healthwatch
Norfolk

Community Based Mental Health Services Norfolk and Waveney

Year Three
Community Transformation Steering Group Evaluation
June 2023– June 2024

Contents

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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.
The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

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

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

At Healthwatch Norfolk we have five main objectives:

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

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

Summary

This is the final report on a three-year project. Healthwatch Norfolk was commissioned by Norfolk and Waveney Integrated Care Board to conduct an independent person-centred evaluation of how well the Community Transformation Steering Group delivered their plan to transform community based mental health services in Norfolk and Waveney.

For this final report the focus has been on feedback from people with serious mental illness (SMI) who use community based mental health services. We collected their feedback through a public survey, interviews and other sources of feedback. We also wanted to hear from the carers of people with SMI. We have a separate three-year project, which focusses on carers of adults with SMI.

We received 149 usable responses to our survey and interviewed 27 people with serious mental illness. People told us that they had used a range of community based mental health services, with most people using mental health support through their doctor's surgery. People also told us about the difficulties they had trying to access services.

We wanted to find out about services and people's experience of using them, such as support via the doctor's surgery, the crisis team, use of wellbeing hubs such as Rest and Steam Café. We also got feedback on services for certain mental illnesses such as personality disorder, eating disorder and mental health support during pregnancy or after the birth of a child. People told us about positive change they had seen, but also told us about issues they had with some services.

I-statement outcomes have been identified by people with lived experience of serious mental illness. Healthwatch Norfolk felt it was important to see if there had been improvement in meeting these outcomes. We asked people to rate the statements on whether they had improved, got worse or stayed the same (and whether they were still good or still bad). We grouped the I-statements into four key areas: waiting times, joined up services, feeling in control and the involvement of carers.

We also considered the views of those people who are homeless and not receiving ongoing support.

We found that there have been improvements and the mental health support via doctor's surgeries has been positive. There were also improvements with the Perinatal Service and the introduction of the wellbeing hubs (Rest Hub and Steam Café). However, most people were negative about their experiences with community based mental health services.

Areas of concern continue to be the crisis team, physical health checks and that people with a personality disorder / complex emotional needs continue to face stigma.

Whilst there were some improvements with the I Statement outcomes, being treated with dignity and respect, having a care plan and the involvement of family and carers, people felt that things had got worse with the I-statement outcomes. Waiting times, continuity of staff and the consistency of appointments and visits from Care Coordinators continue to be issues for people and are areas where people made the most suggestions about how things could be improved. Many of the people we spoke to were lonely or did not feel that their voices were heard.

We have made the following recommendations (full details can be found in the Recommendations section of this report):

1. **Ensure that adults with serious mental illness have reliable and consistent support**

   Adults with SMI should have regular visits at agreed times from the same member of staff. Cancelled visits must be notified as soon as possible with an alternative date and time.

2. **Ensure that adults with serious mental illness have regular ongoing support to minimise the need for crisis intervention.**
   It is important that people have the ongoing support they need to stop them going from crisis to crisis.

3. **Do not lose the valuable voice of people with lived experience**
   Make sure that people with experience of using services help to review services and shape future services.

4. **Keep the mental health roles in primary care**
   The new mental health roles in GP Practices should be continued.

5. **Finalise the VCSE Strategy and partnership with the VCSE Sector**

   The VCSE sector is a key partner in supporting people with SMI and the strategy should address how the work with this partner can be strengthened.

Why we looked at this

> “I’m 59 years old and have struggled for a long, long time. My whole life has been difficult and I've only just been diagnosed with CPTSD, EUPD and ASD. I feel like opportunities have been missed lots of times and my life could have been so much better.”

Feedback left on Healthwatch Norfolk website – February 2024

Healthwatch Norfolk was commissioned by Norfolk and Waveney Integrated Care Board to conduct an independent person-centred evaluation of how well the Community Transformation Steering Group delivered their plan to transform community based mental health services in Norfolk and Waveney. This is the final report of a three-year project; the reports from Year One and Two are available on our website (Healthwatch Norfolk, n.d.).

The aim of Community Based Mental Health Services is to deliver mental health care for adults with severe mental health needs as close to home as possible, allowing them to have greater choice and control over their care and live well within their communities.

The NHS Long Term Plan and NHS Mental Health Implementation Plan 2019/20 – 2023/24 set out that the NHS would develop new and integrated models of primary and community mental health care. The Norfolk and Waveney Integrated Care Board received funding to support the transformation of community mental health care services. The new community-based offer should include access to psychological therapies, improved physical health care, employment support, personalised and trauma informed care, medicines management and support for self-harm and coexisting substance use.

In years one and two of this project, Healthwatch Norfolk spoke to members of the Community Transformation Steering Group (a multi-agency group with representation from Norfolk and Suffolk Foundation Trust, the Integrated Care Board, Experts by Experience, Voluntary, Community and Social Enterprise Sector (VCSE)and Norfolk County Council) to find out what the transformation plans included and the progress they were making. We also spoke to adults severely affected by mental illness, carers of adults severely affected by mental illness, representatives from the VCSE, the mental health workforce, primary care workforce and wider stakeholders to understand their experiences of community based mental health services and the transformation of these services.

In this final year of the project, we felt it was important to take a snapshot of the views of adults severely affected by mental illness to understand their experience of community based mental health services and whether they had experienced positive change in these services, looking at waiting times, joined up services and whether people felt in control of their care. We also wanted to understand the experience of those who care for and support adults severely affected by mental illness.

We trust that our findings will provide an indicator of the impact of the transformation plans and highlight any areas that still need to be addressed.

How we did this

For this final year of this three-year project, we wanted the focus to be on those adults with serious mental illness (SMI) who have used community based mental health services within the past five years. We wanted to hear from adults living and/or providing care for those with:

- Psychosis
- Bipolar Disorder
- Schizophrenia / Schizoaffective Disorder
- Personality Disorder
- An Eating Disorder
- Severe depression
- A mental health condition resulting in a need for rehabilitation.

We were also keen to hear from anyone who needed support with a serious mental illness during pregnancy or after birth.

We wanted to understand whether adults with SMI have experienced positive change and if the families and carers of adults with SMI have experienced positive change following the work of the Community Mental Health Transformation Steering Group. We felt it was important to stress that the services may still not be as good as people would like, but we wanted to understand any positive changes that people had seen.

We wanted to show that:

- Community-based services are providing care that is joined up.
- Adults with SMI receive specialist interventions in a timely and appropriate way.
- Adults with SMI feel included in decisions and in control of their care.

Survey

We designed a public survey, which was created through SmartSurvey. The survey was set up so that those people who had not used community based mental health services in the past five years did not get to complete the full survey, which allowed us to easily identify those who did not meet our criteria. Initially the target audience was adults with Serious Mental Illness (SMI) who lived in Norfolk, however we were later asked by the commissioners to include adults with SMI who lived in Waveney.

We ran a survey for people with SMI living in Norfolk. The survey ran from 4th March to the 20th May 2024.

We used a variety of means to promote the survey to the public as widely as possible. The survey was promoted through our website, newsletter and social media. We approached the local press, who ran a short article about the project with links to the survey. We also approached GP surgeries to advertise the survey on their practice website. Leaflets and flyers were designed and sent to wider stakeholders such as voluntary, community and social enterprise (VCSE) groups, including members of the Mental Health Providers Forum, The Waveney VASP (Voluntary and Statutory Partnership) and the Community Transformation Steering Group.

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Share your story

Have you been diagnosed with a Serious Mental Illness (SMI)?

We would like to hear about your experiences of changes to community mental health services in Norfolk.

You can share your experiences or find out more by:

Scanning the QR code to fill in our survey

Logging on to https://www.smartsurvey.co.uk/s/SMISurvey3/

Calling us on 0808 168 9669 to arrange a chat

Sending an email to enquiries@healthwatchnorfolk.co.uk

healthwatch Norfolk

Share your story

Have you been diagnosed with a Serious Mental Illness (SMI)?

We would like to hear about your experiences of changes to community mental health services in Norfolk.

A Serious Mental Illness could be:

- Schizophrenia
- Schizoaffective Disorder
- Bipolar Disorder
- Psychosis
- an Eating Disorder
- a Personality Disorder
- Other long term mental health conditions which severely impact a person's life

All your anonymous responses will be analysed and form part of a report with recommendations for Norfolk and Waveney Integrated Care Board.

You can share your experiences or find out more by:

Scanning the QR code to fill in our survey

Logging on to https://www.smartsurvey.co.uk/s/SMISurvey3/

Calling us on 0808 168 9669 to arrange a chat

Sending an email to enquiries@healthwatchnorfolk.co.uk

Figure 1. An example of the leaflet used to promote the survey

The same survey for those living in Waveney was open from 1st April – 5th July 2024. The opening period for the Waveney survey was extended as it included the time to promote the survey. We used similar methods to promote the survey in Waveney, receiving support from the Waveney VASP (Voluntary and Statutory Partnership for Mental Health) to reach voluntary, community and social enterprise groups supporting adults with SMI in Waveney. We also used local media to highlight the survey.

Extending the reach of the survey

We were aware from previous years that it was harder to reach people with an eating disorder and those who needed mental health support during pregnancy or after the birth of their child. We therefore targeted our communication to these groups, designing specific flyers and using paid social media advertising to reach those who needed mental health support during pregnancy or after the birth of their child.

healthwatch Norfolk

Share your story

Have you received support with a Serious Mental Illness (SMI) during pregnancy or after birth?

We would like to hear about your experiences of changes to community mental health services in Norfolk.

You can share your experiences or find out more by:

Scanning the QR code to fill in our survey
Logging on to https://www.smartsurvey.co.uk/s/SMISurvey3/
Calling us on 0808 168 9669 to arrange a chat
Sending an email to enquiries@healthwatchnorfolk.co.uk

Figure 2. An example of a targeted flyer for people who had support for a serious mental illness during pregnancy or after birth.

Survey Data Analysis

The survey included a range of question types, including open-ended, closed-ended, and multiple-choice questions as we wanted to get quantitative and qualitative data from the survey.

Answers that were closed-ended or multiple choice were exported from SmartSurvey and analysed in Excel. Percentages in this report are rounded to the nearest whole number. Answers where participants could write their own comments were analysed to identify themes using NVivo. Any comments used as direct quotes in this report have been left unchanged to ensure originality. Any major grammatical or spelling errors will be marked with “[sic]”.

A copy of the survey questions can be found in Appendix 1.

Carers

At the same time as this project was underway, Healthwatch Norfolk was commissioned by the Norfolk and Suffolk Foundation Trust (NSFT) to find out more about the experiences of carers of adults with Serious Mental Illness (SMI) to see how their experiences can be improved and how carers can be better supported. This three-year project should be completed by the end of July 2026. An interim report has been published, which covers the period from July 2023-July 2024. (*Experiences of Carers of Adults with SMI Year One*, 2024)

Rather than hold another survey targeted at carers we decided to incorporate a key question about changes to community based mental health services and use the relevant data within this project.

The survey for carers was open from Monday 22nd January 2024 to Monday 11th March 2024.

Other sources of data

We looked at the feedback data left by members of the public through our website (https://feedback.healthwatchnorfolk.co.uk/) over the previous three years to see if there was any change in the nature of comments and number of comments being left about community based mental health services.

We also asked for feedback data collected by key services of Norfolk and Suffolk Foundation Trust. We received feedback from the following services:

- The Perinatal Service
- Norfolk Community Eating Disorder Service (NCEDS)

One VCSE (Voluntary, Community and Social Enterprise) group asked members of their group to give their feedback and comments on whether people have experienced change to community based mental health services (positive or negative), waiting times and joined up working. The anonymous comments were collated and returned to us for use.

Interviews

We interviewed adults with SMI and carers of people with SMI. The interviews were semi-structured, to allow for consistency of questions asked, but also to provide flexibility for the individual to put an emphasis on those issues that were important to them. A copy of the questions can be found in Appendix Two.

The aim of the interviews was to gain more in-depth information about people's experiences of community based mental health services.

We identified people to interview through the survey – contacting those who had given their consent to be contacted. We also asked voluntary, community and social enterprise groups and specific community based mental health services if they were aware of anyone who would like to be interviewed.

Interviews were conducted on a one-to-one basis, with some interviews being face-to-face and others over the telephone. We also held one focus group. We asked for consent to record the interviews and explained that the recording would be transcribed and anonymised, and that the transcript would be used for direct quotes and may also form the basis of a case study. Where case studies were written up, they were sent to the interviewee to ask if they wanted to make any changes, but we did not always receive a response.

The interviews were thematically analysed using NVivo, a software programme that helps to identify themes or patterns from transcripts of interviews and comments from surveys.

Limitations

There were some limitations in collecting data and feedback for this evaluation. In year one we set a recommendation for ourselves to find ways to engage with a greater range of adults with SMI. Despite our increased efforts to promote our survey more widely, the numbers of survey respondents stayed in line with those from Year One.

NICE guidance recommends that primary care should keep an up-to-date register of people living with bipolar disorder, schizophrenia and other psychoses who require monitoring of their physical and mental health. During the fourth quarter of 2023 there were 9117 people on the GP mental health register for Norfolk and Waveney with a clinical diagnosis of a severe mental illness who should have received health checks in the preceding 12 months (NHS England, 2023). This gives an indication of the numbers of adults with SMI living in Norfolk and Waveney.

We received a total of 375 responses to our survey (in Year One of this project we received a total of 221 responses). Although we cannot say that our results are representative of the population of adults (over the age of 18 years) with SMI in Norfolk and Waveney, our response rate is comparable to that of the Care Quality Commission (CQC), who undertake an annual national community mental health survey (Care Quality Commission, 2023). The survey was open to people from the age of 16 years who received treatment for a mental health condition between 1 April and 31 May 2023. This survey received 280 responses from people who had used the services of Norfolk and Suffolk NHS Foundation Trust.

When designing our survey, we omitted to ask the question about whether the person had received mental health support during their pregnancy or after the birth of their child. This meant we have been unable to identify this cohort from the survey responses. This is a group of people who are particularly hard to reach and we were unable to interview anyone from this group. We did enlist the help of the Perinatal Team but they couldn’t find anyone who was willing to speak to us, however they did provide us with Friends and Family feedback.

We have been conscious that people who make the effort to respond to surveys often do so because they are unhappy with a particular aspect of a service and have tried to balance this by seeking service user feedback from the specific services that has been collected by Community Mental Health Teams. We asked a number of services to share their “Friends and Family” feedback or equivalent data for their service. The services had to ensure that they only shared feedback where consent had been given to use the feedback more widely.

We have tried to include as many of the survey responses as possible to the open-ended questions, particularly “What positive changes have you seen in Community Mental Health services?” and “What do you think can be improved about Community Mental Health services?” however there were some responses that could not be included due to the nature of the content or because they were not relevant to the question.

We also recognise that there must be a sense of frustration for people with SMI (and others) that they are often asked to respond to surveys or give their feedback about services but may feel that there is little change as a result. We struggled to find ways to contact adults with SMI and the services we approached, both statutory and those in the voluntary and community sector, also found it difficult to find people who would be willing to engage with this project.

Who we received response from

People who completed the survey

We wanted to hear from people who had used or tried to use, community based mental health services in the last five years as our expectation was that these people would be most likely to be aware of any changes in these services.

332 people accessed the Norfolk survey and 43 accessed the Waveney survey. We removed any multiple responses from the same person, those that were incomplete or were not from Norfolk or Waveney residents. We then discounted any responses from people who said that they had not used or tried to use, community mental health services in the last five years.

This left us with a total of 149 (40%) applicable responses to our surveys (126 from Norfolk and 23 from Waveney).

We asked people if they had been diagnosed with a mental health condition. All 149 people answered the question. People were able to select more than one response. The responses reflected those received in Year One, with most people 40% (82) stating that they had severe depression, the second largest group was those with a personality disorder 18% (37) and the smallest response from people with schizophrenia / schizoaffective disorder 1% (3). A small percentage of people 8% (17) were not diagnosed by any of the conditions listed. We asked those who had not been diagnosed with any of the listed mental health conditions what they had been diagnosed with. Of these 17 people, 13 (76%) did not respond. The other four described their issues as depression, anxiety, ADHD, suspected bipolar and autism.

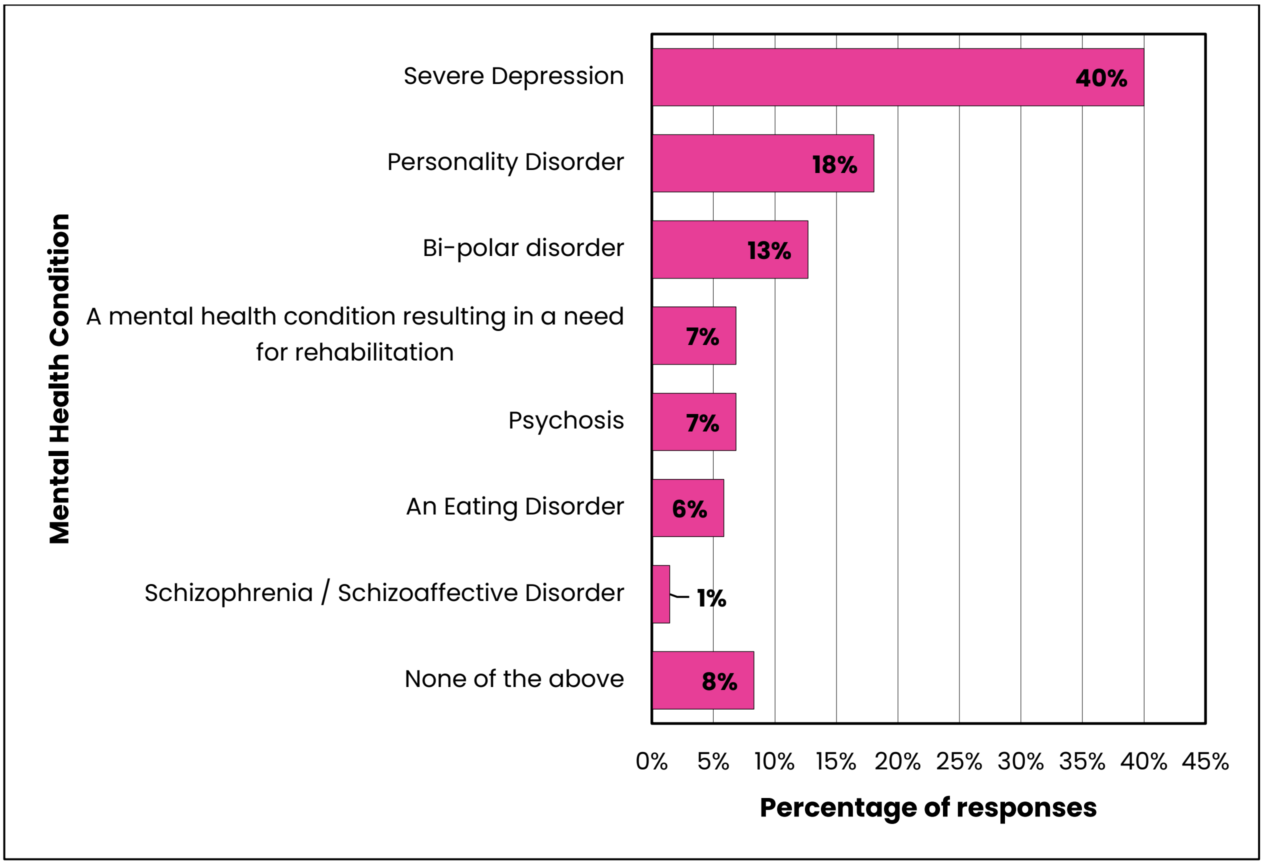


Figure 3. A graph showing responses to the question "Have you been diagnosed with any of the following conditions?"

We asked people their age. The age distribution of respondents is displayed in Figure 2. The most common age category was age 56 to 65 with 25% (37) of respondents, but this was closely followed with 24% (36) of those in the 46-55 age range. No one who responded was over 85 years old and 10% (15) of respondents did not declare their age. In Year One most responses were received from people in the 46-55 years age range, with 67% of respondents aged between 26-55 years.

As in Year One, most respondents 66% (98) were female, with 21% (31) male, 1% (2) genderqueer and 1% (1) non-binary. 11% (17) of respondents chose not to state their gender.

We also asked people to state their ethnic background. Most respondents, 79% (118) were British / English / Northern Irish / Scottish / Welsh, which was broadly in line with Year One. 11% (16) did not state their ethnicity, 4% (6) people stated that they were Irish, 3% (4) stated that the were of mixed / multiple ethnic groups background and the remaining 4% (5) were Caribbean, other white background, other ethnic group and other black / black British background. Graphs showing the demographic data for gender, sexuality and ethnicity can be found in Appendix Three.

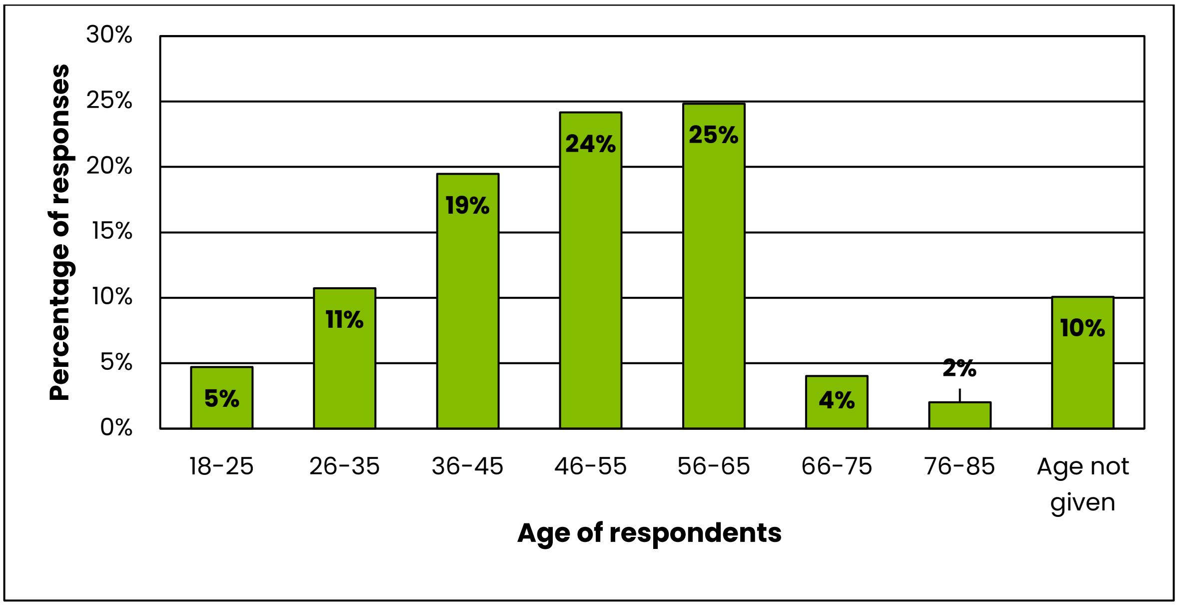


Figure 4. This graph shows the age range of the respondents to the survey.

Feedback from Healthwatch Norfolk Feedback Centre

We looked at comments made on our website, or via our Healthwatch Norfolk "post boxes" since the beginning of June 2021 to the end of May 2024. In 2021/22 we received 19 comments about community based mental health services. In 2022/23 there were 12 comments and in 2023/24 we received a total of 10 comments about community based mental health services. A small decrease each year in the number of comments.

When people leave a comment, they are asked to provide an overall rating of the service, from 1 to 5 stars, with 1 being poor and 5 being excellent. We looked at the ratings for the comments, counting 1-2 as negative, 3 undecided and 4-5 as positive.

All comments were analysed to identify themes using Nvivo, the qualitative data analysis software.

Feedback from Community Based Services

The Norfolk Community Eating Disorder Service (NCEDS) provided us with feedback from six carers of people affected by an eating disorder. These comments were collected during the period June 2023 to June 2024.

The Perinatal Service provided us with feedback from ten people collected through the Friends and Family Test during July 2024.

Carers

The question in the survey that was used for analysis in this project was "*Have you seen any changes to Community Mental Health services in the last 3 years? If yes, what changes have you seen? (Were they positive or negative changes?) If no, what changes would you like to see?*". This allowed respondents to give more information about the changes they have seen and would like to see.

The survey for carers received a total of 72 responses. Once we had identified the usable responses (those that met the project criteria), there were 64 responses.

Interviews

We spoke to a total of 27 adults with SMI (including nine people from Waveney) through one-to-one interviews or in a group setting. We also spoke to 12 carers through a series of one-to-one interviews.

In Year One we made the following recommendation for ourselves "*to 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).*"

This year there was a slight decrease in the number of men completing the survey 21% (31) compared to 24% (52) in Year One. However, of the 27 people we interviewed 14 (52%) were male, 11 (41%) were female and 2 (7%) identified as non-binary.

Potential interviewees were identified from the survey. We approached people who had indicated in the survey that they would be happy to be contacted. To try and extend our reach we approached various voluntary organisations that provide support to people with SMI, both directly and through the Mental Health

Providers Forum, to ask if they could put us in contact with people with SMI who would be happy to share their experiences of using community based mental health services. We also approached various NSFT community teams to ask for their help in reaching adults with SMI.

We also reached out to one Mental Health Hub but did not receive a response.

What we found out

Feedback from people who have used community based mental health services in the past five years

Community based services used

We asked the 149 people who had used community based mental health services over the past five years which services they had experience of using. Respondents could select more than one service.

