to make sure that this evaluation heard from all the steering group's priority cohorts. In year one, the priority cohort workstreams were Eating Disorders, Personality Disorders and Rehabilitation. Five survey respondents skipped this question. Healthwatch Norfolk publicised the survey for adults severely affected by mental illness extensively to ensure that each cohort was listened to.

In outcome three, we had a small sample size. 5 out of 12 Experts by Experience completed our survey, a 42% response rate. Despite the survey being presented to the Reference Group, the small sample size could be due to a number of reasons, for example: people becoming fed up with completing surveys, the nature of the survey (co-producing the transformation of community mental health services) or being too busy. We were able to interview three Experts by Experience. Again, this is a low response rate (25%). 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.

Within outcome five, Healthwatch Norfolk were only able to engage with three Primary Care Managers. Due to the reorganisation of Norfolk and Waveney

Clinical Commissioning Group into an Integrated Care Board (ICB) and increasing Covid-19 rates, engagement with primary healthcare professionals and Primary Care Networks has been difficult, due to time constraints. 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.

What we found out:

Outcome 1: Adults severely affected by mental illness

Who we received feedback from

Survey responses

The survey received responses from 221 adults severely affected by mental illness (SMI). The most common condition that respondents had been diagnosed with was severe depression with 56% (120) of respondents. The diagnosed conditions of respondents are presented in Figure 1.

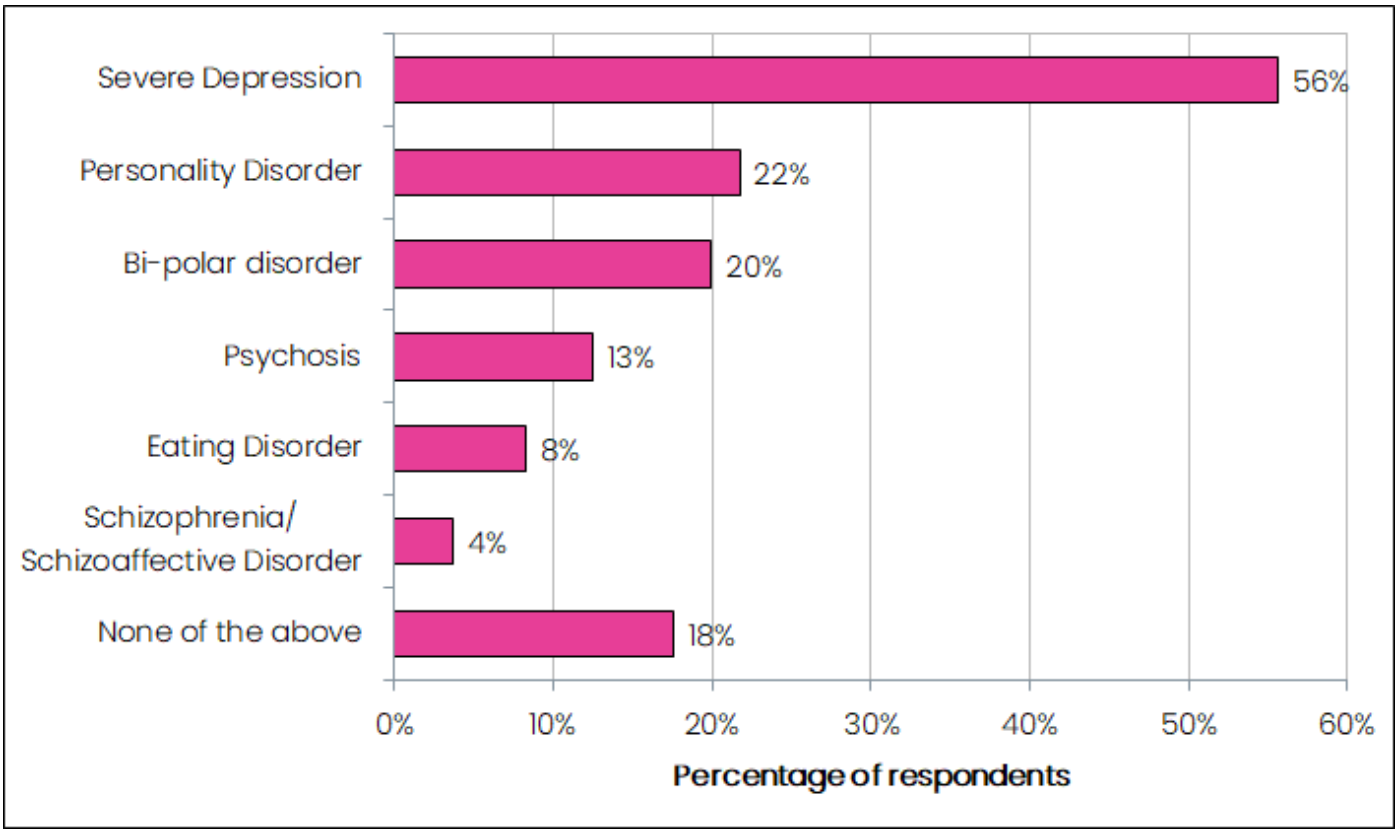

Figure 1. Responses to the question "have you been diagnosed with any of the following conditions". Respondents were able to select more than one option.

The age distribution of respondents is displayed in Figure 2. The most common age category was age 46 to 55 with 27% of respondents (58). No one who responded was over 85 years old and one respondent chose "I'd rather not say"

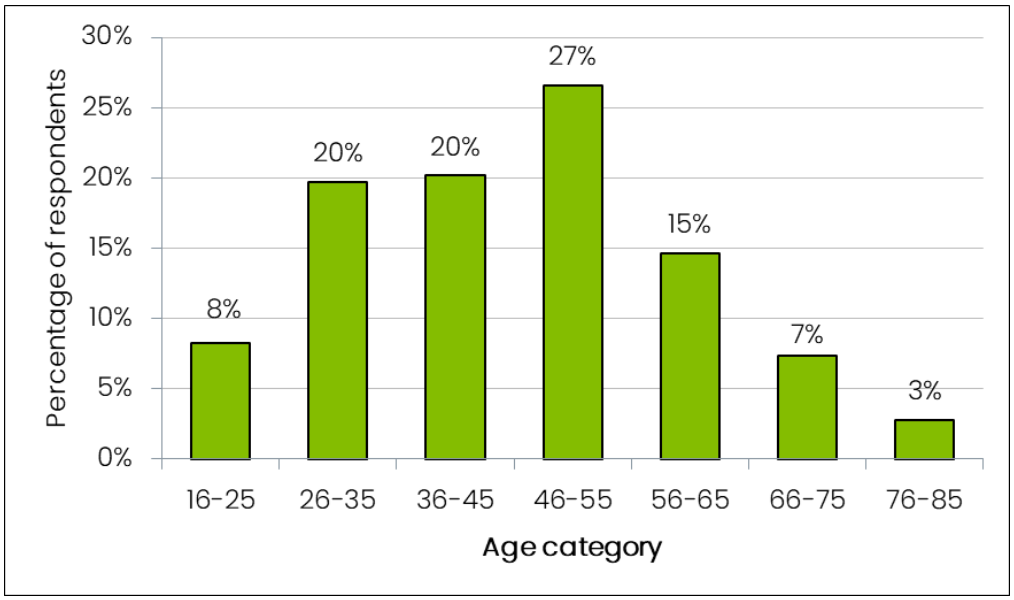

Figure 2. Age distribution of respondents.

Healthwatch Norfolk asked survey respondents some questions about themselves and their life to help us make sure that we engage with people from different backgrounds in every project that we complete. Most respondents to this survey were female (71%, 156), while 24% (52) were male, 1% were trans women (3), 1% were trans men (2), 1% were non-binary (2), 2% of respondents shared that they would rather not say (5). Two thirds of respondents told us that they considered themselves to have a disability (67%, 146), 26% (57) told us they did not have a disability, and 7% (15) preferred not to say.

Most respondents told us that they are heterosexual/straight (70%, 149). Other responses included queer, asexual, and sexually fluid. Most respondents shared that their ethnicity was 'White British' (90%, 192). Other ethnicities with less than 1% (1) of respondents for each were 'White and Black Caribbean', 'White and Asian', and 'Indian'. In addition to this, 3% (6) shared their ethnicity as 'Other' (including "*English*", "*White Jewish", "Mixed ethnic group", "British American Jewish",* and *"White American (Caucasian)")* and 6% (12) said they would rather not say.

It is also worth noting that in the answers across this question it appeared that some respondents had no contact recently with mental health services in Norfolk such as being on waiting lists, or that their experiences may have been several years ago.

NHS care plan

Only 22% (49) of respondents told us that they had a current NHS care plan, while 54% (120) told us they did not and 24% (52) shared that they were unsure. Respondents who were age 45 or under were slightly more likely to tell us they had a care plan (29%, 38) in comparison to those over 46 (16%, 18). Respondents who told us they did not have a disability were more likely to tell us they did not have an NHS care plan (60%, 34) compared to those who disclosed having a disability (50%, 73).

Respondents who told us that they had a NHS care plan were asked how useful they found it. Over half of these respondent shared that they found it 'not useful' (53%, 26) while 31% (15) found it 'ok' and 16% (8) found it 'useful.

Respondents were asked to explain why they chose their answers. Five respondents provided a comment on why they found their care plan 'useful'. Reasons why it was seen as useful included that it is "*helpful to have an insight of the treatment you are receiving or will be receiving*".

"My care plan was written with me and I was able to read it through before it was finalised to make sure that it met my needs. It's tailored specifically to me."

Reasons why respondents' care plans were seen as 'ok' included that "*its ok, pretty bland*", it was not kept up to date, and that it was "*more helpful for people looking after me, in noticing behavioural warning signs and triggers*".

For those who told us that the care plan was 'not useful' reasons largely centred on respondents seeing the care plans as being inadequate. This included the plan not being kept up to date (for example: out of date telephone numbers) and not updating as their mental health needs changed. Some also told us that their care plans were not used, they are "*kind of just left and then dug out when someone's due to look at it*".

One interviewee reported that although they have a positive relationship with their care coordinator, they don't think their coordinator has the time to keep their care plan regularly updated.

I get on very well with my care coordinator, but that was the first time it had been updated in two years. I don't think that's okay. I think that my care coordinator doesn't have the time, and I totally get that because I know how much work they have on, but that's not okay when it comes to what I need in my care. So that's still an issue where they're not getting updated regularly enough.

Involvement in care

Respondents were asked about how included they feel in decisions about their own treatment and care, responses to this question are displayed in Figure 3. As the graph shows only 21% (46) of respondents shared that they felt very included in making decisions. It is worth noting that male respondents were slightly more likely to feel 'not included' (50%, 26) when compared to female respondents (38%, 59).

Alongside this, those who considered themselves to have a disability told us they felt 'not included' more frequently (43%, 63) than those who did not have a disability (30%, 17). Finally, in addition to this, those aged over 46 were slightly more likely to feel very included (27%, 30) compared to those under 45 (14%, 15).

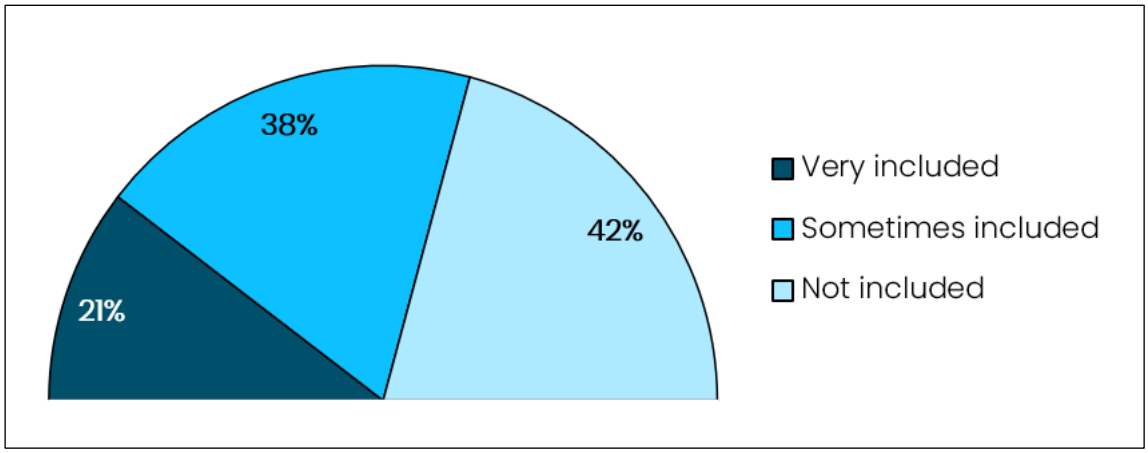

Figure 3. Responses to the question "how included do you feel when making decisions about your own treatment and care?".

Respondents were asked to explain why they chose their answers. For those who felt included in decisions they mentioned how they felt listened to and that they were involved in discussions around their care: *"we discussed what would work for me"*. Others mentioned how they were "*consulted throughout and care received is constantly reviewed*".

On the other hand, those who did not always feel included in decisions about their care mentioned that they felt that when they did express their opinions professionals had "*no real interest in listening to the patient perspective",* that they "*don't feel my own viewpoints are respected enough*", some shared that they felt they had to *"beg to be seen*".

Others mentioned that they felt there were no options offered to them, that "*they tell you what they'll do, but you can only take or leave it"*. In particular feeling like there "*never seems to be any treatment options except drugs*". Linked to this, one respondent did highlight they did feel listened to, but their involvement was limited by constraints *"because services are so limited there's needs that can't be met so it makes me feel less in control of my care/able to meet my care needs"*.

Some respondents also shared how decisions were made without the opportunity to have any input, that "*meetings are held to decide what to do with me but I am not asked to attend*". For some respondents these decisions may result in them being discharged from services:

> Initially I was contacted by the mental health team and a care plan was put together for me, however after a number of weeks, but only 2 phone calls, I was "dropped" by the same team and passed to recovery college. This was 'done to me' as I had no say over this and was definitely not ready to engage with the recovery team which led to further self harm and the feelings of complete loneliness.

Respondents were then asked whether anyone within Community Mental Health Services have asked them about their care and how they feel they've been treated. Over three quarters of respondents told us that they had not been asked (76%, 169) and 10% (22) were unsure. Across comments on this question, some respondents told us that they did not feel like their feedback was listened to or taken seriously. Others noted that they may not have been asked directly but they *"offer this information freely when I am able*". It is also worth highlighting that some respondents told us that they did not have any contact at all with Community Mental Health Services, it is unclear in these responses whether they are service users or not.

When asked "Is your family, someone close to you or an advocate involved in your treatment and care as much as you would like?" a quarter of respondents said 'yes' (25%, 56) while 35% (79) answered 'no' and 11% (24) were unsure. It is also worth noting that 28% (62) of respondents said that this question was not applicable to them for reasons such as having no family or friends or not

wanting them involved in their care. It also appeared that some respondents said that family and advocates were not involved as much as they would like but stated that they did not have or want anyone to be involved.

It is worth noting that it was unclear in some responses whether services actively involved family and advocates or if service users chose to involve them themselves for example: *"because whatever is discussed between me and the mental health service I discuss openly with friends and family"*.

Finally, it should be highlighted that a few respondents commented that their family already struggled with their own responsibilities and they *"don't like to be a burden to anyone"*, for example one respondent shared that their "*husband is my registered carer but he is struggling with capacity himself and it has been very hard for him to access support for himself and the family"*. Others mentioned that they would like to have an advocate at their meetings: "*I think I might need an advocate in near future, but I think I should had one years ago".*

Involvement of carers of adults with SMI is discussed further in the next section: "What we found out: Carers of adults severely affected by mental illness survey".

Contact with professionals

Most respondents to the survey told us that staff at Community Mental Health Services often or sometimes (72%, 144) treat them with kindness, dignity, and respect as displayed in *Figure 4*. It is worth noting that some who selected 'never' told us that they had not had contact with the service at all (9%, 18).

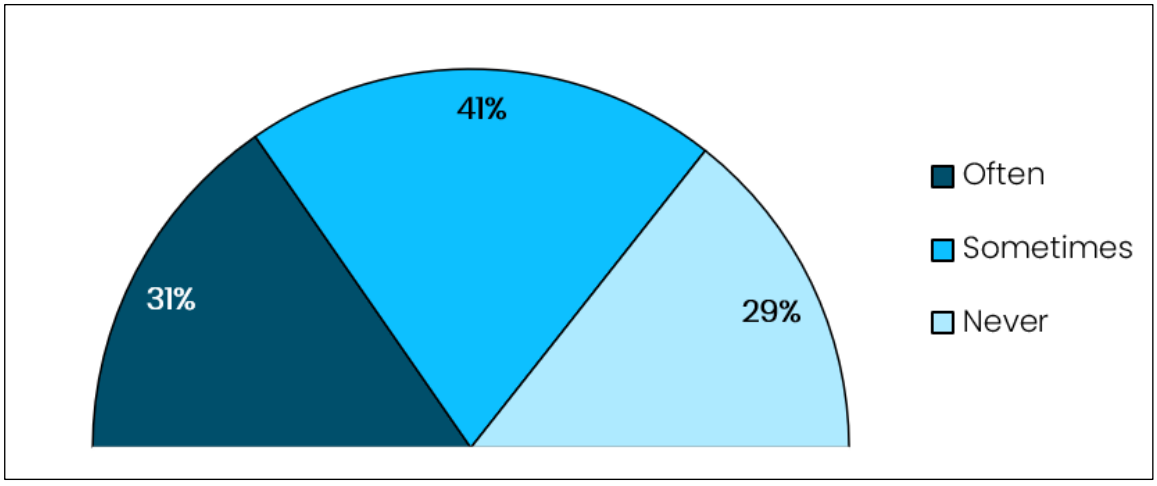

Figure 4. Responses to the question: "How often do Community Mental Health Services staff treat you with kindness, dignity and respect?"

Respondents were given the opportunity to explain their answer, those who told us they were often treated with kindness, dignity, and respect told us that they

were friendly, understanding and *"always very kind"*. Other respondents told us that *"over the years I've been treated very well"* and *"the people who I've met seem friendly"* and that *"there are some wonderful staff"* within community mental health services.

> "I have never experienced anything other than kindness, dignity and respect from my community mental health services they are all so lovely"

While those who were not always treated with kindness, dignity, and respect told us this was because their experiences varied depending on who they spoke with, with some staff "*lacking empathy*". Others noted that their treatment depended on the pressures the staff may be under which sometimes resulted in feeling they *"don't have the time for me"*.

Survey respondents were asked about their encounters with mental health professionals within community-based services. For some survey respondents, the service they received from mental health professionals left them feeling disappointed, *"You should not be let down by the people who are supposed to care for you and then have to chase them to do their job."*

We asked what survey respondents thought about the professionals they had spoken to on the phone or attended appointments with and discovered that they thought staff lacked empathy towards service users, "they treat *me like a number not a person. I feel no one empathises with what I am going through,"* that there appeared to be a lack of. respect for the service user *"there's a lack of any genuine or sincere care. No concern for moving patients forward in a fully appropriate manner and an Insulting attitude towards patients."* and that some staff had been unhelpful with providing appropriate support," *I don't think they're very helpful. I get that they're understaffed and underfunded and everything, but it's just a bit rubbish, really. Like recently, with one of the referrals, I was speaking to this guy, and he basically just said because I'm not suicidal enough and that, that they can't do anything. And I sort of said to him-, "You want me to get to the point where I'm really bad, and then you'll help me.", "But what if I kill myself and it's too late?" And he was just like, "Well, it's just one of them things, really. That's how the system works."*

One interviewee described how they were asked to rate their wellbeing according to a scale between one and five during check in calls.

> Calls at the moment from the wellbeing service, check-ins, and they're basically…they've almost admitted as such, just basically checking that I'm not planning to commit suicide. And the constant, at the start of every call, "On a scale of one to five, how depressed have you been in the last two weeks? On a scale of one to five, how much have you been thinking about self-harm?"… and unfortunately, people's well-being doesn't really fit on a one to five scale sometimes.

One survey respondent reflected on the attitude of a receptionist situated in a local mental health hub who they encountered when trying to sort their mental health treatment, *"I rang up [the Mental Health Hub] and the receptionist was so snotty… She was nonchalant… she sounded like you're wasting her time. I've got no trust there. And I think it all stems from how the receptionist speaks to you."*

There were further reports of unhelpful and unprofessional mental health staff attitudes, with survey respondents describing the following experiences:

Unhelpful Staff Attitudes
Lack of support, empathy and patience.
Lack of respect for me.
Lack professionalism and organisation.
Just generally ignored, dismissed, unsupported despite repeated crisis throughout the year.
I would say my new Mental Health nurse comes across as not bothered/patronising.
Less practical support and empathy. The staff didn't engage. They literally sat in the office room on a phone.

One survey respondent revealed that they were accused of lying about their situation when they had approached the crisis team for support.

> I rang in a place of crisis, I rang the access team, which is the out-of-hours service, and I think it was someone who was on cover or maybe a locum. I think they were struggling to use the computer system, and they said that there was no record of me and that I was lying about being on the system. And then that was it, and the phone call was ended, which was not a good place to leave someone in crisis.

Another theme emerging from the survey responses was the perception of community mental health services being understaffed through staff sickness and leaving the Trust, *"things have gone from bad to worse. So many staff including doctors have left the Trust,"* services being overwhelmed by demand, *"staff are great but are too busy and pressured which can mean you lose touch with them at critical moments…service just getting busier all round recently",* and the effect this can have on a person's continuity of care.

A lack of staff and high levels of staff sickness have meant a lack of continuity in my care. Leaving me unsupported and having to fight to get the support I needed at a time when a social issue was extensively damaging my mh [sic.].

A shortfall in available mental health staff can mean fewer and shorter one to one appointments for service users, *"a reduction in staff levels meaning I see my Care Co-ordinator a lot less and she doesn't have the time she would want to spend supporting me, and others."*

Changes to designated coordinators of mental health treatment and care is something that isn't always clearly communicated to the service user, meaning that they risk being lost in the mental health system. One survey respondent spoke about trying to contact their care coordinator and being told that member of staff had left, without anyone letting them know.

> "Oh, well, she's not coming back, so we have to hire someone new."... Never heard from them. Kept calling and calling, and they said, "Oh, well, that's the wrong person. We've changed it to somebody else."

One survey respondent mentioned that they were aware of the staff shortages and were left feeling like a burden on the mental health service, when they asked for help.

I appreciate that things are especially difficult due to staffing issues and current demand however I have been made to feel like my case isn't severe enough to warrant treatment on multiple occasions and often feel like a burden on the service.

There were several reports in the survey of community mental health services in Norfolk and Waveney appearing overwhelmed and understaffed, as quoted in the table below.

Overwhelmed and Understaffed Services
Staff still seem very overwhelmed. Lots of sickness.
They always say they are understaffed and so appt [sic.] are cancelled.
Not enough people employed by them who can bring down waiting lists.
Overworked staff who don't have time to do what their job entails.
Over-stretched due to shortage of staff and increase in clients.
Lack of available treatment by suitable and fully trained professionals.
Lack of funding and people [staff] leaving Norfolk services.

Difficulty accessing mental health services and receiving updates about the status of their treatment and care has meant that some service users find themselves chasing referrals. One interviewee told us how they chased their treatment referral multiple times and still did not receive a clear answer.

> I was referred to someone who was on actual leave and then never came back to the job, so the referral was given to someone else. I had to call 4 times just to find out this information and then another few calls because nobody followed up with the referral. So, I finally got demanding and left a somewhat angry message and someone finally got in touch, but they weren't sure what to do it how to help, so nothing ever happened. Last time we spoke she was going to speak to my GP, but she never followed up and I just got tired of having to chase people up and never persued [sic.] it again.

Another interviewee discussed how there was a breakdown in communication between mental health staff and their doctor, leading to an interruption to their treatment.

> Sometimes, there's issues with information not being passed to the GPs, and that can be difficult. So, say if I need to access emergency medication or something from my GPs. For some reason, the last medication review hasn't been sent to the GP, so they're only going off old information, and it can be very difficult to get things sorted out.

When asked who their main point of contact was within the Community Mental Health Services, only 30% (66) of respondents chose one of the job role titles in the survey as displayed in *Table 1.*

Table 1.

Who is your Main Point of Contact?

Main point of contact	Percentage of respondents	Number of respondents
Mental Health Nurse	14%	32
Mental Health Practitioner	7%	15
Psychologist	3%	6
Occupational Therapist	3%	6
Psychiatrist	2%	4
Social Worker	1%	3

In addition to this, 33% (73) of respondents selected 'other', 22% (48) of respondents said that they were unsure, and 15% (34) chose not applicable. It is worth highlighting that the majority of those who chose 'other' indicated that they were not in contact with the service at all or did not have a contact. Other points of contact included GP or Doctors' Surgery (10%, 21 respondents) and Support Workers.

Respondents who had chosen one of the job roles or 'other' were asked questions about their experience with their main point of contact as displayed in

Figure 5, Figure 6, and Figure 7. These figures also display differences between responses from service users whose main point of contact was mental health nurses, mental health practitioners, and GPs or doctors' surgeries. It is worth noting that the number of respondents for each of these options were limited so caution should be taken when looking to draw any conclusions.

Figure 5 shows that nearly half of respondents (47%, 66) told us that they rated the organisation of their treatment and care by their main point of contact as 'bad', while 26% (36) rated it as 'ok' and 27% (37) as 'good'. Male respondents were slightly more likely to rate organisation as 'bad' (55%, 17) compared to female respondents (43%, 43). Mental health practitioners were seen as 'good' more frequently (47%, 7) than mental health nurses (16%, 5) or GPs and doctors' surgeries (38%, 8).

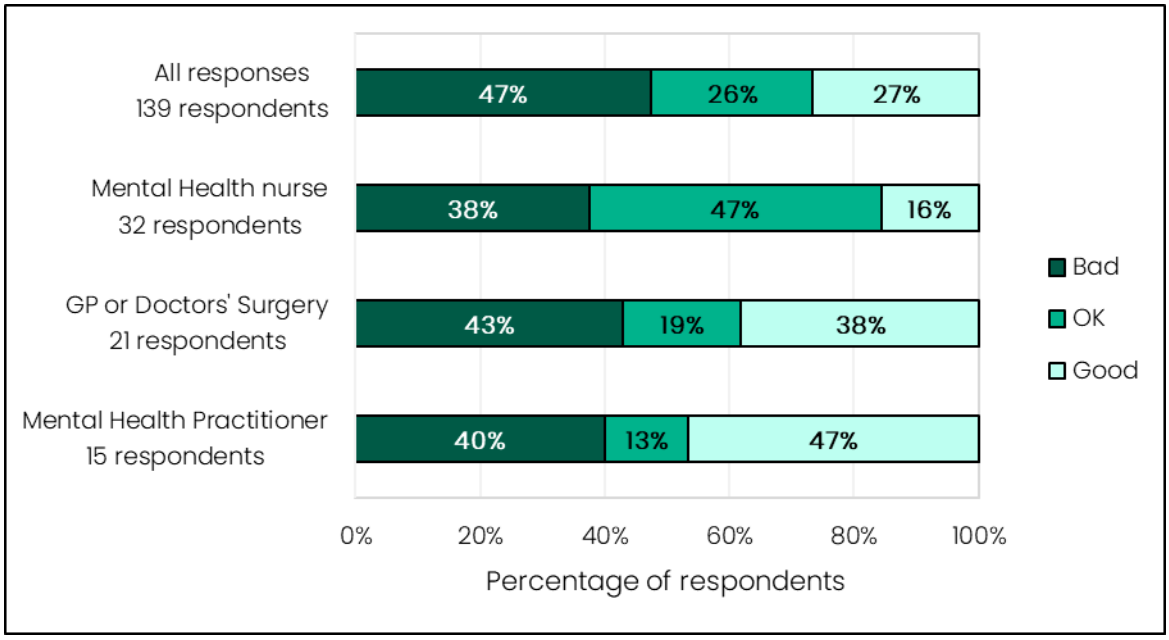

Figure 5. Responses to the question "how would you rate the organisation of the treatment and care you receive from the [main point of contact]?"

Reasons that an organisation was seen as good included when staff would listen to service users and kept in regular contact with them.

On the other hand, reasons that organisation was seen as bad included cancelling appointments, lack of continuity of care, feeling like meetings were tick box exercises, and poor communication.

> "They forget to contact me. I have to chase all the time. I was contacted 2 weeks ago and was left with - I'll find out and get back to you. I've heard nothing and have chased twice and still not got back to me"

One of the reasons given that organisation was seen as bad was the lack of continuity of care, *"I needed one voice to really speak for me with all of these coordinated services"*. One Interviewee recounted the high number of mental health professionals they had to speak to, before accessing the right therapist, *"I had to share traumatic experiences with 9 different people before being able to speak to my assigned therapist. This was retraumatising and incredibly distressing."* Another interviewee commented how they felt *"passed around to frequent staff as no one was willing to help"*.

One interviewee described how they felt their treatment by community based mental health staff felt like a tick box exercise and how it could make service users feel invalidated.

> I think sometimes everything feels a bit tick-boxy, like the amount of times I've had to fill in a bloody thing to say... and then they give you a score on how depressed you are or how high anxiety you are. I think sometimes that makes you-- I feel like if someone didn't hit a high score with it, I feel like it could make them feel sort of like their feelings and what they're going through is a bit invalidated.

One of the reasons that the organisation of treatment and care was seen as bad was due to poor communication between mental health professionals and between primary, acute and secondary care services.

> There is poor communication between acute physical health hospital MHLT and secondary services... I think having duty workers is a good idea, but it would be good to inform patients about the changes, so they are aware, and don't fall through the cracks like I have.

From the survey responses, service users described how they were often left without contact from their mental health treatment coordinator and were often left waiting for someone to call them back, as shown by quotes in the table below.

Poor Communication
None, poor communication, poor continuity, need an allocated worker start to finish and promises fulfilled.
A massive setback in my mental health due to lack of contact and involvement.
I've not heard from my mental health worker for months.
Someone was supposed to ring me back, and that was about three months ago.
They were supposed to call me back, and I've just not heard anything, and I've just been dealing with stuff, so I've been too busy to chase it up... they're terrible. You have to chase everything.

One interviewee described how they rang their local mental health hub to speak to their support worker whilst experiencing a mental health crisis. They were asked to leave

a message because they could not be put through to their support worker and no-one from the duty team returned their call.

> There is a difficulty with leaving messages. You ring up and ask to speak to a support worker, and this is normally if she's just rang me and I've just missed her call. I ring up to speak to her, but they can't put me through to her. They'll then send her an email, by which time she's got it, she's then out of the office. Sometimes, I've rang up in crisis to speak to a member of the duty team, and they haven't rung back, so that just disappears. If they can't ring back that day, they don't ring back at all, and then you're just dropped off. No one catches up with that, which I think is a bit of an issue. I'm not someone that rings very often, so if I ring in crisis, I am in crisis.

Figure 6 shows that slightly more respondents do not believe that their main point of contact understands how their mental health needs affect other areas of their life (45%, 61) versus those who do (40%, 54). Male respondents appeared to be more likely to report that their main point of contact does not understand (58%, 18) than female respondents (38%, 37). Respondents whose main point of contact was their GP or doctors' surgery were less likely to believe that they understood this (29%, 6) when compared to mental health nurses (38%, 12) or mental health practitioners (43%, 6).

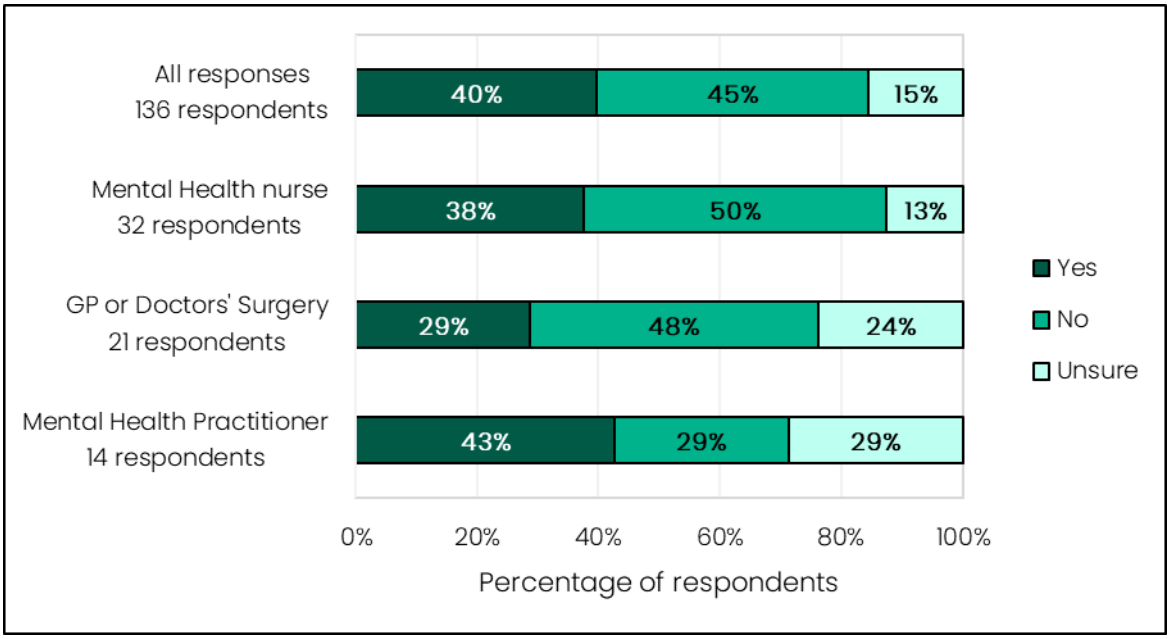

Figure 6. Responses to the question "does the [main point of contact] understand how your mental health needs affect other areas of your life?"

Those who shared that their main point of contact understood how their mental health needs affect other areas of their lives shared that they would listen and ask appropriate questions to find out more.

> "[Psychologist] is extremely understanding and takes time to listen and understand how my mental health affects all aspects of my day-to-day life."

On the other hand, when professionals were seen as not understanding this was because they were often seen as not listening, not asking, or ignoring the service user.

Figure 7 shows that most respondents told us that they had not discussed their NHS care plan or how their treatment and care is working with their main point of contact (57%, 78).

The graph shows that service users for whom GP or doctors' surgery were their main point of contact were particularly unlikely to have these discussions with only three (15%) respondents saying they had had these conversations. On the other hand, those where their main point of contact was a mental health nurse were more likely to have had these discussions (53%, 17).

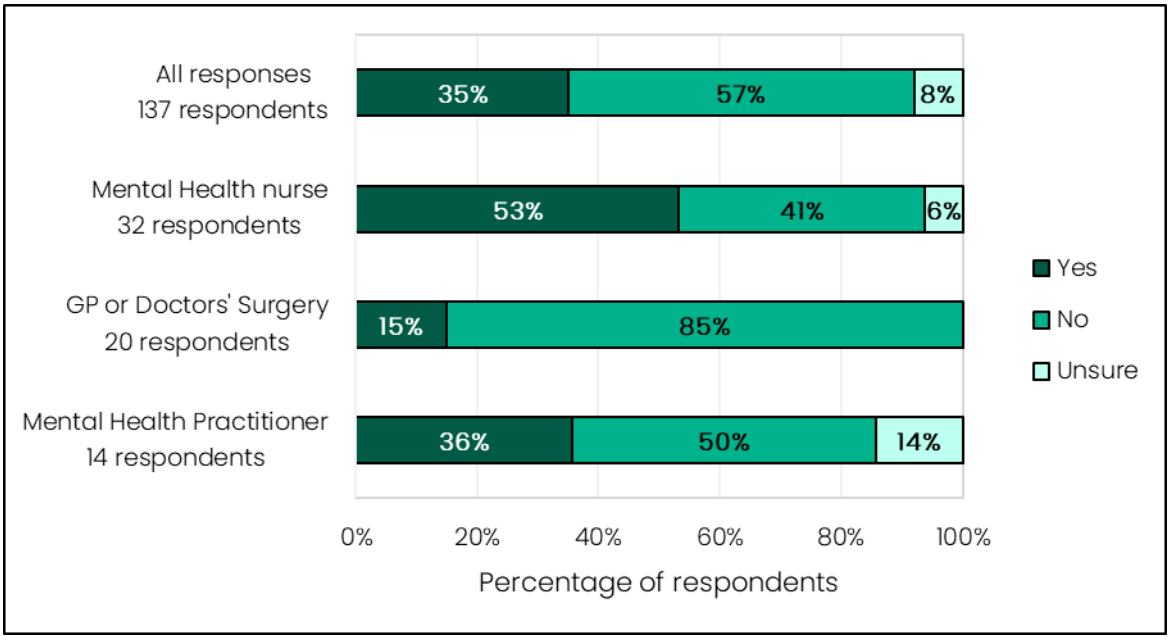

Figure 7. Responses to the question "in the last 12 months have you discussed your NHS care plan and how your treatment and care is working with the [main point of contact]?"

For those who answered 'no', reasons included that they did not see the point, or they had not been given the opportunity to have the discussion.

For some respondents who answered 'yes' their experiences were not positive, they said that *"we discuss things that never happen"* or *"a very one sided process where they just tell me what's happening"*.

Across responses to these three questions, some respondents mentioned the pressures that staff were under which made organisation and understanding difficult, for example: *"the team do not have capacity for the workload so it is not possible to provide continuity of care or have capacity for personalized care"*.

Services available to you

Over half of respondents (56%, 123) told us that they have needed to contact the Out of Hours Crisis Team in Norfolk and Waveney in a mental health crisis. Female respondents were more likely to have needed to contact the crisis team (61%, 95) compared to male respondents (40%, 21). Respondents 45 and under appeared to be more likely to have used the crisis team (65%, 68) than those 46 and over (48%, 54). Finally, respondents who told us they have a disability were more likely to have used the crisis team (61%, 89) than those who did not have a disability (44%, 25).

Of these respondents who had used the service, 62% (76) told us that the crisis team were not aware of their treatment history and NHS care plan.

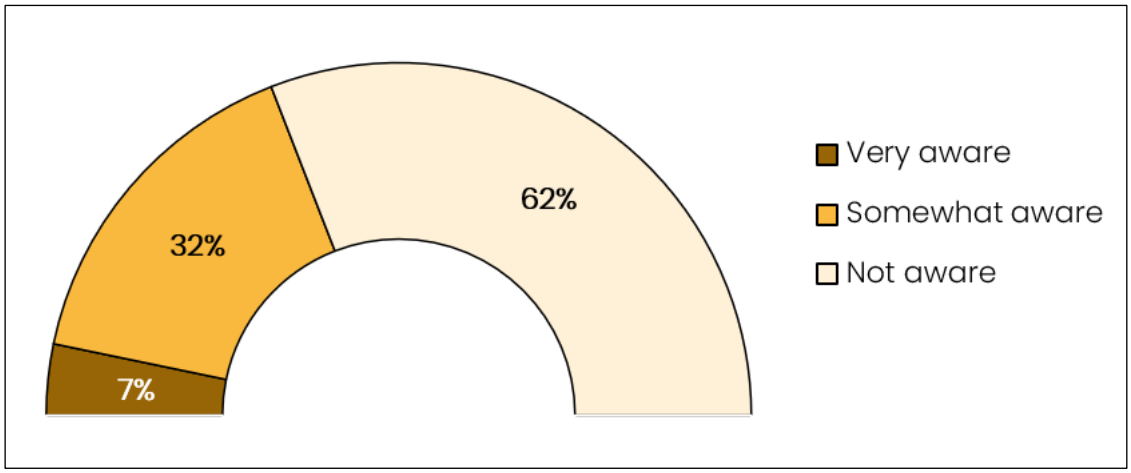

Figure 8. Responses to the question "how aware of your treatment history and NHS care plan were the Out of Hours Crisis Team?"

When respondents were given an opportunity to expand on their answer it is worth highlighting that, although not completely relevant to the question of treatment history awareness, the most common response surrounded service users not finding the crisis team helpful for them. It is worth noting that it was unclear in some responses whether they were commenting on the out of hours team or the crisis team more generally.

> I struggle to use the phone so am unable to contact them. No other access to them. They have phoned me and I've felt critisised [sic.], an inconvenience and an urgency to get me off their caseload. Daft temporary suggestions such as watching tv, especially when struggling to concentrate, or make a hot drink have been put forward. They don't call when they say they will and don't issue medication on time. There is no continuity. I always have to retell my story and there is no thought about my history.

As displayed in the above extract, one reason why respondents felt that the crisis service was not aware included no continuity of care, they told us that they would speak to different people, or their information was not shared: "*sometimes it feels like it's difficult to get continuity of care as you speak to different members of the crisis team*". Another reason was that they could not be found on the system.

For those who told us they were somewhat aware of their treatment history and care plan, reasons included the information the team had access to was not accurate or helpful:" they *were very aware however unfortunately it was full of mistakes, irrelevant information and an incorrect out of date diagnosis and so it was pointless."*, or that knowledge varied based on who they spoke to.

Figure 9 displays respondent's awareness of Community Mental Health services or support available to them. As the graph shows nearly half (48%, 107) of respondents told us that they saw their awareness as 'bad'. It is worth noting that this was slightly lower for those who told us they had a disability (42%, 61) compared to those who did not (58%, 33).

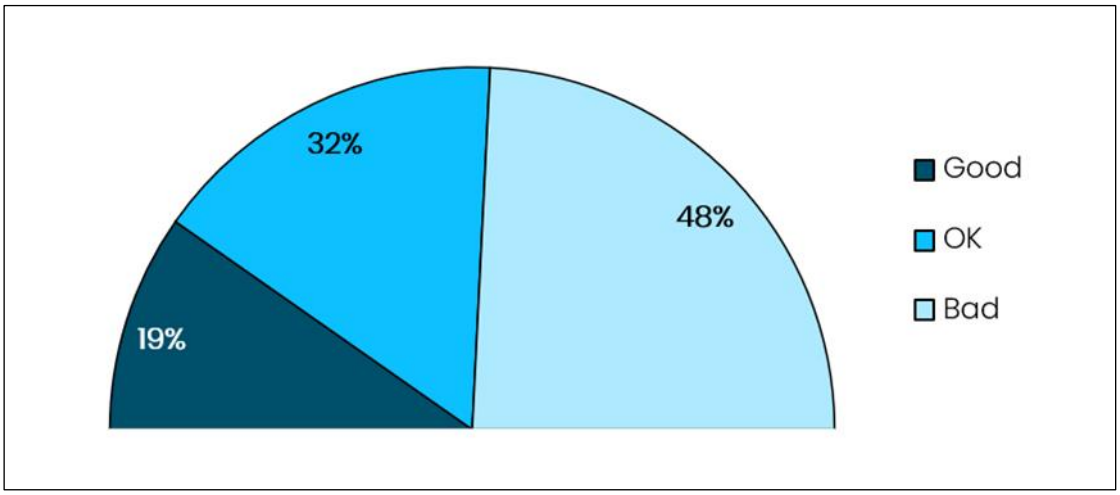

Figure 9. Responses to the question "how would you rate your own awareness of what Community Mental Health services or support is available to you?"

Across responses to this question some respondents told us that they had not been told about services which are available to them for those who had a 'good' or 'ok' awareness they shared that they had to find out about them themselves: *"now I've found them I understand fully, but the difficulty was that nobody made me aware of the services at all"*. For those whose awareness was 'bad' they told us that they *"have never been told about any support"*.

> "I moved into the area in October 2021 with a long-standing bipolar diagnosis and complex medication routine … I have no information at all about the support services on offer. I would not know what to do if I became unwell, apart from make an appointment to see my GP".

Other respondents shared that they felt communication about services could be improved and that *"resources aren't made easily available to find - there's things I would probably benefit from if I knew about them".*

Similar to the theme shown across this survey, some respondents again shared that they felt that *"there is no help"*.

Respondents were asked about the different types of support they may have had from the Community Mental Health Services in the last 12 months. The

options and the results are displayed in Table 2. Most respondents (77%, 167) selected 'none of the above'.

Table 2.

In the last 12 months did you receive any Community Mental Health Services support with any of the following?

	Percentage of respondents	Number of respondents
A physical health need (e.g. an injury or a disability)	11%	23
Joining a group or taking part in an activity	10%	22
Money or benefits advice	10%	22
Looking for or securing work (paid or voluntary)	3%	6
Finding or securing accommodation	1%	3

Those who had used these services were given the opportunity to comment on how helpful they found the support. One of the biggest themes that came from this survey question was the lack of support from mental health staff for signposting service users to relevant organisations and charities that could help them with: support for a physical disability, socialising, seeking benefits advice or finding accommodation, as shown by quotes in the table below.

Lack of Signposting Support from Mental Health Staff
Not very helpful, just given a list of phone NOS. [sic.] Or websites.
I have asked about next steps - volunteering and supporting me into work - there doesn't seem to be a system in place for this. I can't go from full on support to being discharged with nothing in place...
I've asked my care coordinator... now, she is, not trained or not up-to-date, and she's very honest about this, is that she doesn't understand or know anything about the benefit system.
It's failing greatly as not aware enough on benefits and groups etc to help people from being isolated.
They are unaware of the benefits systems so won't help with forms... I asked about activities and was sent an email with a range of social activities to try.

One interviewee told us how they felt at risk of being dropped from mental health services if they managed to find a job.

> I've recently just started to return to work, and this is something that's been an issue with me coming in and out of the services over the years, is that it's very much once you mention that you're ready to look at work, you're kind of dropped from the services. I've often found that when I return to work, it's incredibly stressful. It's a difficult period, and there's not much sort of plan for people around a transition of care. It's something I had to really battle for again this time about that. "Please, can you just hang on until I'm settled?" because there's often things that come up with working.

Changes to Community Mental Health Services within the last 12 months

Within the survey, Healthwatch Norfolk asked adults severely affected by mental illness about any good or bad changes they had seen to Community Mental Health Services within the last 12 months. The survey results reported 29 references from respondents in the comment boxes from adults severely affected by mental illness who thought that there has been no change at all to community based mental health services, as shown by the quotes in the table below.

No Changes to Community Mental Health Services
As bad as ever.
I have been in and out of community mental health service since 2015 I haven't seen really any good changes since that time it's all very much the same.
I've not heard from my mental health worker for months.
For me, nothing has changed, in regard to me being abandoned by the mental health service in Norfolk.
None.. im [sic.] given tablets and sent on my way.
It still feels like the same old inadequate service that it has been in the past.
No changes, same lack of anything as ever. Same for the last like 10 years.

There were 16 references to community mental health services becoming worse over the last 12 months, *"things have gone from bad to worse"* and *"it's gotten worse. I've been in the system for more than 20 years and I've never felt so alone. "*

In contrast to this, there were 12 responses in the survey from adults severely affected by mental illness saying that the services they receive from community mental health services have been *'good', 'positive'* and *'excellent'* over the past 12 months, as shown by quotes in the table below.