Mental health support via the doctor's surgery (including support from a Mental Health Practitioner or Enhanced Recovery Support Worker) was the most frequently used service with 57% (85) of the respondents using this service. The Crisis Support team was used by 23% (57) people, 20% (30) people had support for a personality disorder or complex emotional needs, 16% (24) of people had used the Rest Hubs and 11% (17) of people had received support from the multi-disciplinary mental health support team (MHICI). 7% (10) of people had been supported with rehabilitation back to the community after hospital care and 3% (5) had been supported with an eating disorder. 11% (17) of respondents were unsure whether they had used the services or had not used any of the services.

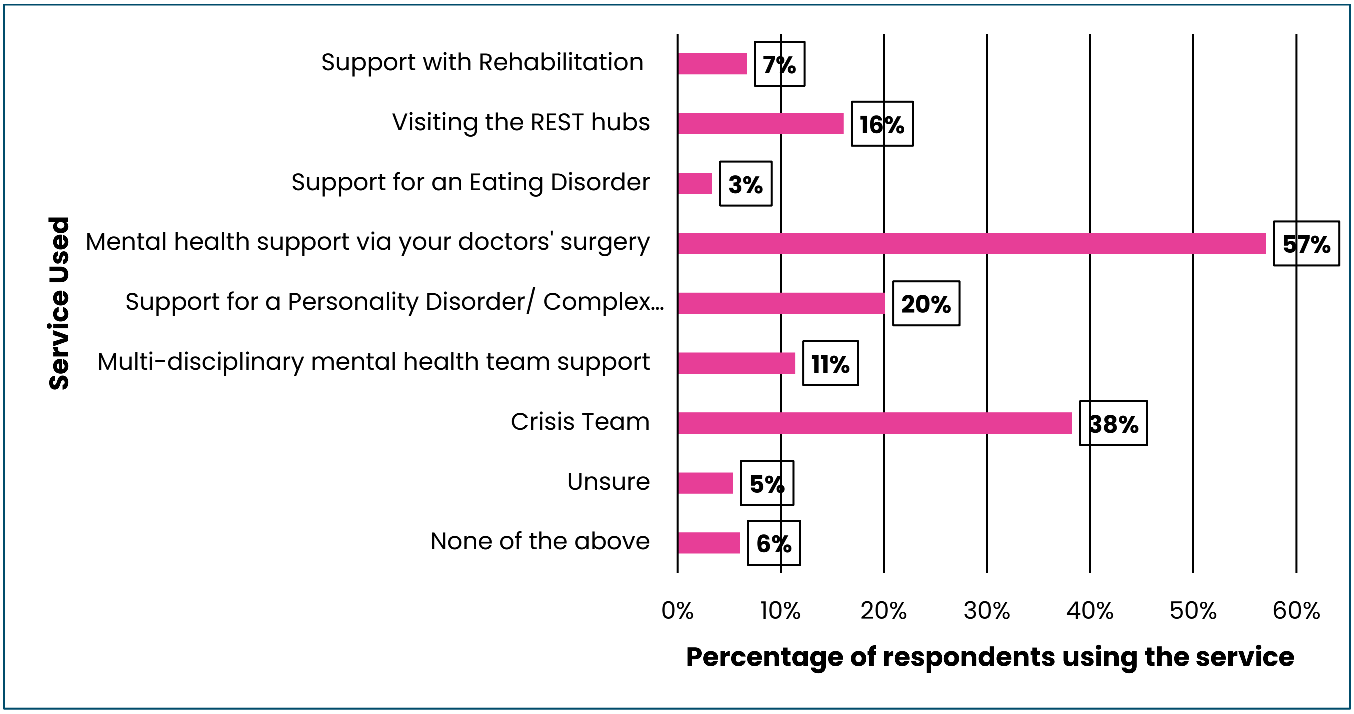


Figure 5. This graph shows the number of respondents that had used the various services. (T*he percentage total is more than 100% as people could select more than one service).*

We also asked which other Community Mental Health Services in Norfolk people had used in the past five years. We did not include the responses that referred to the services we had already asked about (as shown above). Of the remaining 26 responses, 14 (54%) of people indicated using voluntary sector services such as Men's Shed, One-to-One Project and Mind. 8 (31%) of people mentioned other statutory services not previously asked about - Child and Adolescent and Mental Health Services and Perinatal Support, 3 (12%) people mentioned specific therapeutic interventions, including the Recovery College, Cognitive Behaviour Therapy and Music Therapy. Lastly one person said that they had accessed private psychiatric care.

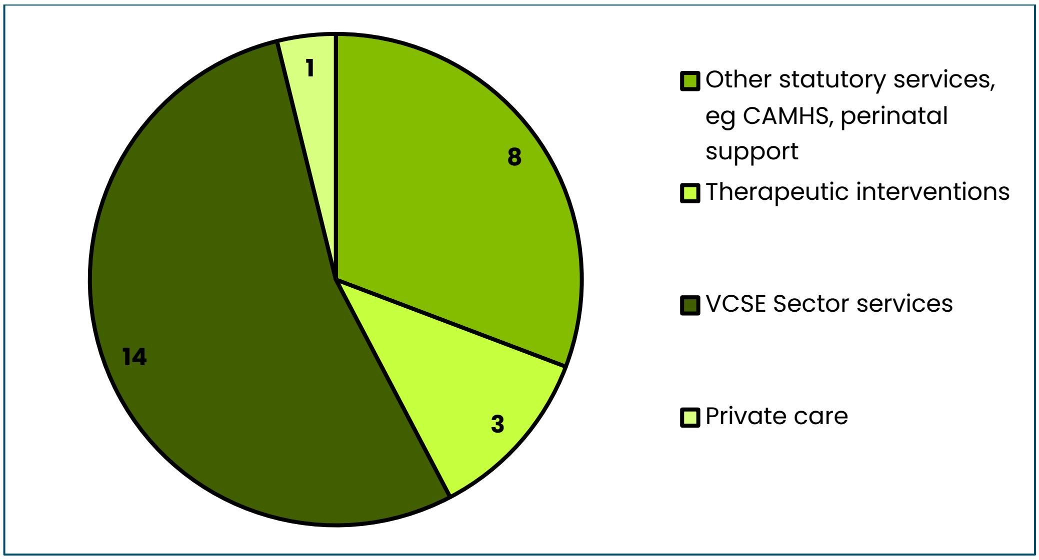


Figure 6. This graph shows other services people have used in the last five years. *Numbers are shown and not percentages as there were only 26 responses.*

Barriers to support

We asked if people if they had tried to access support, what support they had tried to access and what had been their experience, and if they had not tried to access support, what had stopped them, or made it difficult for them?

89% (132) of respondents skipped this question. 11% (17) of respondents left a comment, which were mostly negative.

People told us:

Barriers to accessing support

- Tried to access counselling and psychiatrist repeatedly. Got referred to Wellbeing who said to me "we cannot help you. We don't do counselling. We don't have a psychologist. We cannot treat PTSD." I've not received any help at all.
- Referred to 72 hour crisis team, no-one contacted me and then I was referred back to the Hethersett doctors MH Practioner (sic), who then cancelled my appt. No one has bothered to contact me apart from a letter since I was referred by the GP 26th Feb
- Not heard nothing
- ii,ve (sic) emailed doctors and spoke with dwp assessors on numerous occastions (sic) with regards my depression due on going health issues and have had no contact seems my doctors just likes me to keep self referring to any where but him.
- I've rung 111 option 2 twice, referred back to GP.
  Have had 3 appointments with the team and they have not attended any of them.
- I tried to get it help from the doctor and I was told I had to contact the mental health team myself and when I did I was told no one could help me.
- I tried to get in touch with the wellbeing service quite a few times, had a few phone calls with them and then they said that they couldn't help me anymore and I needed to try somewhere else.
- I am awaiting an appointment
- Help trying to see the dr's I've had to use Chatterton mh services nurse to get my bloods done for high cholesterol because (name) surgery has given me passive resistance and I'm getting NO health care from them. Haven't had tablets for over a Ur (year) now for my heart and they won't and don't do nothing AS a drs for my health
- Doctor's surgery, mental nurse fully booked. Crisis team, not allowed to use as need to be within 1 year of being discharged,, psychiatrist, need to be referred and I'm afraid to see him as I was discharged and I thought it was too early but there is no one else to see. I had a doctor and he was brilliant. He thought that mental health issues should initially be seen by a doctor who specifically has training to take the strain from hospitals. I also used to see a cpn every week while I needed help.

- Child ADHD moving to adult ADHD. No connectivity, no support for people who were in the system as children transferrign (sic) into adult services
- Tried to see if there was EMDR therapy or new depression therapies. Have tried multiple antidepressants with little relief for depression. GP MH nurse went through usual questionnaire and antidepressants even though I said I'd had depression a long time and tried most of them. I order to have more sophisticated prescribing (sic), I would need referral to specialist prescribed. I thought this was happening but it didn't.

  Also had referral to some MH service at a distance. Again, they went through questionnaire, told me I didn't have PTSD (which is laughable) and that I could not have EMDR. They said there were counselling services available in my area run by charities and I could negotiate a fee. I'm on a v low income. All in all, hopelessly inadequate. I was refused a place on a CBT course because it was not ideal for me and I would rather have had counselling but only CBT available. Presumably they thought it would be a waste of time if not my choice of treatment.
- I have been repeatedly referred the Access and Assessment team and repeatedly bounced back to the well-being service despite having severe anxiety and depression for which I have been medicated for over 20 years.
- I am to scared to come out of my hse (sic) alone due to severe anxiety, lack of mobility and in case I get attacked again. I have not managed to step out into my back garden yet

People's experiences of community based mental health services

We asked people to tell us about their experience of using community based mental health services and how the services may have helped them. Most of the people who responded to this question did not have a positive experience. Of the 61 comments left 84% (51) were negative, 6% (4) comments were positive and 10% (6) were mixed.

We also looked at the ratings from comments made by the public in 2023/24 in our feedback centre. We received ten comments in total, and most of these were negative. 8 (80%) receiving an overall rating of 1 (poor), 1 (10%) had a rating of 2 (Okay) and 1 (10%) a rating of 5 (excellent).

The comments we received about people's experience of using community based mental health services have been used throughout the report in the relevant sections.

Changes people have seen

In this year's survey we asked respondents to tell us more about any changes they have noticed or their experience of Community Mental Health services over the past five years. 42% (62) of respondents replied and most people 87% (54) who left a comment gave a negative response.

We also asked "What positive changes have you seen in Community Mental Health services?". As with the previous question, most respondents, 58% (87) skipped this question. 33% (25) left a comment and 18% (27) of respondents told us they had not seen any change.

We have highlighted in blue text boxes the comments we received in the survey about positive changes seen, in the relevant sections throughout this report.

What can be improved

We asked "What do you think can be improved about Community Mental Health services?". Half of respondents, 50% (74) gave some feedback on things they felt could be improved. 46% (68) of respondents skipped the question or did not know and 5% (7) left comments such as "everything" and "where do I start?".

We have highlighted in pink text boxes the improvements that people suggested in the survey that could be made, in the relevant sections of the report.

Communication of Changes to Community Based Mental Health Services

One of our recommendations from Year One was:

- The Community Mental Health Transformation Steering Group improve communication about successes more widely.

We therefore asked people in this year's survey if within the past three years, they have received any information from mental health staff or services about the changes being made to Community Mental Health services in Norfolk. 68% (101) of people told us they had not received any information, with only 8% (12) of people saying they had received information. 16% (24) people did not answer the question and 8% (12) were unsure.

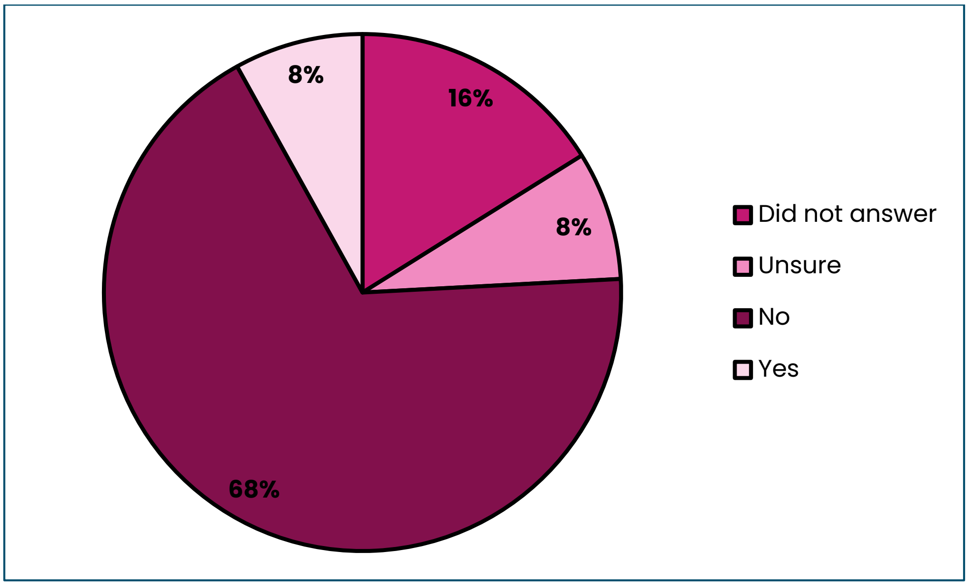


Figure 7. This graph shows if people had received information about changes to Community Mental Health Services.

We asked those who had received information to tell us about the information they received and where they got it from. People talked about wider communication regarding the transformation of services and some people talked about their care. Comments we received:

The information you received and who from

- My GP surgery
- Some by email newsletter.
- Adult CMHT has appalling communication and I'm not informed of anything like this. They don't seem to have people participation either. Utterly appalling.
- A decade in special measures is terrible I saw it on the media and and nurses and other patients told me
- Last minute call from enhanced recovery worker saying moving jobs and not being replaced. They were not the only staff to get information last minute that they then had to pass onto vulnerable clients. Very bad planning and where was the thought and coproduction in this? In Norwich, with a handful of service user panels out of Norfolk.
- Mens hub Norwich Castle partnership (doctors)
- Very poor communication between service from my personal experience. I have had contradictory advice from charity and local

services. Norfolk wellbeing rely on the charity sector as they unable to offer support in many cases, they have very poor knowledge of other organisations systems. Lack of muli (sic)agency communication in this area.

- I was only told that there were possibilities things might improve that's all
- Wellbeing services and my local GP Kirkley Mill.
- it would be helpful if there was a pathway hand out and also who does what!
- Didn't know any changes are being made....

Mental health support via the doctor's surgery (including support from a Mental Health Practitioner or Enhanced Recovery Support Worker)

> "The care at my GP service is brilliant as it always has been and the introduction of Mental Health Nurses is first class.
>
> Survey Respondent

In Year One and Two we looked at the introduction and recruitment of new mental health roles in primary care, including recruitment of Mental Health Practitioners and Recovery Workers. We made the following two recommendations relating to these mental health roles:

- Support the development and integration of the new roles into the wider system
- Ensure the most effective use of existing and new staff to best meet the needs of adults severely affected by mental illness.

In Year Two most of the Mental Health Practitioner roles had been filled and the integration of these roles were successful, with primary care staff recognising the value of these roles.

During this year the Community Transformation Team has monitored the progress of these roles and have identified ongoing issues around the recruitment and retention of these posts, which they are seeking to understand.

We asked in our survey whether people had used mental health support via their doctors' surgery (including support from a Mental Health Practitioner or Enhanced Recovery Support Worker). Of the 149 respondents, 57% (85) said yes and 43% (64) said no. People with Bipolar Disorder and those with Schizophrenia / Schizoaffective Disorder were most likely to access mental health support via their doctor’s surgery. Those who did not have an SMI diagnosis were least likely to access mental health support via their doctor’s surgery. Approximately half of people with an eating disorder or severe depression had accessed mental health support via their doctor’s surgery.

There were far more positive comments from the survey regarding support from the doctor’s surgery than negative comments.

Positive comments included:

> “I have been supported fully by Norwich Medical Practice in Rouen Road by all the amazing, caring, kind, supportive, hard working and dedicated people along a very challenging mental and physical health journey that will continue with much appreciated support from all the GPs Mental Heath Support Teams amazing nurses whom I have laughed and cried with- you are my heroes.“

> “The best services are provided by the GP surgery”

> “When I am distressed about my mental state I go and get support from my mental health worker at my doctors”

> “I was referred to the mental health nurse in my doctors surgery via my Doctor about my mental health issues surrounding my borderline personality disorder and other issues i was experiencing. Found the nurse to be very helpful and understanding and she listened to my issues and referred me to the WAVES programme.

> "The mental health practitioner at Curlers Hill surgery is great, she has proven really helpful”

Some respondent's comments were heartfelt, "*Am very (lucky) to have found such a supportive knowledgeable caring and supportive Medical Centre and would like to thank all people who dedicate themselves to our wellbeing - THANK YOU - would not be here without the support of the NHS*" and "*My experience with my dr (sic) surgery was amazing*".

Some of the people we interviewed talked about the limitations of the new practitioner roles:

> "I think they're really good with someone who is going through a short-term like situation or depression or grief. I think that they could be incredibly useful in that regard. But if you've got a gap that people with severe mental illness is (sic) going to keep falling into, and you plugged it with something that's only good for people who have short-term things, but that is not a gap because that's covered in wellbeing...but we can't go to wellbeing, can we, because they don't take people with severe mental illness."
>
> Interviewee

People also told us that they were sometimes frustrated because their GP was only focussed on their mental health and did not take the time to pay attention to their physical health issues, "*Yeah, you don't automatically want a GP to see you in the surgery and think, oh, mental health, and not look any further than that.*" and "*That is a little bit of a problem though if you go to your GP with what you think is a physical illness, they automatically assume it's your mental health problem and don't really take an awful lot of notice of what you're trying to tell them about a physical problem.*"

Although there were some negative comments about lack of understanding and support from the doctor's surgery, others expressed that they only had confidence in their GP "*But yeah, I'd say in general I feel a lot more satisfied with my GP support than I do the mental health trust, to be honest.*" and "*So I've got more confidence myself in the GP system and MIND....*"

In the survey question "what positive changes have you seen in the last five years?" we received a number of responses about GP support:

Positive changes seen by people accessing mental health support via doctor’s surgery

- More quality support from Gp's. (sic)
- Since my GP was very worried about me as I was so incredibly low, I am now on the radar and have been relieved that I am being checked in on more and was referred to the mental health nurse.
- People in more rural areas are able to access PCN staff at surgeries.
- Mental health nurses in GP surgeries an improvement but they still have to put everything past the doctors at Hellesdon to get things improved which is a slow process.
- I do like the increase in roles in primary care, I think what they are there to do needs to be made clearer.
- Briefly being seen at my local g.ps in a confidential setting. (Very brief)
- More help for all ages. And more service more different types of mental health service available in all area of the uk.
- Not many in all honesty except more awareness for the lack of services and medications available.

In our survey this year we asked what people thought could be improved about Community Based Mental Health Services. There were some responses that related to support via a doctor’s surgery:

What could be improved – mental health support via doctor’s surgery

- Why discharge people, why not pass them to mental health doc/ nurse at local surgery so still some sort of support. How can you see people then discharge them when everything not great. You don’t struggle everyday with mental health, but days you do you need to talk to a professional person for help and advice
- Multi agency practice are being developed and every surgery needs a practicing mental health professional team and help to guide patients forward
- a dedicated mental health practitioner available at all GP surgeries not just one or two days per week as most seem to have always been

Support from the multi-disciplinary mental health support team (MHICI)

In our Year Two report we talked about the progress the Community Transformation Steering Group was making in meeting our Year One recommendation to:

- Support the development and integration of the new roles into the wider system and ensure the most effective use of existing and new staff to best meet the needs of adults severely affected by mental illness.

Part of their response was a "soft" launch of the Mental Health Integrated Community Interface (MHICI), a locality-based team for people that have complex needs (for example: for people with post-traumatic stress disorder or a brain injury), which it was hoped would bridge the gap between primary and secondary care. We also highlighted the challenges that the Community Transformation Steering Group were facing in recruitment and retention of new primary care roles.

We asked in our survey if people had used the multi-disciplinary mental health support team (MHICI). 11% (17) of respondents said they had. Only one respondent directly referred to the MHICI, "*MHICI said they'd 'done all they could' and discharged me*".

We asked people to rate their overall care. 8 (47%) people rated it as bad, 5 (29%) said good, 2 (12%) said okay and 2 (12%) were unsure or did not respond.

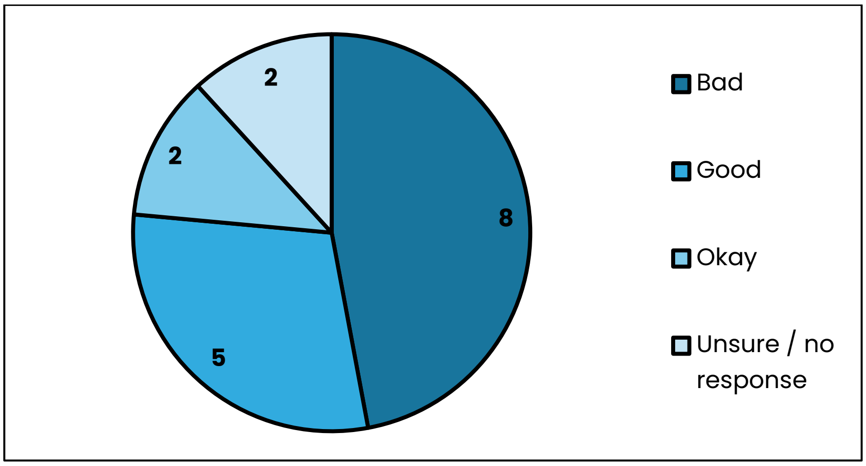


Figure 7. This figure shows the overall rating of care for those who have been supported by the multi-disciplinary mental health team.

Of the 17 people that said they had received support from the multi-disciplinary mental health support team, 12 (71%) people said they had severe depression, 6 (35%) had bipolar disorder and 5 (29%) had a personality disorder / complex emotional needs. 3 (18%) had psychosis, 2 (12%) an eating disorder and one person (6%) schizophrenia / schizoaffective disorder (please note that people were able to identify more than one SMI).

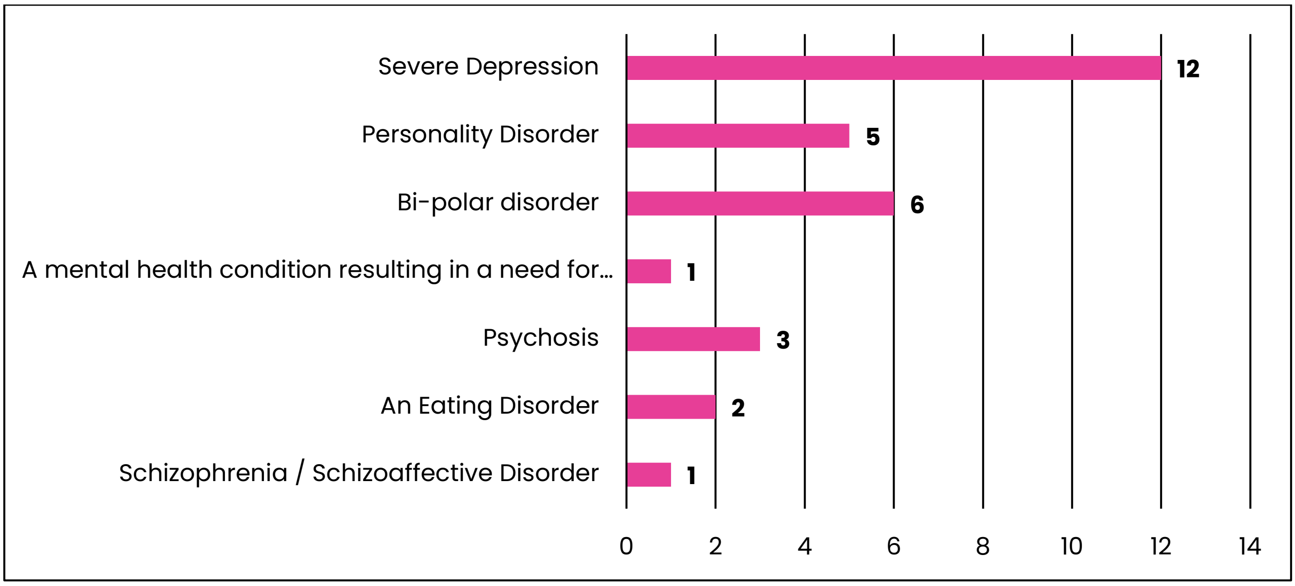


Figure 8. This graph shows the SMI of people supported by the Multi-Disciplinary Mental Health Team

General comments from this group of people about the support they received were variable, *"In the last two years my treatment has been good. Previous years things have been poor and I didn't always get the right treatment"* and *"I have been under the care of Gateway House, Wymondham for a long time now. But my latest Councillor (sic) left before Christmas. This then meant that I also lost my support worker. I am really struggling to hold things together. No one has even bothered to contact me to see if I'm even still alive! I don't go to the doctors about my mental health and disorders anymore as I just keep getting referred back to Wymondham. This means that I am on their waiting list again. It's constantly going round in circles".*

In the survey question "what positive changes you have seen in the last five years?" comments left by this group of people were:

Positive changes seen by people supported by multi-disciplinary mental health support team
• The level of support

- My tablets are always delivered on time by the hospital
- They are more open
- Safety huddle responsive help from Victoria house and quick intervention to prevent further hospital admissions
- When I was in youth services I felt fobbed off a lot but the two individuals stated above in adult cmht really helped me.
- People in more rural areas are able to access PCN staff at surgeries

The Crisis Team

Our findings from the Year One survey about the Crisis Team was a lack of response from the Crisis Team and that the Crisis Team did not have accurate information about the adult with SMI. Of those people who responded to our Year One survey and had used the crisis team, 62% said the team had no knowledge of their treatment history or care plan.