Positive Feedback about Community Mental Health Services
Psychological therapy offered over zoom has been excellent.
The only positive I can put forward is the introduction of video appointments as an option.
I've been able to keep the same care Co which hasn't been the case for the past 10 years so I'm happy.
Staff seem to be trying their best with what they have
The opportunity to take part in NSFT projects such as Hellesdon new wards and the clinical strategy development workshop is excellent.
Provision of a Psychologist for weekly Zoom sessions excellent [sic.]
I have seen very positive shift towards recognition of community resources, peer support and access to psychological interventions, which have been vital in my own journey, and been very encouraged by a shift towards more joined up services.
I have seen that more information is available and is accessible.
improved in the level of kindness and compassion they have given me which has helped me feel like I can trust them more were they have been harmful in the past.
Making more of an effort to co-produce participation with service users - e.g., interview panels e.g., clinical psychologists need to develop this though. like fact they are holding governance meetings in public.

For survey respondents that reported they had noticed bad or negative changes to community mental health services in the past 12 months, many of the themes they spoke about were the same as the themes mentioned earlier in the survey, including *'understaffed and overwhelmed staff', 'no access to services', 'lack of continuity of care'* and mental health services being affected by *'Covid-19'.*

There were 15 references to community mental health services being understaffed, *"it's a revolving door of staff and makes things very difficult".*

> Unfortunately, my experience with the mental health team has worsened over the last 12 months. I appreciate that things are especially difficult due to staffing issues and

current demand however I have been made to feel like my case isn't severe enough to warrant treatment on multiple occasions.

A further 15 survey respondents mentioned that there is little to no access to community mental health services, *"it's impossible to access services"* and "no *help even when desperate - getting an appointment with a proper qualified psychiatrist is impossible, literally harder than finding a speck of gold in a desert."*

Ten survey respondents shared how they believe COVID-19 has affected community based mental health services. The responses included: fewer appointments available, *"less appointments and shorter appointments, not based on need or discussion and agreement"*, no face to face appointments being offered, "*case managers are still getting away with no face to face, still blaming Covid"* and even longer waiting lists for treatment, "*got worse and I keep being told that the lists are higher due to Covid"* and *"over run since the pandemic, can't actually get help unless you are dangerous."*

Three survey respondents mentioned 'extremely long wait times' and this was echoed by a small number of interviewees who told us that they had turned to private treatment due to long waiting lists.

> "I've actually sought private therapy now which I'm paying for because I wasn't getting anywhere else. And that's been quite good, but I can't get any more appointments until June now because she's all fully booked up. I went private and they have done more for me in 4 months than the NHS could in over 2.5 years."

Healthwatch Norfolk asked adults severely affected by mental illness what improvements or additional support they would you like to see Community Mental Health Services offer. We received 176 responses to this question and the answers are summarised in the next table.

Improvements Requested for Community Mental Health Services
More support when leaving the services. Just because someone enters work or training doesn't mean they are 'cured' in fact it often brings a lot of new stressors and relapses are likely.
For [mental health staff] to see mental health as important as physical and not discharge people as soon as they are physically well.
More social support. More support from charities like Mind and less reliance on medication to solve issues.
Quicker response times to people who have tried to end their lives or in crisis.
More after support needed when person or person leave hospital.
Improve the support to patients and families with drugs and alcohol issues.
Clearer and more direct communication offered and to be given alternatives if a service can no longer be provided.
To feel more involved and have choices in my treatment plan as I often feel excluded from this too and have to accept whatever the team decide.
Greater staffing to meet demands.
Professionals talking to young people within the school, such as assembly and questionnaire or something. Caught early, awareness, teachers could learn more signs etc [sic.] Stop it getting worse.
More face-to-face appointments.
More benefits support.
A named care professional, and team who can help you... Support workers able to help for months rather than a few weeks ... Recognition that some conditions are long term and need long term support.
To actually write and share care plans. To include carers.
PTSD therapy and support.
Trauma based [informed] psychological interventions.
Better medication reviews.
To know what help I can get as I always get given the wellbeing service
To be given formal confirmation of why treatment cannot be offered and a clear explanation for this too.
More support with employment issues.
More support for people thinking of making a career in mental health.
Obvious information that there are services and how to contact them.
I would like to be treated as if my mental health and I matter.

The following case-study is based on an interview we conducted with an adult severely affected by mental illness and their carer who live in Norfolk and have been involved with community based mental health services.

Personal stories: Adults Severely Affected by Mental Health Illness

"Mike and Elaine's Story*"

Mike and Elaine told us about the difficulties they had accessing community based mental health services and how getting a diagnosis was hard…

Mike has been with his partner, Elaine, for about 12 years. Elaine has had mental health issues since she was a teenager, which were put down to depression and anxiety and treated with antidepressants.

Mike and Elaine felt that there had not been any real attempt to understand the reason for her mental health issues and as a result her treatment was "…. basically, kind of keeping her above a level of self-harm but unable to really socialise, work, live a normal life, experience things in a normal way…."

Prior to the pandemic, Elaine had been doing well and had come off her medication, however, the lockdown and issues at work had a negative impact on Elaine and she again contacted her GP for help. Although there was a response, Mike and Elaine's concern was that there was still no attempt to understand what was causing Elaine's issues.

Elaine eventually went to see a private counsellor who suggested that Elaine may have complex PTSD. Elaine and Mike informed the wellbeing service of this but did not get the response they had hoped "…. we were just told, "We don't do that. Your needs are too high. So if you're saying that that's the issue, we're going to have to close that case." So, "Okay, well what happens then?" Nothing. And to be honest, we just sort of then muddled through for about a year."

Following another crisis, continued attempts by Mike and Elaine to see a psychiatrist, and support from a local community hospital providing mental health services, Elaine was eventually seen by a psychiatrist, who diagnosed complex PTSD. Mike's frustration was that there had been a previous appointment offered at the hospital, which they were unaware of "it may have

been something that my partner was told over the phone. But of course, even at that stage when she was having some of these phone calls, she's disassociating, she's having memory problems, it's incredibly stressful. If that wasn't followed up with a letter or an email then if I'm not there to be with her for the appointment, she's not going to remember that. So I mean, they may have just forgotten to get the information to us altogether. But even if they have, if that was only verbally to my partner then that's not going to be enough."

He was also concerned that the wellbeing service was not a positive service for the individual "... the appointments themselves with professionals can be distressing and can instigate symptoms. She gets calls at the moment from the well-being service, check-ins, and they're basically-- and they've almost admitted as such, just basically checking that she's not planning to commit suicide. And the constant, at the start of every call, "On a scale of one to five, how depressed have you been in the last two weeks? On a scale of one to five, how much have you been thinking about self-harm?" All of those just sort of grind her down I think, and it can be very difficult and traumatic to deal with in and of itself."

Mike talked about the impact of supporting his partner and suggested how this could be helped "the amount of people you end up dealing with, the amount of appointments and letters can become overwhelming and sometimes feels like one point of contact and someone to take a little bit of the admin burden could be helpful as well."

Since Elaine has had her diagnosis, things have improved greatly "once you get through the systems and get to the person you need to, that's been fantastic. Everything confirmed in letters very quickly, made aware of where we are in the process, made aware with the medication review that if it isn't working we can change the dosage or we can go back and try something else, and that's an ongoing thing. So very much feel, at the moment, that things are going okay."

*** All identifying information has been removed.**

What we found out:

Outcome 2: Families and Carers of adults severely affected by mental illness

Outcome two of our evaluative framework aimed to find out if families and carers of adults severely affected by mental illness report improvements to community based mental health services and support for themselves. To explore this outcome and gather their feedback, we created a survey.

The carers survey received responses from 58 people. The age distribution of respondents is displayed in Figure 10. As the graph shows, the survey received no responses from any carers under the age of 36 or above 85.

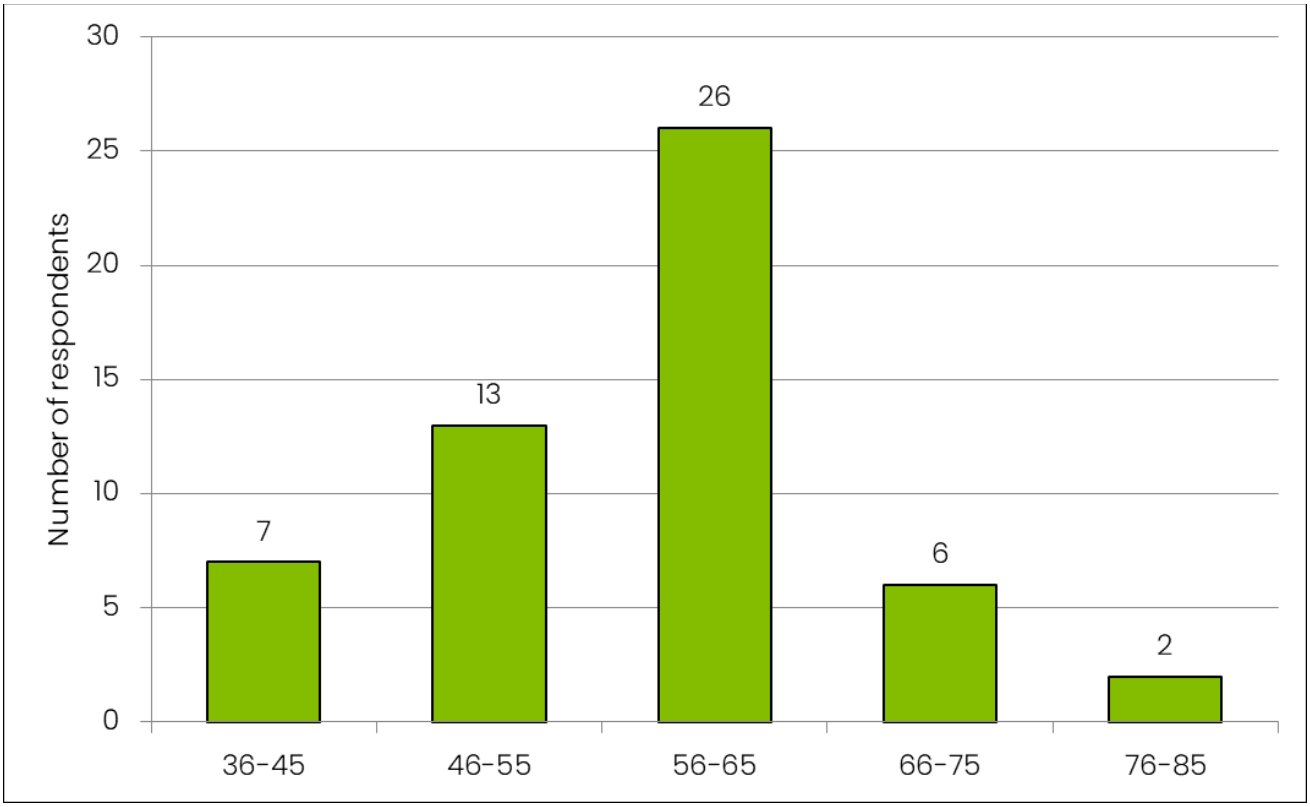

Figure 10. How old are you.

Healthwatch Norfolk asked survey respondents some questions about themselves and their life to help us make sure that we engage with people from different backgrounds in every project that we complete. Respondents were overwhelmingly female, with 49 respondents (89%). Only four respondents (7%) told us they were male and two (4%) preferred not to say. Most respondents were heterosexual or straight (40, 83%). One respondent (2%) was bisexual, and one respondent (2%) was pansexual, six respondents (13%) said they would rather not say. Most respondents told us they were White British (48, 91%), one respondent was White and Asian (2%). Two (4%) chose 'other' and two (4%) chose 'I'd rather not say'.

Over a quarter of respondents told us they consider themselves to have a disability (14, 26%), 38 (72%) said they did not have a disability, and one (2%) said they would rather not say.

Figure 11 displays responses to questions about carer involvement in the care offered by Community Mental Health Services. As the chart shows, carers most frequently reported not being involved in discussions and told us they are not kept up to date about the needs of the person they support or how they could change.

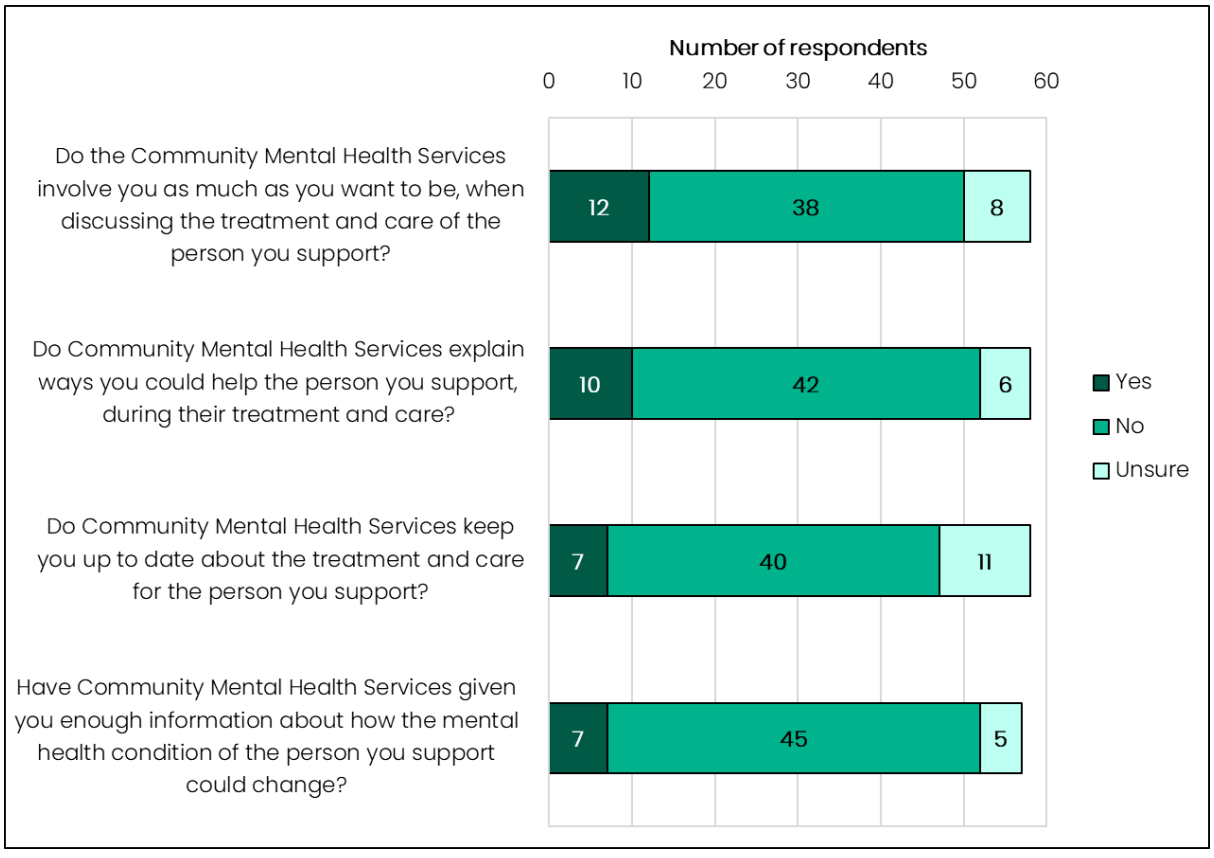

Figure 11. Responses to questions about carers involvement and knowledge of Community Mental Health Services.

For each of these questions survey respondents were given the opportunity to explain their answers. The overwhelmingly most common response across questions from carers was that they were not contacted at all or that there was "*no communication. Anything I have found out has been through my son, the patient*". This resulted in some carers telling us that "*neither of us feel 'kept in the loop' about what is happening or what the long term diagnosis/ treatment plan is".* This also resulted in them feeling unsupported "*I didn't know if I was helping or doing the wrong things"* and "*I feel I am left to deal with situations by myself especially in times of a mental heath [sic.] crisis".*

> "The care is patient led. That is understandable but does not take into account the views of the people living with them. Therefore it can be detrimental to the unwell person if they are only seeing things from their perspective. Other people are there to support but if we are not made aware of how or what to do it can do more harm than good."

The carers that we interviewed recognised that the person they care for may not always want them involved, but also identified that when consent is given it can make a huge difference to the individual.

> Luckily my partner's is in a position to help me with some of this stuff. There must be a lot of people in that situation who are on their own or isolated, and even if they get the right referral or they're able to articulate sometimes very difficult, very traumatic, very personal things, if they miss an appointment or they don't understand a letter or an email goes awry, and that can be that.

Alongside this limited contact, some respondents told us that they had experienced "*chaotic communication and no consistency in the information provided. No-one is contactable […] no-one knows where anyone is based or how to get hold of them. You can leave multiple messages and never get a reply*".

Other comments included how communication from the service "*depends on the worker*" for example in the following extract from one respondent.

> The psychiatrist has been wonderful- and involved me regularly. The lead care professional does not appear to have the skills to know how to include me- or appreciate my role, or how to deal with strong emotions and carer fatigue.

Finally, a small number of respondents did share positive experiences with how they were communicated with and involved for example: *"the team always have suggestions and ways to help move forward, they give advice to aid through difficult and happy times"*.

Linked to this, respondents commonly told us that they were often (11, 19%) or sometimes (18, 32%) treated with kindness, dignity, and respect by Community Mental Health Services as displayed in Figure 12. For some of those treated with kindness, dignity, and respect they shared this was when they "*listen to my views*" and they "*always they ask about the whole family, their health etc and offer support always*".

It is worth noting that some who chose 'unsure' or 'never' then explained that they themselves had not had direct contact with the service. Others reported negative and mixed experiences such as feeling "*patronised and an inconvenience*" and that they did not "*feel welcomed*".

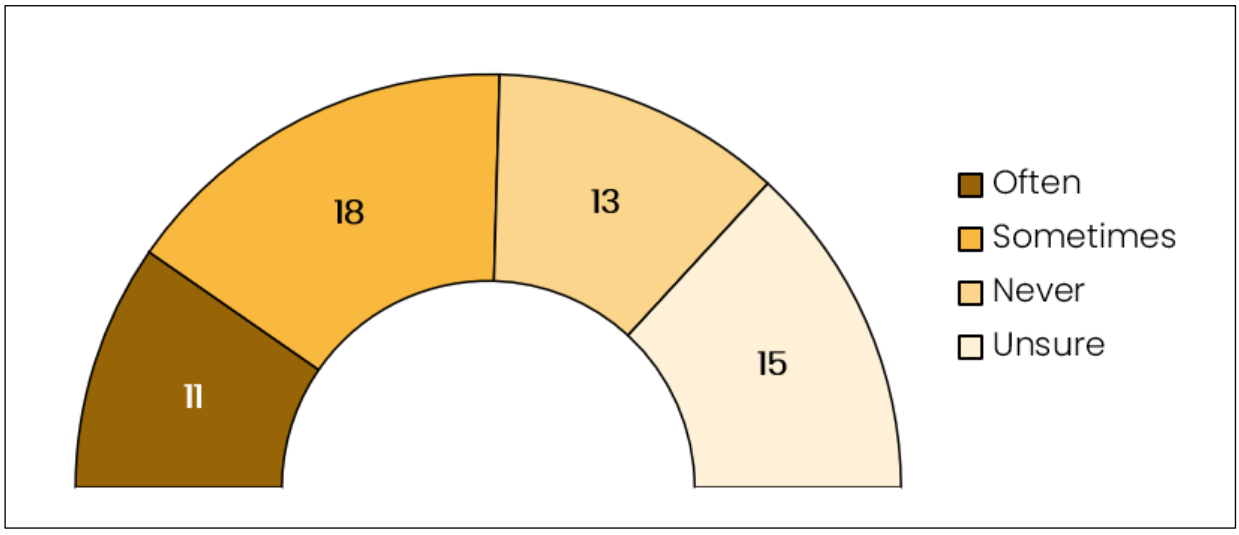

Figure 12. Responses to the question: *"how often do Community Mental Health Services treat you with kindness, dignity and respect?"*

Over two thirds of respondents (40, 70%) told us that as carers they have needed to find help or support for their own wellbeing. Table 3 displays where respondents were able to find help or support. 'Other' responses (18, 44%) included family or friends, private counselling, and support groups.

Table 3.

Where Respondents Have Been Able to Find Help or Support for Themselves

	Number of respondents	Percentage of respondents
Doctor	13	32%
Local Organisation (e.g. Carers Matter / Carers Together / Carers Voice)	7	17%
Community Mental Health Services	3	7%
Social Services	3	7%
Other	18	44%
None of the above	11	27%

One carer told us how limited the support is for carers of adults affected by mental illness and that they had to find the support for themselves.

> "Very little support [for carers]. I'm aware, through work, there is a carers support service in Norfolk. Again, I don't think I've had anything mentioned directly through the NHS or wellbeing with that."

Another carer described how they had received no support at all, *"I've not actually had any help whatsoever until we got referred to-- the crisis team intervened".*

During an interview with one of the carers, they spoke about how it feels to be a carer who hasn't received any signposting for support for themselves and has had to spend time researching it themselves.

It is a huge burden because, you then feel responsible for this person's life. And that's a big thing, it's a huge thing, with nowhere to go apart from helplines or charities, things like that… found through my own resource.

From the survey results, less than half of carers told us that they would know who to contact within Community Mental Health Services if the person they support has a crisis (28, 48%) or who to go to for support for themselves. 27 carers (47%) reported that they would not know who to contact if the person they support has a crisis and 3 carers (5%) were 'unsure'.

Good or bad changes

Carers were asked what good or bad changes they have seen to the Community Mental Health Services in the past 12 months. Some respondents used this opportunity to share what had changed for the person they care for in this time rather than the service in general, for example being assessed or accessing treatment. However, the most common response was that services had not improved, this included negative changes or that services had not changed at all.

Respondents shared that they felt access to services was difficult including "*long waits to be seen*" and that it is "*even harder to get in touch with anyone*" including that this carer felt "*there is no-one to contact in an emergency and then sadly the alternative is a&e [sic.] for the patient*".

Another concern raised by respondents was a lack of continuity of care and how this could impact the wellbeing of service users: *"think once you have support in place and the trust has been built that a person should be kept with the patient not to keep changing as this can set them back and trust has to built [sic.] again"*. This was linked by one respondent to a *"big turnover of staff"* and similarly another highlighted that "*the service is severely affected by shortages i.e. staff and bed placement in hospital"*.

Improvements needed

Respondents were also asked what improvements or additional support they wanted the service to offer. Respondents again mentioned that more resources were needed: *"would be good to have more people available as due to high demand on the services at present they are all a bit stretched"* and continuity of care here as well.

The most common suggestion for improvement was a need for a more holistic approach. This included not only focusing on the patient but to provide support for those around them such as carers and family: *"support for the carer as well*

as the patient as the carer is dealing with it and the effects on their mental health".

Others discussed how there needed to be "*support to take people with mental health out into the community to help them integrate back into society".* Suggestions within this included *"more groups for people to access for self-help and friendships"* and expanding *"Recovery College so it's in real life and online. Also put sessions around the county. Have OT sessions community patients can attend: cooking, gardening, crafts, physical exercise"*.

Other suggestions from respondents included a more "*proactive approach*" and more contact with service users in general that they need to "*check up on them, find out if they need support or help*". Another improvement suggested was a need for easier access to crisis support teams:

> There needs to be improvements when it is reported that a person's mental health has deteriated [sic.] and they are having a mental health crisis. Waiting for an appointment for several weeks to be seen is not good enough.

Any other comments

Finally, carers were asked to tell us anything else about the support they receive as a carer from the Community Mental Health Services. Over half of respondents who answered this question told us that they felt there was not any support for them or support was minimal.

Other comments included:

- That it "*would be a good idea if more info was sent to carers about more help, financially"*.
- *"Mostly it has been the occasional carers group (not great if you don't like groups) often at times which aren't necessarily easy to make. It doesn't feel as though support for carers is easily accessible".*
- *"As a carer the mental health services refer me to voluntary [sic.] or charity organizations".*
- That a carers panel would be a good idea: "*carers are a valuable assessment informant who are vastly undervalued and underused […] listen to carers the information they have can save lives and save money for the mental health trusts."*

- *"People are always kind and want to try help but there doesn't seem enough people to assist everybody, we have had a lot of support over the years and they all work hard it's just a shame it is suffering from not enough resources"*

The following case study is based on an interview Healthwatch Norfolk conducted with a carer of an adult severely affected by mental ill health living in Norfolk and Waveney.

Personal stories: Carer Case Study

"Andrea's Story*"

Andrea is a carer for her husband who has serious mental health issues, which he has had during the whole time of their relationship. Being a carer for her husband is stressful and has a huge impact on her "And it is your whole life, and it's all the time. You have slight occasions where things seem to improve, but over the years, you know that actually they aren't going to last. So you're kind of waiting for them to drop down again or whatever and something else to happen. Always. It's always on the agenda. And there are obviously times when you think actually you can't do this anymore…"

Andrea has had experience of the support provided by the crisis team but feels that once this support ends there is no ongoing support "Recently, you (we) had use of the crisis team, and they're very, very good, but they're only there for 10 days, and after those 10 days, it seems there's-- although there's supposed to be things in place, there's nothing. So they say that's fine and people keep rebounding back into the crisis team, well, they will. Because there's this big void."

She does not feel that her husband had has support from community based mental health services "The only thing is, we did hear, this is towards the end of last year with my husband's GP practice, he went to see-- he was going to see his GP. He said, "… we now have a mental health nurse attached to our practice. I'll refer you to them…… The referral was made. He had to wait many weeks for an appointment and then that got cancelled because the person was off sick, and then never heard another word about it again."

Andrea is fortunate that her employer has always been very supportive "…I have to say, because obviously when he took his overdose recently I had to have time off. And they're been very, very supportive. I'm very lucky with where I work. …… It makes a huge difference."

However, wider support provided to Andrea has been very limited until recently. Following the recent deterioration in her husband's mental health she has since been linked with wider support "….it's only recently that I've used anything. Before, I've used counselling through work, which I'm lucky to get, and I get that quite quick and (I'm) very, very lucky. Most people don't have that. But it's now since we've been involved with the crisis team I've been in touch with a wellbeing service, Norfolk wellbeing service. They've been good. I got referred to some stress courses that we use to manage stress. There didn't seem much else that they could do for me. I do have a number, though I don't think it's the wellbeing service, I think it's more the crisis team, that I can ring at any time. Through the crisis team there is a carer support group and I know the person who runs that. And I know I can just send a text or I can give them a call at any time. And I can join in so they have meetings once a week and I can join their meetings. Yeah. So I do now have that. But in all these years beforehand I didn't have anyone."

Andrea's role as a carer it made more difficult as the services do not involve her or keep her informed of services that are offered to her husband so that she can support and facilitate his engagement "….. I don't know if they've even-- I don't know if they've been offered. Maybe they have and he's said no. But I don't know. I have no idea. No idea. It would be useful to know. And as his carer, we need more involvement and engagement with whatever is happening, definitely" or know that something has been offered but this has been turned down "Because then you've either got a role in terms of reassurance that, look, you have been referred and this is coming and we just need to hang on, or that hard realisation that he's had the offer and he's not accepted it…".

Andrea has seen some positive changes and hopes that more change will happen to improve the outcomes for people with mental health issues “I hope they're going forward, things will improve for people. And people's lives, sort of, no one wants to see someone living their whole life in misery, really, do you? Because that's such a shame, such a waste”.

* All identifying information has been removed.

What we found out:

Outcome 3: Progress of the Community Transformation Steering Group

The first part of outcome three in the evaluation framework involved analysing governance of the Community Transformation Steering Group, reviewing, and monitoring their terms of reference, reviewing the meeting minutes (to ensure that actions are being delivered and reported back to the group) and that there is a strong sense of progress and wider engagement being delivered by the Community Transformation Steering Group.

Community Transformation Steering Group

Healthwatch Norfolk have attended the Community Transformation Steering Group meetings since September 2021 and reviewed the minutes of the meetings. The Terms of Reference for the Steering Group show that membership should include representation from Experts by Experience and the voluntary, community and social enterprise (VCSE) sector.

There are three Experts by Experience who are members of the Community Transformation Steering Group. Attendance by these members is consistent, with at least two members attending each meeting (the minutes from November and December do not show who was present at the meetings). There is also representation from Rethink who run the Experts by Experience Reference Group. In March 2022, one of the experts by experience was appointed as a Co-Production Officer by Rethink and continues to attend the steering group meetings, leaving a vacancy on the steering group. The Experts by Experience Reference Group also have representatives on the wider workstreams and working groups.

Together UK joined the Community Transformation Steering Group in January 2022 and in February 2022 Norfolk Community Advice Network (NCAN) joined the group to represent the VCSE sector.

For this outcome, Healthwatch Norfolk wanted to know what the Community Transformation Steering Group report as their main areas of progress made this year. To find this out we spoke to a representative from Norfolk and Suffolk Foundation Trust (NSFT) and a representative from the Integrated Care Board (ICB) who are part of the Community Transformation Steering Group.

Both representatives from the Community Transformation Steering Group reported that the main areas of progress of the Community Transformation this year have been:

- Steering Group attendance
- Co-Production with Experts by Experience and the involvement of other stakeholders
- The Rehabilitation Pilot
- The Complex Emotional Needs (Personality Disorders) care pathway
- Integrating new mental health roles into primary care settings

Steering Group Attendance

The ICB representative started off by talking about the successful and regular attendance of the Community Transformation Steering Group members, since it first met over 18 months ago, *"the Steering Group has done really well to meet regularly on a monthly basis to have exceptionally good attendance and consistent attendance as well. It's been really fantastic at this stage, 18 months on, to have a group that's committed to attend a monthly meeting."* Whilst the ICB representative recognised that most Steering Group members actively participate in the meeting, some are *"not quite as active as I would sometimes like, but I that's developing".* The ICB representative spoke about how the Steering Group is evolving to become more active by *"developing the conversation and not having an update each meeting. Part of the meeting is about updating of the work of the month and the developing piece to evolve that into a discussion piece so that we're not just updating for people to passively absorbing that information".*

The ICB representative also commented on how forming a better infrastructure for the transformation of community mental health services has meant that the Steering Group are *"able to come together and say, okay, what's the learning? What can we do better? Where haven't things worked as well?" and learn as they progress*.

Co-Production

Healthwatch Norfolk asked the NSFT representative what they thought the Community Transformation Steering Group has been successful with delivering. They replied that one of the things the steering group have done well is co-producing services and that this has been built into each workstream and in the

delivery of projects. They reported that the Community Transformation Steering Group co-produced the remodelling of the care pathways with the Experts by Experience. This involved working with system partners including the Experts by Experience reference group and the clinical reference group to sense check their work and make sure that service user's perspectives were included within work they did.

The ICB representative agreed that involvement of the Experts by Experience reference group has been a success because *"they do contribute actively and positively. And by positively, I don't just mean seeing positive good things about work that's underway. I mean, positively challenging as well."* The ICB representative reported that the Steering Group have *"really good relationships with the expert by experience reference group"* which was formed through attendance at their fortnightly meetings and sharing where the Steering Group are within the transformation.

The ICB representative noted that the work between the Steering Group and Reference Group *"does feel close to an equal partnership"* but added that they *"hesitate to say an actual equal partnership because that's still evolving".* They stated that the Steering Group have *"done well, not good enough and could have done more"* and this is something that they are working towards.

Rehabilitation Pilot

The rehabilitation pilot has been the establishment of a multidisciplinary, multiagency team that work together to provide wraparound support to an individual. 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, county council, district council, social care and the VCSE sector representation including Change, Grow, Live (CGL), MIND and Norfolk Integrated Housing and Community Support Service (NIHCSS). Norfolk Community Advice Network (NCAN) were also involved, which led to a legal advisor being part of the team. 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.

The pilot received approval in January and has recently launched. The team, including a Mental Health Rehabilitation Housing Support Programme Lead will be supporting nineteen people who are current inpatients to help them to return to the community with full wraparound support in place.

The NSFT representative reported that another success for the Community Transformation Steering Group had been the recruitment of new mental health staff for the rehabilitation pilot. The Community Transformation Steering Group received approval to kickstart recruitment for the pilot in January 2022 and had a target go live date for July 2022. All the new posts have now been recruited and will support 19 current inpatients to get back into the community. The ICB representative added that *"the mental health rehab work stream has gone particularly well because that's resulted in the launch of the mental health rehab pilot. So the testing of that through this year will result in launch of a new team".*

Embedded Practice

The NSFT representative described another of the Community Transformation Steering Group's successes as creating a new system for embedding new, psychology led practices into the care pathway for people with complex emotional needs (personality disorders). This involved recruiting new staff, creating new training packages (including a Knowledge and Understanding Framework) and training social workers, mental health practitioners and relevant VCSE partners. The aim was to embed a complex emotional needs strategy into existing teams to avoid any service users being misdiagnosed.

The ICB representative reported that dividing the Complex Emotional Needs workstream into two pilots and *"rolling out training has gone really well and has been a standout success".* They added that the rollout with the pathway has been more difficult, resulting in a recruitment delay and a pause in recruitment *"to protect the funding and make sure that the rollout was the right thing to do in the form that it was in".*

Blended Workforces

The representative from NSFT stated that another of the Community Transformation Steering Group's successes was developing the new blended workforces within primary care. New mental health roles (for example: Mental Health Practitioners) can provide wrap around care for adults severely affected by mental illness, in addition to the support given by their doctor. The funding allows each Primary Care Network to recruit an inhouse Mental Health Practitioner each year, for three years to assist primary care staff with supporting adults severely affected by mental illness. These blended workforces will include Recovery Workers to support the Mental Health Practitioners to be another first contact practitioner in general practice. The ICB representative added that already *"having 37 mental health practitioners in post at the moment is a standout success".* They reported that communication between the Community Transformation Steering Group and Primary Care teams *"hasn't been easy"* but that Steering Group members have committed to *"attending more regularly the PCN lead*

meetings to form better understanding and better relationships" and the result of recruiting 37 Mental Health Practitioners makes it *"worth all of those at times difficult conversations, but honest conversations to get to the point that we're now".*

The NSFT representative reported that that the Mental Health Practitioners will be able to carry out short term interventions with people, rather than refer them to NSFT, with the aim to gradually reduce service waiting lists. They acknowledged that at the moment, because there aren't enough Mental Health Practitioners and because the demand is so high, people are still being referred in to NSFT. The Community Transformation Steering Group have been working towards being nominated as a pilot site for the No Time to Wait campaign that aims to get a Mental Health Practitioner based in every GP practice.

Another new mental health focussed role being introduced into GP surgeries are Enhanced Recovery Workers who are going to work alongside Mental Health Practitioners to be another first contact practitioner. Enhanced Recovery Workers offer practical help and support to patients to access other support and Mental Health Practitioners will carry out more psychological interventions. The NSFT representative explained that Enhanced Recovery Workers can help patients link up with voluntary organisations, accompany patients to a counselling session to help their confidence or support patients with a Wellbeing Service referral on a short-term basis.

Communication

The NSFT representative reported that the Community Transformation Steering Group still have some work to do with communicating transformation news to members of the public and frontline staff.

The steering group have communicated the transformation updates to the Mental Health Providers Forum, Experts by Experience Group and local carers groups. They spoke about a comprehensive piece of work the Community Transformation Steering Group were involved in communicating the transformation broadly to NSFT teams and their managers but noted that it hasn't quite filtered down to frontline staff. The Community Transformation Steering Group have realised that there is now a demand for a separate piece of communication work for frontline staff to explain what the changes to community mental health services are and how it will specifically affect them. The NSFT representative explained that up to this point in time, transformation plans haven't been communicated in detail to the public or frontline staff to avoid passing on a vague, unsettling message.

The ICB representative acknowledged that they would have liked *"to have communicated more widely, and it's the communication work stream and the service*

directory work stream are two pieces of work that we haven't managed to progress or communicate as effectively as [they] would have liked". They added that the Steering Group *"could have communicated what was happening and what was coming next probably better",* but they explained that the Steering Group *"have a plan for an engagement stakeholder event around the revised community model… and in retrospect, I would have wanted much more frequent communications to let people know what the journey is: where we're at, what we're doing, and to invite more feedback".* The ICB representative noted *that "both comms and development of the service directory are top priorities for me and for the steering group at the moment".*

Future Work

Carers

The Community Transformation Steering Group are aware that there is a need to develop 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. added that this should be standard practice.

System Wide Transformation Board

The NSFT representative spoke about the Community Transformation Steering Group's plans to create a system wide Transformation Board. The Board's aim would be to join up all the different mental health service sectors at a board level, (for example: the wellbeing service, prevention workers and those involved in urgent emergency care). The current plan involves merging all the transformation steering groups and operations groups to form one system wide operational steering group that involves VCSE organisations.

Engagement with the VCSE Sector

For this evaluation, Healthwatch Norfolk also looked act the Community Transformation Steering Group's engagement with partner organisations within the voluntary, community and social enterprise (VCSE) sector. Healthwatch Norfolk spoke to ten local VCSE organisations as part of outcome 3.

We have anonymised the names of the organisations, to encourage open and honest feedback from them about the transformation of community mental health services. The types of support offered by the organisations includes benefits advice, housing support, counselling services, bereavement support, mental health advocacy, wellbeing advice, social inclusion, residential support, supporting carers and employment support, support with substance misuse and peer support.

Representatives from the Community Transformation Steering Group attend the monthly Mental Health Provider's Forum and provide updates on the progress of the transformation. Healthwatch Norfolk spoke to several key stakeholders in the VCSE sector about how engaged they felt in the transformation plans.

> We're pretty late to the party, because we were only just asked to be part of the steering group… I think I've only been to about three meetings. A lot of the work feels like it's already progressed quite far, and we're kind of coming on at the end of that, which is a shame because it would've been good to have been involved more in the planning.

Co-Production

Healthwatch Norfolk wanted to find out whether local voluntary sector organisations felt that they have had enough involvement from the Community Transformation Steering Group at a co-production level. Two organisations responded that they did not believe they had been involved enough with co-producing services. Organisation six reported that they believed their input was included too late in the development of community based mental health services and this isn't the basis of true co-production.

> I think some of it is we're involved because of what we do, and we're quite agile, and we're voluntary sector. But I think sometimes we're presented with what I would call a fait accompli that has been decided at the statutory level saying, "Can you implement it?" And then we have to go through that, "Well, we don't think this is right." So I would have preferred to have been involved at the co-production level to design the solution rather than implementing the solution.

The same organisation commented that co-production begins during the designing of services, at their conception, rather than further along in the process.

"Co-production should be at the start of the project rather than part way through, it's too late by then. You've already developed a solution, and then you're saying to somebody, "What do you think?" And they think, "Well, I think it's crap." And then you have to go back down. So I think it's a good idea, but they haven't thought it through how they do true co-production, getting them involved at the conception."

A representative from organisation nine revealed that they believe that the Community Transformation Steering Group reached our too late for engagement with the voluntary sector, *"for me, the VCSE sector stuff came along too late... when we came along to the project, it was pretty much everything we were reviewing stuff that had already been pre-agreed."* A representative from organisation two detailed that they believe the steering group have preconceived idea about what co-production is and how it should be used within the transformation process, *"the trouble is they've got their own views on, "Ah, we do co-production with this organisation." Okay, but that organisation is not led by disabled people, so you're not doing co-production."*

One of the voluntary organisations we spoke to reported that they believe the Community Transformation Steering Group are doing a good job of listening to the voices of people with lived experience, that once would have been a token gesture.

A couple of years ago, I probably would've gone to a meeting where it was more of a token gesture bringing someone in with lived experience, and I think the reference group has done a really good job to make sure that the voices are heard.

Organisation ten agreed with this and were very positive about the inclusion of lived experience and programme of co-production with Rethink Experts by Experience within the transformation process.

I think co-production feels like it's really taken off from when I first joined the steering group because they're working with Rethink Mental Health, and it feels like there's always really always really meaty updates from them about what they're doing and about getting more people involved rather than just kind of before it kind of felt like it

was just a few service users that they relied on, whereas now there's a whole programme of co-production and engagement, and they are a really active voice.

Healthwatch Norfolk spoke to a representative from Norfolk County Council also commented positively on the involvement of Experts by Experience within the transformation process.

I think the commitment from the former CCG to involve people from an early stage and to resource that properly through funding Rethink which used to be involved and to kind of stick with that commitment and has set up a kind of meaningful way of enabling people to be involved, supporting them with the training, to gain their confidence to be involved is really paying off.

The Council representative reported that they believed that the Experts by Experience are *"growing in their confidence"* and *"making very positive impressions on the whole process".*

However two VCSE organisations were concerned that the voice of Experts by Experience was limited to the Rethink Reference Group and should be extended to include those from other mental health services provided by the VCSE sector, *"the whole Experts by Experience programme in Norfolk and Suffolk slightly worries me because it just feels a little bit like getting people in….and then they're the people you consult rather than going, "Well, we need to consult with the people who have got an issue with the service".*

At one of the mental health provider sessions, when there's a presentation, I said, "we've got clients who are really engaged in coproduction, I'm sure they'd be able to provide something which would be very helpful in terms of feedback and would probably be quite happy going off and doing a little project". But nothing came of it… We've got some amazing clients who are really, focused on making a difference, who have a lot of time, who have lots of professional skill as well, who could be doing an awful lot more… and it would be really helpful for their recovery as well to feel like they're making a difference on a bigger scale and having more structure… so it just feels like a bit of a missed opportunity.

Positive Feedback

Healthwatch Norfolk received praise for the workstream leads within the Community Transformation Steering Group, that they are providing regular updates for voluntary

and charitable organisations through the Mental Health Provider's Forum on the progress of the community mental health transformation.

As part of the VCSE sector, the leads have been very present, coming out to do presentations and giving updates... and make sure that my team are all aware, and that filters right down to the frontline because there is a lot of frustration around and things are not perfect.

After speaking to representatives from each of the ten locally based VCSE organisations, organisation one started by describing how they perceive changes to community based mental health services as positive and that the changes the Community Transformation Steering Group are creating innovative changes with *'new ideas and people with real passion'.*

I think it's good to see money finally making its way through to mental health services in general and not just to us, but to other providers as well. I think everybody acknowledges that it's a sector that's been far too under-funded for far too long, and so it's nice now to be able to be working with commissioners and other providers that are being quite creative about how to spend money.

Organisation one praised the Community Transformation Steering group for adopting a positive flexible and collaborative approach to transforming community mental health services and reported that they have been open to new ideas.

> "[the Steering Group] have been quite flexible in their approach, and rather than sort of saying that, "Thou shall do this," they've been very receptive to ideas and been flexible in their approach about how to spend the money, and they've been very collaborative, wanting to bring all organisations together. They've started to form a lot better vision of what they want it to look like, and in the past, that's been potentially missing a little bit."

Organisation four talked about the positive experience that they had when they were approached by the Community Transformation Steering Group to start co-designing and provide feedback for the transformation of community mental health services.

I think our own experience has been quite positive in that regard. [the Community Transformation Steering Group] approached us to say, "we're not sure what this should look like. We know there's a need. We know some parameters around it." But they've invited us to come to the table with our ideas and help to develop a specification and help to get it implemented and to get it off the ground. And I think that felt really refreshing to be able to be in that place where we could design and say what we thought was needed.

The Norfolk County Council representative agreed that the Community Transformation Steering Group had been *"very open to the involvement of partners across the board and committed to a wide range of partners being involved… particularly from the voluntary and community sector".*

Organisation ten reported that the steering group's strategy to include VCSE partners is a 'good start' but that there has been some confusion with some charitable partners surrounding the purpose of the strategy, *"what's the point of the strategy, or how is it going to actually influence the other things going on? It feels a bit siloed like, "Oh, we're doing this VCSE strategy over here because we think it's important," but how does that actually influence [the transformation]?"*.

A representative from organisation ten said they felt the strategy they were presented with felt "transactional" and *that "charities might be an add on, rather than actually the voluntary sector could not only support people recover quicker but also could prevent people needing your services to begin with."*

Protecting the Integrity of Third Sector Organisations

A representative from organisation four expressed their concerns that joined up working between third sector organisations and statutory bodies like NSFT could alter the dynamic of nature of voluntary, charitable and community-based organisations.

If you're going to collaborate with someone, whether it's in this arena or any other, don't try and make them behave like yourselves. You're collaborating with us because of what we bring, and then you get this pressure and expectation of being squeezed in to look like somebody like a statutory organisation… third-sector organisations are really special.

Organisation nine echoed this concern and believe that the unique essence of voluntary sector organisations should be protected, when working in collaboration with statutory bodies.

> "I'm conscious of the values that we as a voluntary sector bring, we need to make sure that we don't lose that essence. When you've got a co-locating team like that, we need to also make sure that our values and the way that we often will challenge statutory services doesn't get absorbed into the team."

Organisation two voiced that they were concerned that the steering group might not engage with enough VCSE organisations within the transformation to capture the spectrum of third sector organisations and the available services in Norfolk and Waveney.

> What worries me that really what's really going on is they're slowly just developing a new structure with the third sector where they're only really going to engage through one or two because I think they engage in a similar way with Mind for specific things. And it just feels like a bit of a closed loop.

Organisation ten expanded on this theme and reported that they believe the transformation still feels very "*clinical*" within their processes and workstreams and that there is a lack of VCSE representation within the steering group, *"there's not really that much voluntary representation in the steering group… I think more voluntary sector representation would kind of be interesting because it wouldn't just be a minority voice. It would be something that's really making a difference that can really generate kind of new ways of doing things".*

Organisation nine extended the positive feedback and reflected upon how well they believe multi-disciplinary working is going, particularly within the Rehabilitation pilot.

> We were talking about earlier around the rehab project is really exciting for me because I think it's the first piece of proper multi-disciplinary team working where you've got kind of co-location of the VCSE sectors within and also the social work and team within the health team, and I think that's really exciting, and I think there needs to be more of that.

Organisation ten added to the positive feedback about the engagement from the steering group with local VCSE organisations by recognising that there has been *"more engagement with the voluntary sector in the last six months than in like five years."*

Finally, the evaluation framework explored the steering group's involvement with co-producing their workstreams and the transformation plans with people with lived experience and with the Rethink Expert by Experience reference group.

Co-Production

As mentioned previously, co-production is a way of working that "involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation," (NHS England and NHS Improvement and Coalition for Personalised Care, 2022).

What the Transformation Programme hoped to achieve

One of the ambitions of the Transformation Model Principles was to *"do everything together, co-producing our service with those with lived experience of SMI, carers and our partner organisations".*

We interviewed three Experts by Experience who have been involved in the Community Transformation Steering Group about their views on co-production and what they thought it meant. One of the Experts by Experience described co-production as *"making sure you know what the needs of the people are, what they need and what is right, with policies connecting this."*

Early in the transformation process several "I Statements", were developed in consultation with service users and carers through a series of engagement events across Norfolk and Waveney in 2021. A series of eleven statements were drafted to show the outcomes that were important for people severely affected by mental illness. These I Statements formed the basis of the development of the Community Mental Health Transformation Strategy and are the basis of Healthwatch Norfolk's evaluative framework.