In our survey this year we asked if people had used the Crisis Team within the last five years. Of the 149 respondents 38% (57) said they had used the Crisis Team and 62% (92) had not.

Those people with a personality disorder or those with mental health condition resulting in a need for rehabilitation were most likely to have used the Crisis Team in the past five years, with those with schizophrenia / schizoaffective disorder or an unspecified SMI being the least likely. A slightly greater proportion of men than women had accessed the Crisis Team in the past five years.

We received some positive feedback about the Crisis Team; *"Crisis probably the best experience."* and there was acknowledgement of the pressures that the Crisis Team are under; *"Crisis team are very good but extremely over worked with the current climate."*

However, the majority of comments from the survey and from interview participants were negative about the support from the Crisis Team.

> *“Crisis team - mixed experience - failed to fully realise my needs.”*
> *“And the crisis team I found to be very hit and miss, depending on who you got, you could get somebody different come out and it's like you have to start over again.”*
> *“The Crisis Team are consistently bad and the last place I would go for support. They almost always make me feel worse, have no real ideas to help with suicidal ideation.”*
> *“Things have improved except for the crisis services— they have worsened.”*
> *“Not good at all—crisis team dreadful. No empathy, not professional. useless advice they don't listen to me no respect for me or my issues.”*
> *I had a severe mental health episode 2 years ago and saw the crisis team and community mental health team, no other support. They were under staffed and sometimes I didn't see anyone for days, my family were told to go to A&E as nobody could come to see me. Sometimes it was like they didn't know what to do even and left me in crisis for days.”*

People frequently mentioned that the advice from the Crisis Team was not helpful or appropriate, *“…it's uncomfortable to phone them because all they do is go like, oh, have a nice bath, have a hot drink.”* and *“(I want) Someone like (sic) to take me seriously. Listen to what I'm saying. Not tell me to have a hot drink.”* One person told us “*I was told to go for a walk one minute from main road when suicidal, told to phone back within a minute of being on the phone, asked what I wanted them to do, told to make a cup of tea or have a bath when I couldn't even get upstairs or move, told they can't find my care plan repeatedly or told their computer isn't on so can't see it. Given specific advice which it says on care (plan) makes things worse and when I said that I was told that is what they normally do.*“

In our survey this year we asked what people thought could be improved about Community Based Mental Health Services. We had a number of responses that related to crisis response:

How things could be improved with the Crisis Team

- So many things as I said before one file per patient that the GPS mental health hospital can all see at all times staff training especially the crisis team as its our last port of call and its the worst I've stopped using it although I need it

- Try listening to urgent calls and responding-could well stop suicide or self harm
- crisis team completely revamped changed around to a caring professional knowledgeable team
- Crisis team need to listen more to fam/friends as they see behind the mask, see the difference.
- better tactics to help those who are suicidal
- more training for duty and crisis teams. get them to accept more responsibility and offer better solutions
- Crisis team listen, read notes, don't offer gardening and walks to someone who has visible adaptions around their house.

Support for personality disorder or complex emotional needs

In our Year Two reporting we looked at the progress that the Community Transformation Team had made within this workstream and spoke to the Personality Disorder Transformation Lead to find out the planned changes, which included embedding new roles into community mental health teams and specific training for staff.

We heard from adults with a personality disorder or complex emotional needs that they were concerned about their support ending and being discharge from services. People also talked about the "stigma" of a Personality Disorder diagnosis and how people felt they were treated as a result of this.

In our survey this year 20% (30) of respondents told us that they had received support for a personality disorder or complex emotional needs – of these nine people said that they had not received a diagnosis of personality disorder.

> "(I access the) Mental health team due to EUPD (Emotionally Unstable Personality Disorder) the difficulties I can have that affect my family life. Some days can be ok! Then things happen and build up, then I have an emotional breakdown and cry and feel low for days. How sometimes things make me feel suicidal and I can't explain why! Just that feels like bricks piled high on my chest and I can't breath (sic). Then I have days where I can't face people, can't leave the home."

Our survey feedback and interviews highlighted that people still feel the stigma of their diagnosis and concern about how they are treated.

Stigma of personality disorder / complex emotional needs

- Get rid of EUPD (Emotionally Unstable Personality Disorder) diagnosis. Worst mistake of my life seeking help and ending up with this label
- More often everything I say or do is blamed on my EUPD. I'm always gaslighted.
- I just feel like any professional I see, any doctor I see, they're going to be thinking, oh, it is this. And even if one of my ways of coping is self-harm, and I think even if, I mean most people would go to the hospital probably and get stitches, I ain't (sic) doing that no more. No way. Because they'll see that on that thing and they will treat me differently. You already get treated quite badly anyway when it comes to that kind of thing because it's like you're wasting their time almost.
- I found things very slow, and as if I was seeking help unnecessarily. I still struggle with life even now.
- I was under the adult mental health services. They signed me off after having me on a waiting list for therapy for a personality disorder they diagnosed me with. I then tried to access wellbeing who have repeatedly rejected me stating they can't help.

We looked at the responses from this group of people to the question *"Overall, how would you rate the care and support you have received from Community Mental Health Services in Norfolk?"*. Three people did not reply to this question. Of the 27 people who did reply, 15 (56%) thought it was bad, 5 (19%) thought it was good and 5 (19%) thought it was okay. 2 (7%) people were unsure.

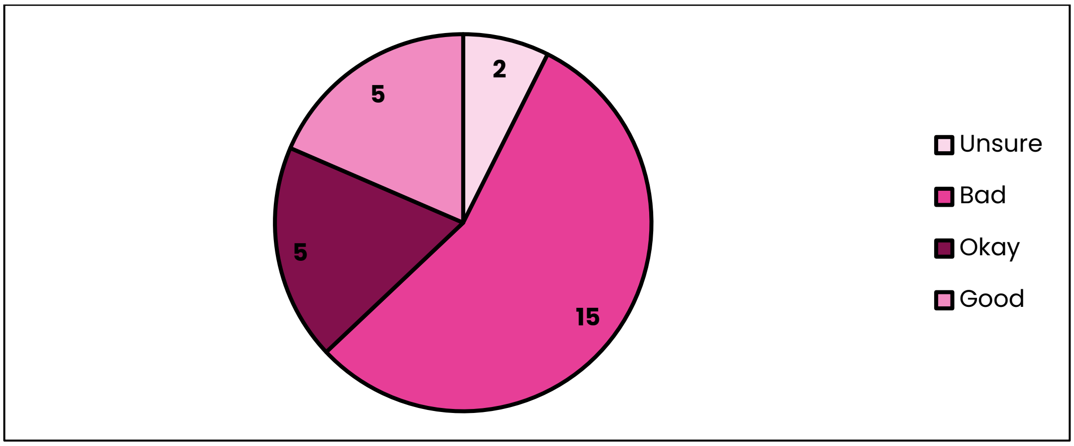


Figure 10. This graph shows how people with personality disorder / complex emotional needs rated the care and support they have received.

Elsie – Case Study

Elsie is in her 40's and has experienced mental ill health since she was a child. She has struggled with anorexia, depression and has attempted suicide on a number of occasions.

Elsie has been an inpatient on a number of occasions, including for support with her eating disorder, when she was admitted to Newmarket House, Norwich. Elsie said the support she received from Newmarket House had a positive impact and she had been doing well, *"then I managed to stay out for quite a while and then there was a massive gap between my second and my third admission, which was a few years back."*

Elsie has also had issues with alcohol, which she used as a coping mechanism, which she has also needed support with. She had some support from Change, Grow, Live (CGL) but it was only telephone support due to the pandemic, which Elsie found unhelpful.

Elsie is currently upset and anxious as she believes that her access to community support for her eating disorder has been cut off as she has been informed that she has now been re-diagnosed with an "Emotionally Unstable Personality Disorder" (EUPD). Elsie believes this means that her weight is no longer monitored, she cannot access the help she needs with her anorexia and that she will be judged differently because of the EUPD diagnosis. *"I certainly don't feel I can approach them for anything, even advice or help at all. I don't want to go to the doctors because now I suddenly have this new label that just isn't me. And the woman I spoke to that has known me for a long time and works professionally there (at Newmarket House), she was like, Elsie, don't let them gaslight you into thinking you don't have an eating disorder. I've seen you for many years and it's had a great impact on your life. But the problem is that label is now stuck on me and it's made me very nervous about going anywhere for help".*

Elsie believes that she is not alone in her experience and she is worried what this could mean for people *"And I'm hearing so many people are getting re-diagnosed under this new thing and yeah, it's going to cost lives."*

Elsie is working to use the support that is available to her but has been frustrated in this by issues with her Care Coordinator. *"Yeah, I've got a Care Co(ordinator). I'm on the waiting list for trauma therapy. But because me* *and my Care Co(ordinator) started trying to do the stabilisation work, it was decided, okay, we'll carry on with that while you wait sort of thing. But getting an appointment and actually going ahead, it's just been awful. Sometimes I'm sat on the step waiting thinking, oh, taxi will be here in a minute, and then it isn't. And I find out that, oh no, she's gone home or different things..... Or she'll arrange one day and then go, oh no, sorry, I meant to say Friday. And then on the Friday she goes home sick. It's like, I mean, I am meant to see her weekly at the most fortnightly, and today I am actually seeing her, but I haven't seen her since late February, maybe early March."*

Elsie is concerned that the delay in undertaking regular stabilisation work will have a negative impact on when she can have the trauma therapy. She is concerned that having intermittent support whilst she is trying to undertake the stabilisation work leaves her trying to deal on her own with the issues this has raised.

"And also I worry that because they think I'm doing this stabilisation work regularly, that my name on the list for therapy, trauma therapy, is probably being pushed down because they think I'm doing stabilisation work, which I'm going to speak to her today and say, I don't think we should because you get homework and things like that. So, you need to be able to go and talk about that the next week, otherwise you're just probing into depths for yourself and being left with it."

Elsie was positive about the support she has from her social worker *"I mean, my social worker is good, but he was off my case for a little while. Now he's back sort of on so I can contact him again. But he was really good…"*

Names and identifying details have been changed to protect the individual's anonymity.

There were some positive changes that people had noticed; *"After being discharged 5 years ago and relapsing and taking an overdose and going to hospital it's a huge improvement to what care was like in hospital before compared to now. There was less stigma around eupd (Emotionally Unstable Personality Disorder) and they showed great support."*

In the survey question “what positive changes you have seen in the last five years?” those people that said they had a personality disorder or complex emotional needs made the following comments:

Positive changes seen by people with a personality disorder

- Understanding and less stigma
- More understanding and feeling believed.
- more understanding of all the different forms of mental illness
- More staff more listening more appointments more respect
- Understanding

We received one comment about support for people with a personality disorder / complex emotional needs in response to the question “what could be improved?”:

How things could be improved for people with a personality disorder / complex emotional needs

- better support and understanding for personality disorders, better training for reception/admin staff answering phones/messages, better support for staff receiving care

Use of the REST / Steam Hubs (Wellbeing Hubs)

> “I have not heard of STEAM OR REST hubs what are they???”
>
> Survey Respondent

Wellbeing Hubs have been set up across Norfolk and Waveney as part of the programme of transformation of community based mental health services. Funded by the NHS but delivered by VCSE organisations, they are intended to be a safe space for people to get support for their mental health and wellbeing.

The wellbeing hubs are:

- REST (Recover, Eat, Support and Talk) Norwich
- REST Aylsham
- REST Thetford
- Steam (Support, Transform, Educate, Aspire, Motivate) House Café, Gorleston
- Steam House Café, King's Lynn

The hubs are centred round a café and are intended to provide a safe space for people to get support for their mental health and wellbeing in their community. This support should also be available for those who are experiencing mental distress.

We asked people we interviewed if they had accessed wellbeing hubs. Most of the people we spoke to were aware of the hubs but had not accessed their local hub. Of the few that had accessed them they were positive about their experience *"I only used them (the REST Hub) for a short time because I was referred to the Evening Sanctuary and I had four sessions like that and that was helpful".*

We also asked in our survey if people had visited the REST or Steam hubs. 16% (24) of respondents said they had. Comments about the hubs were mixed. Positive comments included "*STEAM cafe very friendly & felt safe going there & talking to the counsellor*" and "*Rest was helpful but with not much capacity*".

People felt the idea was good, but there was concern about the staff's ability to provide appropriate support, especially if someone was in crisis: "*Gp (sic) requested support last year and luckily REST Norwich responded quite quickly but accessing professional support seems to be swapped with peer support workers led by (a) peer support worker. Not ideal when health condition needs healing*" also "*Steam cafe Kings Lynn - support was variable. I have attended in crisis and found no support. It depended largely on which staff were there. Haven't always had a positive experience. Also long waiting time to get appointment for 1-1 support*" and "*Rest cafe staff are nice but don't know what to do".*

Some people felt that because some of the hubs were public cafés it made it difficult to access them at times of crisis, "*I had a bad experience using the rest hub in Norwich. I believed it was a crisis hub but now I know that is only in the* *evenings and by referral. I was not in crisis when I arrived but I was very upset. They told me to go sit in the public cafe to wait until a member of staff was back from lunch. I felt this was inappropriate and there should be a better place to wait if you arrive upset considering it is a drop in service for people with a mental health concern. I left feeling worse and humiliated"* and *"People said we want something that is 24/7, where you can go if you are in crisis or just having a really bad time, which can be a safe space for you to go. Now you rock up to the rest hub, (the) Mind one, Norwich, in the middle of the day, it's a public cafe…. It's not the same thing as what people wanted."*

There was concern that these services were replacing clinical support, *"Rest hub was a great idea but it does not provide treatment that needs to be clinical. It's very risky to mix the two especially if people needing band 6 and above or clinical support are told to use these services instead"* and *"Instead of appointments with care coordinator or usual duty/ crisis care you are told to speak to rest which cannot actually provide crisis services"*.

Some of the wider issues raised were a lack of free parking in Norwich *"Rest hub in Norwich is very good but no free parking so it's hard for some people out off (sic) the city to attend as they may not have money to pay for parking"* the hours that the hubs were open and also how changes to the offer are communicated *"Sadly steam cafe Gorleston(sic) has changed the way it work(s) to only offering 8 sessions, poor communication around this change."*

In the survey question "what positive changes you have seen in the last five years?" we received some responses about the Rest / Steam hubs:

Positive changes seen relating to the mental health hubs

- The provision of the Mind hubs.
- Rest norwich (sic)
- Is quicker to access for the crisis team
- Rest hubs positive but my one (Aylsham) is tiny and I worry about seeing people I know in there so tend to avoid it.
- Although my experience with STEAM was not great I think these and the Rest hub are a positive change to community services.

In our survey this year we asked what people thought could be improved about Community Mental Health Services. We had several responses that related to the REST / Steam hubs:

How things could be improved with the mental health hubs

- Extended hours for Steam/Rest. Steam Kings Lynn has reduced its opening hours and there is a large part of the day where they are closed. There is nowhere to go in crisis when these are closed other than A&E. you can’t contact the crisis team unless you are open to them. Helplines are not enough, people need somewhere they can go when in crisis and this needs to be available 24/7.
- The hubs need looking at as I've mostly heard negative feedback
- More facility for people struggling to manage but also don't want to be visiting places with certain members of society. Hate to be a snob but mental health does not only affect the benefit bashing bone idols and homeless. The steam cafe is unappealing and always feel that you are being boxed into a certain 'type' whenever you approach anything like this. Those of us that suffer with long term clinical depression but still manage a family, work, study and more because we have no choice and financially relying on holding it together because no one will help us, get forgotten.

Support with rehabilitation back to the community after hospital care

In our Year One report we looked at the rehabilitation pilot, which was bringing together a multi-disciplinary, multiagency team to provide support to the person returning to the community after a stay in hospital. We looked again at this in our Year Two report, hearing from the Transformation Lead about the establishment of the multi-agency teams and the work to support those who were returning to the community after a stay in hospital. We reported that the work on the rehab pilot was a success and felt that the partnership working with stakeholders, embedding the views of Experts by Experience in the design of the service and the holistic approach to those with SMI were contributory factors in this success.

We asked in this year’s survey if people had received support with rehabilitation back to the community after hospital care. Only 7% (10) of respondents said yes. We were interested to see how these people rated the care and support they have received from Community Mental Health Services in Norfolk. 4 (40%) people told us that it was good and the same number of people said it was bad. One person said it was okay and one person was unsure.

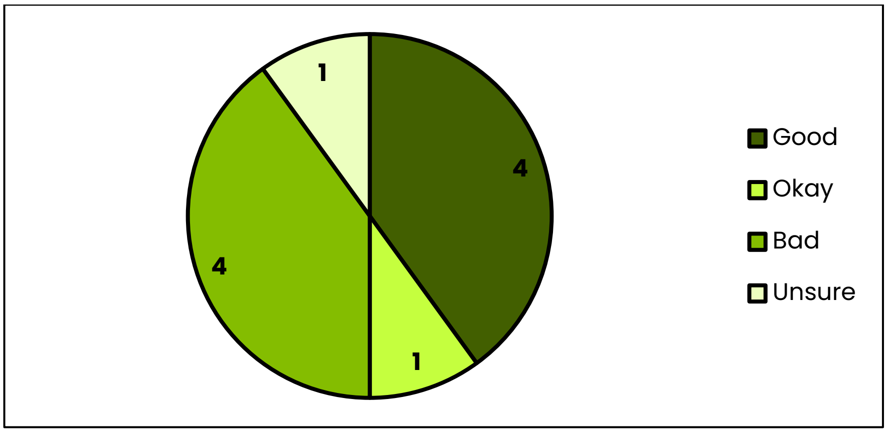


Figure 11. This graph shows how people rated the care and support they had received from community based mental health services.

We also asked people to tell us about their experiences of the services they had received. One person could see an improvement, *"In the last two years my treatment has been good. Previous years things have been poor and I didn't always get the right treatment"* and one person had made positive progress following their time in hospital, *"I was sectioned and detained in Hellesdon hospital in July 2022. I was referred to CMHT in autumn 2022 and offered CAT* (cognitive analytic therapy) *following psychology assessment. I have now successfully completed all my therapy sessions and after an assessment on 12/03/24 I have now been discharged to Primary Care services"*.

One person did not think that rehabilitation was good, *"Except for the support workers who come to my home once a week they are great. The rehab after hospital is dreadful and non-existent no real aftercare at all".*

In response to the question "What positive changes have you seen in Community Mental Health services?" people who had support with rehabilitation back to the community after hospital care told us:

Positive changes seen relating to the rehabilitation pilot

- The level of support
- More understanding and feeling believed
- Very in tune with my needs.
- Safety huddle responsive help from Victoria house and quick intervention to prevent further hospital admissions

> “Some people did not think there had been positive change “*None that I can think of*” “*unsure*” and “*In my opinion things are not getting better, I have noticed this not just for myself but others with a different diagnoses*”.

In our survey this year we asked what people thought could be improved about Community Mental Health Services. We had three responses relating to rehabilitation:

How things could be improved with rehabilitation

- The interim time between discharge from hospital waiting for therapy sessions.
- Better rehabilitation for people leaving mental health hospitals, seems nothing available for people over 70
- Each area knowing which criteria they deal with in terms of illness/risk/severity. Phased discharges like the hospital I’ve come from. It gives accountability that the discharges are safe, and also gives time to cross over care properly and keep an eye on someone transitioning into a different type of care. It’s still really poor now as I was given a letter to say there’s no criteria, just ring your GP, even though I’ve been told in the past I’m too complex or have too severe OCD so need to be with city anchorage. People still fall through gaps as their signposting is irrelevant and dead ends and they are already out of the system. Each transition should be stepped down like it is stepped up and phased so that it matches up. People can be on waiting list for a different service whilst in contact so that it’s a smooth cross over with better communication and continuity. Currently there’s none and it’s so risky.

We spoke to Paul previously for our Year Two report. He told us about his positive experiences of the Rehab Pilot. We contacted him again to ask about improvements he had seen in community based mental health services.

Case Study – Paul

Paul had some difficult experiences in the last year and had struggled with alcohol misuse and his mental health, which had resulted in his admission to Accident and Emergency. He was offered the opportunity to engage with Change, Grow, Live (CGL) a national charity for alcohol and drug behaviour change, but found it difficult to engage as it was a drop-in service.

"I went twice to CGL trying to find somewhere to park so it's not easy. And sat there for an hour and they said, so we've got no more appointments. So I left. I then, so it's a drop in with appointments. Yeah, only twice a week. Exactly. First come, first served, be there at 10. But I quickly learned that no, you need to be there as soon as the doors open and be the first one on the seat. So, it's not necessarily a great environment when you're not, you've got issues. You're not fine, right? Yeah, exactly. And I appreciate with everyone who came is in the same situation. And then the second time I waited for five hours and then they said, you are on the list now. So, I waited for five hours, and the sadness of watching other people come in who were just as desperate to get help being turned (away) and had an assessment."

Paul also tried to get help with his medication as he was concerned that his dose was not right. He approached his GP for support, who suggested increasing the dose. However, shortly after starting this Paul had another crisis point which resulted in his admission to the West Suffolk Hospital in Bury St. Edmunds under a Section. Whilst there a care plan was drawn up in consultation with Paul, but he has never received a copy of his plan.

"..we did a care plan at Bury St. Edmunds on the first day actually with the lady I never met again, because I think it was the way the shift rotation works, but it's a very personal thing to sit down and go through a lot of stuff with somebody you can see again, and you just see different stuff. There's no continuity with that. And I never ever saw that care plan again since that date. That has never been, it's disappeared. Yeah, it's never been presented to me. It's never been offered to me."

His contact with Norfolk and Suffolk Foundation Trust was limited to a follow-up telephone call three days after his discharge from hospital. Paul asked if he could be allocated a care worker and was told this could be arranged.

"I'd like to get a care worker again, meet with someone on a regular basis, I did find it helps. Okay, we'll see what we can do. So that would've been around about now that, no, that'd been the second or 3rd of January. I heard nothing from him since."

He was contacted again by an Occupational Therapist who explained that she was covering the area on behalf of someone else. She was shocked that Paul had not had any contact and promised to make a referral. At the time of our interview Paul had still not heard anything.

"And she was really nice, asked a lot of questions and she said, I saw your name on the list. And she said, "no, I can't believe you hadn't had no contact. And you're the first one I phoned because I've been given a list of people and you're there at this date of being discharged and no one's contacted you. So you're the first one I phoned". She says, "it just doesn't seem right". And I said no. And I said, I don't know how to engage with 'em and I don't know the value of engaging with 'em at the moment. Anyway, we had a nice long chat and she then told me that she would refer me urgently to who the services for sorting a care plan / help worker contact. So there's none last weekend, two, so two, maybe three weekends ago."

Paul's experiences in the last year do not reflect any positive change to waiting times or feeling in control, and are a contrast to his positive experience of the rehab pilot. However, there has been a success through his engagement with a charity that supports men's physical and emotional wellbeing, which Paul was referred to by NSFT. He has engaged in a number of activities and has since become a volunteer with them.

"And so I've been volunteering with them …. I found that really, really good for me being around people, it gives me a bit more focus because realising that part of my problem is maybe the identity I found myself in at my age and not working and who I am. I still want to give something back. I want to be around people. I find it rewarding."

Names and identifying details have been changed to protect the individual's anonymity.

Support with an Eating Disorder

In our Year Two report we looked at the changes to the Eating Disorder pathway and reported on the All-age Strategy Document for Eating Disorders in Norfolk and Waveney, which was due to be published on the Norfolk and Waveney ICB website. A survey had been coproduced by Rethink Mental Illness, which focused on what service users wanted from the service and their priorities.

The Eating Disorders Care Pathway and Guidance 18 yrs and over (Norfolk & Waveney) was published on the Norfolk and Waveney Integrated Care System website in May 2024. (Norfolk and Waveny Integrated Care System, 2024).

In our survey this year we asked people to tell us if they had an eating disorder. 8% (12) of respondents said 'yes'. Less than half 41% (5) of these people who said they had an eating disorder also said earlier in the survey that they had received support for an eating disorder.

All of those with an eating disorder also said that they had another serious mental illness. Eight people (67%) said they had severe depression, four people (33%) had psychosis, two people (17%) had bipolar disorder and one person (8%) said they had a mental health condition resulting in the need for rehabilitation. Some people identified that they had more than one serious mental illness.

Of the 12 people that said they had an eating disorder, 11 (92%) were female and one person declined to say what their gender was.