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.

Other key features of the aspirations for co-production were that people with lived experience would have chair or co-chair roles in all steering groups and to engage with other existing opportunities to seek input, such as through the VCSE sector.

We felt that it was useful to use the I Statements to frame our evaluation outcomes and assumed that the steering group were using them to check that the transformation process would lead to these outcomes. We therefore requested a copy of the finalised statements, but there is a lack of awareness within the Community Transformation Steering Group of the I Statements and a final set has not been published. At the time of writing the statements were being reviewed and refreshed by the Experts by Experience Reference Group.

Due to the delay in refreshing the I Statements, Healthwatch Norfolk will approach each of the Community Transformation Steering Group workstream leads to ask how their work fits with the outcomes identified in the I Statements.

Experts by Experience

Initially, the Access Community Trust were partners in the transformation process and provided access to Experts by Experience, but this later changed, and Rethink were commissioned to provide representation of Experts by Experience. Rethink established a reference group, which initially had 12 members. These members are paid for their time, but there is a limit to the number of hours they can work on this project.

This evaluation wanted to explore if the transformation work taken place has been co-produced with people with lived experience. There are currently three members on the Steering and Operational groups (two Experts by Experience and one carer) and one member of the reference group who attends the partnership board meetings, to ensure the voice of lived experience exists at a decision-making level and that the views of the reference group are heard.

The Community Mental Health Steering Group has a standing agenda item for feedback from Experts by Experience. This update is provided by a Senior Co-production Officer from Rethink.

The minutes from October 2021 to May 2022 reflect the following actions and engagement by the Experts by Experience Reference group:

- The establishment of the reference group, with 12 members (now at 10 members)
- Reference group members have delivered webinars on an introduction to coproduction and the transformation process. This training was coproduced with the reference group and delivered to system partners at the end of last year/start of this year. This included people from Norfolk and Suffolk Foundation Trust, Norfolk and Waveney Clinical Commissioning Group (now the Integrated Care Board) Norfolk County Council, and the voluntary, community and social enterprise sector etc.
- Reference group meetings taking place twice a month
- Attendance at the Partnership Board in April by two members of the reference group. There has been ongoing attendance by a member of the reference group in order to ensure the voice of lived experience exists at a decision-making level and that the views of the reference group are heard too.
- A presentation was given on the "Theory of Change" to enable the group to "to measure how far (they) have come and measure co-production".
- Two additional members of staff employed - a Community Coproduction Officer and a Coproduction Officer
- Follow up webinars delivered on putting coproduction values into practice with new employees within the mental health system.
- Assisted in the co-design of the questions and feedback for eating disorder survey and shared this when it went live. They also had an Eating Disorder Event to look at how to connect with more people in the community around eating disorders.
- Looked at the proposal on the rehabilitation service
- Worked with the Urgent and Emergency and Inpatient Care (UEC) workstream to support how to integrate the voice of lived experience into the programme work.
- Planned a workshop with the UEC workstream.
- Working with the Improving Access to Psychological Therapies and Prevention workstreams to plan how to integrate the voice of lived experience into programme work
- Working with Norfolk County Council around suicide prevention work
- Presentation on the Smoking Cessation Early Implementation presentation made to reference group. One of the reference group will be joining working group.
- Attendance at the clinical huddles.

- Had a presentation about physical health checks with Julian Dias presenting from digital team.
- Presentation given at Steam House Café in Gorleston regarding Mental Health Awareness Week.

The reference group were proactive in identifying the following concerns:

- the need for staff wellbeing support and identified staff burnout, transferable skills, more roles to be made available around support staff to free up clinicians, community service model clarity and the transition between clinical environment and transition to community working. Training needed around leadership, racism and unconscious bias.
- An individualised person-centred approach which works for different people regardless of their diagnosis and the need for a physical place of safety was highlighted during the discussion

Future plans of the group include:

- Developing an asset map to map connections/contacts across Norfolk and Waveney.
- Plan to discuss outcomes of the huddles updates.
- Working on plan to include the voice of lived experience into the slippage working group.
- Working with Norfolk County Council regarding prevention and wellbeing.

Rethink Experts by Experience Survey Results May 2022

About the respondents

Healthwatch Norfolk wanted to find out how supported the Experts by Experience feel by Rethink and asked for their feedback through a survey. The survey received responses from five Reference Group Members. Three of the respondents had been involved in coproduction work for the Community Mental Health Transformation with Access Community Trust (ACT) and/or Rethink for seven to 12 months. One respondent had been involved for less than six months and the final respondent for between one and two years.

Three respondents shared that they spend nought to five hours a month on average completing coproduction work. The remaining two respondents spend six to 10 hours. Responses to the question "What co-production work have you been involved in within the Community Mental Health Transformation?" are displayed in Figure 13 below.

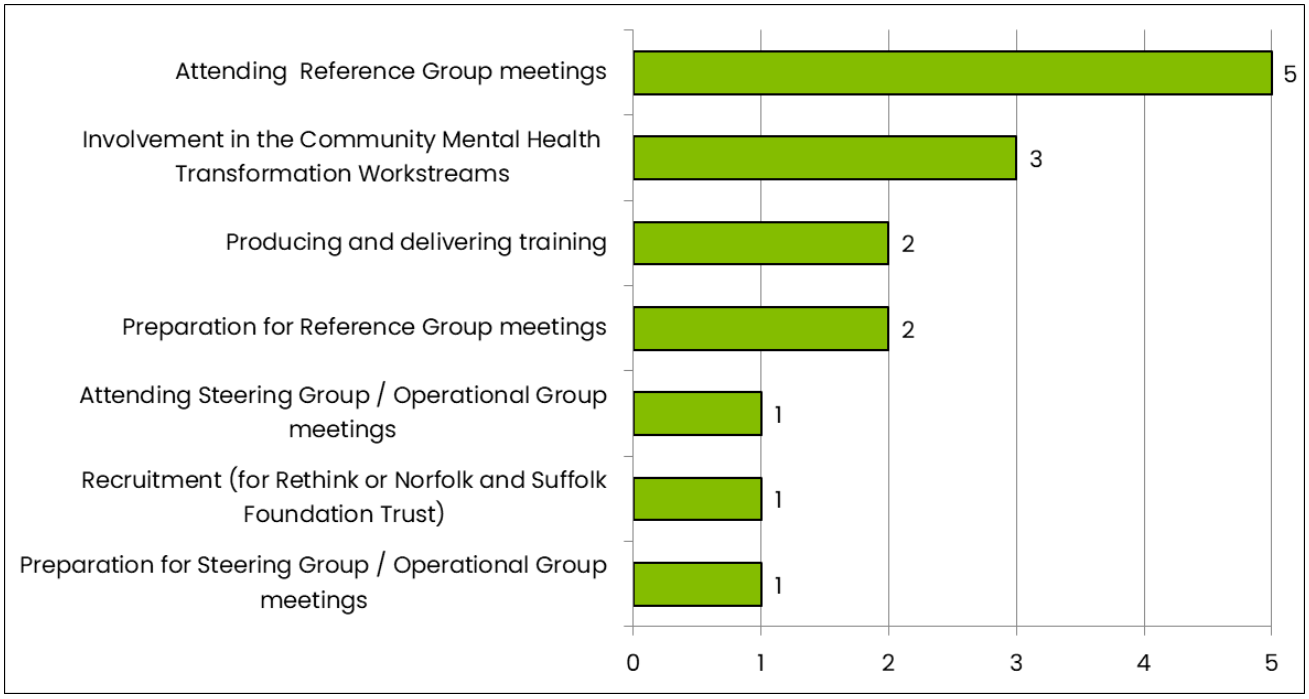

Figure 13. *Responses to the question "*What co-production work have you been involved in within the Community Mental Health Transformation*?".*

Support from Rethink

Four respondents said they were very satisfied with the support they received from Rethink. The remaining respondent said they were satisfied. Some of the reasons why they are satisfied or very satisfied are shown in the table below:

Support From Rethink
I trust rethink but I'm yet to see anything back from the service we ment [sic.] to be helping which makes me wonder if they want this to happen.
A lot of support provided.
We are always informed in good time when the meetings are going to be, and we receive a diversity of training as well as doing the main job relating to Steering Group updates and policy work.
The support both in the meetings and [the co-production officer's] forethought when it comes to checking when I have not been able to attend has been amazing and makes me feel like I am wanted as part of the team rather than a burden.

Two respondents shared that they sometimes experience barriers to this coproduction work and one said they often experience barriers. These barriers included *"working fulltime"*, being *"unable to contact people relating to when [workstream and Steering Group] meetings are happening"* and from *"not being included propley [sic.]"* by the Steering Group.

Four respondents said that they were very satisfied with the communication from Rethink and four respondents said that they were very satisfied with the facilitation of Reference Group Meetings, with one respondent saying that *"it is transparent and honest, and you are also given the opportunity to include your ideas into meetings"* and another describing how *"communication flows easily and everyone is given an opportunity to input".*

Diversity and inclusivity

Three respondents said that they think the Reference Group is as diverse or inclusive as it could be. One respondent said it is not and one was unsure. One respondent commented that they feel the Reference Group *"do have a good range of experiences and backgrounds. However, as has been noted by others in meetings, it's possible we're not hearing from those with other experiences by the nature of the circumstances those experiences create. For example, people who have experienced housing insecurity *and* mental health issues and/or disability".*

Training

Training had been attended by two respondents and one respondent shared they had not received training but that this was "by choice, I have been offered more but as I work full time and am part time in university so prefer to allow others to progress". Some ideas given for extra training included *"anything that can help me grow in doing this line of work"* and *"more knowledge on some of the work streams and also understanding some of the medical terminology that is used".*

Four respondents thought that bringing their lived experience to the transformation process had led to changes. One responded said that they "*have been able to discuss how some therapies are being delivered to service users to the heads of training, they took onboard my ideas, I'm now working with NSFT to deliver the training and help improve training"* and another commented how their *"input on a Survey was so readily received"* and they felt *"listened to"* by the Steering Group.

A few of the Experts by Experience said that they require more training from Rethink to support their role, *"we haven't actually had any training from Rethink, so… that is something that we need to address. Although, [Rethink EbE Group Facilitator] has co-produced some training, kind of for experts by training, so for people working mostly in the NHS I think it was who attended. And some of the experts by experience were involved*

in the workshops producing that. So of course, they would have got the training themselves kind of coincidentally, I guess."

Any other comments

We asked the Experts by Experience if they had anything else they would like to add, and their feedback is shown in the table below.

Any Other Comments
It has been a very empowering time so far; I still think some health professionals are still not fully committed to the idea of using EBE in the transformation process and that at times can be a little deflating.
I think [the Rethink EBE Group Facilitator] has a good sort of style. She gives you the right information in a friendly manner that's kind of easy to understand. I think she's always been quite prompt about getting things, notes out, and information, invites, and everything.
I cannot give more praise to [the Reference Group facilitator] and some of the other team members from rethink that have come in to talk about there [sic.] experiences and look forward to working with you all more in the future.

Co-Producing Services with the Steering Group

Healthwatch Norfolk interviewed three Experts by Experience to find out what they thought of the Steering Group's delivery of community based mental health transformation and how engaged they have been with co-producing services.

One Expert by Experience described how the Steering Group are becoming more aware of not using acronyms during the meetings.

> "The steering group are getting better at explaining abbreviations and jargon and things like that. It does get easier with time."

Another Expert by Experience told us that being part of the Steering Group and sharing their lived experience has helped them understand how NHS Community Mental Health Services work.

At first, I had no idea how the NHS worked kind of behind the scenes, if you like. I mean, that is fascinating. And I think that's one of the things, at least, that you gain is that there is so much behind it that you have no idea about when you just see the sort of front door if you like.

One of the Experts by Experience who sits on the operations group had nothing but positive things to say about their experience and how affirming it is *"to feel listened to, valued and see the implementation already of ideas and suggestions. "*

All three Experts by Experience agreed that working and building relationships with NSFT staff has been a positive experience for them, *"I think probably the things in the steering group where it's been good is kind of building relationships with [key NSFT staff] and getting them involved in coming to the reference group."*

One Expert by Experience reported that it can be difficult to understand what the Steering Group is, what it does and how it is different from the Operational Group.

> "I'm still not sure I exactly understand how the steering group works, but overall, I think I find it easier than I did... Sometimes, I'm not quite sure what we do that's different from the operational group, I've only been to one operational group, which was a bit different. A bit of explanation about kind of what the remit of the steering group is would be useful, I think."

The Experts by Experience often have a pre-meet before the Steering Group to prepare for it and have invited members of staff from NSFT to join them, but it was decided that *"it's best if there's only one of them [NSFT workstream leads] there. Otherwise, they tend to talk between themselves and use the space to prepare their own work, which is totally understandable, but it's not actually a good use of our [the Experts by Experience] time."*

There have been occasions where members of NSFT Staff cancel their attendance with little to no warning, *"I think [NSFT workstream lead] did tell [the Reference Group facilitator] that she wasn't going to come [to the pre-meet], but it was kind of last minute."*

All three of the Experts by Experience that we spoke to in the interviews told us that the Steering Group Agenda is often not sent until *"very shortly before"* the meeting is due to take place and *"when they send an email, they just send an email to everybody. It's not blind copied or anything, which is actually really bad".* One Expert by Experience suggested that it would be more helpful to have the agenda more in advance of the Steering Group being held.

> I think one thing that would be much better would be if we got the agenda much sooner. So at the moment, we're getting it on a Friday afternoon, which is actually after our pre-steering group meeting. Steering group pre-meet. So if we had it at least in advance of that, we could discuss the agenda in that meeting, which would be really helpful.

When we asked the Experts by Experience if they thought the work they do with the Steering Group is a true reflection of co-production, one of the Experts by Experience commented that it's not, yet.

> Not yet.... they've just recently produced a new strategy, but it wasn't co-produced. It was already almost finished before they were presented with it. Then the same for the rehab proposal for the people with severe complex psychosis and repeat admissions. It was already presented as a model, and it's been tinkering around the edges. So that's not co-production. It's engagement, but it's not co-production. It's not sitting down together and saying, "Okay, how are we going to do it?" Co-production shouldn't just be about designing a service; it should also be about delivering it, which means that experts by experience have to be in the clinical teams and things like that. So that would be peer support work.

Transformation Action Plan

The final part of outcome three in the evaluation framework related to the Steering Group's transformation action plans. We were due to organise a session with the Community Transformation Steering Group to link their actions, plans and workstreams to the desired service outcomes expressed by service users within the I Statements. The I Statements are due to be refreshed with the Rethink Expert by Experience reference group and we will revisit this part of the evaluation in year two.

What we found out:

Outcome 4

For Outcome 4 of our evaluation, we wanted to understand whether community-based services could see positive change in the support for adults severely affected by mental illness because of the transformation plans, which include the impact of the transformation on the joining up of services and waiting times.

Healthwatch Norfolk spoke to ten local voluntary, community and social enterprise (VCSE) organisations as part of outcome 4 and one statutory partner.

We have anonymised the names of the organisations, to encourage open and honest feedback from them about the transformation of community mental health services. The types of support offered by the organisations includes benefits advice, housing support, counselling services, bereavement support, mental health advocacy, wellbeing advice, social inclusion, residential support, supporting carers and employment support, support with substance misuse and peer support.

Overall Feedback

All the organisations that we spoke to were positive about the commitment of the Community Mental Health Steering Group to try and make positive change and what they are attempting to do, *"I would say the steering group seems much more trustworthy and transparent, and I feel like I have a better understanding of where they are and the problems that they're facing."* One organisation summarised what they thought was working well with the Steering Group.

> What's working well is that it does feel like there is a real appetite to improve and to make changes and to really work across sectors and not be siloed. Social services had to work with the NHS and the voluntary sector… in terms of just the actual individuals involved, there is a lot of enthusiasm for that and a recognition that if this kind of is done well, then can make a massive difference in people's lives.

Joined Up Services

Most organisations that we spoke to talked about the need to view people severely affected by mental illness in a holistic way, understanding that issues such as benefits, debt and housing can negatively impact on their mental health and the need for support around these issues. Two organisations that we spoke to talked about their work around advocacy and support and how this supports people's mental health.

Case Study: Evolve East Anglia CIC

Evolve East Anglia CIC is a small organisation employing approximately 30 staff. The majority of their work is with adults with serious mental illness, and they hold a number of contracts with health and social care to deliver their services.

Services range from supported living schemes to outreach support. The professional backgrounds of the two directors include social work and housing. The organisation adopts a person-centred approach within a psychologically informed environment.

Evolve has a service for people leaving hospital and returning to the community. Most of the people who have used this service over the past six years have not returned to hospital, despite many of them previously returning to hospital once or twice a year. The Directors of Evolve believe that this success is due to their approach.

"We sort out their accommodation, make sure that they have enough money to survive, give them a community to engage with – somewhere they are already accepted - they can attend our activities and training programme on an ongoing basis. If they have a problem, for example a council tax bill, they can turn up and someone will help them deal with it free of charge. Just with that stuff, most people seem to stay well."

Gemma, Director,, believes that simple practical issues like these, which could be resolved easily would have a big impact on the wider system:

- More training to recognise the possibility of domestic abuse and coercive control within family networks, and the impact it has.

- Giving mental health professionals some basic practical housing training. Recognising the threshold at which other statutory services should become engaged.
- Delayed Transfer of Care (DToC) meetings which used to be held weekly at Hellesdon Hospital, which Evolve attended, along with representatives from all the wards, and Adult Social Care social workers were suspended during the pandemic. Evolve felt those meetings were a valuable way of sharing wider knowledge about each patient's needs and circumstances with both health and social care in the room. Early discussion with all the professionals involved allowed early planning and an opportunity to address some of the potential barriers to moving on, prior to discharge being discussed. Evolve were able to sort out people's benefits and housing issues and build a relationship with patients before they were discharged and link them to their services. This resulted in better, quicker transitions from the hospital and a quicker move on from Evolve accommodation into the individual's own home.

She attends the Mental Health Provider's Forum and has appreciated the information that has been shared there by senior health and social care staff about the mental health transformation programme.

"Being able to see the people involved in that work, at the top of that work, coming to the meetings and being really, really straightforward, I feel like we have a lot more information than we would have previously. I feel like I understand what they are trying to achieve. I think the people who are trying to achieve it are good decent people who understand the sector….. unless they are going to have more people who are going to deliver the services, the right kind of people with the right kind of training, it's difficult to see…. The whole system is totally clogged up… the number of beds with people who are delayed transfer of care, people who can't leave hospital because they've got housing issues etc., Sorting out those things would have a big impact….It feels like there are some really simple practical things which could be addressed, with a very small amount of money, lots of the bigger things…..you need more bums on seats, you need more people trying to deliver those services, more supported living places, more step down for our clients to see a massive difference in what they receive."

The demands for advocacy services are increasing as Equal Lives explained:

Case Study: Equal Lives

Equal Lives is a Disabled Person's Organisation (DPO), which is run by disabled people for disabled people, including people that face mental health barriers. They provide advocacy support, advice, and support people with their direct payments. Equal Lives is also a member organisation, providing support to their members.

The main services people facing mental health barriers use in Equal Lives are the advocacy service, particularly the community advocacy service, and the advice service. Equal Lives has seen increasing levels of need over the past ten years for people with mental health barriers, for people who also have a physical disability, but also those who do not. Within the advocacy services, they overwhelmingly support people who have some sort of mental health issue.

An Equal Lives representative believes this increasing demand reflects the fact that there are no longer community support workers who can help with advocacy issues, such as the telephone supplier has cut someone off, or their internet has been cut off, and the individual needs support to get issues like this resolved.

Equal Lives has also seen an increase in complaints about the support from Norfolk and Suffolk Foundation Trust (NSFT) – approximately 30 a day. Equal Lives only supports those people who really can't make a complaint themselves, however very few of these are resolved, mainly because NSFT continually delays responding to complaints.

From the representative's perspective there are still ongoing issues with the Foundation Trust, *"NSFT services themselves are still very, very problematic".*

The other issue that causes concern is the adversarial nature of the benefits system. People who acquire a disability usually have done so in a traumatic way, leaving them with other issues, including mental health issues. Trying to navigate a way through the systems makes it much harder *"the benefit system is horrific: really, really horrible for people. And*

that leaves you in, kind of, a really horrible, horrible situation and just makes all of those things worse, exacerbates them all".

Regarding changes as a result of the transformation programme, the Equal lives representative believes there is a way to go before the changes are felt by those who need to use the services "*I can't point to something that is working well that we hear about. We do hear about pockets of really good practice, and there are people who will stand up and point to a particular service, particularly in NSFT".*

The representative believes that more support to individuals around the wider issues they are struggling with could make a difference *"we would see a huge reduction in our advocacy service if there was individual support for Joe Bloggs who's got a severe mental health issue. They need that support, essentially to stay on top of their lives. We're dealing with lots and lots of situations where we are supporting someone to try and stay on top of their lives because their rent is… all of those sorts of issues that then kind of come up because they are not managing on a day-to-day basis".*

There is positive acknowledgement from VCSE organisations for the work surrounding introducing mental health services and roles into the community and primary care, especially to the more rural and remote parts of Norfolk.

So going out into the community and taking these services into the community, so rurally to village halls or community centres or faith centres, local GP surgeries. So a lot of that, I'm excited because I can see a lot of that coming on with the recovery workers and mental health teams being placed in primary care. So that's quite exciting.

The role of the Voluntary, Community and Social Enterprise (VCSE) Sector

Healthwatch Norfolk aimed to capture the impact of the engagement with the VCSE sector and the services that they provide to people who are severely affected by mental health issues, because the VCSE sector should play an integral role in the transformation.

There is a huge demand on this sector to support advocacy work and other support for adults severely affected by mental health issues, but concern that there may not be any additional funding to support this. Organisation two reported that *"we're doing so much advocacy work.... they're not funding any of it".* Organisation six commented on the lack of funding available for VCSE organisations, *"we're putting these hubs in place. We need some finance. And we're financing it as well. You need to come and start putting things back in the community".* Organisation six expanded on this by saying *"when we're looking at VCSE, the funding there is quite low, and even with social care, it's only maybe one or two staff in comparison to staff in teams of 15 from health".*

There can often be a tension between VCSE providers as they are often competing for funding, and there can be tendency for larger, county-wide services to be commissioned to provide services. Organisation five acknowledged how the VCSE sector can become overlooked by funders.

> The VCSE [sector] does get overlooked. I mean, obviously, there's talk all the time about, "The VCSE need to support... actually, they're the ones who can enable themselves to deliver it." But there's no funding that goes towards it. The funding tends to go towards the bigger boys, and some of those smaller organisations get overlooked.

This can create a climate of mistrust at times in the VCSE sector and can make it difficult for statutory providers to know how best to engage.

A representative from NSFT described how working with the VCSE sector has been difficult because there are so many organisations based in Norfolk and Waveney representing so many different sectors and types of support. They spoke about having the most effective types of co-production with the same VCSE organisations and that the Community Transformation Steering Group engaged with other VCSE sectors in workstreams and projects that were particularly relevant to that organisation's core services.

When we asked more about the Community Transformation Steering Group's involvement with the VCSE sector in co-producing the different workstreams, the NSFT representative mentioned that they included as many VCSE sector as possible to look at specific health inequalities in each working group and that it's not physically possible to co-produce with every VCSE organisation.

The Norfolk and Waveney VCSE Assembly is being established as a mechanism for engagement with the VCSE sector for the Integrated Care Board, and has three ambitions:

1. To provide a VCSE engagement forum across N&W, with a focus on health inequalities and prevention, and with connection at neighbourhood, place and system levels.
2. To provide a mechanism to support collaborative design of services and the capability to respond to emerging needs.
3. To increase influence and participation of VCSE organisations and groups in the design and delivery of health and care services within the ICS.

The Chair of the Assembly was appointed in May 2021. The Assembly is developing a place network model, consisting of five place networks and having three main themes:

1. Children and young people
2. Mental health
3. Older people

The Assembly is currently still in development and at present recruitment is underway for the Place Network Leads. (See Appendix 13 for further details)

There is an awareness of the Norfolk and Waveney VCSE Assembly, but people are uncertain about its development both within the VCSE sector or the steering group.

> Hopefully, they'll try and somehow link it [The VCSE Health and Social care Assembly] in, but at the moment, I feel like it is separate because it's come from the community transformation work and was almost like a sort of requirement of that as a system that you have to have a VCSE strategy. So it wasn't kind of done through the ICB or the assembly. But then the assembly doesn't really feel like it exists at the moment, so I don't really think there... there wouldn't really be anything for it to do in that sense. I mean, we've obviously got a chair, and there is a steering group... it doesn't feel like anything tangible exists right now.

The NSFT representative from the steering group stated that they wanted to engage with the VCSE Assembly, but that it has not yet been possible.

The VCSE sector should be a key partner in the delivery of mental health support, due to the range of services provided and the experience of the workforce, but several organisations identified that there was a lack of understanding of the professional nature of the VCSE sector. Organisation six reported that "*when they*

talk about the voluntary sector they suspect that we're all volunteers, but we're actually quite a professional business".

This perceived lack of understanding can have an impact on whether the VCSE sector feels like a valued partner in the transformation process. One organisation reported that *"for many, many years, we've had a lot of what's felt like quite tokenistic conversations about the value that the third sector brings to the table in working alongside statutory mental health services and the need to collaborate, and then it kind of doesn't come to fruition. Or actually, the day-to-day experience on the ground is that-- whilst people at the top might talk about respect and value, actually, you don't feel like you're a valued partner on the ground".*

Organisation four suggested that the approach toward partnership working could be looked at from a completely different perspective:

> It's part of the conversation about not only what's the role of the third sector in this, but what's the role of the statutory sector? What's the role of NSFT? What do they need to provide that the third sector can't provide? There are some things that they must provide. But then when you think about the bigger picture of, "well, what do people actually need out there? What's going to make a difference to their lives?" I think a lot of the things that really make a difference to their lives can come from the third sector and that relationship-building with people, really understanding what's happening in somebody's life, giving them the time, validating their experiences, sitting alongside them, being their ally.

Holistic Support

Organisation four commented on the importance of statutory bodies treating adults severely affected by mental illness as a person and not as a subset of Key Performance indicators (KPIs) and maintaining the unique qualities of voluntary sector organisations when commissioning services.

> I think it is difficult then when your KPIs might give you some lovely data, but they don't mean a whole lot, and they certainly don't mean better situations for the people we're supporting... I've never worked with anyone who when I've asked them what they wanted from the services, "I want you to hit your KPIs." People want tangible, real things that make a difference in their lives. We have to be careful in the commissioning of these services that it doesn't become so focused on things that don't matter to people and then turn into something like a quasi-statutory service.

Organisation seven expanded on this by describing the rigid treatment criteria present in some community mental health services that can affect when and how adults severely affected by mental illness are treated, *"getting mental health support for those people is a real challenge because there are so many barriers and so many criteria that they might meet one day they may not meet the next*." Organisation eight responded with similar feedback, *"we are frustrated that traditional referral pathways often don't work for those who are hardest to reach".*

There were concerns raised by VCSE organisations that adults severely affected by mental illness are not being offered by support from community mental health services for other aspects of a their life for example: employment, relationship, financial or physical health concerns.

> [Mental health services] are not really getting that another part of someone's life is falling down and that the environment that someone is in matters. I don't just mean the physical environment. Your partner, your relationship is going to the dogs because your partner's picking up everything. They're stressed. They're overworked. They're slowly heading towards having a breakdown. We need to have someone who's going to come in a couple of hours a week, sit down, do the paperwork with me so I can discuss the issues that I don't want to discuss with my partner.

Waiting Times

The organisations that we interviewed believe that it is too early to have seen an impact in waiting times for people with SMI, which is consistent with the expectations of the Transformation Steering Group.

Several organisations identified the negative impact of high staff turnover on services. One organisation reported that "they've got issues with workers being constantly changed. I know they've got challenges in terms of staff turnover, but that does impact as we know on care and support provided". Another organisation also reported on staff changes within community mental health services, "in terms of how we experience engaging with the Mental Health Trust, it depends a lot on which team. Over a long period of time, it's difficult, isn't it, if you get rid of… was it 40% of your staff?..... But if you don't have enough resource, it's really, difficult to give people a really good service".

Rehabilitation Pilot

Organisation nine extended the positive feedback and reflected upon how well they believe multi-disciplinary working is going, particularly within the Rehabilitation pilot.

We were talking about earlier around the rehab project is really exciting for me because I think it's the first piece of proper multi-disciplinary team working where you've got kind of co-location of the VCSE sectors within and also the social work and team within the health team, and I think that's really exciting, and I think there needs to be more of that.

Organisation ten also commented on the great progress of the Rehabilitation pilot.

The main thing that I'm sort of aware of mostly is the rehab pilot that's happening in Norwich for people with serious mental health illness, and the model and the progress of that. It's a multidisciplinary team that will work around people for intensive support and includes access to a legal advisor who can link people in with all that sort of long-term specialist legal advice they might need around finances or family issues or benefits and then also CGL [Change, Grow, Live] workers and clinical staff. That seems to be progressing really well.

Communication

During the interviews with local VCSE organisations, there were reports that although the engagement with voluntary organisations has been positive, the transformation updates haven't always been communicated well with frontline staff or members of the public. Three of the organisations reported to Healthwatch Norfolk that the Community Transformation Steering Group need to communicate better with service users and frontline mental health staff about the changes being made to community mental health services.

> "In terms of kind of communicating the development and the change... I don't see too much of that going out to kind of the frontline delivery staff level, and for the public, I've not seen anything go out that I would say, "Oh yeah, they've communicated via this," or any publications or anything like that, I've not seen. But certainly, for our

Organisation seven asked their staff about what they thought about the Community Transformation Steering Group's communication style, and they replied that *"high level or strategic actions are being made but they're not communicated as well to providers or the people receiving the service"* and that information about the changes is "*not necessarily filtering down effectively"*. Organisation six recommended that the Community Transformation Steering Group need to communicate better with local

people about the proposed changes and in an accessible way, *"they need to communicate more at a level where people can understand, "How is it going to affect me living in Diss? How is it going to affect me living in Thetford?" So we think more clarity on the communications would be a benefit."*

Healthwatch Norfolk spoke to a representative of Norfolk County Council about their thoughts about communication around the transformation to community mental health services. They commented that communication has been *"mostly clear"* and the use of *"slide packs to build, to inform kind of each meeting, and then sort of to prompt discussion"* is helpful at the start of each transformation meeting. They also mentioned that *"some of the decision-making* [from the steering group] *has kind of maybe not been communicated so well".*

There is positive acknowledgement from VCSE organisations for the work surrounding introducing mental health services and roles into primary care, especially to the more rural and remote parts of Norfolk.

> So going out into the community and taking these services into the community, so rurally to village halls or community centres or faith centres, local GP surgeries. So a lot of that, I'm excited because I can see a lot of that coming on with the recovery workers and mental health teams being placed in primary care. So that's quite exciting.

Organisation One summarised their view of the transformation of community services as a *'good start'* and the start of a much longer journey.

> "It's a good start, and we're very much on the sort of first couple of steps of quite a long journey, and we, as a group, including NSFT and CCG and acute hospitals... think there's certainly some work to do around bringing the whole system into focus to make those improvements. So I think we've made some really positive steps, but it's still a long road. "

What we found out:

Outcome 5

Outcome 5 of the Healthwatch Norfolk evaluation investigated whether mental health workforces report improvements in community-based services for adults severely affected by mental illness. The first part of outcome five in the evaluation framework explored whether the Community Transformation Steering Group had recruited and developed a skilled workforce through the delivery of a mental health workforce and training strategy.

Skilled Workforce

The Community Mental Health Transformation plans outlined that new mental health worker roles would be recruited and based in GP surgeries, creating a blended workforce. The plans stated that 23 Clinical Psychological Associates, 25 Recovery Workers and 46 Mental Health Practitioners would be recruited during the first year of the transformation.

Healthwatch Norfolk requested data from the Community Transformation Steering Group that reflected how many people had been recruited into these roles in April and May 2022. This was minuted as an action in the May Steering Group Meeting. The current figures were not released to Healthwatch Norfolk, despite NSFT being contacted on three separate occasions. At the July Community Transformation Steering Group it was reported that 31 out of 46 of the Mental Health Practitioner roles across the 20 Primary Care Networks have been recruited and 23 out of the 25 Recovery Worker roles have been recruited across the 20 Primary Care Networks.

The Peer Support Worker roles are currently being recruited by Norfolk and Waveney Mind. These roles were originally advertised by Norfolk and Suffolk Foundation Trust (NSFT) and candidates were invited to interview, but the interviews were cancelled the day before with no full explanation. Candidates were told the 'positions no longer exist'. The Rethink Experts by Experience were unaware of the changes being made to the recruitment of this role. Healthwatch Norfolk and the Experts by Experience Reference Group advised the Community Transformation Steering Group that candidates needed a full explanation and how they could apply for the roles through Norfolk and Waveney Mind.

The ICB representative recognised that there were concerns raised about this at a Steering Group meeting after this occurred.

> We should have, at the time, had those conversations more clearly about why the recruitment had been paused to alleviate those concerns, then they wouldn't have resulted in such distress, because there was such a misunderstanding about the reason for that... I think we've picked up from that and we're stronger as a result. I would say there's still success there. And lots of learning in that.

The second and third part of outcome five in the evaluation framework reviewed the integration of new mental health services into Primary Care to develop a blended workforce and if these teams are working effectively.

Integration of Blended Workforces

For this part of the evaluation, Healthwatch Norfolk interviewed three Primary Care Managers. We wanted to find out if the new mental health posts (for example: Mental Health Practitioners) are being successfully and effectively integrated into Primary Care to create a blended workforce.

There has been successful recruitment and retention of Mental Health Practitioners into Primary Care in central Norfolk, "*one of the things that's gone well so far is recruitment and retention into those roles. I know in other parts of the county; recruitment has been challenging and equally as challenging as retention.*"

But other parts of the county have experienced the recruitment and retention of the new posts as challenging.

> One of the most difficult things for our patients is staff retention We have had a designated mental health practitioner and they attended the surgery once/twice a week and saw people face to face, this was an excellent service, but the person only spent a few months with us before their role was moved to another surgery. The new practitioner is less well qualified and is requiring supervision to gain adequate skills to be able to provide therapy.

One of the Primary Care Managers described the enthusiasm for blending primary and secondary mental health services as helping the process to work well, *"I think what's working well is actually our enthusiasm for it and that it's been well received in a lot of the primary care networks that we're working in."*

Two of the Primary Care Managers recognised the value of integrating mental health professionals into primary care settings and how employing Mental Health Practitioners helps them to provide support for patients that don't quite meet the treatment threshold for certain mental health services (for example: IAPT services).

> They've embedded within practice very quickly, and referral numbers are good… they're a really valuable asset to primary care because of the amount of low-level intermediate mental health issues that people are facing but don't kind of meet the threshold for secondary care or maybe slightly too complex or need stabilising before engaging meaningfully with IAPT services.

One of the Primary Care Managers reported that there *'"is absolutely recognition that there's a need for those roles, and practices across the primary care network have made all the accommodations they possibly can"* to make the integration of mental health and primary care services run effectively in GP surgeries.

There have been some challenges faced by creating blended work forces, including the difference in culture and work style between the primary and secondary care services and ways of working.

> One of the challenges that has arisen is the difference in culture between secondary and primary care. I think one of the things that has potentially sort of surprised secondary care colleagues is just the sheer volume of demand that primary care has been holding in terms of [patients with] mental distress and for a long period of time. Conventionally, those people haven't met the threshold for secondary care or have been discharged as a result of non-engagement.

In this new way of working, there will need to be an adjustment from both primary and secondary care professionals to reduce these cultural tensions and the *"lack of recognition potentially on both sides of how sort of the other half works and trying to sort of meet somewhere in the middle"* to create an effective blended work team.

One of the Primary Care Managers suggested that *"the cultural tensions can be addressed on a locality-by-locality kind of individual basis because the way primary care works in in each area is completely different."*

One of the Primary Care Managers described the way community mental health services can view a patient's mental health condition as 'binary' and needing to be treated by a secondary care mental health service, or not.

My impression is that the system approach to mental health is very binary in it's either secondary care or it's not. I think that this has been one of the challenges in delivering mental health nationally … mental health is potentially the least kind of binary form of health.

One of the Primary Care Managers described how there needs to be adjustment from both primary and secondary care professionals to understand the value of and adjust to the new blended workforces.

I think in terms of those kind of blended roles, there must be acknowledgement on both sides, from a primary care perspective, that these practitioners are not traditionally primary care practitioners, and secondly, from secondary care practitioners, that they're not sitting in secondary care anymore and it's not about severe mental illness. It's about the individual and not delivering based on kind of a secondary care SLA, KPI type scenario.

Two Primary Care Managers agreed that the new blended workforce integration needs consideration. One of them commented that the transformation leaders had access to a lot of money, but there wasn't the focus on the longer-term effects of spending it on integrating the workforces, *"there's a lot of money in mental health transformation, so we better spend it really quickly, without focusing on kind of the long-term integration aspect of it."*

The same two Primary Care Managers reported positive outcomes from the integration of the new mental health roles into primary care. These included how aware primary care staff have been trying to work to the strengths of the new Mental Health Practitioner roles, *"There's an attempt to play to individual practitioner's strengths, which is good because they all have different training, different experience…* I *think it's fair to say that those roles have been welcomed purely based on the number of referrals that have been made."*

One Primary Care Manager commented that one of the roles of a Mental Health Practitioner is to communicate with primary care staff they work with and *"to try and answer any questions that they can."*

There has been positive feedback given about the new Mental Health Practitioners to one of the Primary Care Managers who said *"I'm told that the mental health practitioners have added value to the practice, that they've had good feedback from service users that have used the service and had appointments with the mental*

health practitioners." The same Primary Care Manager asked for feedback from one local Primary Care Network and they described the Mental Health Practitioners as "*a delight to have in their practice, that there used to be disintegration and access to services used to be poor but they feel that this has improved, that the mental health practitioner that they have is professional and personally excellent and they feel has definitely made a difference".*

There has been some confusion reported from a few Primary Care networks about the Mental Health Practitioner role and exactly what services they are able to offer patients.

> I think while it's great that the individuals [Mental Health Practitioners] have particular areas of interest, whether it be CBT or EMDR, there needs to be a bit of consistency in terms of what the deliverables actually are because it becomes very complicated very quickly to explain to practice staff what these new roles are actually capable of and who is appropriate to refer and so on and so forth based on their individual skills.

Primary Care staff have also reported need to describe to their colleagues what a Recovery Worker is, what the job role entails and how the new mental health roles are different from one another.

> [Primary care staff] haven't really known. We've been explaining the difference and how things can work differently with recovery workers. What's also been a new phrase, I suppose, or new role to them and again has taken a bit of explaining is peer support workers or experts by experience.

One of the Primary Care Managers expressed concern that all the new mental health roles and change to service being brought in by the Community Transformation Steering Group might cause confusion to existing service users.

> When you're thinking about kind of the patient journey or service user journey, potentially, the rate of transformation and all of the new programmes, job roles and projects that are coming up actually makes that journey more complicated for someone who's already potentially going to be in a position where navigating the system is going to be a challenge at the best of times.

Another issue that makes it slightly more difficult to integrate the workforces and the role of the Mental Health Practitioners is primary and secondary care staff working from home, meaning getting to know new staff can take longer, *"you can't have those corridor conversations with the practitioners and say, "Oh, what do you specialise in? What can you deal with?" because a lot of it is remote still. And so there are those*

challenges". One Primary Care manager provided feedback that creating personal relationships with the new members of mental health staff is made more difficult working in this way.

> They are remotely based during working hours. A lot of primary care teams are now. That includes social prescribers and first contact physiotherapists. I don't think there's anything wrong with that, per se. It does mean, though, that building those kinds of personal relationships with colleagues can be challenging. If you don't get to know someone, it's harder to ask questions, isn't it?

In year 2 of the Healthwatch Evaluation we will be completing interviews with staff that have been recruited into the new blended workforces based in primary care:

- Clinical Associate Psychologists
- Peer Support Workers
- Mental Health Practitioners
- Recovery Workers
- Specialist Pharmacists in Primary Care

What this means

Outcome 1:

Adults severely affected by serious mental illness report improvements in and access to community based services

It is important to recognise that this is the first of a three-year evaluation of the Community Mental Health Transformation process and that the transformation is also in its first year. We also recognise that there are many adults severely affected by serious mental health illness whose voices we have not been able to capture.

The results of the survey for adults severely affected by serious mental health illness gives us a baseline and helps to identify areas that can be further improved upon and for the Community Transformation Steering Group to ensure that the transformation plans are addressing these issues.

The survey was able to reach those people who are severely affected by a serious mental health illness. 82% of the respondents to the survey had one of the following identified serious mental health illnesses:

- Severe depression
- Personality disorder
- Bi-polar disorder
- Psychosis
- Eating disorder
- Schizophrenia / schizoaffective disorder

Nearly three-quarters of the people that responded to the survey were women (71%). However, the survey highlights that there is some disparity in how men and women experience community services:

- Less men than women report feeling included in their care,
- More men than women rate the support they receive from their main point of contact as poor
- Less men than women believe that their main point of contact understands that their mental health needs affect other areas of their life
- More women than men have needed to access the out of hours crisis team

- People who classed themselves as having a disability were more frequently not included in their care, although more likely to have a care plan.

I Statement Outcomes

Approximately one fifth of survey respondents appear to have the following outcomes:

- They have a care plan in place
- They feel very involved in their care
- They feel that their family are appropriately involved in their care

However, the survey results show that the I-statement outcomes "*I want my care plan to be up to date with my current mental health and my life*", *"I want to be part of my care"* and *"I want my loved ones and I to have an agreed care plan that is about me"* are not being met for many adults with SMI. 54% of respondents reported that they did not have a care plan, 42% stated that they did not feel involved in their care and 35% said that there family were not involved in their care. Only 35% of respondents reported that there had been a discussion with their main contact about their care plan and how their treatment and care is working.

Person-centred care should treat people with care, dignity and respect and 31% of respondents felt they were always treated in this way, with 41% stating they sometimes were. 76% of respondents said that they had not been asked about their care or how they have been treated. Respondents recognised the pressures that staff were under due to staff shortages and tried to make allowance for this, however unhelpful attitudes and approaches were highlighted by others.

An additional feature of person-centred care is the provision of coordinated care, support, and treatment. Over 40% of respondents knew who their main point of contact in community mental health services was, however, 47% of respondents who had a main point of contact felt that the organisation of their treatment and care was bad. This was due to a lack of continuity in care, appointments often being cancelled and poor communication. Individuals also highlighted in the survey and interviews that the professionals they have contact with are "going through a tick-box exercise".

There is still progress to be made in respect of the outcome "*I want to experience person-centred care, wherever I can - with, about and for me*", which should focus on improving helpful communication and the coordination role of the main contact.

The survey results also identify that when people needed to access the out of hours crisis team, over half of these people (62%) said that the crisis team were not aware of

their treatment history or the NHS plan. This identifies that the outcome "*I want continuity in my care team*" is not yet fully being met.

In relation to the outcome *"I expect professional carers to have an understanding of mental health needs"* the survey results identified that 45% of respondents did not feel that their main contact understood that their mental health needs affected other areas of their life. The follow-up interviews with carers also supported that there is an unrealistic expectation about people who are seriously affected by serious mental illness to keep on top of appointments and follow up with things, especially at time of crisis.

Regarding wider community support and the outcome "*I want services and support to be well advertised in my local community*" there was an even mix of awareness about wider support services available with 48% of respondents stating that their awareness of community mental health services available was bad and 52% stating it was good or okay.

Are people experiencing positive change?

We asked respondents what changes they had seen (both good and bad) to community-based services within the last twelve months and the overwhelming response was that people have not experienced any positive changes. We should balance this with the recognition that those people who are more likely to complete a survey like this are people who take the opportunity to express their concerns. However, we cannot ignore the responses from this survey.

Outcome 2

Families and carers of adults severely affected by serious mental illness report improvements in and access to community based services

Most respondents to the carers survey were women (89%), which is higher than the national statistic: 58% of carers are women (Carers UK, 2019).

Many carers that responded to the survey did not feel involved in discussing their treatment and care of the person they support (66%), how they can help the person they support (70%), nor feel kept up to date about the treatment and care of the person they support nor given enough information about how the mental health of the person they support could change (79%). This lack of

involvement of carers suggests that the following outcomes are not likely to be met:

- I want my loved ones and I to have an agreed care plan that is about me
- If I am unable to make my own decisions for myself, my prior wishes, and my family /carer views will be considered

Just over half of carers (51%) reported that they felt that they are often or sometimes treated with kindness and respect, which is less than those people severely affected by a mental health illness. However, this also reflects the lack of contact that carers have with the community based mental health services.

Two-thirds of carers have needed to find support or help for their own wellbeing, with 32% using their GP for support. People also accessed voluntary and community sector support for carers (17%) and community mental health services (7%) and social services (7%).

Are carers experiencing positive change?

As with adults severely affected by a mental health illness, carers also reported a lack of change and expressed frustration about waiting times, having difficulty contacting people and staff changes.

Outcome 3

The Community Transformation Steering Group can evidence they have made changes that have positively impacted on community mental health provision for adults

Much of our evidence for this outcome is based on what the steering group have told us they have achieved, feedback from the Experts by Experience and feedback from the Voluntary, Community and Social Enterprise (VCSE) sector.

There is clear evidence of involvement throughout the transformation process of Experts by Experience, which has been reported by the Experts by Experience Reference Group. This is also evidenced through the attendance at the Steering Group and the activities the Reference Group have been engaged in. Partners have also been positive about the involvement of Experts by Experience.

The Reference Group supported by Rethink currently consists of ten members and the levels of engagement appear to vary, which is understandable due to people's personal commitments etc. Within the reference group there is a

smaller cohort that are consistently and enthusiastically engaged with the process and have developed in confidence and have been raising issues to be addressed and putting forward ideas. Whilst the involvement of Experts by Experience has generally been a success, there is a reliance on this small cohort to "speak for" all those who are affected by mental health issues and there is opportunity for wider involvement and engagement through the VCSE sector.

There has been concern raised about how the Community Transformation Steering Group engage with the Experts by Experience Reference Group in their communications, the timings of papers and cancellation of meetings. At present we believe that the Steering Group is involving and engaging Experts by Experience, but there is a long way to go before they have equal partnership in the earliest stages of service design, development and evaluation.