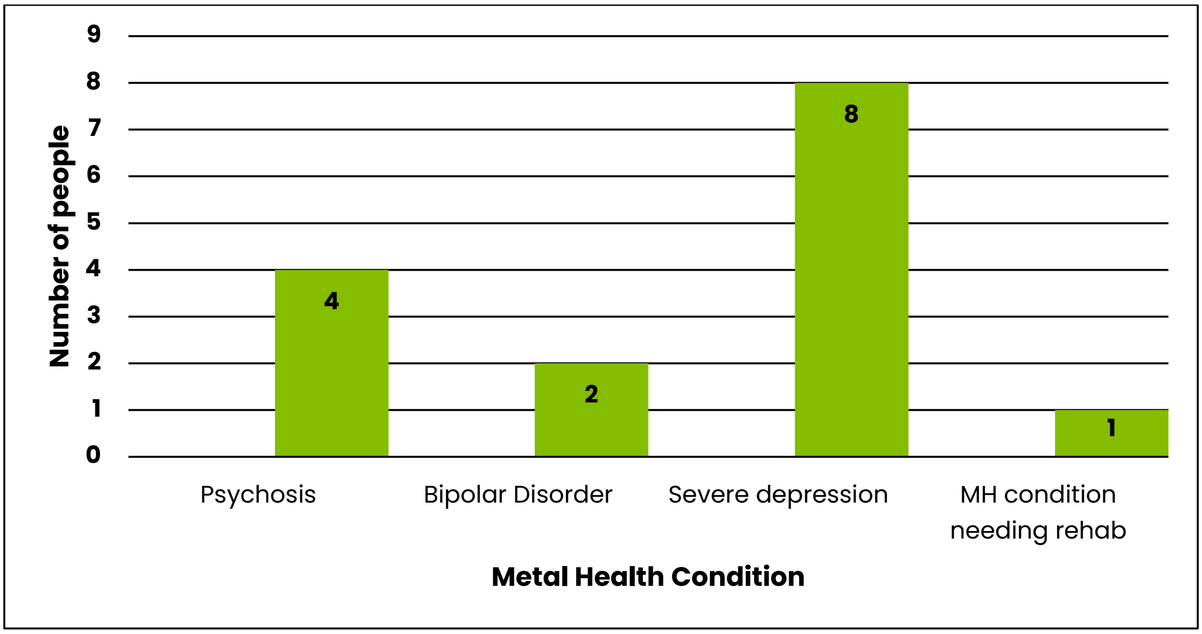


Figure 12. This graph shows the range of serious mental illness that people with an eating disorder also had.

In response to the question "please tell us about your experiences using any of these services" the following comments specifically mentioned support for an eating disorder:

Comments about support for an eating disorder

- I had therapy – cat (Cognitive Analytic Therapy), I also had a care co(ordinator) from cmht (Community Mental health Team) and have had support on(sic) the past also. I see my GP for my mental health and medication.

- Was meant to receive support for eating disorder but that is none (sic) existent. Told to look at a website.
- Eating disorder - I had an assessment with the ED (Eating Disorder) service. They were lovely, by far the most helpful and caring staff member I've met.
- ED (Eating Disorder), only suggestion was BEAT, even though BMI has dropped and concerns raised by g.p (sic) practice for some physical health checks such as DEXA scan, xrays (sic), blood tests for vitamin levels. No actual Ed (eating disorder) support.
- Eating disorder. Waiting over a year for an appointment since last May. Got one in June. It's been changed already once by them. I have Bern (been) diagnosed in last 5 year with BED (Binge Eating Disorder) and bulimia. I have (sic) 15 1-2-1 session (in lockdown) with springs but my BMI has increased now about 58 so obese cat 3.
- NCEDS (Norfolk Community Eating Disorder Service) who I have worked with at different times (successfully) now appears to not have a heart or disregard success of past. I have had anorexia since the age of 14. I have had successful admissions and stayed out of hospital afterwards.....The new way NCEDS treat you after feels tailored to strike people off their list and relabel. This has had a massive, negative impact on me. I find it hard to talk in a group as I don't want to trigger others with my struggles. I have heard I am one of many who have experienced this. it's cruel and damaging - people will die under this new way of working.

In response to the question "how would you rate your overall care?" two people (17%) said it was good, 3 people (25%) said it was okay, two people (17%) were unsure or did not respond and five people (42%) said it was bad.

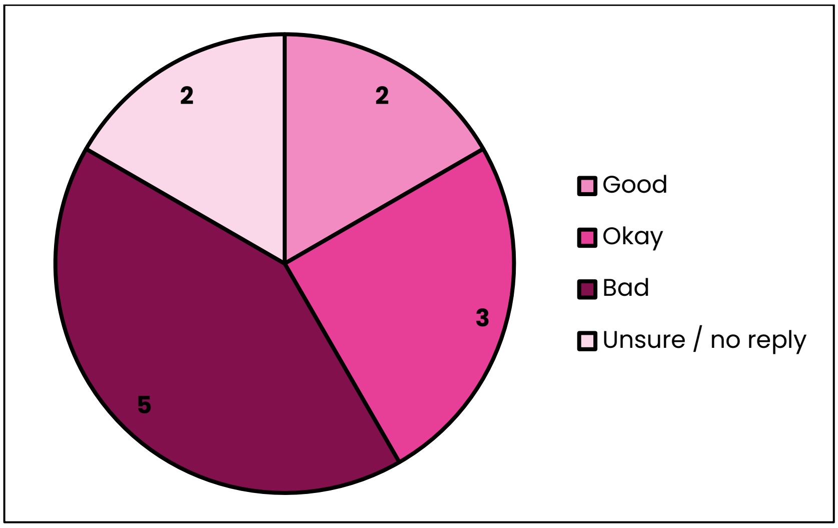


Figure 13. This graph shows how people with an eating disorder rated their overall care

We asked for the Norfolk Community Eating Disorder Service to help put us in touch with current or recent users of their service, but they were unable to identify anyone who was willing to speak with us. They were able to share feedback they had received via their carer's questionnaire for the period 1st June 2023 to 30th June 2024, which was a total of eleven responses.

The carers questionnaire included the question "How would you rate the overall service received for the person you care for?". Four people (36%) responded to this question. The comments shared were as follows:

Service rating from carers of a person with an eating disorder

- It's taken so long from assessment to starting therapy she has relapsed
- Really very very good, and in particular (name removed) and the surgery, especially the reception staff, have been outstanding and really kind and helpful in communicating, explaining and organising monitoring and support and follow up for our daughter.
- It's taken too long to get started however I have hope as the person my young adult is seeing has their trust which is good

In the survey question "what positive changes you have seen in the last five years?" one person mentioned changes in the Eating Disorder Service:

Positive changes seen to the Eating Disorder Service

- I feel that one of the good decisions in Eating Disorder services was to no longer judge treatment or referral by BMI.

In our survey this year we asked what people thought could be improved about Community Mental Health Services. We had some responses that related to waiting times:

How things could be improved with the Eating Disorder Service

- Help for eating disorders other than just a signpost to a website.
- NCEDS - please look into how they treat people after being treated for anorexia in hos(pital) - People will die, its shocking to me how bad things have gone!!! Not everyone has eupd (emotionally unstable personality disorder).

- I would like to see (which is something I noticed during my eating disorder recovery period, only in the last few years) less focus on the idea of 'maintenance' calories or 'maintenance' weight. I have unfortunately seen this in the last few years or so within the UK system and it feels very much counter to the intuitive eating principles I was presented with in therapy.

Mental health support during pregnancy or after the birth of a child

As outlined in the limitations section, we omitted to ask in our survey if people had received mental health support during pregnancy or after the birth of their child. However, two people in the survey told us that they had used the perinatal service in the last two years. In response to the question about how they rated their overall care, one person said “okay” and the other declined to answer. Both people had accessed support via their GP surgery. Neither person left any comments regarding community mental health services.

We approached the Service Manager for Perinatal Services and her team to ask if they could put us in contact with any current or recent users of their services, but they were unable to find anyone who was willing to be interviewed. However, they did provide a snapshot of Friends and Family Test feedback for the month of July 2024.

The comments are shown below:

Perinatal Support Feedback – July 2024

- My partner and I worked with K who spent time to really hear us. Our sessions felt like ours rather than something we had to do. K's kind and completely down to earth manner meant that both myself and my partner could put aside our anxiety in order to make some big changes
- The support I have had from K has been excellent. She is helpful and gives me a lot of information.
- T really listens and thinks carefully about what might help, supporting us to make informed choices. She is so normalising, friendly, genuine and respectful. She was fantastic in advocating for us with physical health care staff when we were with baby in hospital and has helped to present our voice to the wider

professional team around our baby, helping to combat prejudice around depression.
- Both J and L have been amazing and fully understanding and empathetic with my situation.
- I am very comfortable with them in my home and around/holding my son!
- Support for me was always there and S always asked how I was doing and provided me with information on groups which was helpful.
- G was extremely helpful and understanding. She didn't judge me and my previous experiences.
- Everyone has been incredibly supportive. K is brilliant.
- G was really understanding. It was very helpful to know I could always call her if I needed. She was really good at understanding my background. She really supported me.
- Consistent, supportive and kind
- Once I had been referred the team got in contact with me straight away and arranged a meeting.
- L was amazing and put me at ease whilst giving my a platform to talk and express how I have been feeling. She was kind, supportive and proactive and I felt heard for the first time in a while.

In response to the question what could be improved the responses were:

How things could be improved with mental health support during pregnancy or after birth

- I didn't get a side room at hospital as discussed in the ICP when I first went in. I did get one eventually but not straight away.
- Nothing, this service has been excellent and very responsive.
- Nothing that I can think of
- No - If there was something I would say
- Not at the moment
- Extend time scale loved working with you all and so very grateful
- I really wish that I had been signposted to this team earlier. I have been struggling for the past 2 months and feel like it would have made a huge difference to my MH and relationship with my baby.

Physical Health Checks

> "So they talked about blood pressure, weight, cholesterol, things like that and stuff."
>
> Interviewee - Norwich

In Year Two we looked at the work that was being undertaken to improve the take up of the physical health checks and the efforts undertaken to support GP practices to get up to date with the backlog of physical health checks. The Community Transformation Steering Group provided data for the last quarter of 2022/23 showing that the percentage of adults with SMI who had all six of the key elements of the health check across Norfolk was on average 53%.

In this year's survey we asked respondents when they had their last physical health check. Of the 125 people who replied, 38% (57) had a physical health check in the last 12 months, 9% (13) people had their last physical health check between one and three years ago and 5% (7) people had their last physical health check over three years ago. 22% (33) people stated that they had not had a physical health check and 10% (15) people were unsure if they had one.

We cross referenced the responses to when people had their last physical health check against the SMI that people identified they had. People with bipolar disorder 54% (14) and psychosis 50% (7) were most likely to have had a physical health check in the last 12 months. Only 33% (27) of people with severe depression had a physical health check in the last 12 months making them the least likely.

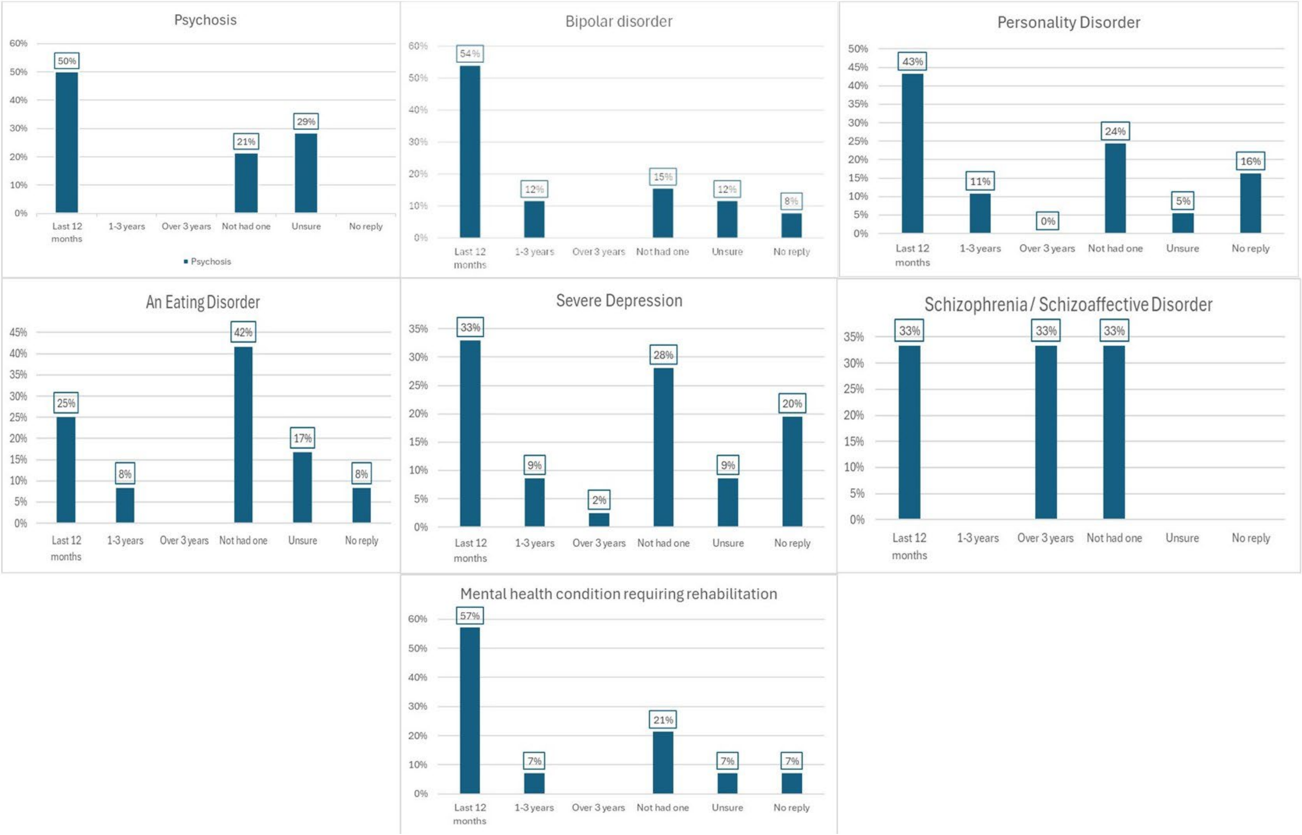


Figure 14. This graph shows people's last physical health check according to their SMI

We asked those people who had more than one physical health check in the last five years to tell us if they had noticed any changes to this service. We received feedback from 30 people, most people told us that things had got worse. 18 (60%) people reported a negative change, 9 (30%) reported a positive change and 3 (10%) were undecided.

Negative responses included comments such as *"I just went through the motions I'm afraid and it was similar to previous health check. Zero interest in my mental health."* and *"I've noticed little if any change."*

Positive comments included *"I have noticed recently that the GP surgery seems to take doing it annually more seriously"* and *"This was a totally new service, was useful as it turned out my blood pressure was amazingly high!".*

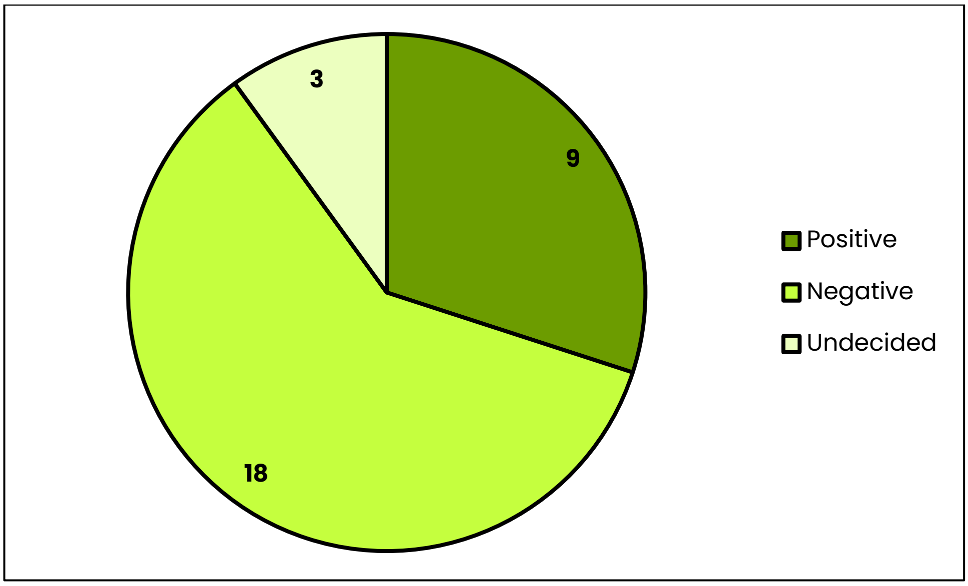


Figure 15. The graph above shows the number of negative, positive or undecided responses to whether people had noticed changes to physical health checks over the past five years

Some of the people we interviewed were frustrated that there was too much focus on their weight when they had their physical health check completed, *"basically she just told me I was overweight. And I don't want to be funny, but I think I can look at myself and decide that myself…I have mirrors. But they seem to just fixate on weight in my surgery"* and *"The last time I had my physical health check with the mental health nurse, she grimaced as she told me she had to tell me I needed to lose weight".*

Other people were positive about the physical health checks, *"They take bloods for me and they found out I had a severe vitamin D deficiency, which was quite helpful. And they put me on a strong supplement for seven weeks"* also *"They do check my blood really frequently because with lithium they have to and then they obviously do a run of other things as well".*

People also talked about the physical impact of their serious mental illness *"my GP had been doing physical health checks on me before I got to 40, to be honest, because of some of the side effects of the medication, putting on weight and things like that really"* and *"Yeah, it was done quite professionally, ….I mean a couple of years short of 50 and I feel my physical health is not totally where I'd like it to be. I get a fair amount of regular exercise, but I feel the medication over years has had a bit of a detrimental effect on my physical health, unfortunately. So the check itself no problem with, but yeah, kind of slight level of sadness and feeling a bit more physically worn out for my age than I'd like to be".*

Carers of adults with serious mental illness

In the carer's survey we included the question *"Have you seen any changes to Community Mental Health services in the last 3 years? If yes, what changes have you seen? (Were they positive or negative changes?) If no, what changes would you like to see?".*

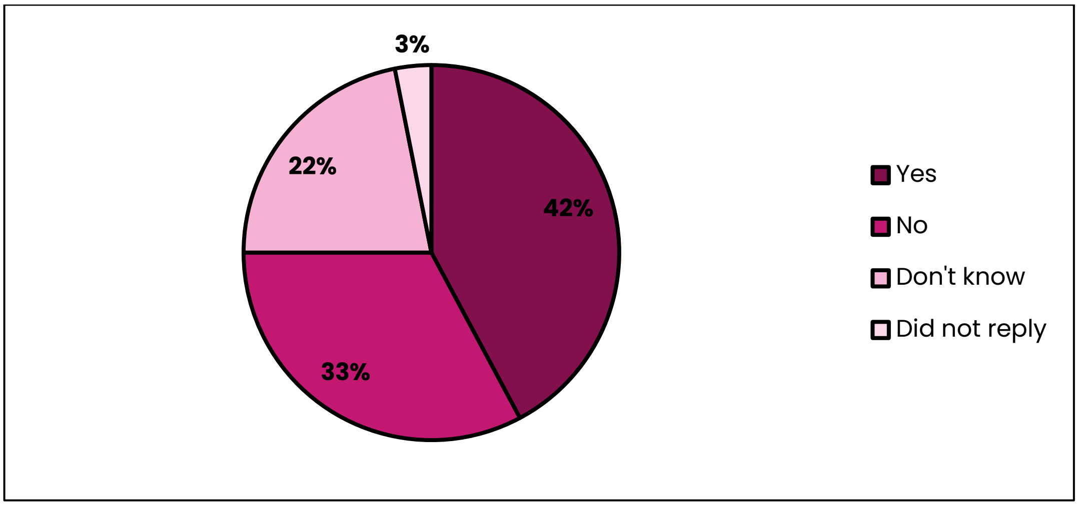


Figure 9. A graph showing the responses to the question "have you seen changes to Community Mental Health Services in the last three years?"

62 (97%) people replied to this question and two people (3%) skipped the question. A total of 27 (42%) people said they had seen changes and 21 (33%) said that they had not. 14 (22%) of people did not know.

Analysis of the 39 comments received show that 34 (87%) were negative and five (13%) were positive. One carer identified that there had been positive change in the support that they and their wife were receiving compared to the previous support they had for the last twenty years.

> Our current experience is positive so there has been improvement. We appreciate the support from and friendly approach from the professional lead care. This is very different from previous experiences where some staff seemed more concerned about their rights and seemed to disregard the fact that after 20+ years we did have an understanding of my wife's illness as well as what worked and what didn't.

Survey respondent

Another respondent identified that there are excellent staff, but this does vary *"Some staff are brilliant but they are few and far between."* Another respondent expressed concern that although there had been changes, these might only be temporary *"The new rehab team is good. But it's only for two years so don't know what will happen then."* Another positive comment identified particular services that they thought were helpful *"The Mind centres and their support seem good. Ditto the Recovery College."*

Most respondents felt that things had got worse, even if they had experienced a positive change in the member of staff supporting their loved one *"It's worse. It wasn't brilliant 10 years ago but we've had so many different psychiatrists and CPNs although we have a very good CPN now."*

Many comments focussed on staffing changes /turnover and the negative impact this has on the care provided.

> Staff turn over is high and impacts the quality and consistency of care available which has a negative effect. Some staff are brilliant, but they are few and far between. Care has become much less focussed on the needs of the individual and more about 'packages' of support available.
>
> Survey Respondent

A few people mentioned that there was less community provision available *"The provision of community groups and activities that a service user can attend without feeling uncomfortable seem to have been reduced or discontinued. To ask someone with SMI to go to a public or commercial group is not always appropriate to their wellbeing. If these still exist where do people find that information."* and "*Reduction in community wellbeing groups*".

The lack of support for carers was also raised, "*More Carer support from mental health services."* and *"Severe decline in access and support for mental health and those who care for relatives with mental health problems."*

We received feedback from the Norfolk Community Eating Disorder Service from carers of people with an eating disorder. The feedback from the carer's questionnaire is as follows:

Have you felt valued and listened to about the support the person you care for has received?

- Yes very much so. (name removed) and her team were absolutely brilliant at running the carers groups sessions and got a good balance between educating and advising and allowing people to express their challenges and experiences and discuss them in a constructive way, and then drawing out the positives.
- (name removed) connected straightaway with (name removed) and (name removed) has become a valued part of (name removed) recovery.
- My daughter has only been 18 for a short while. At the beginning I felt very lost and unsure if I had a voice now she is in adult services however after calling for some help I felt much more reassured.
- Not about the care they receive. I feel very much out of it I'm afraid. 18 may be an adult in the eyes of the law but as a young person with an eating disorder parents/carers/loved ones should be able to have more of a voice.

Have you felt included and involved in all stages of the journey for the person you care for?

- The carers group was brilliant, and our daughter has received good support from the service, but these things have been quite separate. The doctors surgery and (name removed) have been absolutely brilliant and communicated really well (with our daughters permission) but we have had no real communication with the other services that our daughter has received from the service, such as the dietician and the councillors. I think this would have been helpful to have had some communication or contact with our daughters permission particularly with the dieticians as we were supporting her when she was at home and on the phone and facetiming with her meals for quite a long period and it would have been helpful to have all been in the loop about the advice and meal planning. However we do really appreciate that there is a coherent service and that our daughter has been supported in accessing it and I do think that this service has been a major reason for her being able to get so much better and to be able to manage her eating disorder anxieties so much better. The carers group has also been a really important factor in helping us develop strategies to help support her in a constructive way. I am not sure she would have been well enough to stay studying at college without the support of your service. I do think it would be good to both facilitate the mentalising programme for patients as well as carers as this was really very helpful for us in understanding and managing our interactions with our daughter and each other, and we think it would have been helpful to our daughter as well. I also think it might be really helpful to try and organise some group family discussions after carers and patients had taken separate courses in mentalising. But we do appreciate that family sessions were offered but that our daughter didn't feel able to attend these.

- My daughter has only just started therapy and has been mostly stuck since moving from child services so I am hopeful that I will be able to continue to help her with support.

How would you rate the support you receive as a carer?

- Should have a "Very Good" option here
- But from a personal point of view I especially found the mentalising course run through the carers group by (name removed) and her team to be really very helpful in helping understand my own emotional reactions and of those of my family members and learning better how to understand and manage relations and behaviours under the pressure of this illness and learning better how to be supportive in my relationships to my daughter and to other family members. This was also really helped by the space in the carers group to share experiences with and from other carers. I cannot commend the carers group and the teams input highly enough and was really sad when the course ended as it was a really helpful part of my week.
- Very supportive for our daughter.
- Up to this point I feel that as a carer there is very little support so again I am hopeful that by taking part in the carers group I will receive some support.
- I'm doing an online course, which is very useful, informative and supportive. Thank you

- After starting the carers group I feel more supported but wish there was more guidance around food/exercise and advice about what happens when things are really hard. I suppose a more personalised experience. Appreciate how difficult this is with the current mental health service.

For further in-depth analysis of the experiences of carers of adults with an SMI and our recommendations for this, please refer to our report, which is published on our website: (Healthwatch Norfolk, 2024)

Progress toward the I Statement outcomes

In Year One we concluded that people with SMI had not seen significant changes to the community based mental health services, but accepted that it was early in the transformation programme. In our Year Two report we noted that there was positive change in some areas but not in others.

In our Year Two report we made the following recommendation:

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

The I-statements are a series of statements that people with lived experience felt were important to achieve, which we explored in our Year One and Two reports. Please see Appendix Four for the I-Statements in full.

To help us understand the impact of the transformation of community based mental health services we felt it was important to see there was improvement in the key issues contained within the I-statements. For the purposes of the survey, we simplified the I-statements and have grouped them into the four key themes, which we explored in the previous years of this project. The simplified statements and key themes are shown below.