This is also the case with the VCSE sector, who have been positive about the information and updates they receive through the Mental Health Providers Forum but have been clear that they have not played a role in the design or development of the transformation.

Engagement with VCSE organisations tends to be focussed on larger, commissioned organisations, which means that some of input from smaller, but experienced organisations may not get the opportunity to support the transformation plans.

The initial plans for the Community Transformation Steering Group included a focus on outcomes that had been developed by people with lived experience, the "I Statements". Unfortunately, as the transformation process gathered pace, these I statement outcomes were overlooked. We believe that it is important to continue to refer to the outcomes desired by people who have lived experience of mental health issues as a key measure in proving the success of the transformation. These statements are now being refreshed in consultation with the Experts by Experience Reference Group.

Outcome 4

Community based services report improvements (local authorities and third sector organisations supporting adults severely affected by mental illness.

The plans for the transformation and the commitment of the Community Transformation Steering Group have been positively recognised by wider stakeholders, who have enthusiasm and commitment to the programme of change. However, this is the first year of the transformation process and the impact of any changes have yet to be experienced by these stakeholders.

Some voluntary, community and social enterprise (VCSE) sector organisations report increasing demand for advocacy services, which they are struggling to meet. They highlight the need for services that address those issues that contribute to the difficulties faced by people with serious mental health issues, such as housing, debt and domestic abuse. The VCSE sector is well positioned to provide these services but requires funding to meet the level of demand. Joined up services should include an appropriately funded VCSE sector and should meet people's wider needs.

The VCSE sector has been engaged in the transformation process but could play a greater role in the design and delivery of services. We recognise that it is difficult for the Community Transformation Steering Group to find the best way to fully engage with the VCSE sector. The Mental Health Providers Forum has been a good mechanism to keep a broad range of VCSE providers updated and informed on the progress being made, which has been appreciated by the VCSE sector. But work on the transformation plans has been limited to a few key, larger, VCSE providers who have been approached directly by the Community Transformation Steering Group for their involvement. This has meant that the input of other, often smaller, organisations has been missed out. If the Norfolk and Waveney VCSE Assembly had been more fully developed, this could have been a valuable means of seeking wider engagement and potentially opportunity for coproduction.

There is concern from the VCSE sector that there is a lack of understanding of the professionalism and expertise within the sector and that the perception is that all services are delivered by volunteers. The VCSE sector strengths include being able to work in a more flexible, dynamic and holistic way, but this should be embraced rather than try to force providers to deliver in the way the statutory sector thinks it should. *"We have to be careful in the commissioning of these*

services that it doesn't become so focused on things that don't matter to people and then turn into something like a quasi-statutory service".

At this stage of the transformation, there is no positive impact on the waiting times for services for these people who are severely affected by mental health issues, which the representatives of the steering group acknowledge.

One area of success that has been recognised by some providers is the rehabilitation pilot in Norwich, which has established multi-disciplinary teams, including VCSE providers, which aim to help people return to the community from hospital. If this pilot is a success and is rolled out through Norfolk and Waveney this should have a positive impact on waiting times.

There is a tension about when is the right time to communicate the changes that are planned and have happened around the transformation. The Mental Health Providers Forum has received regular updates, but there has been criticism that communication about the changes is not going to the people who use or deliver the services.

Outcome 5

Mental Health Workforces will report improvements in community-based services for adults severely affected by mental illness

The recruitment of Mental Health Practitioners and Recovery Workers is well underway, but there are more posts to recruit to. The Mental Health Practitioners are employed by Norfolk and Suffolk Foundation Trust but linked to a GP Practice.

These posts have been welcomed by GP Practices and patients, but there are challenges around the integration of the roles. There is a difference in the culture between this employed in primary care and those in secondary care, which must be overcome to ensure successful integration. The Mental Health Practitioners also have a variety of backgrounds and experience, which can be a challenge for primary care colleagues in understanding what the Mental Health Practitioners can offer to patients. This made worse because these posts are not based in the surgery, but are remote working, making it more difficult to develop strong working relationships.

The changes to the recruitment of Peer Support Worker roles (originally being employed by Norfolk and Suffolk Foundation Trust (NSFT) and changing to being recruited by Norfolk and Waveney Mind) were poorly communicated to

applicants by NSFT. A delay in addressing this at a Steering Group meeting and not providing timely communication to applicants for the reasons behind these changes, left people feeling undervalued and confused.

Recommendations

Recommendations for Healthwatch Norfolk

Healthwatch Norfolk will explore other ways of engaging with adults severely affected by mental illness and their carers to get their feedback about community mental health services. This could be achieved by engaging with even more VCSE organisations, attending local Mental Health Hubs in Norfolk and Waveney, and having a presence in the local Mental Health Cafes (for example: the Steam and Rest Cafés). Healthwatch Norfolk will be mindful of engaging those who are part of seldom heard communities (for example: men as 71% of respondents in the adults severely affected by mental illness were women).

Recommendations for Community Transformation Steering Group

Outcome One

The Community Mental Health Service Transformation Steering Group should use the I Statement outcomes as the benchmark for the transformation process.

- 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.

Outcome 2

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.

Outcome 3

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.

- 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.

Outcome 4

Seek ways to incorporate wider VCSE support to adults with serious mental health issues into the transformation plans

- 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.

Update the Community Transformation Steering Group Communication and Engagement plan for 2022 – 2023

- 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.

Outcome 5

Support the development and integration of the new roles into the wider system

- 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.

References

Carers UK (2019). *Facts about carers*. Available at: https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures#:~:text=58%25%20of%20carers%20are%20women,hours%20of%20care%20per%20week.&text=As%20of%202020%2C%20Carers%20UK,people%20caring%20through%20the%20pandemic.

McKeown, M. (2014). It's the talk: A study of involvement initiatives in secure mental health settings. *Health Expectations: an international journal of public participation in health care and health policy, 19*(3), 570-579

National Health Service (NHS) (2022). *Digital Quality and Outcomes Framework - Official statistics*. Available at: www. digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data

National Health Service (NHS) (2022). *NHS England and NHS Improvement and Coalition for Personalised Care: A Co-production Model.* Available at: https://coalitionforpersonalisedcare.org.uk/resources/a-co-production-model/

Nesta (2012) *People powered Co-production Catalogue.* Available at: http://www.nesta.org.uk/ sites/default/files/co-production_catalogue.pdf

Appendix

Appendix 1: Evaluation Plan

Goals
Healthwatch Norfolk 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	Outputs	Task	Timeframe
Outcome 1 Adults severely affected by mental illness (SMI) report improvements in and access to community-based services.	**Joined up services** Community-based services are providing care that is joined up. **Admin and processes** **Waiting times** To ensure that adults with SMI receive specialist interventions, in a timely and appropriate way. **Rehabilitation** To ensure 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	Contact 3rd Sector Organisations for advice on how to engage with each adult with SMI priority group. **Baseline data collated in year 1** Survey for all adults with SMI in year one – repeated in year 2 Measured against 'I Statements' 1:1 interview for identified adults with SMI, ensuring representation for priority cohorts identified in years 1, 2 and 3. Year One Confirmed priorities: Eating Disorders Personality Disorders Rehabilitation	January 2022 February 2022 – May 2022 February 2023 – May 2023 April 2022 – June 2022 April 2023 – June 2023

	and in control of their care. **Ongoing change** Have adults with SMI already seen any change in community-based services?	Year Two and Year Three Priorities Awaiting Steering Group Confirmation: ADHD Perinatal Physical Health Checks Dementia Care Learning Disabilities and Autism Focus Groups 'themes' to be identified by transformation group. Rehabilitation Focus group to be held at beginning of evaluation and repeated in year 2 with a cohort identified by the lead Psychiatrist.	 April 2022 – June 2022 April 2023 – June 2023 April 2022 – June 2022 April 2023 – June 2023
Outcome 2 Families and carers of adults severely affected by mental illness (SMI) report improvements in and access to community-based services.	**Joined up services** Community-based services are providing care that is joined up. **Feeling in control** Families and carers of adults with SMI feel included in decisions about their care. **Support** Support made available to Families and carers of adults with SMI.	Survey for all families and carers of adults with SMI (integrated into adults with SMI survey) in year one and repeated in year 2. Focus Groups held in year one and repeated in year 2.	February 2022 – May 2022 April 2023 – June 2023 April 2022 – May 2022 April 2023 – June 2023
Outcome 3 The Community Transformation Steering Group can evidence that they have made changes that have positively impacted on community health provision for adults	**Governance** The Community Transformation Steering Group (CTSG) is meeting its own standards around governance. **Partnerships**	Governance Review terms of reference and monitor. Review of minutes of steering group – ensure are actions being delivered and reported back, general sense of	November 2021 and ongoing March 2022 / September 2022

severely affected by mental illness (SMI).	Have been formed and bring value. **Plans** Linked to spending and to outcomes for adults with SMI. **Co-production** The transformation work has been coproduced with people with lived experience.	progress and wider engagement. Partnerships Interviews with partnership organisations to obtain feedback on partner engagement. Transformation Action Plans Session with the Community Transformation Steering Group to link the actions to outcomes for service users. Review of plans and responses to feedback. Co-production Interviews/Focus group with Rethink Experts by Experience Review the evaluation data/outcomes from the Community Transformation Steering Group's own evaluation processes.	 March 2023 / September 2023 April 2022 / April 2023 May 2022 May 2023 September 2023 February 2022 February 2023 TBC when available
Outcome 4 Community based services report improvements (local authorities and 3rd sector organisations supporting adults severely affected by mental illness (SMI).	**Joined up services** Community-based services are reporting improvements in joined up working. **Waiting times** To ensure that adults with SMI receive specialist interventions, in a timely and appropriate way.	Engage with Mental Health Providers Forum and ask for assistance for promoting survey. Focus Groups with VCSE mental health providers for feedback on joining up of services and waiting times Feedback Focus Group report findings to TG	January 2022 August 2022 October 2023 December 2022 December 2023

Outcome 5 Mental Health Workforces will report improvements in community-based services for adults severely affected by mental illness (SMI).	**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.	Request data that identifies whether the new staff roles identified in transformation plan have been recruited. Work with Healthwatch Suffolk to engage with the 2 PCNs in Waveney. Attendance at PCN meetings across the county in different localities. Provide a project presentation and ask for feedback. After attending a PCN meeting, conduct follow up interviews with GP practice managers that are representative of different localities within Norfolk. Interviews with staff in the new workforce posts, for example: Clinical Associate Psychologists Peer Support Worker Mental Health Practitioners Recovery Workers Specialist Pharmacists in Primary Care	April 2022 April 2023 January 2022 April 2022 – July 2022 April 2023 – July 2023 July 2022 – October 2022 July 2023 – October 2023 July 2022 – October 2022 July 2023 – October 2023

Appendix 2: Project Participant Information Sheet

Community Mental Health Transformation Project:
Information for Participants

About us

Healthwatch Norfolk is an independent champion for people who use health and social care services. There is a local Healthwatch in every area of England. We find out what people like about services, and what could be improved, and we share these views with those with the power to make change happen. Healthwatch also help people find the information they need about services in their area.
Nationally and locally, we have the power to make sure that those in charge of health and social care services hear people's voices. As well as seeking the public's views ourselves, we also encourage health and social care services to involve people in decisions that affect them.

Through our work we will collect and share peoples' experiences as a way of driving change and improvement.

About the Project: Summary of research

The NHS is working in partnership with Norfolk and Suffolk councils, charities and community organisations to improve key Community Mental Health Services, so the needs of carers of adults severely affected by mental health conditions are better met.

Healthwatch Norfolk is currently working on a project that will evaluate the changes made to Community Mental Health Services in Norfolk and Waveney. If you are a carer or support an adult (aged 18+) living in Norfolk or Waveney affected by a mental health condition in the past 12 months, we would like to hear about your experiences of treatment and care. We would like to know what you think works, what could be improved and whether you have seen any recent improvements to Community Mental Health Services.

We are interested in hearing from carers of adults severely affected by mental illness (SMI), particularly those affected by:

- Psychosis
- Bi-polar disorder
- Schizophrenia / Schizoaffective Disorder
- Personality Disorder
- an Eating Disorder
- Severe Depression
- a mental health condition resulting in a need for rehabilitation

How the data will be used

Anonymised interview data will be shared with Norfolk and Waveney Clinical Commissioning Group (CCG) and Norfolk and Suffolk Foundation Trust (NSFT) to enable them to review their progress with the Community Mental Health Transformation.

The interview data will also be used by Healthwatch Norfolk to make recommendations to service providers as part of our evaluation report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:
www.healthwatchnorfolk.co.uk/about-us/privacy-statement

Explanation

We would like to speak to people who have used or tried to use community based mental health services, or those that are the parents/carers of people who have. We are doing this in two different ways:

- Online survey
- Conversation/discussion with Healthwatch Norfolk staff (either face to face, virtual or telephone)

What would taking part involve?

If you would like to take part then we will arrange a time and place for you to speak with us that its convenient for you. If you would like someone to support you then it is fine to invite a friend/family member or carer. We will also ask you if you need any

other support such as a BSL interpreter. Once we have booked the meeting with you, we will send a confirmation email or letter.

At the meeting

If we speak with you in person, there will be two members of Healthwatch Norfolk staff present, this is so that one member of staff can take notes.
We will ask you questions about your experiences of getting support from community mental health services. For example:

- How included you feel when making decisions about the person you support's treatment and care.
- What good or bad changes have you seen to Community Mental Health Services within the last 12 months.
- What improvements or additional support would you like to see Community Mental Health Services offer.

Healthwatch Norfolk staff are not therapists or counsellors and we will not ask you any questions about any traumatic events that you may have experienced. We can give you contact details for organisations that can help you.

It may be the case that you have tried to get help, but you haven't been able to. It's important that we hear about this too as it helps us to understand what the problems are and what might be done to improve things.

It's important that you understand you can stop or pause the meeting at any time. If our conversation hasn't finished by the end time of the meeting, then we will arrange a further session with you if you are happy to do so.

At the end of the meeting, we will ask you to check that our notes are correct, and we can make changes if they aren't. We will also check if you would like an email a week after our meeting, to check that you are ok. At any point you can contact Healthwatch Norfolk who will be able to signpost you to another service if its required.

What are the possible benefits of taking part?

There are not any direct benefits to you for taking part. We hope that this piece of research will help commissioners and local service providers to understand what adults severely affected by mental illness need from community mental health services.

What happens to the information you provide?

We will collect some contact information from you such as your telephone number and email address, etc… so that we can get in touch with you about the project. This information will be stored securely and only accessed by Community Mental Health Transformation project staff.

The information you share with us about your experiences will be anonymised in our report. Healthwatch Norfolk will not disclose any confidential information unless there is a genuine and urgent concern for an individual's safety or wellbeing or if the individual concerned consents to the sharing of the information.

Ethical considerations

You have the right to withdraw from the project at any time. You also have the right to withdraw your responses and these will no longer be used in our analysis. Information will be kept anonymous and confidential so that you cannot be identified in any publication. You can access Healthwatch Norfolk's privacy information here: https://healthwatchnorfolk.co.uk/about-us/privacy-statement/

Data subject rights

As a participant you will have a right to:

- access any data that Healthwatch Norfolk hold about you
- ask for that data to be rectified if it is inaccurate.
- ask for the data to be deleted or not to be used in specific ways.
- make a complaint to the Information Commissioner's Office (www.ico.org.uk) if they consider that personal data has not been processed in accordance with the law.

Contact details

If you would like further information, wish to withdraw from the project or lodge a complaint then please contact Healthwatch Norfolk by email or telephone.
Email: enquiries@healthwatchnorfolk.co.uk
Phone (ask to speak to someone about the Community Mental Health Project project): 0808 1689669

Appendix 3: Adults Severely Affected by Mental Illness Survey

Adults Severely Affected by Mental Illness Survey: Community Based Mental Health Services Healthwatch Evaluation

Introduction

Please note: this survey will be discussing mental health issues. If you are struggling with your mental health and are looking for advice on where to get support, visit this link for organisations who can help you.

We have a separate survey to capture the experiences of people supporting and carers of adults severely affected by mental illness: https://www.smartsurvey.co.uk/s/carersadultmentalhealthservices/

Who is Healthwatch Norfolk?

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

What is this survey about?

The NHS is working in partnership with Norfolk and Suffolk councils, charities and community organisations to improve key community based mental health services, so the needs of adults with mental health conditions are better met.

Healthwatch Norfolk are currently working on a project that will evaluate changes made to community based mental health services in Norfolk and Waveney.

If you are an adult (aged 16+) living in Norfolk or Waveney and support or care for an adult affected by a mental health condition, we would like to hear about your experiences of involvement and support from Community Mental Health Services.

We would like to know what you think works, what could be improved and whether you have seen any recent improvements to Community Mental Health Services.

We are interested in hearing from adults severely affected by mental illness (SMI), particularly those affected by:

- Psychosis

- Bi-polar disorder
- Schizophrenia / Schizoaffective Disorder
- Personality Disorder
- An Eating Disorder
- Severe Depression
- A mental health condition resulting in a need for rehabilitation

The survey will take around 10 minutes to complete.

How the survey results will be used

All survey responses will be anonymous and all personal information included in the survey (for example: identifying information) will not be shared in the report. The survey results will be used to make recommendations to health and social care providers as part of the Healthwatch Norfolk evaluation report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:

www.healthwatchnorfolk.co.uk/about-us/privacy-statement

If you would prefer to do this survey with us over the phone, please call Healthwatch Norfolk on 01953 856029 and we will arrange a time to ring you back to complete the survey. Alternatively, please email: enquiries@healthwatchnorfolk.co.uk for further support.

Survey Closing date: 30th May 2022

1. Please tick the box here to confirm that you have read and understood the privacy policy: *****

☐ I have read and understood the privacy policy.

2. Healthwatch Norfolk produce quarterly newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

Involvement

3. Do you have a current NHS care plan?

NHS Care Plan: is a plan that describes in an easy, accessible way the needs of a person affected by mental ill health. The care plan outlines their views, preferences and choices, the care and treatment resources available to them and the actions recommended by members of their mental health care team, to meet those needs. It should be put together and agreed with the person, through the process of care planning and review. *

- [ ] Yes
- [ ] No
- [ ] Unsure

4. How useful do you find your NHS care plan?

- [ ] Useful
- [ ] OK
- [ ] Not Useful

Please use this space to tell us why you have chosen this answer:

5. How included do you feel when making decisions about your own treatment and care?
*

- [ ] Very included
- [ ] Sometimes included
- [ ] Not included

Please use this space to tell us why you have chosen this answer:

6. Has anyone within Community Mental Health Services asked you about your care and how you feel you've been treated?
For example: what was good or bad about your treatment? *

- [ ] Yes
- [ ] No
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

Involvement of Family and Friends

7. Is your family, someone close to you or an advocate involved in your treatment and care as much as you would like? *

- [ ] Yes
- [ ] No
- [ ] Not Applicable
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

8. Within the Community Mental Health Services, who is your main point of contact? This would be the person organises / coordinates your treatment and oversees your NHS care plan.

- [ ] Mental Health Nurse
- [ ] Social Worker
- [ ] Psychologist
- [ ] Psychiatrist
- [ ] Occupational Therapist
- [ ] Mental Health Practitioner
- [ ] Unsure
- [ ] Not Applicable
- [ ] Other (please specify):

9. How would you rate the organisation of the treatment and care you receive from the main point of contact?

- [ ] Good
- [ ] OK
- [ ] Bad

Please use this space to tell us why you have chosen this answer:

10. Does the main point of contact understand how your mental health needs affect other areas of your life?

- [ ] Yes
- [ ] No

- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

11. In the last 12 months have you discussed your NHS care plan and how your treatment and care is working with the main point of contact?

- [ ] Yes
- [ ] No
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

12. Waveney if you have experienced a mental health crisis? *

- [ ] Yes
- [ ] No
- [ ] Unsure

13. How aware of your treatment history and NHS care plan were the Out of Hours Crisis Team?

- [ ] Very aware
- [ ] Somewhat aware
- [ ] Not aware

Please use this space to tell us why you have chosen this answer:

14. How would you rate your own awareness of what Community Mental Health services or support is available to you? *

- [ ] Good
- [ ] OK
- [ ] Bad

Please use this space to tell us why you have chosen this answer:

15. How often do Community Mental Health Services staff treat you with kindness, dignity and respect?

- [ ] Often
- [ ] Sometimes
- [ ] Never

Please use this space to tell us why you have chosen this answer:

Support and Wellbeing

16. In the last 12 months did you receive any Community Mental Health Services support with any of the following? (please select all that apply)

- [ ] A physical health need (e.g. an injury or a disability)
- [ ] Money or benefits advice
- [ ] Finding or securing accommodation
- [ ] Looking for or securing work (paid or voluntary)
- [ ] Joining a group or taking part in an activity
- [ ] None of the above

17. Please tell us how helpful you found the support given to you to by Community Mental Health Services for: a physical health need (e.g. an injury or a disability) money or benefits advice looking for or securing work (paid or voluntary) finding or securing accommodation joining a group or taking part in an activity.

18. What good or bad changes have you seen to Community Mental Health Services within the last 12 months?

19. What improvements or additional support would you like to see Community Mental Health Services offer?

20. Please use this space to tell us anything else about the support you receive from Community Mental Health Services in Norfolk and Waveney.

21. If you would like to be involved in this project, please leave your first name and email address or a contact number here and we will be in touch to arrange an interview about your experiences.

Demographics

In this section we will be asking you some questions about yourself and your life your answers help us make sure that we engage with people from different backgrounds and that we understand the needs of different groups in our community. All of your answers are strictly confidential, and the survey is anonymous.

- How old are you?
- What is your gender?
- What is your sexuality?
- Do you consider yourself to have a disability?
- What is your ethnic group?
- Where did you hear about Healthwatch Norfolk?

Appendix 4: Interview Questions for Adults Severely Affected by Mental Illness

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.

Please could you tell me a little bit about yourself and your experience of living with a mental health issue / a severe mental illness?

- Do you have a diagnosis?
- When were you diagnosed?
- What has diagnosis meant for you?

Can you tell me a bit about your experience of being supported by community mental health services in Norfolk and Waveney?

How would you describe your experiences of being supported by community mental health services?

- What services have you received?
- What about your experience has been good?
- What about your experience has not been good?

Have you seen any recent changes to the community-based support you receive? If so, what are these?

What changes to community mental health services could be made to make things better for you?

Thank you for your time! [Debrief]

Appendix 5: Families and Carers of Adults Severely Affected by Mental Illness Survey

Carer Survey: Community Based Mental Health Services Healthwatch Evaluation

Introduction

This survey is aimed at people who care for someone with mental health issues. If you are struggling with your own mental health or would like information about support for carers please visit this link for organisations that can help you..

We have a separate survey to capture the experiences of adults severely affected by mental illness: **Error! Hyperlink reference not valid.**

Who is Healthwatch Norfolk?

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

What is this survey about?

The NHS is working in partnership with Norfolk and Suffolk councils, charities and community organisations to improve key community based mental health services, so the needs of adults with mental health conditions are better met.

Healthwatch Norfolk are currently working on a project that will evaluate changes made to community based mental health services in Norfolk and Waveney.

If you are an adult (aged 16+) living in Norfolk or Waveney and support or care for an adult affected by a mental health condition, we would like to hear about your experiences of involvement and support from Community Mental Health Services.

We would like to know what you think works, what could be improved and whether you have seen any recent improvements to Community Mental Health Services.

We are interested in hearing from carers and people that support adults severely affected by mental illness (SMI), particularly those affected by:

- Psychosis
- Bi-polar disorder
- Schizophrenia / Schizoaffective Disorder
- Personality Disorder
- An Eating Disorder
- Severe Depression
- A mental health condition resulting in a need for rehabilitation

The survey will take around 10 minutes to complete.

How the survey results will be used

All survey responses will be anonymous and all personal information included in the survey (for example: identifying information) will not be shared in the report. The survey results will be used to make recommendations to health and social care providers as part of the Healthwatch Norfolk evaluation report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:

www.healthwatchnorfolk.co.uk/about-us/privacy-statement

If you would prefer to do this survey with us over the phone, please call Healthwatch Norfolk on 01953 856029 and we will arrange a time to ring you back to complete the survey. Alternatively, please email: enquiries@healthwatchnorfolk.co.uk for further support.

Survey Closing date: 30th May 2022

1. Please tick the box here to confirm that you have read and understood the privacy policy: *****

☐ I have read and understood the privacy policy.

2. Healthwatch Norfolk produce quarterly newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

Involvement

3. Do the Community Mental Health Services involve you as much as you want to be, when discussing the treatment and care of the person you support? *

- [ ] Yes
- [ ] No
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

4. Do Community Mental Health Services explain ways you could help the person you support, during their treatment and care? *

- [ ] Yes
- [ ] No
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

5. Do Community Mental Health Services keep you up to date about the treatment and care for the person you support? *

- [ ] Yes
- [ ] No
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

Carer Support

6. Have Community Mental Health Services given you enough information about how the mental health condition of the person you support could change? *

- [ ] Yes
- [ ] No
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

7. Do you know who to contact within Community Mental Health Services, if the person you support has a crisis and you need help right away? *

- [ ] Yes
- [ ] No
- [ ] Unsure

Carer Wellbeing

8. As a carer, have you needed to find help or support for your wellbeing? *

- [ ] Yes
- [ ] No
- [ ] Unsure

9. As a carer, where have you been able to find help or support for yourself? Please select all that apply: *

- [ ] Community Mental Health Services
- [ ] Local Organisation (e.g. Carers Matter / Carers Together / Carers Voice)
- [ ] Doctor
- [ ] Social Services
- [ ] None of the above
- [ ] Other (please specify):

10. How often do Community Mental Health Services treat you with kindness, dignity and respect? *

- [ ] Often
- [ ] Sometimes
- [ ] Never
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

Community Mental Health Transformation

11. What good or bad changes have you seen to Community Mental Health Services within the last 12 months?

12. What improvements or additional support would you like to see Community Mental Health Services offer?

13. Please use this space to tell us anything else about the support you receive as a carer from Community Mental Health Services in Norfolk and Waveney.

14. If you would like to be involved in this project, please leave your first name and email address or a contact number here and we will be in touch to arrange an interview about your experiences.

Demographics

In this section we will be asking you some questions about yourself and your life your answers help us make sure that we engage with people from different backgrounds and that we understand the needs of different groups in our community. All your answers are strictly confidential and the survey is anonymous.

- How old are you?
- What is your gender?
- What is your sexuality?
- Do you consider yourself to have a disability?
- What is your ethnic group?
- Where did you hear about Healthwatch Norfolk?

Appendix 6: Interview Questions for Families and Carers of Adults Severely Affected by Mental Illness

Interview Questions for Families and Carers of Adults Severely Affected by Mental Illness

Thank you for agreeing to discuss your experiences of supporting someone receiving community based mental health services. 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.

Please could you tell me a little bit about yourself and your experience of supporting/caring for an adult living with a mental health issue / a severe mental illness?

- Do they have a diagnosis? / When were they diagnosed?
- What has diagnosis meant for you as a carer?

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?

How would you describe your experiences (as a carer) of being supported by community mental health services?

- What services have you received?
- What about your experience has been good?
- What about your experience has not been good?

Have you seen any recent changes to the community-based support you receive? If so, what are these?

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 Third Sector and Voluntary Organisations

Interview Questions for Third Sector and Voluntary Organisations

Please could you tell us a little bit about your organisation, what type of support is available and to whom support is provided to within Norfolk and Waveney.

What experience does your organisation have with supporting adults severely affected by mental illness (SMI)?

Thinking about the Community Mental Health transformation programme, what do you think is working well? What do you think is working less well?

Are there particular issues or things that your organisation think need addressing?

How engaged and involved have your organisation and service users been in the planning and process around community transformation?

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 (SMI) 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?

Would it be possible for your organisation to provide an anonymised case study for use in our report that reflects how things are working in relation to the Community Mental Health transformation programme?

Appendix 8: Co-production Survey

Survey For Expert by Experience Leaders Reference Group Members Norfolk and Waveney Community Mental Health Transformation

What is this survey about?
Rethink Mental Illness and Healthwatch Norfolk have developed the following survey to ask for your thoughts and feedback on your experience of being part of the reference group and co-production work for the Community Mental Health Transformation in Norfolk and Waveney.

Who is Healthwatch Norfolk?
Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather your views of health and social care services to ensure they are heard by the people in charge.

About the Survey
This survey has 14 questions and will take approximately 10 minutes.

How the survey results will be used
All survey responses will be anonymous and all personal information included in the survey (for example: identifying information) will not be shared in the report. The survey results will be used by Rethink to evaluate their role in supporting Experts by Experience to be part of the reference group and co-production work for the Community Mental Health Transformation.

Survey responses are being collected and analysed by Rethink Mental Illness and Healthwatch Norfolk. You can read the full privacy policies here:

Rethink Mental Illness: www.rethink.org/privacy/
Healthwatch Norfolk: www.healthwatchnorfolk.co.uk/about-us/privacy-statement

Survey Closing date: Wednesday 11th May 2022

We will ask you to fill out the same survey in another six months to see whether Rethink are making progress with this work.

Please Note: As this survey is anonymous, we will be unable to respond to any individual queries or comments.

1. Please tick the box here to confirm that you have read and understood the privacy policies: *

- [ ] I have read and understood the privacy policies.

2. Healthwatch Norfolk produce quarterly newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

3. How long have you been involved in co-production work for the Community Mental Health Transformation with Access Community Trust (ACT) and/or Rethink? *

- [ ] 0-6 months
- [ ] 7-12 months
- [ ] 1-2 years
- [ ] 2-3 years
- [ ] more than 3 years

4. How many hours do you spend on average doing this co-production work a month? *

- [ ] 0-5 hours a month
- [ ] 6-10 hours a month
- [ ] 11-15 hours a month
- [ ] 16-20 hours a month
- [ ] 21-25 hours a month
- [ ] 26-30 hours a month
- [ ] 31+ hours a month

5. What co-production work have you been involved in within the Community Mental Health Transformation? Please select all that apply. *

- [ ] Attending Reference Group meetings
- [ ] Attending Steering Group / Operational Group meetings
- [ ] Involvement in the Community Mental Health Transformation Workstreams (e.g. Personality Disorder / Rehab)
- [ ] Producing and delivering training
- [ ] Recruitment (for Rethink or Norfolk and Suffolk Foundation Trust)

- [ ] Preparation for Reference Group meetings
- [ ] Preparation for Steering Group / Operational Group meetings
- [ ] Other (please specify):

Support from Rethink

6. In your role as an Expert by Experience, how would you rate your satisfaction with the support you receive from Rethink?

- [ ] Very Satisfied
- [ ] Satisfied
- [ ] Neither Satisfied or Dissatisfied
- [ ] Dissatisfied
- [ ] Very Dissatisfied

Please use this space to tell us why you have chosen this answer:

7. How often have you experienced barriers to taking part in this co-production work? For example: a barrier could be meeting timings clashing with childcare responsibilities or not receiving meeting agendas on time) *

- [ ] Never
- [ ] Sometimes
- [ ] Often

If you have experienced barriers to this co-production work, please give examples here:

8. Do you think the Reference Group is as diverse or inclusive as it could be? *

- [ ] Yes
- [ ] No
- [ ] Unsure

If no, how do you think Rethink could make the Reference Group more diverse and/or inclusive?

9. How would you rate your satisfaction with the communication you receive from Rethink? *

- [ ] Very Satisfied
- [ ] Satisfied
- [ ] Neither Satisfied or Dissatisfied
- [ ] Dissatisfied

- [ ] Very Dissatisfied

Please use this space to tell us why you have chosen this answer

10. How would you rate the facilitation of the Reference Group meetings?

- [ ] Very Satisfied
- [ ] Satisfied
- [ ] Neither Satisfied or Dissatisfied
- [ ] Dissatisfied
- [ ] Very Dissatisfied

Please use this space to tell us why you have chosen this answer:

11. What extra training have you received to support you in your role?

12. What extra training would you be interested in receiving to support you in your role?

13. Do you think that bringing your lived experience to the transformation process has led to any changes so far?

- [ ] Yes
- [ ] No
- [ ] Unsure

Please use this space to tell us why you have chosen this answer:

14. Please use this space to tell us anything else you think it's important for us to know about your role as Expert by Experience leader for Rethink.

Appendix 9: Co-production Interview Questions

Interview Questions for Rethink Experts by Experience

Thank you for agreeing to discuss your experiences of co-producing work with the Community Mental Health Service Transformation Steering Group, guided by Rethink (as an Expert by Experience).

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.

What does true co-production mean to you?

What training opportunities have been offered to you?

When did Rethink take over from the Access Community Trust (ACT)?

Why are the hours limited as an Expert by Experience?

What does Rethink do well and what could Rethink do better to support you as an Expert by Experience?

Have you had enough support from Rethink to be an Expert by Experience?

Appendix 10: Primary Care Workforce Interview Questions

Interview Questions for Primary Healthcare Staff

Thinking about the transformation process what is working well and what is working less well?

Are there particular things that should be done or addressed?

How engaged have you been in the process and planning?

Have you seen improvements in:

- joined up working?
- waiting times for adults with SMI to get the support they need?

How engaged/involved have you / your GP practice / primary healthcare colleagues been in the planning and process around community mental health transformation?

Do you think there have been improvements in joined up working between primary healthcare and mental health staff? Could you give an example of this?

Do you think there have been improvements in waiting times for adults with Serious Mental Illness (SMI) to get the support they need? Could you give an example of this?

Thinking about the mental health workforce and training strategy, what is working well and what is working less well?

What progress has been made to integrate mental health services into primary care? What's working well / what's working less well?

Do you have any additional comments that you would like to make regarding the community mental health transformation programme?

Appendix 11: Information Sheet: Organisations in Norfolk and Waveney Providing Support for adults severely affected by mental illness

Organisations in Norfolk and Waveney Providing Support for adults severely affected by mental illness

This page contains organisations who can provide a range of support for people with common mental health concerns.

Please remember that if you are in a mental health crisis and need emergency help, please dial 999. If you need additional support, please contact your GP or Samaritans on 116 123.

If you are already under the care of mental health services and not in crisis, go directly to your provider in the first instance.

111 mental health helpline

If you have urgent mental health needs, call 111 and then select option 2. This is the service that used to be known as First Response.

The helpline is still available 24/7, 365 days a year and the team is still the same. If anyone is at serious risk of harm, call 999 and ask for the police.
Visit Site

4C Counselling Centre

4Cs (Centres for Christian Care and Counselling) is staffed by both male and female counsellors who work on a voluntary basis. All the counsellors have a personal Christian faith.

4Cs do not charge a fee for counselling, but ask that clients make a donation to the not-for-profit charity, suggesting between £5 and £40 per session in order to cover costs.

Address:
Norwich Central Baptist Church
Duke Street
Norwich
NR3 3AP

Website: https://www.fourcs.org.uk/

Armed Forces support services

Norfolk has lots of support services for Armed Forces personnel and their families. Norfolk County Council have a list of services that can help support you and your loved ones.

Website:

CAM Crisis Messenger Text Service

CAM Crisis Messenger text service provides free, 24/7 crisis support across the UK. If you are experiencing a mental health crisis and need support, you can text CAM to 85258.

Finding the right support is important, especially if you need someone to talk to right now. CAM aim to get every texter in touch with a trained volunteer to provide help in a crisis. They will listen to you and help you think more clearly, enabling you to know that you can take the next step to feeling better.

The trained Crisis Volunteer will introduce themselves and invite you to share at your own pace. You'll text back and forth, only sharing what you feel happy to tell them. By asking questions, listening to you and replying with support, they will help you sort through your feelings until you both feel you are now in a calm, safe place. You might be sent some information about other services that can provide you with further help.

Crisis Messenger can help with urgent issues such as:

- Suicidal thoughts
- Abuse or assault
- Self-harm
- Bullying
- Relationship issues

Website:

Childline

Childline is here to help anyone under the age of 19 in the UK with any issue they are going through. The counsellors are trained staff and volunteers. You can reach Childline via telephone, via online anonymous message boards, or via the Ask Sam service on the website. Childline is a service provided by NSPCC, and offer counselling and support for a range of topics for children and young people:

- Bullying, abuse, safety, and the law
- You and your body
- Your feelings
- Friends, relationships, and sex
- Home and families
- School, college, and work

And the website also includes a dedicated page of advice for parents, covering issues and topics such as:

- Children's mental health
- Keeping children safe at home and away from home
- Online safety
- Reporting abuse
- Talking about drugs and alcohol

Telephone: 0800 1111
Website: https://www.childline.org.uk/

Every Mind Matters

Every Mind Matters is a NHS resource offering tips on how to deal with stresses of life – from the everyday anxieties to the bigger issues. It is regularly updated and now provides support for anxiety caused by coronavirus.

Find support and advice on the following topics:

- Anxiety
- Low mood
- Stress
- Sleep
- Urgent support
- Helping others
- Possible causes

They also have a handy 'Your Mind' quiz, in which you can answer a few questions and get advice on how best to ease your stress.

Website: https://www.nhs.uk/oneyou/every-mind-matters/

Kooth

Kooth is an online platform that offers online counselling and emotional wellbeing support for children and young people. It is accessible through mobile, tablet and desktop and free at the point of use.
Once registered, you can:

- Access the Kooth magazine
- Join and contribute in discussion boards
- Set smart personal goals and track your progress
- Keep a Kooth journal
- Access Kooth chat and messenger, for confidential conversation

Watch the quick useful video on their website to find out more about what Kooth can offer.

Website: https://www.kooth.com/index.html

The Mental Health Foundation

The Mental Health Foundation website aims to provide and equip everyone with information and tools on preventing poor mental health.

Topics covered include:

- Children, young people and families
- Mental health in the workplace
- Mental health in later life
- Influencing UK policy
- Challenging mental health inequalities

On the website you can listen to podcasts, watch videos and read stories, from other people struggling with and succeeding in spite of, mental health issues.

Website: https://www.mentalhealth.org.uk/

MIND

The MIND team will look for details of help and support in your local area. They will provide information on a range of topics including:

- Types of mental health problems
- Where to get help
- Medication and alternative treatments
- Advocacy

Telephone: 0300 123 3393

Email: info@mind.org.uk
Text: 86463
Website:

Norfolk and Waveney Mind

Norfolk and Waveney Mind offers lots of useful resources on their websites about managing your mental health. Mind covers lots of different topics for more individual care and support. They focus on the recovery and healing of those struggling with mental health.

Topics covered on the Mind website are:

- Residential care
- Mindfulness
- Support groups
- Gardening and nature
- Support programmes
- Suicide and bereavement
- Getting active

Norfolk and Waveney Mind have a support line which offers a safe, confidential and non-judgmental space for you to talk to someone. They can offer emotional support, coping strategies, signposting and practical advice. This includes help with developing plans to tackle and limit crisis situations. Call their support line on 01603 432457.

If you call in for the first time and have not accessed these services before the call handler will explain how you can do so and what they might be able to offer you.

Email: mindsupportline@norfolkandwaveneymind.org.uk
Website: https://www.norfolkandwaveneymind.org.uk

The Norwich Centre

The Norwich Centre provides professional counselling to individuals and organisations. It is a BACP Accredited Counselling Service. You will need to pay a fee for your counselling but you can negotiate the fee you pay. More information about fees is available on their website.

Address:
7 Earlham Road
Norwich
NR2 3RA

Tel: 01603 617709
Website: https://www.norwichcentre.org/

NSFT Helpline

If you are supported by one of NSFT's services, you can call the helpline to check your care plan, and during office hours you can contact your care coordinator or the duty number for the team that is supporting you.
Website:

Or call the urgent mental health helpline on 111 and select option 2.

If you need urgent help and you are not supported by NSFT's services:

- Call 111 and select option 2 to speak to the 24-hour urgent mental health helpline
- If you are with someone who has attempted suicide, call 999 and stay with them until the ambulance arrives.
- If anyone is at serious risk of harm, call 999 and ask for the police.

OCD UK

OCD UK is a resource for anyone who is struggling or suffering from their OCD. It offers a breakdown of the disorder and explains the impacts of OCD to help people form a better understanding.

There is advice on diagnosis, blogs, access to support groups and forums.
If you are looking for support better focused to OCD related mental health, you will find support here.

Website: https://www.ocduk.org

Off the Record

Off the Record offers affordable counselling and psychotherapy to teenagers (* from 16yrs), and adult individuals and couples.

Their counsellors are experienced at working with a wide range of issues, including:

- relationships
- low self-esteem and self-confidence
- anxiety and panic attacks
- bullying and self-harm

- depression
- bereavement and loss
- work-related stress
- trauma and abuse issues

Address:
The Surgery
Trinity Street
Norwich
NR2 2BQ

Telephone: 01603 626650
Website: https://www.otr-norfolk.org.uk/

Parent workshops with NSFT

If you're concerned about your child's mental health, Norfolk & Suffolk Foundation Trust (NSFT) are running free online workshops. The workshops are designed to help parents and carers support the mental health of the children they care for.

Workshops available include:

- Supporting young people with anxiety
- Supporting young people with challenging behaviour
- Supporting young people manage uncertainty
- Supporting young people with low mood
- Supporting young people who self-harm
- Supporting young people to manage big feelings
- Supporting children/adolescents with sleep (11 Years+)

PAPYRUS

PAPYRUS provides confidential support and advice to young people struggling with thoughts of suicide. PAPYRUS also engages with communities and volunteers in suicide prevention projects and deliver training programmes to individuals and groups. This includes equipping local councils, healthcare professionals and school staff with suicide prevention skills. If you are having thoughts of suicide or are concerned for a young person who might be you can contact the Hope Line helpline for confidential support and practical advice.

PAPYRUS offers:

- Online digital support platform Hopelink
- Dedicated helpline: Hope Line
- Help and advice resources

- LGBTQIA+ support
- Access to wellbeing apps

Call: 0800 068 4141
Text: 07860 039 967
Email: pat@papyrus-uk.org
Website:

Point-1

The Point 1 emotional wellbeing service offers professional mental health support to infants, children and young people experiencing emotional problems and early signs of mental ill-health. Run in partnership with MAP and Norfolk and Suffolk Foundation Trust, the service is available to any child or young person living in Norfolk or Waveney, or registered with a Norfolk of Waveney GP. They offer a range of support services, including:

- Advice and information
- Telephone support
- Individual/family counselling, talking, play and creative therapies
- Helping you understand your child's needs and guidance on how to support their emotional wellbeing
- Parenting guidance (group and individual)

Telephone: 0800 977 4077
Email: Point1@ormistonfamilies.org.uk
Website: https://point-1.org.uk/

Samaritans

Whatever you're going through – you can call the Samaritans for free, any time, from any phone on 116 123. They are there 24 hours a day, 365 days a year. If you need a response immediately, it's best to call them on the phone. This number is FREE to call. You don't have to be suicidal to call.

Telephone: 116 123
Email: jo@samaritans.org
Write to them:
Freepost RSRB-KKBY-CYJK,
PO Box 9090,
STIRLING,
FK8 2SA
Website: https://www.samaritans.org/

Shout

Shout is the UK's first 24/7 text service, free on all major mobile networks, for anyone in crisis anytime, anywhere. It's a place to go if you're struggling to cope and you need immediate and urgent help. Shout is powered by a team of volunteers, who are at the heart of the service. We take people from crisis to calm every single day. It is free and confidential to text the service from the following major networks: EE, O2, Three and Vodafone

Text: 'Shout' to 85258
Website: https://www.giveusashout.org/

The Silver Line

The Silver Line is the only confidential, free helpline for older people across the UK open every day and night of the year.

Their specially trained helpline team can:

- offer conversation and friendship
- provide information and advice
- link callers to local groups and services.
- refer people on to receive regular friendship calls.
- protect and support older people who are suffering abuse and neglect

Telephone: 0800 470 8090
Website: https://www.thesilverline.org.uk/

St Barnabas Counselling Centre

St Barnabas Counselling Centre offers online and telephone counselling as well as a limited amount of face-to-face counselling at the Centre. The service has no need for doctor's referral, not time limited, available to those aged over 18 years old and can be one-to-one or for couples. There is a sliding price scale depending on circumstances, starting from £15.

Call 01603 625222
Email admin@stbcc.org.uk
Website: https://www.stbcc.org.uk/

Wellbeing Service

Wellbeing Norfolk & Waveney provide a range of support for people with common mental health and emotional issues, such as low mood, depression or stress. They

work with you to help you make any changes needed to improve your wellbeing and quality of life.

If you are aged 16 and over you can get support through your GP or any other health or social care professional. If not, you can complete a form on their website or by calling 0300 123 1503. A self referral form is available on the Wellbeing website.

Website:

YANA (You Are Not Alone)

YANA is here for anyone who works in farming, agriculture, or any related profession/job. By calling the YANA helpline you can speak to someone who really understands the industry and its problems. YANA provides unique support and advice for the wide farming community from sympathetic GPs and counsellors. Anything you discuss is “off the record” and totally confidential.

YANA offers:

- Advice and support
- YANA Mental Health First Aid Courses
- Dedicated confidential helpline
- Knowledge of the farming and agricultural industries

Telephone: 0300 323 0400
Website: https://www.yanahelp.org/
Email: johoey@yanahelp.org

Appendix 12: Interview Questions for Community Transformation Steering Group Representatives

Interview Questions for Community Transformation Steering Group Representatives

Thank you for agreeing to discuss your experiences of being key members of the Community Transformation Steering Group. If you would like to pause the interview at any moment, please let me know.

The purpose of the interview is to receive feedback from key members of the Community Transformation Steering Group about what you think the community mental health transformation process has delivered so far.

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".

We would like to record this interview and would like to ask your consent to proceed.

Please could you confirm your role in the Community Transformation Steering Group and your responsibilities?

Can you summarise what the transformation process has achieved and outline any changes that have occurred since the transformation process started? For example: The Rehabilitation Pilot

What outcomes would you expect to see for adults severely affected by mental illness because of the actions of the Community Transformation Steering Group?

How has the Community Transformation Steering Group communicated the changes made to partners, to adults severely affected by mental illness and their families and carers?

How successful has the Community Transformation Steering Group been with implementing co-production practices – with people with lived experience and with wider partners (for example: VCSE organisations and Norfolk County Council)?

Can you tell me a little more about the Community Transformation Steering Group's engagement with the housing sector and Job Centre Plus (for example: support with benefits and employment)?

Please could you tell me about the work on the VCSE strategy? Does this work link to the new Health and Social Care Assembly, which supports the work of the ICB?

Thank you for your time! [Debrief]

healthwatch Norfolk

Healthwatch Norfolk
Suite 6 The Old Dairy Elm Farm
Norwich Common
Wymondham
Norfolk
NR18 0SW

www.healthwatchnorfolk.co.uk
t: 0808 168 9669
e: enquiries@healthwatchnorfolk.co.uk
@HWNorfolk
Facebook.com/healthwatch.norfolk