Waiting Times

- Waiting times for services

Joined Up Services

- Staff are aware of details about me and my life, the history of my illness, and the care that I am receiving
- Staff understand how mental health can affect other areas of my life e.g. employment, physical health, finances
- Staff provide information and advice on other wider organisations that may be able to help me e.g. benefits advice, housing support

Feeling in Control

- Being treated with dignity, kindness and respect
- Feeling listened to
- Being communicated with by staff
- Feeling involved in my care
- I have a care plan that is kept up to date and is relevant to my needs
- Feeling involved in creating my care plan
- Organisation of my treatment and care by my care coordinator
- Consistency of appointments / visits from my care coordinator

Involvement of Carers

- Family / Friends / Carers are involved in my mental health care as much as I would like

In the survey we asked people to rate these statements on whether they felt things had improved or got worse. We reminded people that things may still not be as good as they would like, but we wanted to understand if the changes undertaken by the Transformation Steering Group had a positive impact. People could rate each theme using the following options:

- ○ It has improved
- ○ It has stayed the same and continues to be good / okay
- ○ It has stayed the same and continues to be bad / poor
- ○ It has got worse
- ○ Unsure

Waiting Times

> Waiting lists which fail individuals and their families - emphasis on signposting to services which do not exist or are unequipped to deal with risk and people die.

Comment left on Healthwatch Norfolk Feedback Centre – January 2024

In our Year Two report we ascertained that adults with SMI and voluntary sector stakeholders had not experienced change with waiting times for people to access services. The Commissioners of the report, the Norfolk and Waveney Integrated Care Board, responded to our findings by making a commitment to improve waiting times. The report can be found on our website (Healthwatch Norfolk, 2023).

In this year's survey we asked people to let us know if they have seen any changes to waiting times. People told us that waiting times had got worse.

77% (115) of people responded to this question. Of these, 8% (9) of people felt that things had improved and 11% (13) felt that it has stayed the same and continues to be good / OK. This was a positive response of 19% (22).

19% (22) felt that waiting times had stayed the same and continues to be bad / poor, with 48% (55) people stating that waiting times had got worse. A negative response of 67% (77). 14% (16) people were unsure.

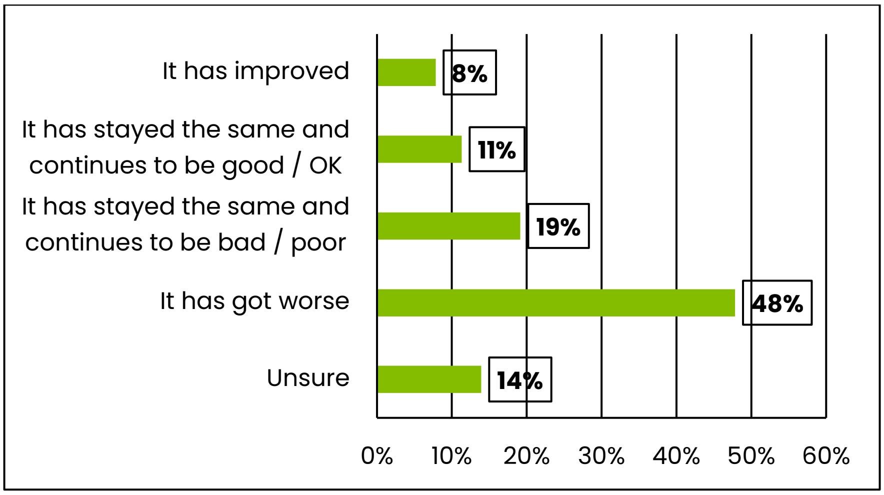


Figure 10: This graph shows people's responses to whether waiting times have changed in the past five years.

There were lots of comments about waiting times. People were frustrated with the length of time they had to wait for support.

> Waiting times are really bad, it makes me feel like I'm not wanted and they don't care. I had to wait 7 months for support.
>
> **Feedback from VCSE service user**

People also told us about long waiting times to access therapy such as CBT (Cognitive Behavioural Therapy) and DBT (Dialectical Behaviour Therapy): "*I've been waiting on a long time to have individual CBT for OCD, which I was on a waiting list to do it at Wardley Hospital in London, but I wasn't able to do it at that time. So I got taken off the waiting list, and it's been a bit of a battle to get people to realise that I'm struggling with my OCD*" and "*I'm waiting for the NHS. I've been on the waiting list for over three years now. I tried to expedite it. I've given letters of support from various specialists. NHS still says nope, now. It was supposed to be this year, but they've said it's probably going to be another year now for me to be seen*".

A number of people told us that they had resorted to paying for private help, "*I think the support in Norwich is appalling. I've ended up having the pay privately to see a psychiatrist and to receive EMDR therapy*" and "*But there is no offer of psychiatric treatment on the NHS unfortunately and it is so expensive to see my private one which* *then causes stress and anxiety. I worry for other people who are unable to pay the £360 per hour to get their medication right…"* and "*You pay a couple of hundred pounds and go to London. That's what we did".*

Frustration about waiting times was a key theme that came up in the open-ended questions of our survey with people suggesting improvements in waiting times should be made, "*Access is good to MH services. However time scale is poor. Some patients need immediate help but this is not available"*, and *"It is no good having long waiting times, people need early intervention and support".*

> Time scale of when you get appointments is dreadful. I feel I'm on a roundabout..
>
> Survey Respondent

In our survey this year we asked what people thought could be improved about Community Mental health Services. We had a number of responses that related to waiting times and levels of staffing:

What could be improved about waiting times

- Need more places as most are over booked and a long wait to see anyone puts me off even asking for help
- Reduce waiting times
- more staff
- Time it takes to be referred to see someone about mental health issues
- That you can see a psychiatrist or someone who can prescribe mood stabilisers like lithium etc.. on the NHS
- More staff, more services including psychiatrists, some support offered. Communication between staff and patients included. Anything other than just wellbeing and antidepressants really.
- More qualified staff more visits
- More support
- Everything! But especially support for people on waiting lists. More people participation would allow better monitoring of patients on

waiting lists and give us some form of contact. It would help and not cost a lot.

- Easier access it makes people a lot more stressed upset and anxious

Joined Up Services

> I feel in control of my care but they are definitely not joined up.
>
> Response from VCSE service user

In Year One we reported that some voluntary, community and social enterprise (VCSE) sector organisations identified a need for more services to address issues such as housing, debt and domestic abuse. We felt that the VCSE sector could support this work, however adequate funding was an issue.

In Year Two we reported that there was a commitment to introduce multiagency working and working in partnership with wider stakeholders within each of the workstreams. There was variation between the workstreams in the amount of multiagency working, but we identified that the Rehabilitation Pilot was an excellent example of multidisciplinary working and a holistic approach, and that Experts by Experience had helped to coproduce changes to physical health checks, which included partnership working with wider stakeholders.

In this section of the survey we focussed on staff awareness of the individual's life and illness history, staff understanding of the impact on the person's mental health on other areas of their life and whether staff provide information and advice on wider services.

Staff are aware of details about me and my life, the history of my illness, and the care that I am receiving

In Year One our survey showed that 62% of people who had used the Crisis Team said that this team were not aware of their treatment history or NHS care plan.

This year we asked in our survey if respondents felt that staff awareness about them, their life, the history of their illness and the care that they were receiving had improved. 79% (117) of people responded to this question. People told us it had got worse.

Of those who responded 15% (17) of respondents felt that staff awareness had improved, with 13% (15) believed that it had stayed the same and continued to be good / okay. A positive response of 28% (32).

25% (29) of respondents felt that it had stayed the same and continued to be bad / poor and 31% (36) of respondents felt that it had got worse. A negative response of 56% (65).

17% (20) were unsure if there had been change.

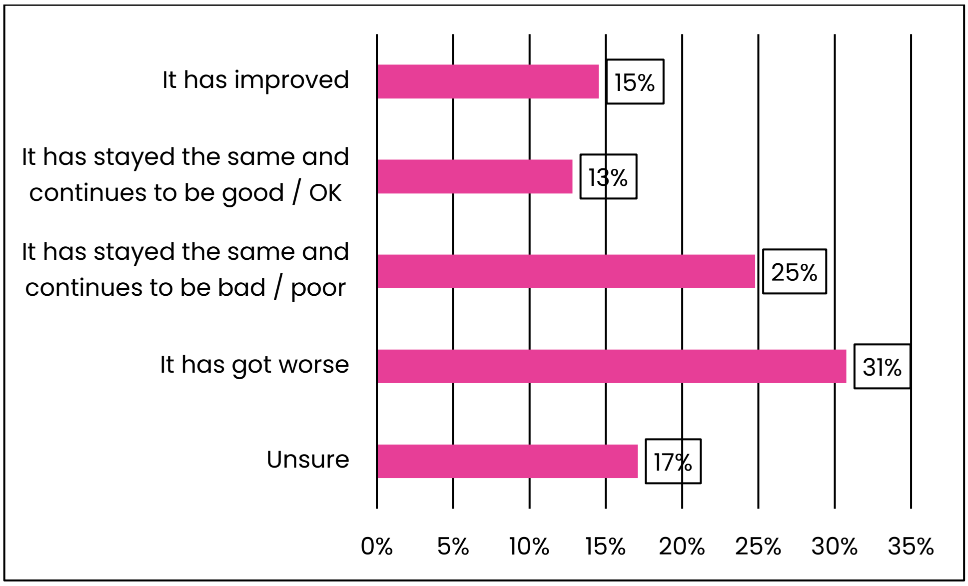


Figure 11: This graph shows people's responses to whether staff awareness has changed in the past five years.

Some of the people we interviewed talked about their experiences of people knowing about their history and the communication between them. One person told us that they felt their care team had a good awareness of their illness history and their care, *"I think my care team do. My care team are great"* and one person thought that whilst communication was good between professionals, it didn't lead to any action on their care "*Well, they know it all. They all communicate. There's just been a lack of action on what they all know, I think, which I don't know what the reasons are exactly, but everyone knows and communicates, just nothing really changes*".

Continuity of care, however, was an issue that was raised in response to the question in the survey about how things could be improved.

What could be improved
• Every appointment I've had with a psychiatrist has been with a different person and I have to answer the same questions time and time again which is incredibly hard and triggering. Seeing the same one will make it easier and be more helpful in care and care plan and overall mental health • support from people in posts long term so they can recognise what stage your (sic) at. • Consistent with care. • There should be a way to speak to the same health practitioner instead of a different person at each time of contact. • More staff, more appointments to see Dr and consultants. Having consistent staff so you see the same person each time who knows you. • Continuity of care should be a priority in mental health services • Frequently changing physiotherapist makes it hard to make a connection • Long term regular support with familiar person/ people. • Continuity of care

Staff understand how mental health can affect other areas of my life e.g. employment, physical health, finances

In our Year One survey slightly more people (45%) told us that their main point of contact did not understand how their mental health needs affect other areas of their life compared to those who do (40%).

In this year's survey we asked whether people felt that staff understanding how mental health can affect other areas of their life had improved. 79% (117) of people responded to this question. People told us that staff understanding of how their mental health can affect other areas of their life had got worse.

Of those who responded 14% (16) of people felt that this had improved, with 21% (24) believing that it had stayed the same remaining good / okay. A positive response of 35% (40).

17% (20) of respondents felt that things had stayed the same and continued to be bad / poor, with 26% (31) stating that it had got worse. A negative response of 43% (51).

22% (26) of respondents were unsure.

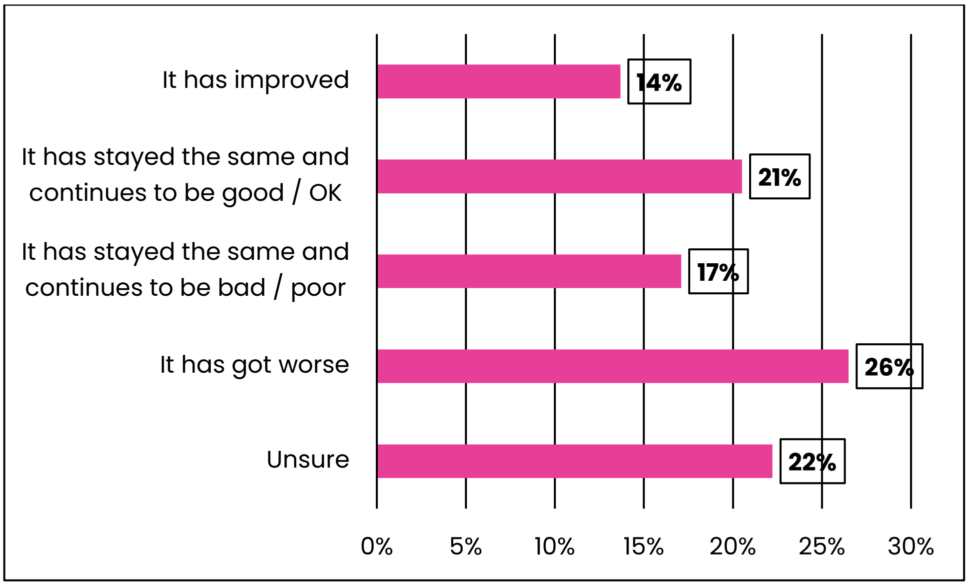


Figure 12: This graph shows people's responses to whether staff understanding of how their mental health can affect other areas of their life has changed in the past five years.

One person talked to us about the need to be more joined up around wider health issues, especially as people aged, "*As you get older you tend to have more health problems, more improvements, more life issues to deal with and so on and so forth. And I think also some form of future support, possibly around people with mental health issues that have got parenting responsibilities. So whether that's children of their own, whether that's nieces, nephews, things like that. I think whether they're only seeing them occasionally or more regularly and so on, I think the whole system could be better integrated and better integrated with physical health and so on".*

Some of the people we interviewed talked about the difficulties they experienced and how their mental health negatively affected other areas of their life. Some people they felt that they had no help with this. One man told us that he had got into serious financial difficulty after taking out a number of contracts over the telephone through unsolicited calls without realising the financial implications but had no help to resolve this. One person told us, "*One thing I will say that I feel like people don't talk about enough is universal credit and DWP. NSFT staff don't know a single thing about how that system works. So if someone comes into them and they're having a crisis, that crisis is mental health related but it's exacerbated by financial situation. There's no advice that they can give usually just about what to do because they just don't know how the system works at all. I mean, it just feels like they're out to get you a little bit. And if you don't turn up to the Jobcentre, you get sanctioned".*

Others also mentioned having difficulty managing their finances when they were in crisis, *"I mean, on my finances, I have spreadsheets, budgets, hit a low, I can spend so much money and… unbelievable amounts of money. It's scary. It's scary"* with one person suggesting *"….I feel like everyone should be allowed autonomy over their finances. But I think it could be good to have that as an option if you know you have a mental health condition that if you go into crisis, it could lead to debt. Do you know what I mean? So you can choose that as an option for yourself, but it shouldn't be something that's forced upon you."*

Some people felt that they had been let down by services and should have had better support from community based mental health services when they were having difficulties with wider issues, *"Left to rot in an abusive household with no finances and no housing offered even when on list by council failing and no doctor support or taken seriously by anyone. Severe depression and health problems which would be made better if moved out of abusive residence. abuse on a daily scale at severe levels of murderous intent. talking therapies don't help. I need a house and funding to live".*

Case Study - Doreen

Doreen moved to Waveney ten years ago having fled an abusive relationship. She has a background in nursing and had always been in employment but following a breakdown because of the abuse, she was unable to continue in her employment. When Doreen first moved to Waveney, she was homeless and stayed with relatives or slept in her car. After a few months Doreen was able to find a private tenancy with an affordable rent, where she still lives.

Doreen has depression and anxiety and has panic attacks. She lives near to her sibling and has good friends close by who are supportive and understand her mental health needs. Until recently Doreen was able to manage her finances as she was in receipt of Personal Independence Payments (PIP) and Employment Support Allowance (ESA) due to her mental ill health. However, she has been informed that the PIP payments will no longer be paid, which will also affect the level of ESA she receives, leaving her financially vulnerable.

Doreen is getting help from East Suffolk Council with her finances, as without her PIP and the reduced ESA she is receiving £500 a month less, making her rent over 60% of her income.

“I've also got an amazing guy who works for East Suffolk…and he's to do with financial inclusion and stuff and he's been helping me with my housing benefit and applying for anything that I'm able to. I’m on less than a thousand pounds a month now coming in.”

She is also getting support from a local charity to appeal against the decision to cancel her PIP but the worry about her appeal being turned down is not helping her mental health.

“But like I said, it's just a waiting game at the moment. But I mean, it’s so detrimental, it's just like, it's just so hard.. and I'm the sort of person I've worked my whole life and not having children and I've always worked and then you get that feeling of guilt. It's awful because they plan. I'm very proud and I'm very independent and I've had to be really strong.”

Doreen has previously been supported by the wellbeing team but feels that she has been overlooked by community mental health services as she is not receiving any ongoing support.

“I feel I've slipped through the system a little bit. I've been under wellbeing services. I've had countless amounts of CBT and the mental health since I was about 14, 15. And I was under CAMHS (Child and Adolescent Mental Health Services) then.”

Doreen tries hard to keep a positive outlook and does what she can to maintain her mental health, such as taking her dog out and gardening, but there are times when it is a huge struggle. She also knows how to seek urgent support if she is in crisis but wishes there was some form of ongoing support.

“I would feel that at times my mental health problems haven't been serious enough (to get support) and that I feel I've been overlooked because like I said, I'm in a category where I think a lot of people at my age and in my situation, you just have to plod along. And I don't think there's, whether it be a team, a department or whatever, a support and help network for people

like me, whether it be through my GP, whether it be through the local council or whatever, I would just feel a little bit let down."

Names and identifying details have been changed to protect the individual's anonymity.

Staff provide information and advice on other wider organisations that may be able to help me e.g. benefits advice, housing support

Would also be good to have welfare/social people in with mental health teams as there (is) never any talk about benefits or food or DLA, which are hard when you're poorly and then severely effect someone's mental health like a cycle. If people had better financial and nutrition and housing in their care it may help people in their recovery. I've only ever been told do you want a food stamp and nothing else. Thank you.

Survey Respondent

One of the themes that was identified in our Year One report was the lack of support from mental health staff for signposting service users to relevant organisations and charities that could help. 51% of respondents felt their own awareness of services available to them was good or ok, but they had found out about services themselves.

In our survey this year, 79% (117) of people responded to the statement "staff provide information and advice on other wider organisations that may be able to help me e.g. benefits advice, housing support". People told us that this had got worse.

10% (12) of respondents felt that this had improved and 19% (22) felt that it had stayed the same and continued to be good / okay. A positive response of 29% (34).

16% (19) of respondents felt that it had stayed the same and continued to be bad/ poor with 25% (29) thinking that it had got worse. A negative response of 41% (48).

30% (35) of respondents were unsure if there had been any change.

One survey respondent said in response to the question about what has improved *"Well being but can't help my housing situation as it is has a huge impact on my well being".*

Many of the survey respondents and people we spoke to, mentioned support from voluntary and community groups. A couple of people told us that they had been given the information about community groups by mental health staff *"That was the…. Anchorage Centre or something. The doctors there put me on to Better Together Norfolk, and they got me"* and *"Well, I just actually finished, I had a therapist through a group called Action for Family or Family for Action. They've given me a number of sessions with a therapist, so over the past year I've been doing that. (The referral) was actually through my GP when we were kind of in crisis with our children and we just reaching out everywhere for support and our GP said, Hey, have you heard of this place? They have a group in Swaffham. I said, no, but please. And so they actually not only gave me therapists, they also gave us, we did a solid whole parenting group as well. So they've been great."*

We received a range of comments through the survey and from interviewees about the support from various VCSE sector groups, which were mostly positive but with two criticisms:

Support from Voluntary, Community and Social Enterprise (VCSE) sector

- *"I have accessed bereavement supports (sic) through Cruise and so on, but not specifically any extra mental health support, no"*
- *"I've had some support from the Shaw Trust in the past. I thought the past support that they gave was quite good. I've been able to access one or two things myself through the County Council".*
- (Waves) *"Best therapy I've ever had".*
- I prefer to get support from the community than NSFT, the waiting times are too long.
- CGL need to make sure they document if someone is physically addicted to alcohol.
- I have had an excellent experience with Mind services
- I feel that when I was attending therapy initially, although granted this was with charities sometimes recommended through the NHS, that things were handled well. Unfortunately, when I've had direct interaction with NHS provision it has been so so. i.e. inconsistency of contact etc.

- *"Yeah, I go to a Men's Craft and the wellbeing socials. I don't go to Costessey Day Centre so much. No"*.
- Mind needs to be more mindful of peoples (sic) basic needs.
- *"The only thing I've noticed is that NSFT have been putting more and more of what they should be doing into the hands of Mind. I know recently someone was going through quite a serious crisis, I'm talking last week, he got sent to see the crisis team and they sent him to Mind for counselling, which is like all for them to look after"*.
- Evolve has given me a bit more of a stable place to move forward. Sadly haveing (sic) to work extra hard after a series of bad events. They have helped me realise when others (sic) behaviours are criminal and helped me find help.
- Mind very good with me Samaritans
- WAVES programme run by MIND stared (sic) using this service in March 2023 this programme ran for a year.
- Respite care, 5 years ago music therapy with mind the gap a music charity for mental health.

One survey respondent mentioned that services they had previously accessed had now closed down, *"It's been sad the loss of peer support groups, like the Unite Social group near Norwich. The Clubhouse concept, does seem a good idea though"* and an interviewee told us *"We used to have a group in the Foxhill Centre like this, all bipolar, and they shut that down as well"*.

One person told us that it was difficult to find information about support in the community especially if you struggled to use the internet, *"I aren't (sic) very good on the internet. A lot of things are posted on the internet"*.

For some people the support they receive from wider services is key:

Harold – Case Study

Harold was a carer for his mother for fifteen years. She had a serious mental illness but was struggling with her medication and was self-medicating. Harold felt that he had no option but to become her carer as the alternative was residential psychiatric care, *"they said that either you look after her or she'll have to go in here. And it was interesting because there was a big table like this, which had people on it, and I was at the other end. And it was like they explained to me. And* *then they all looked to me like, it's up to you, you've got to do it. And then the pressure was on".*

Harold lived with his mother fulltime, but was not named on the tenancy, despite trying to arrange this. He was told that as her carer he would be supported in his role. Later his mother developed terminal cancer. Harold got support from the MacMillan Nurses *"I got some, whilst mom was ill and that with cancer, Macmillan nurses set me up with … I got a free psychiatric, what do you call it, psychotherapy sessions with a trained clinician at a surgery. But no, I didn't get it from health authority, no one approached me. I was just totally abandoned."*

After her death, Harold was told he was going to be evicted, but found himself struggling to deal with this on his own, "*And what annoys me was they said when you become a carer you'll get this, you'll get that, you'll get the moon, the stars, don't worry about anything, we'll sort everyone out. I got nothing."*

He found the situation very stressful and his mental health deteriorated as a result. He was also struggling with the loss of his mother and living on his own. He reached out for support from the Community Mental Health Team, but did not get the response he needed, *"And when it came down to losing my house, I told them, and they didn't want to really know."* He did get support from Shelter and Age Concern, which was helpful. "*They (the Macmillan nurses) were brilliant, yeah. And the private agencies were pretty good, Age Concern (and Shelter)".*

Harold's situation was eventually resolved and he able to remain in the home after he was able to provide evidence through social services that he had been living in the property for fifteen years "*So I asked them for some receipts. And finally they did it for me. And I got it about a week after, finally after Shelter had intervened. A week later after finally getting the tenancy resolved. They could have chucked me out. And that would've arrived too late. Done."*

Harold felt let down by the statutory services, who he felt had done nothing to support him when he needed it most, "*But the people that should have stepped up to the plate was the health service and also social services who did absolutely, I'm sorry to say it, absolutely f*** all. Nothing."*

Names have been changed to protect the individual's anonymity.

In the survey question “what positive changes you have seen in the last five years?” one person mentioned community groups:

Positive changes seen in staff providing information and advice about wider support organisations

- There seems to be more community things that you can attend now where you can go and chat and do things etc..

In our survey this year we asked what people thought could be improved about Community Mental Health Services. We had a number of responses that related to signposting and community groups:

How things could be improved in staff providing information and advice about wider support organisations

- More help to find resources. I was told to ‘go find places to go to meet people’ That was it.
- More services that are not charity run.
- To feel part of community.
- Better referal (sic) services and signposting/knowledge of charity sector support services.
- There should be more support groups, particularly West Norfolk. A lot of services seem to be centralised in Norwich. There should be more available locally.
- something that can be done is offer more mental health workshops for people to come have a cup of tea or whatever they drink and a chat with likeminded people that’ve been struggling.
- better education for support workers about other services available to help their clients

Feeling In Control

One of our findings from Year Two was that adults with SMI still did not feel in control of their care, which was supported by some VCSE providers.

In this section we have focussed on how people feel they are treated and whether they feel listened to and communicated with. We wanted to look at whether people had an up-to-date care plan and whether they felt involved in creating their care plans and we also looked at the role of Care Coordinators.

How people feel they are treated

> My wishes are respected. I am more involved in decisions about my care. Things are done with me not to me.
>
> Survey Respondent

In Year One we asked people about this in our survey and found that 31% of people felt that they were often treated with dignity, kindness and respect and 41% felt this was sometimes the case. 29% said they were never treated with dignity, kindness and respect. Those who felt positively about how they were treated talked about the kindness and care of staff. Those who didn't, talked about variability of staff, they also identified that staff being under pressure was a factor in how they were treated.

In our survey this year we asked people about being treated with dignity, kindness and respect. 79% (118) of survey respondents replied to this question. People told us that things had stayed good or okay.

Of these 16% (19) of people felt that the way they had been treated has improved, 35% (41) felt that things have stayed the same and continues to be good / okay. A positive response from 51% (60) of respondents.

25% (29) of people felt that things had stayed the same and continued to be bad / poor. 16% (19) felt that it had got worse. A negative response from 41% (48) of respondents.

7% (10) of people were unsure about whether things had changed.

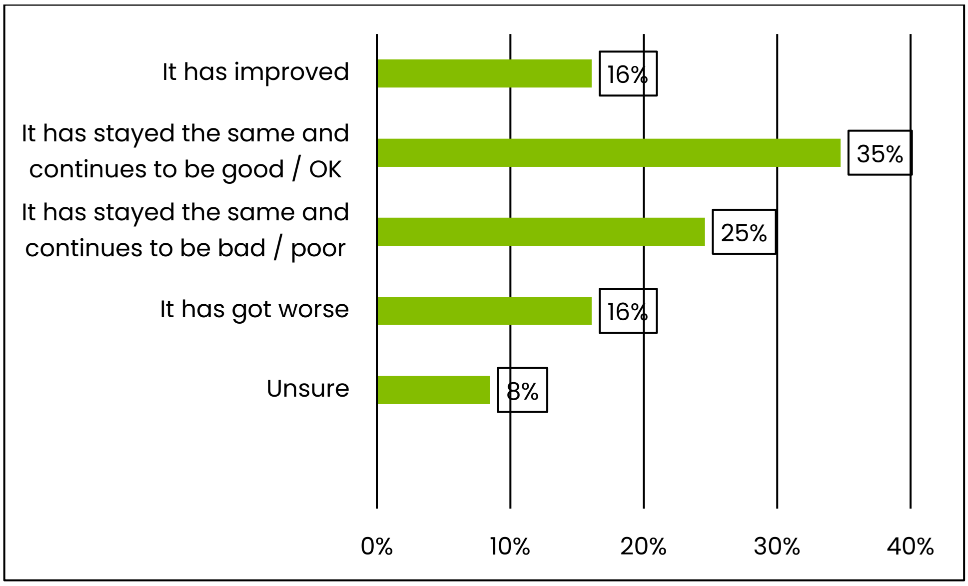


Figure 13: The above graph shows whether people felt that the way they were treated has changed in the last five years.

One survey respondent told us about their experience of using community based mental health services, "*Its appalling at the moment. I feel like I have been totally forgotten. I don't blame the staff as when you see one they are brilliant but they are overstretched and underfunded and it means people like me just get left".*

Another survey respondent expressed concern about the limited training for some staff.

> I find that because there is such a backlog of people needing to use the service, more and more people are being trained in the basic requirements to classify themselves as a mental health worker /support /carer etc, but not enough have been trained in some of the deeper more psychological issues which I think is absolutely paramount to teach any mental health practitioner…

Survey respondent

Comments in the survey about positive changes to community mental health services that people had seen in the last five years included:

Positive changes seen in how people are treated

- The staff genuinely care. The above rating is nothing to do with the staff themselves I cannot praise them enough".
- More staff more listening more appointments more respect

One person in response to the question about how things could be improved, talked about the importance of the environment and welcome:

How things could be improved to how people are treated

- Spend some money on the Local Offices and provide more welcoming spaces. A lick of paint, a range of chairs to suit all types of people and be a bit more imaginative in putting relevant posters in waiting areas rather than every space covered in institutional looking information posters or magazines which are two years old. Should not be somewhere that looks depressing, institutional and you feel invisible. A reception area should at least have someone with a hello to greet you.

One interviewee was very keen to stress the difference in the treatment they had received and how things have improved.

Case Study - Brenda

Brenda is in her early thirties and was keen to tell us about her positive experiences of community based mental health services.

As a result of early childhood traumas, Brenda struggled during her teenage years. She found it difficult to make the transition into High School from primary.

"There was almost like a fog over my childhood from all the trauma, but from what I remember, I really liked my football, so I used to play football, and I just started noticing that as I was going through my teenage years that I was just feeling down all the time, just sad and all this kind of weird strange feelings that I'd never felt before, other than sadness."

Her school tried hard to support her by providing her with counselling, but after Brenda took an overdose, she was referred to Child and Adolescent Mental Health Services (CAMHS). Brenda was diagnosed with Emotionally Unstable Personality Disorder (EUPD). Support from CAMHS continued until she was discharged at sixteen. She was then supported by the Youth Team.

Brenda moved into supported accommodation in Lowestoft but continued to struggle with depression and severe anxiety. Following devastating news about her family circumstances, things spiralled out of control.

"At that point I just went off the rails. I was drinking, taking drugs every day as a way to just cope. I just couldn't cope with life and everything that was going on in it."

Brenda continued to seek help from her GP for her depression and had a number of A&E visits. She eventually recognised that the alcohol and drugs were not helping and had become a problem. She was introduced to Access Community Trust and met their Dual Diagnosis Worker, who provided her with support.
It was only after Brenda stopped drinking and taking drugs that she became overwhelmed by her feelings, which led to numerous suicide attempts. She felt that each time she was admitted to hospital she was treated badly due to her diagnosis of EUPD. She felt that there was a stigma associated with EUPD and that staff felt she was just "attention seeking". However during her last hospital admission, she saw a significant change in attitude. On this occasion she felt she was being treated with respect and with compassion. This had a huge impact on Brenda and was a turning point for her.

"What I took away from it, was these things are moving forward and with that, I have to move forward and that's when I started going, you know what, I need to start looking for some therapy (for the past trauma) because obviously I hadn't dealt with it."

She continued to seek support from Access Community Trust and with their support returned to education, taking her GCSEs and eventually going to university and gaining her degree. Brenda has maintained her contact with Access Community Trust but has also had good support from the Community Mental Health Team, through her Care Coordinators.

When asked about her view of the Community Based Mental Health Transformation, Brenda said:

"NSFT are working so hard at the moment – I've really seen a change in behaviours and attitudes. Just from my time and the people I have spoken with, there is definitely a movement happening. I want people to bear with; they will get it right, they're gonna get it right. It's just going to take time."

Names and identifying details have been changed to protect the individual's anonymity.

Being listened to

> I was seen by (name) clinical lead for mental health. He was amazing. First time I've seen someone so compassionate about his job. A good listener and a credit to you all. Shame there wasn't more like him.

Comment left on Healthwatch Norfolk Feedback Centre – November 2023

In Year One people gave feedback on issues with communication. When rating the organisation of their treatment and care, staff who would listen to them and kept in regular contact, was a key reason for rating the organisation of treatment and care as good. In Year Two we heard from people with a personality disorder or complex emotional needs that they did not feel listened to.

In this year's survey we asked people if they felt that being listened to has changed in the past five years. 79% (117) of people responded to this question. People told us that it had got worse.

Of these 15% (17) said that it had improved and 25% (29) felt that it had stayed the same and continued to be good / okay. A positive response of 40% (46).

18% (21) of people felt that being listened to has stayed the same and continues to be bad / poor and 32% (38) of people thought that it had got worse. A negative response of 50% (59).

10% (12) of people were not sure whether being listened to had changed.

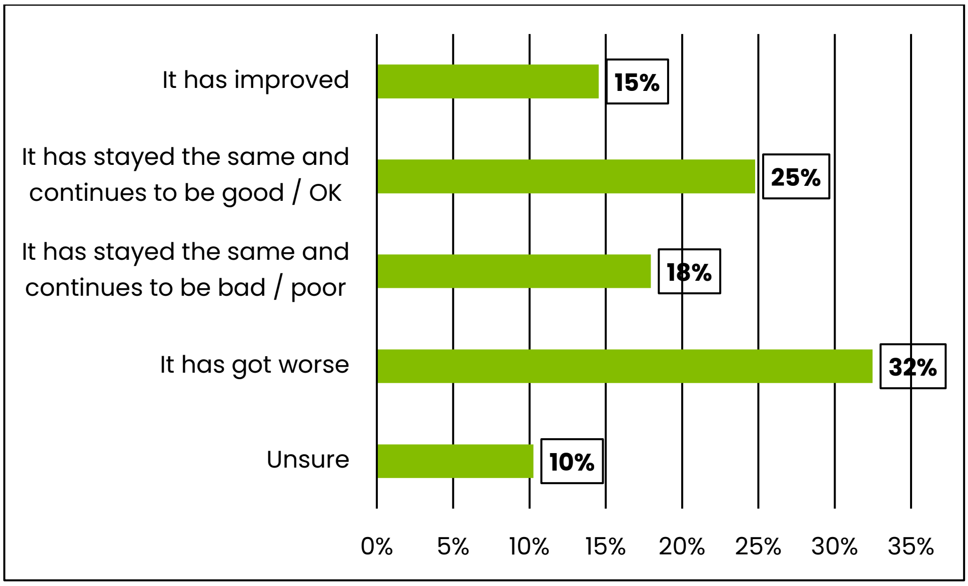


Figure 14. This graph shows the responses to whether people felt that being listened to has changed in the last five years.

As mentioned earlier in this report there was much positive feedback from those people who had mental health support during their pregnancy or after the birth of their child including comments about being listened to. One person in the survey gave positive feedback about being listened to, “*Very good support, felt my wishes and preferences were heard and respected*”. However, we also received comments through the survey that people did not feel listened to, “*The social worker I had at the time wasn't interested in what I was saying. And the only reason I got my placement here was because (member of staff) was the one that suggested it to my social worker*”, “*Dire. They were rude, had clearly come in already decided what the issue was. I was told to "sit there!" like I was a dog, wasn't given time to think about the answers I want, turned up one day and I had a new nurse, no explanation why. They didn't listen, kept going on and on about mood swings when the problem was my mood had been stuck for months. They didn't pay any attention to my GP. Discharged me so the GP referred me back. Did it again so a MHA was threatened. In the end I took two overdoses because I felt so hopeless and alone*” and “*Mental health staff aren’t aware of my story because I’m waiting to tell it to them… and believe me, I’d love the opportunity*”.

One interviewee told us that they had to keep pushing for staff to hear what they were trying to say, “*I kind of force myself into the equation kind of. It's taken a lot of repeating myself to be heard about things like OCD, but I'm pretty good at trying. But people weren't listening to me for quite a while and there was suddenly a change around and they were like, oh, OCD*”.

Feedback to Healthwatch Norfolk - January 2024

A friend was at a really (sic) crisis point with their mental health and despite being so exhausted, phoned the service in the hope they'd get some help. Unfortunately whilst the person helping was well intentioned, they focussed in on certain elements in the conversation which were not relevant nor useful. It felt like they weren't really being listened to at all and unfortunately left them feeling worse than when they called. They were honest on the phone about how they were and to hear that the phone call was how it was, was really infuriating and worrying given the state of their mental health that it hadn't been addressed really and they were just left to it .

It left them thinking that they are just expected to do it alone. The service therefore needs a total rethink, and actually some listening to the individual properly and some proper help rather than suggesting ideas that the person had already thought of or done. The nature of the call, could have had serious consequences and left me in genuine concern for my friend that evening more than I was already and therefore the system does need to be looked at.

Sadly, one survey respondent felt that their responses to the survey would not be believed and that no one ever believed them, "*And the best part in my opinion, as that whoever is reading this, despite this being entirely accurate, will just assume I'm lying. I've seen the look any time I've brought this up. Nobody believes a nutter*".

Being communicated with by staff

In Year One adults with SMI identified examples of unhelpful and unprofessional staff attitudes and said this could depend on the member of staff. There was also recognition that communication could be impacted by staff being under pressure due to staff shortages. In Year Two adults with SMI that had experienced the Rehabilitation Pilot, felt that communication had improved, which was echoed by VCSE stakeholders. However poor communication had been identified as something that needed to be improved by a focus group of people with a personality disorder.

In our survey this year we asked people to rate whether people believe that being communicated with by staff has improved in the last five years; 22% (33) of respondents skipped this survey question. People told us that being communicated with by staff had got worse.

Of those who did respond, 15% (17) felt that being staff communication had improved and 23% (27) felt that it has stayed the same and continues to be good / OK. A positive response of 38% (44).

20% (23) of people felt that it has stayed the same and continues to be bad / poor and 34% (40) felt that it has got worse. A negative response of 54% (63).

8% (9) people were unsure if staff communication had improved.

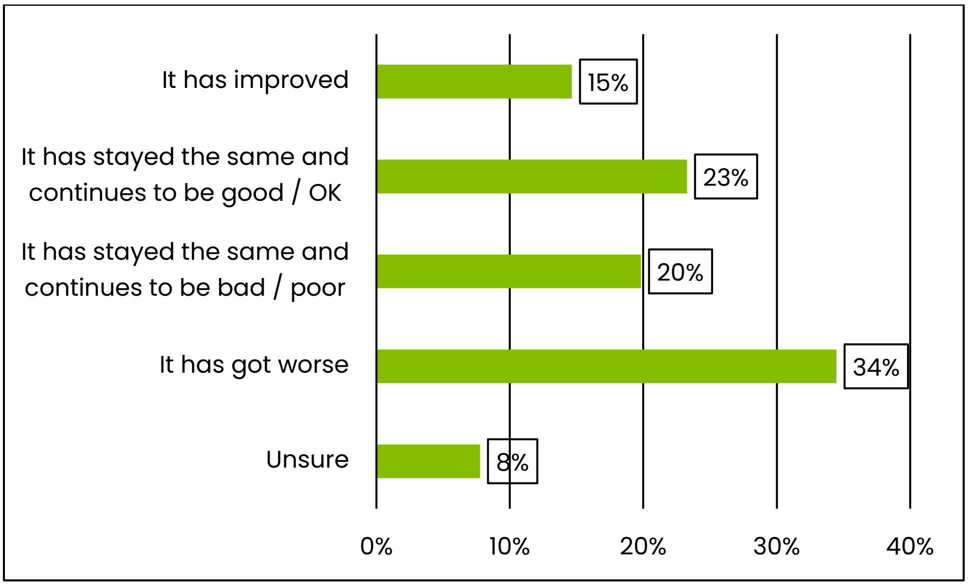


Figure 15: This graph shows whether people believe that being communicated with by staff has improved in the last five years.

One of the themes from the survey was being discharged from services, "*any opportunity to be passed to another body is used, then discharged*" "*.....there hasn't been much contact at all and keep being discharged....*" and "*Feels like they don't want to help. Want you to do therapy in groups which is too overwhelming. They see you a couple of times then discharge you. Then I feel like I'm dropped in the deep end and struggle to stay afloat by myself*" and also, "*Feel like they push you out faster then (sic) you enter the fount (sic) door*".

We received a number of comments about communication through the survey when we asked how things could be improved. People told us:

How things could be improved with staff communication

- More communication with professionals.
- Start talking to the Service users
- More staff, more services including psychiatrists, some support offered. Communication between staff and patients included.
- Proper engagement with service users and their families. Service users to be informed of when staff leave and how long before someone else will support.
- Everything including listening to the patient fully and understand every person is different. It took an overdose for them to listen.
- better communication
- People who WANT to be in the job
- People can be on waiting list for a different service whilst in contact so that it's a smooth cross over with better communication and continuity. Currently there's none and it's so risky.
- Communication needs improving in every area. People currently still have no say in their course of treatment. My opinion on what I need does not matter. Neither does that of the GP when it comes to referral.
- Listening and supporting families and replying to messages not discharging when on a good spell only to slip back and begin whole process again which is endless exhausting and non productive
- Listening to patients.
- More communication with professionals.
- Follow up just because you think the medication of long term mental illness it might not be working. Can't get any help
- better communication

One person identified the need for those who are in the community working with adults with SMI to be listened to, "*Look after your on the ground front line staff, make them feel valued and listened to*".

Involvement in care and care plans

In our Year One survey we asked how included people felt in decisions about their own treatment and care. 58% of respondents told us that they felt included in their care. Those who felt they were involved in their care talked about being involved in discussions and consulted.

We asked in this year's survey whether people felt that being involved in their care had improved or not. 78% (116) of people replied to this question. People told us that it had got worse.

16% (18) felt that this had improved, 22% (25) felt that it had stayed the same and continued to be good / okay. A positive response of 38% (43).

20% (23) of people felt that it has stayed the same and continued to be bad/ poor with 31% (36) of people stating they felt that it had got worse. A negative response of 51% (59). 12% (14) were unsure.

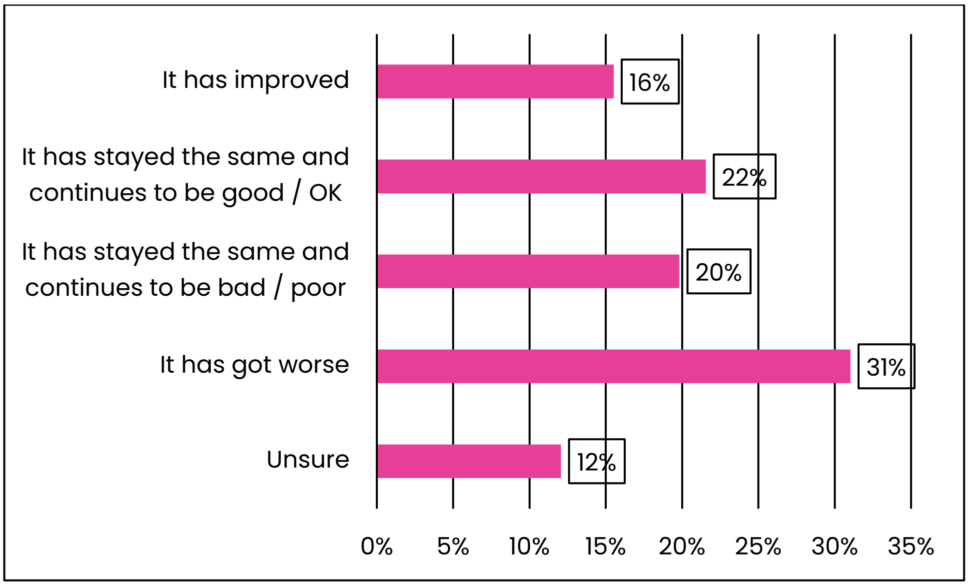


Figure 16: This graph shows whether people believe that being involved in their care has improved in the last five years.

In our Year One survey the majority of respondents, 54%, did not have a current NHS care plan and only 22% did. 24% of respondents were unsure. Just over half of the people with a care plan (53%) didn't find it useful, with the main reasons for care plans not being useful, were either that it was out of date and not kept updated or it was not used at all.

In our survey this year those people who had a care plan told us that having an up to date and relevant care plan had stayed the same and continued to be good / okay.

11% (13) of people felt that there had been an improvement in them having an up to date and relevant care plan and 12% (14) felt it had stayed the same and continues to be good / okay. This was a positive response of 23% (27).

9% (11) of people felt that things had stayed the same and continues to be bad / poor, with 11% (13) saying that having an up to date and relevant care plan has got worse. A negative response 20%.

11% (13) were unsure about whether there had been any change. 45% (53) of people stated that they have never had a care plan.

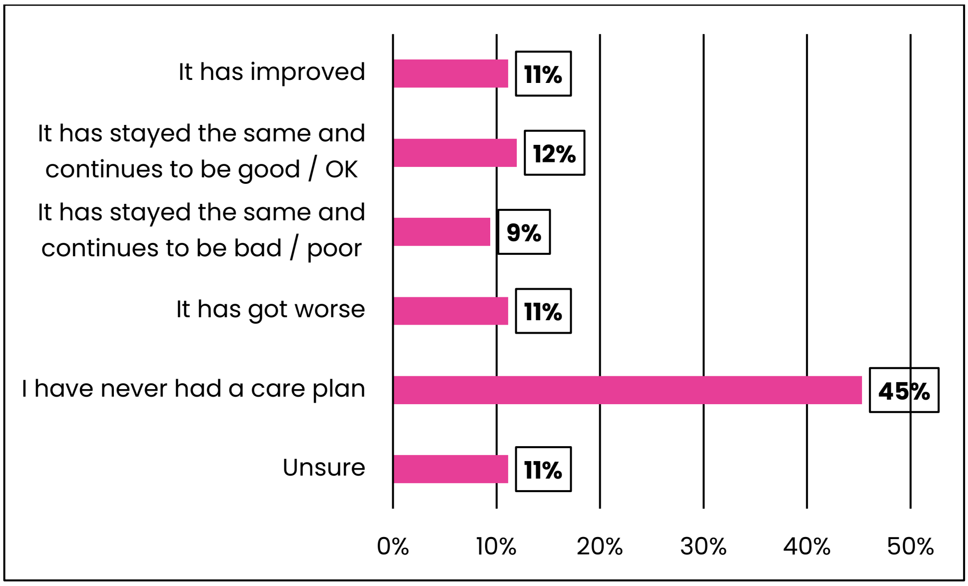


Figure 17: This graph shows whether people believe that having a care plan that is up to date and relevant to their needs has improved in the last five years.

We wanted to understand a little more about those people who stated that they had never had a care plan. In Year One we found that respondents who were over 46 years and those without a disability were less likely to have a care plan.

In our survey this year, we found that those adults with SMI who indicated they had never had a care plan were less likely to have a disability 38% (28) and to be in the 65-75 year old age group.

We also looked at the mental health condition that people stated they had and found that those with psychosis were less likely to have a care plan and those with a personality disorder were most likely to have a care plan.

People we interviewed talked about their care plans and told us that although they had a care plan there were sometimes issues that meant the plans were not being followed, for example, people going on leave or the Care Coordinator has left and a replacement has not been allocated yet.

Casey – Case Study

Casey is a young person in their early twenties, who has needed support for their mental health since the age of 14 years. They were a long-term inpatient in hospital and then moved into supported living accommodation.

When we interviewed Casey, they had been without a Care Co-ordinator for six months as their Care Coordinator had been off sick. Before this Casey was doing well and meeting regularly with their Care Coordinator, but now they were frustrated because although they had a Care Plan in place, the plan was reliant on regular contact with the Care Coordinator.

“I was having the regular sessions with my Care Coordinator and we'd go over DBT (Dialectical Behaviour Therapy) skills and it was kind of like doing a regular risk assessment as well, because I've got a positive behaviour support plan thing that links into being able to live here. But a lot of the conditions were based on the fact that I'd seen my care coordinator once a week and for regular risk assessments and to implement any strategies that might help me”

Casey was working hard to follow the plan and is keen to be in control of their recovery, but feels that the lack of a Care Coordinator is slowing up their progress. Their previous experiences with Care Coordinators had been positive and they felt that the support from a consistent Care Coordinator had been helpful. Since their Care Coordinator had not been working, Casey was reliant on the Duty Team, but found having to deal with different staff members each time was unhelpful.

“Also just, things just haven't been happening. So, I guess I do have to repeat myself, but not because of different services, just to the same service over and over again.”

Casey was hopeful that a new Care Coordinator would be allocated soon as they were aware that their previous one had now moved into a different role. Casey was frustrated that others who’d had the same Care Coordinator had already been allocated a new one and couldn’t understand why they had not.

“So I will be with someone completely new, just frustrating. And from my point of view, there are other people I know who have the same Care Co[coordinator] as me, and their Care Co has been replaced very quickly, relatively quickly, and I'm the only one who it hasn't. And it's exhausting, and it feels very personal.”

Names and identifying details have been changed to protect the individual's anonymity.

One survey respondent expressed frustration about their care plan being ignored, *"Despite my GP handing the nurse my discharge letter, he didn't read it, hadn't read any notes, did opposite of care plan, told me hf (sic) didn't know why I was there, told me he couldn't do anything and could pass me to other people or community team who were the very people who had discharged me because they had to be seen to treat me"* and another felt that the plan was used to avoid providing crisis support, *"My mental health worker is great. The reception staff are also good. However when my support worker is on leave I have no support because the crisis team is awful and the duty team dont' (sic) want to do anything (citing the care plan as an excuse to do nothing even if something unexpected happens). This is unfair both to me and my support worker. I should be able to get consistent care. The duty team need to accept more responsibility".*

In Year One we found out that 57% of survey respondents had not had a discussion with their main point of contact about their care plan or treatment. Respondents were then asked whether anyone within Community Mental Health had discussed their care plan or treatment with them. Over three quarters of respondents, 76% told us that they had not been asked about their care and how they feel they've been treated.

In this year's survey we asked if respondents felt that being involved in creating their care plan had improved over the past five years. 77% (115) of the total eligible respondents replied to this question. People told us that being involved in creating their care plan had got worse.

12% (14) of people felt that it had improved and 16% (18) of people felt that it had stayed the same and continued to be good / okay. A positive response of 28% (32).

16% (18) of respondents felt that their involvement in creating their care plan had stayed the same and it continued to be bad / poor. 23% (27) people felt that it had got worse. A negative response of 39% (45).

33% (38) of these respondents were unsure.

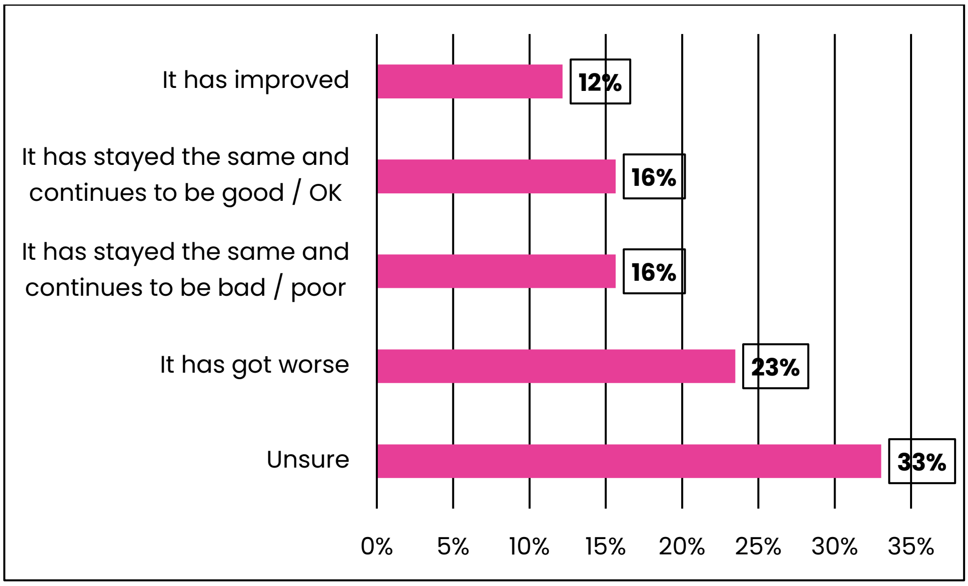


Figure 18: This graph shows whether people believe that being involved in creating their care plan has improved in the last five years.

One survey respondent told us, "*Asked to have an appt to go through my care plan and I was sent them in the post and told if it needs changing make changes and send them back. I'm not sure what I am allowed to put on these sheets and am awaiting to follow recommendations as none were met from hospital I've had to try and chase them all to make sure they happen".*

In our survey this year we asked what people thought could be improved about Community Mental Health Services. We had a number of responses that related to people's care needs:

How things could be improved in involvement in care and care plans

- More help from qualified professionals that can give actual therapy not support workers who tell you tapping your face and to have a cup of tea.
- Treating someone holistically.
- Links to Autistic services and some understanding of Autism
- Gaps in services need closing.
- Actually providing some care and treatment
- Availability of Dr's when needed.
- continuing support and help to avoid a crises - a crises should be avoided
- Definitely more access to face to face counsellors ..
- Everything! Just to provide some care, diagnosis, treatment etc would be a start!!!

- Investment in recruiting and training mental health support workers.
- More NHS psychological therapies definitely required
- More peer support networks. More input from those with lived experience. Less emphasis on medication. More support for talking therapies.

Care Coordinators

> My new Care Co (ordinator) is amazing. And he's clearly read up on me, knows my triggers and what to look out for if I'm not well. He's really good. I'm very impressed.
> **Interviewee**

In Year One people were positive about their Care Coordinators but recognised the stresses they were under and saw how this resulted in care plans not being updated, people also told us that they were not always aware that their Care Coordinator had left. In our Year Two report we highlighted that some visits from Care Coordinators were sporadic or cancelled at short notice. People with personality disorders or complex emotional needs that we spoke to were not positive about the care planning with their Care Coordinators and some talked about their Care Coordinator being keen to discharge them.

In this year's survey we asked two questions that related to people's care and the role of their Care Coordinator. Firstly, we asked people to rate whether the organisation of their treatment and care has changed in the past five years and then we asked them whether the consistency of the appointments with their Care Coordinator has changed in the last five years.

In response to whether the organisation of their treatment and care has changed in the last five years 78% (116) of people responded to the question. People told us that it had got worse.

10% (12) felt that it had improved and 16% (18) felt that it had stayed the same and continued to be good. A positive response of 26%.

30% (35) of people felt that the organisation of their treatment and care had got worse, with 16% (18) saying it had stayed the same and continues to be bad / poor. A negative response of 46%.

28% (33) of respondents were unsure.

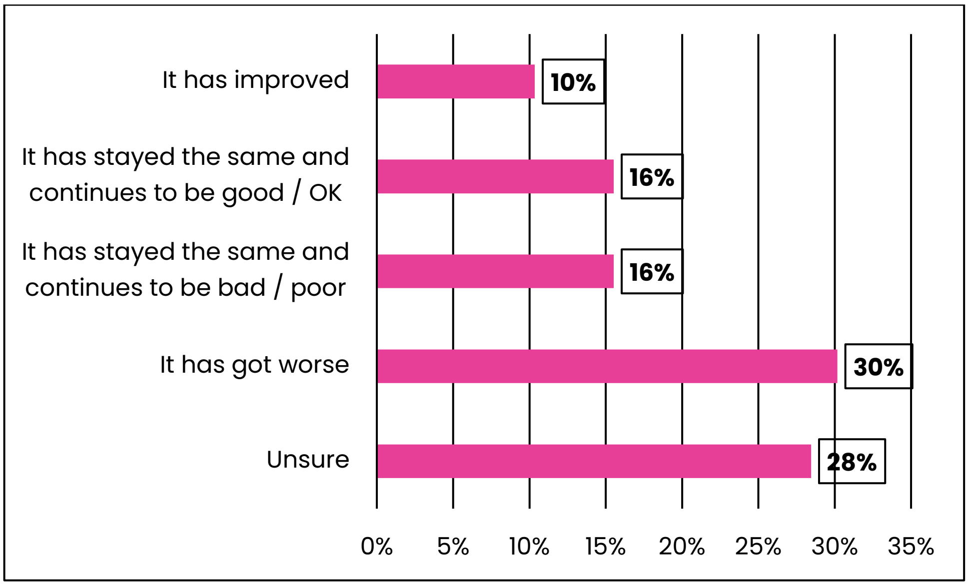


Figure 19: This graph shows people's responses to whether the organisation of their treatment and care has changed in the past five years.

In response to the rating of the consistency of appointments / visits from my Care Coordinator, 79% (117) people answered this question. People told us it had got worse. 8% (9) of people felt that it had improved and 14% (16) felt that it had stayed the same and continued to be good /ok. A positive response of 22%.

36% (42) of people felt that it had got worse and 16% (19) felt that it has stayed the same and continues to be bad / poor. A negative response of 52%.

26% (31) of people were unsure.

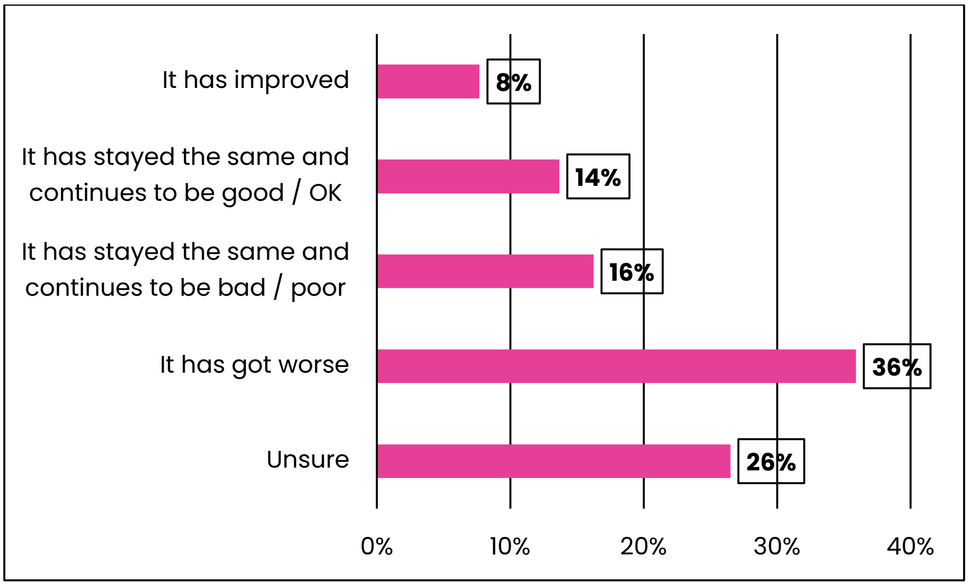


Figure 20: This graph shows people's responses to whether consistency of appointments / visits from their Care Coordinator has changed in the past five years.

We received a lot of comments from the survey about people not having a Care Coordinator:

Lack of Care Coordinator

- I don't have a current care coordinator
- My G.P and my Psych have both been requesting for me to have a coordinator and support team for months! They are told it will be arranged but still a year since requests were started and 2 overdoses later (last one beey (sic) close (to) successful) but nothing.
- I do not know what a care Co ordinator is and I have not spoken to or ever had one
- I never had a care coordinator.
- I don't have a care coordinator and the service has done very little to help me. It's a total disaster.
- *I've never had a Care Co for the simple fact is because they think I've got (partner).*

A couple of the people we interviewed were positive about their Care Coordinators, "*So when I had my old Care Coordinator, I saw her once every six to eight weeks. But my new one I've seen once every three weeks*" and "*I've just changed care coordinator…Yeah, it's been absolutely fine. They've been great*". One person told us that having their Care Coordinator at the time when they were being rehabilitated back to the community had helped them with the transition.

Others told us about some of the difficulties they had experienced with staff changes or staff being on sick leave, “*Well, I know my care coordinator, she's now not on long-term sick. She's completely changed roles”* and “*Yeah, she went on long-term sick and now has been off since then. And I haven't had a replacement*”.

Survey respondents talked about cancellations of appointments *“I have a lot of problems with my Care co @ city anchorage. Sudden cancellation of appointments, not being made aware that appointment cancelled big gaps in appointments”* and “*Care cos (Coordinators) need to feel stable and trustworthy. Also if they are not able to see you, someone needs to inform client”.* Another survey respondent talked about last minute cancellations. *“Support worker sometimes doesn’t turn up to home visits with only a letter a few days later of another appointment.”*

One survey respondent identified that sometimes Care Coordinators are not helped in their role, “*Good community care co ordinators who were told they had to discharge me by their manager because nsft (Norfolk and Suffolk Foundation Trust) did not know how to treat me despite telling me I had to move before I could get treatment which I did. This left me with no support*”.

In the survey question “what positive changes you have seen in the last five years?” a couple of people mentioned their Care Coordinators and one their support worker:

Positive changes seen about Care Coordinators

- Care co ordinators (sic) remained good. However, their role was made impossible by restrictions put on them, eg work load and lack of help or support.
- I finally got a decent mental health support worker after two terrible ones.
- My care co (name)r and psychologist (name) were both brilliant. Also my peer support worker (name).

In our survey this year we asked what people thought could be improved about Community Mental Health Services. We had two responses that related to Care Coordinators:

How things could be improved about Care Coordinators

- Listen to care co ordinators who know the patients. Listen to what they need and say their patients need.
- I would like to see a psychiatrist and have a care coordinator

Involvement of Carers

In Year One our findings showed that a quarter (25%) of respondents said ‘yes’ but 35% answered ‘no’ when asked “Is your family, someone close to you or an advocate involved in your treatment and care as much as you would like?”. 28% 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.

In this year’s survey we asked whether people felt that the involvement of their family / friends / carers in their mental health care as much as they would like, had improved in the last five years. 33% (39) of respondents said this was not applicable. We assume that this is for similar reasons as in Year One. People talked to us about the difficulties a serious mental illness has on relationships, *“Just relationships are hard. Being able to maintain relationships wherever they may be while having a serious mental illness is not an easy feat”* and how this leaves them without support *“Yeah. Probably 90% of people who are bipolar are divorced and so they haven't necessarily got a spouse to support them. I'm an only child as well, so I have no siblings, I have no cousins, so I'm head of the family”.*

10% (12) of respondents told us it has improved and 21% (24) felt that it had stayed the same and continued to be good / okay. A positive response of 31% (36).

7% (8) of respondents told us that things had stayed the same and continued to be bad /poor. 18% (21) felt that is had got worse. A negative response of 25% (29).

11% (13) were unsure whether there had been any improvement.

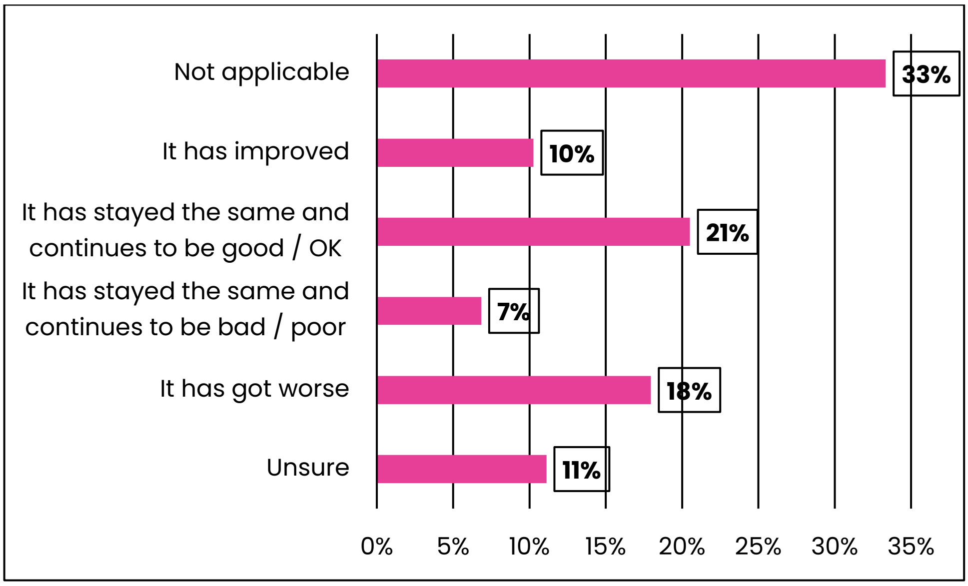


Figure 21: This graph shows people's responses to whether the involvement of family/friends / carers in their care has changed in the past five years.

Only one person told us about a negative experience "*Friends involved in my care - my friend/counsellor was not listened to*". Most of the comments that people made about the involvement of their family / friends / carers was to identify that they were supported by them, "*I have to deal with most things on my own or involve family and friends*", "*I got my wife. I got my wife*".
For one woman we interviewed, the involvement of her ex-husband was crucial, "*And my ex-husband took over the case and sorted it all out. And we went to the Manchester court together. And he sorted it out. I was in no fit state. I mean, I was mentally shot at that point. I could not have handled it. I couldn't have got extra finances. I couldn't have worked. I'd have lost my children. I'd have lost my home unless he stepped in. So I was really fortunate in that respect*".

I-Statement Outcomes – what is better and what is worse?

I have a care plan that is kept up to date and is relevant to my needs

Being treated with dignity, kindness and respect

Family / Friends / Carers are involved in my mental health care as much as I would like

Consistency of appointments / visits from my care coordinator

Feeling involved in my care

Being communicated with by staff

Organisation of my treatment and care by my care coordinator

Feeling listened to

Feeling involved in creating my care plan

Staff understand how mental health can affect other areas of my life e.g. employment, physical health, finances

Staff are aware of details about me and my life, the history of my illness, and the care that I am receiving

Waiting times for services

Staff provide information and advice on other wider organisations that may be able to help me e.g. benefits advice, housing support

Homelessness and adults with SMI

> From a social point of view, when I'm out in the street, my mom had schizophrenia, so I know, and you see people on park benches and that, and they're wandering around and they're talking to themselves. And I just keep thinking who's looking after these people? And some of them are getting quite shouty. They'll probably end up at the police station or something eventually. I'm thinking, well, who's looking after these people? I saw a guy today on a park bench just talking to himself. And someone was there in front of him. I keep on seeing this over, over and over again around Norwich. Everywhere. I say it breaks my heart to see this. I'm thinking nobody's looking after these people. They're not in say a communal setting with people around them. They're just left abandoned on their own on a park bench talking to themselves.
>
> VCSE service user

After reaching out to the Suffolk Voluntary and Statutory Partnership (Suffolk VASP) for support in reaching adults with SMI, we were contacted by an Outreach Worker for Citizen's Advice in East Suffolk who was in regular contact with adults with SMI through the Lowestoft Foodbank, who feel like they are being let down by all services. She particularly wanted to highlight some adults with SMI who had been evicted from their supported accommodation due to their behaviour and then as a result were banned from other homelessness services, such as access to washing facilities, hot drinks and wider support services during the day, leaving them homeless and vulnerable. These people were keen to have their voices heard, as they believed they had been treated unfairly, so we took the opportunity to speak with them.

Gerald – A case study

Gerald told us he had struggled with mental health issues since childhood and had been through the care system. Now in his early forties he has been homeless for two years and prior to this has been in several supported housing placements. He feels that because he keeps himself clean and has good self-care skills that this counts against him. He told us that he lost his placement at one supported placement because the manager said he did not need to be there:

"… because I can dress myself, because I can get in the shower and wash myself; no real addictions – only smoke a bit of cannabis – no heroin addiction, no alcoholic dependency, they turned around and told me, the manageress told me, "you don't need to come here, there's nothing wrong with you". The lady from the council told me there's nothing wrong with me; she wouldn't even help me fill out a local welfare assistance form because 'there is nothing wrong with me'."

Gerald recognises that he does have issues with his anger, but does not feel he is getting the support he needs. He has been diagnosed with ADHD and Complex PTSD and has had some support from his GP. He was critical of the support from the community mental health team, who discharged him after he refused to take the medication he was prescribed, because he was worried about becoming addicted. He does take Valium but the medication for his ADHD creates issues:

*"I ain't getting no support, I'm getting nothing from Access, I got nothing, apart from having addictions from Northgate, I got nothing from Victoria House, they put me on Elvanse, which is a ADHD medication, that did make me focus a little bit more…. So we're making progress, but my anxiety, my homelessness, my depression, my everything else is causing the problem of not waking up until about seven, if I can't sleep at night because I'm homeless and I'm sat there the wind's blowing, it's p***ing down with rain, I'm not sleeping until about five or six o'clock the next morning".*

Gerald is frustrated because he keeps being denied permanent accommodation, but feels other people are being given priority over him – including those who have threatened him. He was in one placement for nine weeks and had the expectation that after eight weeks he would be given a higher banding for housing, which he hoped would lead to being permanently housed. This didn't happen and again he saw other people given priority over him.

Gerald has been offered psychotherapy for his Complex PTSD but he does not want this, he was offered this as a child, which he did not feel it was helpful. He has had some support from his GP, but he feels that the help he needs is to have a permanent home.

Names and identifying details have been changed to protect the individual's anonymity.

Austin's story

We also spoke to Austin, a man in his mid-thirties, who was living in a tent after being evicted from his supported housing placement as a result of his behaviour.. Austin has also been through the care system

"the council have deemed me a non-priority, even though I have mental health issues, even though I'm a care leaver, and I'm homeless. They deemed me a non-priority".

Austin has issues with drug dependency and says being in the hostel environment doesn't help him *"I don't want to be surrounded by drugs. They keep moving me into hostels, I keep giving up drugs on the streets, and then they put me into hostels for drug addicts and expect me to socialise with said drug addicts".*

Austin is very vulnerable; someone had set fire to his tent the previous night and he had lost his possessions including a precious photo. During our interview with him he was approached and threatened by another man over an alleged incident.

Names and identifying details have been changed to protect the individual's anonymity.

In total we spoke with three men with SMI, including one who had recently been released from prison. They are examples of the vulnerable people who are living on the fringes of society with often chaotic lives and unregulated serious mental illness. We recognise the huge challenges in providing support to this group of people, but believe it is important that their voices are represented. We also acknowledge the amazing work of the Lowestoft Foodbank and the Citizen's Advice Outreach Worker in providing such a vital lifeline and a sense of dignity to those we met.

Support we received in undertaking this work

Our sincere thanks go to all the individuals who shared their experiences either by completing the survey or by agreeing to be interviewed.

We would also like to thank the following organisations that helped us to reach out to people with serious mental illness by promoting the project. We are especially grateful to those who also helped to organise interviews with adults with SMI:

The Mental Health Providers Forum
Waveney VASP (Voluntary and Statutory Partnership)
The Different Day Group, Better Together Norfolk
Evolve East Anglia
Waveney LEAF (Lived Experience Advisory Forum), Access Community Trust
Citizen's Advice East Suffolk
Norfolk and Waveney Mind
Perinatal Service, Norfolk and Suffolk Foundation Trust
Norfolk Community Eating Disorder Service, Cambridgeshire and Peterborough NHS Foundation Trust
Age UK Norwich
Men's Craft

Apologies to any organisation that helped to promote our project that we have omitted to mention.

Progress of the Community Transformation Steering Group

Stocktake and impact

In this year the Community Transformation programme had a financial overcommitment and there was a significant delay in receiving the planning guidance that identifies the overall funding and where funding is allocated. These things meant it was very difficult to plan for the year ahead.

A working group was established to undertake a review of the original transformation plans and relevant data. This stocktake was seen as an opportunity to ensure that transformation plans were still fit for purpose and likely to achieve the intended outcomes, or if they needed to be updated taking into account the financial situation and the changing landscape.

As a result there was a pause in both the recruitment for Norfolk and Suffolk Foundation Trust (NSFT) services, including the mental health posts in GP surgeries and any planned further or new investment in services until the stocktake was completed.

What this means

During this three-year project to evaluate how well the Community Transformation Steering Group delivered their plan to transform community based mental health services in Norfolk and Waveney, we have seen evidence of the work undertaken at a strategic level to effect change. There have been positive developments and our expectation is that those people who receive community based mental health support should be experiencing the changes implemented. However, this year, whilst there was some positive feedback, the majority of people continue to report a negative experience of accessing and using community based mental health services, which suggests that the changes have yet to impact on how services are delivered.

There is a challenge to reach a broad range of adults with serious mental illness and even those services that provide support, struggle to get feedback from them. It would be easy to dismiss the views expressed as not representative and just those who want to complain, but there is valuable learning in listening and responding to those who do not feel the services meet their needs. Our experience is that people were also willing to acknowledge where there has been positive change.

Progress that has been made and recognised includes the new mental health roles in GP surgeries, which have been almost universally welcomed. Awareness of the REST Hubs and Steam Cafes is also good, but people's understanding of what they provide and the proportion of people using them is lower.

Work on the transformation of the Perinatal Service has been successful, judging from the feedback from the users of this service. There was mixed feedback about the Eating Disorders Service, although carers of people with an eating disorder are positive about the support they receive.

People feel that there are many barriers to getting the support they need and there is a sense that people's access to therapeutic interventions is limited, with long waits being a barrier. The VCSE sector can play a key role in supporting people with SMI, but cannot act as a replacement for therapy from appropriately qualified practitioners.

There are still issues with the crisis team with comments about how this service could be improved and no positive change identified by service respondents. Some people feel let down and patronised by the response they have had from the crisis team and do not feel that they are being listened to.

We were struck by the loneliness of many of the people who spoke to us and the importance of regular contact with someone who genuinely cared about them, whether that be a Care Coordinator, GP, Support Worker or member of staff from a community group. It is telling that there was such a strong negative response to waiting times and the consistency of appointments and visits from Care Coordinators, which suggests that this continues to be a significant problem. If people are not receiving the ongoing support they need to stop them from going from crisis to crisis, this will put additional pressure on the crisis and duty teams.

Throughout our research for this year's report, people were keen to talk to us and to have their voices and stories heard. For a few, that was because they wanted to stress the good experiences they had, but for many, it was because they felt that no-one was listening to them and they were not getting the support they needed. Many of the people we spoke to, thanked us for listening and said that being heard made a difference to them. Communication and people not being listened to, continue to be areas of concern. People feel that there is a haste to discharge them from care.

People with a personality disorder or complex emotional needs are still reporting that they are stigmatised, however there were some positive changes reported.

The changes to the physical health checks do not appear to be noticed with most people giving negative feedback about their physical health check.

The progress toward the I Statement outcomes give an overview of how people feel about the support they are receiving. When people are appropriately supported, they feel that they are treated with dignity and respect, have a care plan and their family is involved. It is encouraging that these were areas that people felt had improved, however the views of the survey respondents and people we interviewed is that most of the I-Statement outcomes are not being met.

The Care Quality Commission (CQC), undertake an annual national community mental health survey. The 2023 report (Care Quality Commission, 2023) identified that people's experiences of Norfolk and Waveney NHS mental health services provided in the community are poor. Most notably, quality of care, crisis care, support while waiting, planning and involvement in care, and support with other areas of life. The findings of our report are consistent with this.

Recommendations

This is the final year of a three-year evaluation of how well the Transformation Steering Group delivered their plan to transform community based mental health services in Norfolk and Waveney. We are conscious that at the time of writing this report the Transformation Steering Group has disbanded and continuing work was being picked up under a new governance framework, which was being developed We trust that the following recommendations will be taken forward by the new governance structure for ensuring continuing change and improvement of services.

Ensure that adults with serious mental illness have reliable and consistent support

We recognise the difficulties of staff sickness and turnover on staff continuity, but it is vital to ensure that adults with serious mental illness:

- receive regular visits at agreed times from a consistent member of staff who knows them and understands the impact of their illness.
- be notified as soon as possible if appointments have to be cancelled with an alternative date and time given.

Ensure that adults with serious mental illness have regular ongoing support to minimise the need for crisis intervention.

Along with regular visits there should be opportunities for a range of therapeutic interventions. It is important that people do not just go from crisis to crisis with limited support in between.

- Ensure that adults with SMI get access to appropriately qualified staff for therapeutic input.
- When people are perceived to be doing well, there should be a sustained level of ongoing support. Maintaining contact allows the opportunity to identify if needs are changing and support needs to increase, preventing a potential crisis.
- Continue to promote the value of the Rest Hubs and Steam Cafes but also find ways to facilitate people’s attendance, such as going with them for the first time.

Do not lose the valuable voice of people with lived experience

Experts by Experience offer the vital perspective of people who use or have used community based mental health services and understand the frustrations and challenges, but also recognise what could make a positive difference. Experts by Experience have played an important role in the transformation planning and it is vital to ensure that Experts by Experience are at the heart of service reviews and future plans.

- Ensure the new governance framework includes a place for people with lived experience to contribute to ongoing service design.
- Continue to identify future opportunities for the coproduction of services.
- Ensure that there are clear and accessible pathways for feedback (including complaints) from service users and their carers. This data should be regularly reviewed at team and management level to identify areas for improvement.

Keep the mental health roles in primary care

The new mental health roles in GP Practices should be continued and our recommendations from Year Two be undertaken (see Appendix Five):

- Support the development and integration of the new roles into the wider system
- Ensure the most effective use of existing and new staff to best meet the needs of adults severely affected by mental illness.

Finalise the VCSE Strategy and partnership with the VCSE Sector

We are uncertain whether this key strategy has been finalised as the work had stalled. The VCSE is a vital partner in providing support to adults with SMI and their carers but often the future of their services is uncertain due to issues of funding and valued groups sometimes disappear. The VCSE sector is often well placed to respond nimbly to changes needed and can work more flexibly. The VCSE strategy should include:

- The role the VCSE can play in meeting the needs of adults with SMI and their carers.
- How the VCSE sector can work with statutory services to deliver their shared priorities.

- The measures that can be put in place to ensure sustainability of services – for example, longer funding agreements and procurement processes that are timely and proportionate to the contract.
- How smaller social and wellbeing groups / opportunities can be funded, as these play a key role in supporting people within their communities.
- How the VCSE sector can ensure that the services they offer are accessible and focussed on the service users.
- How VCSE services can be promoted to operational staff working with adults with SMI.

Response from Norfolk and Waveney ICB

Norfolk and Waveney Integrated Care Board did not provide a response to this report.

Appendices

Appendix One: Community Mental Health Services - Year 3 Healthwatch Evaluation Survey

1. Introduction

Community Mental Health Transformation in Norfolk

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.

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?

Healthwatch Norfolk has been working on a three-year project to evaluate changes made to Community Mental Health Services in Norfolk. We held a survey in 2021 to find out the experience of adults severely affected by mental illness of using Community Mental Health Services.

In this final year of the project, we would like to understand if adults severely affected by mental illness can see and have experienced changes in Community Mental Health Services in Norfolk. Things may still not be as good as you would like, but it is important to understand if the changes implemented are starting to make things better.

If you are an adult (aged 18+) living in Norfolk and have been affected by a mental health condition in the past five years, we would like to hear about your experiences of 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

Anonymised survey data will be shared with Norfolk and Waveney Integrated Care Board (ICB) and Norfolk and Suffolk Foundation Trust (NSFT) to enable them to review their progress with the Community Mental Health Transformation. Healthwatch Norfolk will not disclose any confidential information unless there is a genuine and urgent concern for an individual's safety or wellbeing.

The survey results 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

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: Monday 29th April 2024

We have a separate survey to capture the experiences of people supporting and carers of adults severely affected by mental illness. This survey closes on: Monday 11th March 2024. To complete this survey, please visit: https://www.smartsurvey.co.uk/s/HWNSMICarers/

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

☐ I have read and understood the privacy policy.

Have you received support from Community Mental Health Services in Norfolk in the past five years? *

☐ Yes
☐ No
☐ Unsure

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

If you would like to be contacted about future Healthwatch Norfolk mental health related projects, please leave your contact details here:

Experiences of Trying to Access Support from Community Mental Health Services

1. Have you tried to access support from Community Mental Health Services in Norfolk in the last five years? *

☐ Yes
☐ No
☐ Unsure

If yes, what support have you tried to access and what has been your experience? If no, what has stopped you or made it difficult for you to access support?

2. Please share any other comments about Community Mental Health services (including any changes) you have noticed.

Your Experiences of Community Mental Health Services

We want to understand if community based mental health services have got better over the past three years. We know that things may still not be as good as you would like, but it is important to understand if the changes which have been implemented are improving things.

Some of the changes made include:

- A rehabilitation service for those who have been in hospital
- Changes to the process for physical health checks
- Introduction of the REST hubs in Norwich, Great Yarmouth, King's Lynn and Aylsham
- A new way of supporting people diagnosed with an Eating Disorder
- New mental health support staff in doctors' surgeries
- New training for understanding Personality Disorders
- Changes to care planning (including having a named care coordinator)
- Introduction of a primary care-based mental health multi-disciplinary team (MHICI)

3. Do you have experience of using any of the following services within the last five years? (Please select all that apply.)

☐ Support with Rehabilitation back to the community after hospital care
☐ Visiting the REST hubs in Norwich, Great Yarmouth, King's Lynn or Aylsham
☐ Support for an Eating Disorder
☐ Mental health support via your doctors' surgery (including support from a Mental Health Practitioner or Enhanced Recovery Support Worker)
☐ Support for a Personality Disorder or Complex Emotional Needs
☐ Receiving support from the multi-disciplinary mental health support team (MHICI)
☐ Crisis Team
☐ Unsure
☐ None of the above

Please tell us about your experiences using any of these services.

4. Within the past three years, have you received any information from mental health staff or services about the changes being made to Community Mental Health services in Norfolk?

☐ Yes
☐ No
☐ Unsure

If yes, please can you tell us a little more about the information you received and who you received it from?

5. Which other Community Mental Health Services in Norfolk have you used in the past five years?

Please also tell us when you first used them. (If you don't remember the date, please give an estimate)

Physical Health Check

6. When was your last Physical Health Check?

☐ In the last 12 months
☐ Between one and three years ago
☐ Over three years ago
☐ I have not had a Physical Health Check
☐ Unsure

If you have had more than one Physical Health Check in the last five years, please can you tell us if you have noticed any changes to this service.

Changes to Community Mental Health services

The following questions are about any changes you have noticed to Community Mental Health services in Norfolk in the past five years. We want to understand if waiting times and access to community based mental health services have got better. Things may still not be as good as you would like, but it is important to understand if the changes implemented are improving things.

Please rate each statement for whether you think they have improved or have got worse.

7. Being treated with dignity, kindness, and respect

☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

8. Feeling listened to

☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

9. Being communicated with by staff

☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

10. Feeling involved in my care

☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

11. I have a care plan that is kept up to date and is relevant to my needs

☐ It has improved
☐ It has stayed the same and continues to be good / OK

☐ It has stayed the same but continues to be bad / poor
☐ It has got worse
☐ I have never had a care plan
☐ Unsure

12. Feeling involved in creating my care plan
☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

13. Waiting times for services
☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

14. Family / Friends / Carers are involved in my mental health care as much as I would like
☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure
☐ Not applicable

15. Staff are aware of details about me and my life, the history of my illness, and the care that I am receiving
☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

16. Staff understand how mental health can affect other areas of my life e.g. employment, physical health, finances
☐ It has improved

☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

17. Staff provide information and advice on other wider organisations that may be able to help me e.g. benefits advice, housing support

☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

18. Organisation of my treatment and care by my care coordinator

☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

19. Consistency of appointments / visits from my care coordinator

☐ It has improved
☐ It has stayed the same and continues to be good / OK
☐ It has stayed the same and continues to be bad / poor
☐ It has got worse
☐ Unsure

20. Please use this space to tell us more about any changes you have noticed or your experience of Community Mental Health services over the past five years.

Your Experience of Community Based Mental Health Services in Norfolk

21. Overall, how would you rate the care and support you have received from Community Mental Health Services in Norfolk?

☐ Good
☐ Ok
☐ Bad
☐ Unsure

22. What positive changes have you seen in Community Mental Health services?

23. What do you think can be improved about Community Mental Health services?

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.

Remember: all your answers are strictly confidential and the survey is anonymous.

24. How old are you?

25. Have you been diagnosed with any of the following conditions:

☐ Psychosis
☐ Bi-polar disorder
☐ Personality Disorder
☐ Schizophrenia / Schizoaffective Disorder
☐ an Eating Disorder
☐ Severe Depression

☐ A mental health condition resulting in a need for rehabilitation
☐ None of the above

26. What is your gender?

☐ Male
☐ Female
☐ Non-binary
☐ Genderfluid
☐ Genderqueer
☐ Intersex
☐ Prefer not to say
☐ Prefer to self-describe:

27. What is your sexuality?

☐ Bisexual
☐ Gay or Lesbian
☐ Heterosexual or straight
☐ Pansexual
☐ Prefer not to say

If you feel the choices do not provide a suitable option, please write how you would describe your sexual orientation:

28. What is your ethnic group?

Arab:
☐ Arab

Asian / Asian British:
☐ Bangladeshi
☐ Chinese
☐ Indian
☐ Pakistani
☐ Any other Asian / Asian British background

Black / Black British:
☐ African
☐ Caribbean

☐ Any other Black / Black British background

Mixed / Multiple ethnic groups:

☐ Asian and White

☐ Black African and White

☐ Black Caribbean and White

☐ Any other Mixed / Multiple ethnic groups background

White:

☐ British / English / Northern Irish / Scottish / Welsh

☐ Irish

☐ Gypsy, Traveller or Irish Traveller

☐ Roma

☐ Any other White background

Other:

☐ Any other Ethnic Group

☐ Prefer not to say

If other, please specify:

29. Please select any of the following that apply to you:

☐ I have a disability

☐ I have a long term condition

☐ I am a carer

☐ None of the above

☐ I prefer not to say

30. Where did you hear about Healthwatch Norfolk?

☐ Social Media (e.g. Facebook / Instagram / Twitter)

☐ News (website / radio / local newspaper)

☐ Our Website

☐ Through a friend or co-worker

☐ Podcast

☐ YouTube

☐ Search Engine (e.g. Google)

☐ Healthwatch Norfolk Event

☐ Other (please specify):

Appendix Two: Interview Questions

Adults with serious mental illness

Background Information for Interviewees

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 Norfolk and make sure they are heard by the people in charge.

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

We have been asked by Norfolk and Waveney Integrated Care Board to evaluate the progress of the changes to Community Based Mental Health Services. This is the final year of a three-year project. The reports of our findings from year's one and two can be found on our website. Hearing the views of people who use these services is the most important part of this evaluation. We will report back to the Norfolk and Waveney CCG on our findings. Our report and any recommendations will be made publicly available via our website.

Thank you for agreeing to discuss your experiences of using community based mental health services. If you would like to pause the interview at any moment, please let me know. If there are any questions that you do not feel comfortable answering, then please say "skip" to that question.

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.

With your permission, I would like to record this interview so that it can be transcribed and we can capture quotes from you to use within the report, along with an anonymised case study highlighting your experiences (if relevant).

Do I have your consent to start recording?

Please tell me a little bit about yourself – your age, your gender, your mental health issues and how long have you been receiving support?

1. Could you please tell me which community-based services you have used in the last five years? This could include any service you receive at home or use whilst you are living at home.

2. What has been your experience of using these services?

3. Could you tell me how easy it was to access the right care?

We want to understand if community based mental health services have got better over the past three years. We know that things may still not be as good as you would like, but it is important to understand if the changes which have been implemented are improving things.

4. Have you used any of the following services recently?

   - Rehabilitation back to the community from hospital care
   - Physical health check
   - The rest hubs in Norwich, Great Yarmouth, King's Lynn and Aylsham (steam café etc)
   - Support for an eating disorder
   - Mental health support via GP surgeries
   - Support for a personality disorder / complex emotional needs

5. Could you tell me which of these services you have used and what your experience has been of these services?

6. Could you tell me how these services have helped you?

7. Have you been able to see any improvements in these or any other community services? If so, could you tell me what the improvements are?

8. If you haven't experienced any improvements in the services, could you please tell me whether you feel the services need to change and why?

We want to understand if there has been improvement in some key areas, such as waiting times, services being joined up and whether people feel in control of their care.

Waiting Times

9. In your experience have waiting times for support improved over the last three years? Could you tell me the reasons for your response?

10. If you have used the crisis team in the last five years, could you tell me about your experience and whether you have seen any improvements in crisis support?

Joined up services

11. Can you tell me about any improvements you have seen in people who are involved in your care, knowing your name, the history of your illness and understanding the care that you are receiving?

12. From your experience have you seen an improvement in the people involved in your care understanding how other things such as housing, worries about your physical health or finance can have an impact on your mental health? Can you tell me a bit more about this?

Feeling in Control

13. Can you tell me about any improvements in how involved you are in your treatment and care? How involved do you currently feel in the decisions made about your care?

14. Do you have a care plan? Do you have a named coordinator in your care plan?

15. Could you tell me how useful your care plan is?

16. Could you tell me about any improvements that you have experienced in the use of your care plan?

17. Can you tell me whether you feel like you have an equal say in plans for your care and your experiences of being treated with respect?

18. Could you tell me your experience of communication with you about your care and changes to your care, including any improvements you have seen?

Thank you so much for your time today. I really appreciate the time and thought you have given to your responses.

The recording from today will be written up and once this has been done, the recording will be permanently deleted. The transcript of the interview will help to give us information for our report. We will use some of what you said as direct quotes and we may use the information as a case study, however your name will not be used on anything – so it will be all anonymous - and we would change any details that would allow anyone to identify you.

Can you confirm that you understand how we will use this information and give me your consent to use it in this way?

Do you have any questions?

Thank you again for all your time.

Carers of adults with serious mental illness

SMI Carers interview guide

Semi-Structured interview guide based on answers in the survey to gather more in-depth feedback. These questions are only a guide- questions will be based on participants survey answers to gather more depth.

The main themes are:

- Information and resources available to Carers
- Carer Health and Wellbeing
- Carers involvement and having their voices heard

Carers of adults with Serious Mental Illness (SMI) interview guide

Interview Questions for Carers of adults with SMI

Thank you for agreeing to discuss your experience of being a Carer of an adult with Serious Mental Illness (SMI).

This interview may be turned into a case study which will then be used in our report and other Healthwatch Norfolk communications. Parts of this interview may also be used in our report and other Healthwatch Norfolk communications. When this report is published you will remain anonymous and we will take great care to ensure that nobody will be able to use your story to identify you.

If you would like to pause the interview at any moment, please let me know. You have the right to withdraw at any time before or during the interview.

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.

Opening questions

1. Please could you tell me a little bit about yourself and your experience of supporting/ caring for an adult with Serious Mental Illness (SMI)?

- Do they have a diagnosis?/ When were they diagnosed?
- How long have you been caring for them?
- What has this diagnosis meant for you as a Carer?

Information and resources

This includes information and resources for Carers (e.g. for your wellbeing, to help you support the person you are caring for, information and resources on the diagnoses of the person you care for etc).

Do you know what information and resources are available to you as a Carer

2. How do you feel about the information and resources available to you as a Carer?

3. What resources/ information have you used? How have you found this? (What was good about these and what could be improved?)

4. What information and resources would you find useful? **(Expand on survey answer)-** Why would you find them useful?

5. Is there anything that would make you more likely to access information and resources for Carers? **(Expand on survey answer).** Why is this?

Carers Identity Passport

6. Are you aware of the Carers Identity Passport?
7. Do you have a Carer's Identity Passport? If yes, how have you found this? How did you find out about it? What is good about it and what could be improved?

   If no, why not? Is it something they think would be helpful?

Carers Assessment

As a Carer you are entitled to a Carer Assessment. Do you know what a Carers Assessment is?

8. If you **have had** a Carers Assessment:

Please could you tell us a bit more about your experience of having a Carers Assessment:

- When was this? Have you had more than one?
- How was this experience? (What was good about it? What could be improved?)
- Are you aware that a Carers Assessment can be reviewed each year?
- Would you have one again? Why/ why not?

If you **have not** had a Carers Assessment:
Please could you tell us a bit more about why you have not had a Carers Assessment?

- If you do not want one, why not?
- If you have never been offered one but would like one, how would you want to be offered one? Do you know how to access one/ who to contact?
- Is there anything that would make you more likely to have a Carers Assessment?

Carers Health and Wellbeing

9. What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing? **(Expand on Survey questions).** Why is this? What (if anything) could be done to improve this?

If you have **received support:**

10. How easy did you find it to get support for your own health and wellbeing? Why was this?

11. Please could you tell us more about your experience of the support you received? (e.g. how did you find the support, how long ago was this experience, how would you rate this experience? What was good and what could be improved?

If you have **not tried to get support**, why is this?
How do you feel about the support available to you as a Carer?

Carers involvement and your Voice being heard

11. Please can you tell me a bit about your involvement in the care of the person you support:
    - Are you involved in the care of the person you support as much as you want to be? Why is this? How has this been across services? What (if anything) could be improved?

12. How informed do you usually feel about the care and support the person you care for is receiving?
13. Do you feel that your Voice has been heard? (In treatment, in development of services etc)

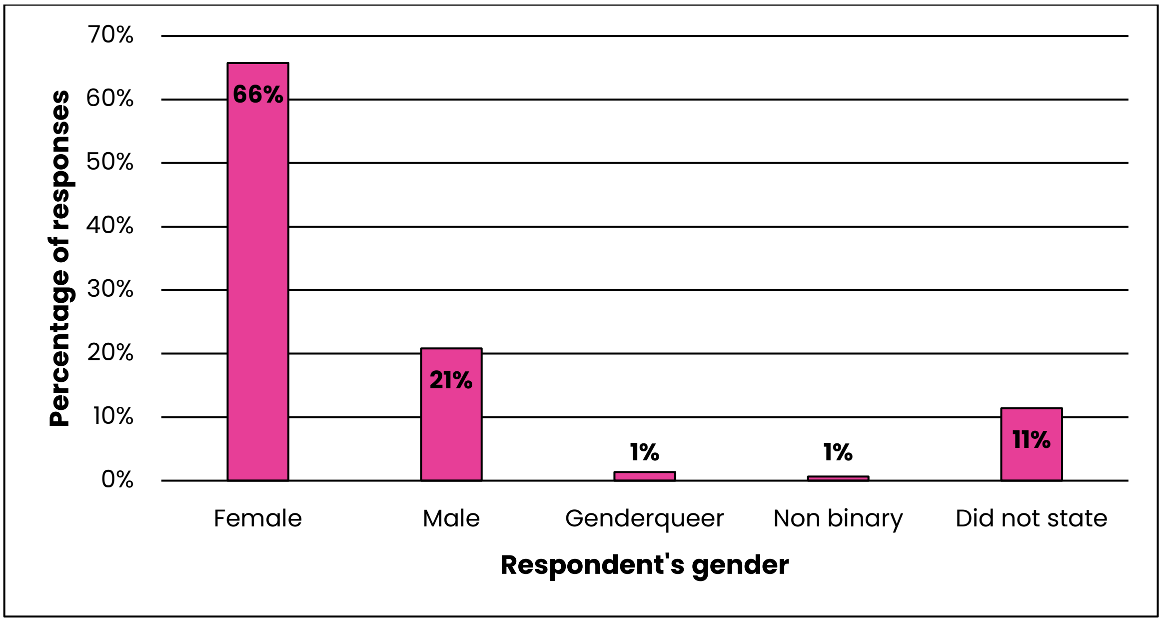
---

14. What challenges (if any) have you faced being a Carer of an adult with SMI?
15. What (if anything) do you think could be done to improve the experiences of Carers of adults with SMI?
16. Have you seen any changes to Community Mental Health services in the last 3 years? What (if any) changes have you seen? What (if any) changes would you like to see?
17. Is there anything else you would like to say about being a Carer of an adult with SMI?

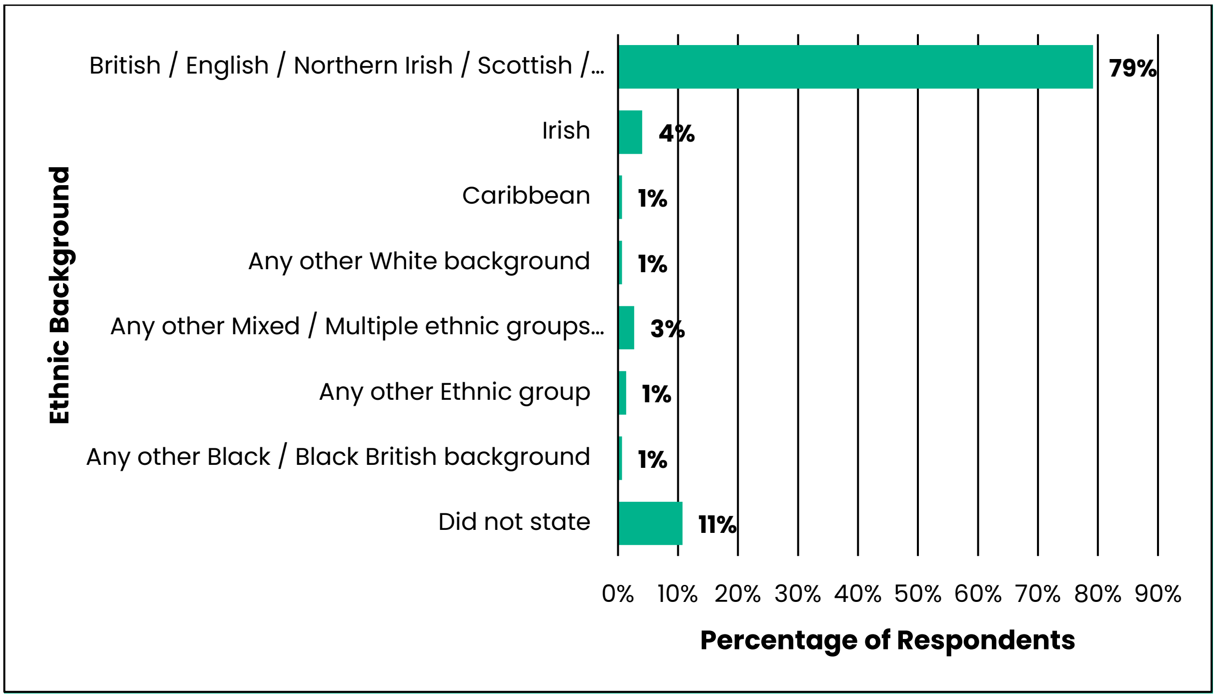
Thank you and debrief

Appendix Three: Demographics of Survey Respondents.

Gender of respondents


Percentage of responses
70%
60%
50%
40%
30%
20%
10%
0%
66%
21%
1%
1%
11%
Female
Male
Genderqueer
Non binary
Did not state
Respondent's gender

Ethnicity


Ethnic Background
British / English / Northern Irish / Scottish /…
Irish
Caribbean
Any other White background
Any other Mixed / Multiple ethnic groups…
Any other Ethnic group
Any other Black / Black British background
Did not state
79%
4%
1%
1%
3%
1%
1%
11%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
Percentage of Respondents

Appendix Four: The I-Statements

I have 24/7 access to community mental health services and support, which are engaging, accessible, embedded and localised.	Access to community services Crisis	Waiting times
I am able to access the right care which ever "door" (referral route) I enter, I am not turned away when I need help.	One door (not turned away)	Joined up services
Everyone involved in my care knows my name, who I am, has read my history, and understands the care I am receiving. I do not have to keep retelling my story. My history is recorded in safe and clear way, it can be easily and quickly accessed, and my needs are understood.	Shared care record and accurate data	Joined up services
My diagnosis is only one part of me. My other physical or mental health conditions, as well as life events, might (or might not) be impacting on my current state.	Holistic support (money, employment)	Joined up services
I am helped to gain perspective, address immediate stressors and life events, and receive holistic care.	Holistic support	Joined up services
I am empowered to access intervention and holistic wrap-	Step-up / step-down support	Joined up services /

around-care, which supports my long-term recovery and on-going health needs.		feeling in control
I experience person-centred care, I am treated as an individual, rather than as a diagnosis. I am a person not just a problem. I have choice in how my care is delivered and my preferences are valued, people focus on “what matters to me”, instead of “what’s the matter with me”. I am motivated and empowered and contribute to my care, I utilise additional resources that are personal to me, I am an expert in my own experience.	Person centred care	Feeling in control
I have a plan for my care and recovery that is written in my own words and kept up to date, which includes the things in my life that matter to me, according to my choices. My care plan is my care plan.	Care plans	Feeling in control
Services communicate with me, and involve me, when changes need to be made to my care, I can prepare for this, and respond to any changes more effectively. My care team value my opinion and trust me.	Communication	Feeling in control
I trust services and will engage with my recovery journey and experience better outcomes, I am heard and able to influence my personalised care pathways.	Being listened to	Feeling in control

I experience consistent relationships with those involved in my care, I feel listened to, validated and that my experience matters. This helps to build my wider capacity for trusting relationships, and this in turn promotes better health outcomes for me.	Care/staff continuity	Feeling in control
My recovery journey is unique to me and its ok to have setbacks sometimes.	Personalised care Fear of discharge?	Feeling in control
I am validated and respected, staff consider and meet my communication needs.	Respect and dignity	Feeling in control
I am treated as an equal in my care, and my lived expertise is recognised, I am motivated to take part in my care.	Equal voice	Feeling in control
Carers and family members can be key protective factors in my recovery. They are fully involved (at my request only) alongside all relevant professionals, this provides the most effective care and promotes the best outcomes. When I experience crisis, these considerations are even more important.	Full involvement of carers	Carers
Professionals are able to recognise the support that my carers require and are able to offer my carers support, their needs are met, and are more able to support me.	Carer support	Carers

Appendix Five: Previous Recommendations: Year One Recommendations

Recommendation 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 the 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 Two

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 Three

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 Four

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 Five

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.

Year Two Recommendations

Outcome One

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

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

Outcome Two

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

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

- To progress with the plans to develop I-statement outcomes for carers, working with VCSE organisations that work with carers of adults severely affected by mental illness.

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

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

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

Outcome Three

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

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

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