healthwatch
Norfolk

Experiences of carers of adults with serious mental illness (SMI)

Year Two

June 2025

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

Healthwatch Norfolk was commissioned to undertake a three-year project by the Norfolk and Suffolk Foundation Trust (NSFT) to find out 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 is the report for the second year of the project and is for the period July 2024 – June 2025.

There were two parts to our work this year. The first part was to research the experiences of three groups of carers: young carers, carers under the age of 45 years (younger carers) and those who have English as a second language. We also looked at the challenges facing NSFT staff who are Care Coordinators or Lead Professionals. The second part was for members of the project carers steering group to work with specific senior members of NSFT staff to implement a seven-point action plan for change, aiming to improve services for carers.

For the research aspect of the project, we undertook a mix of desk-based research of national findings and local research carried out with carers. We contacted young carers' groups and spoke to staff from five young carers organisations and nine young people from two young carers groups, to get their views and experiences. We ran a social media campaign and used the local press and radio to try and engage with younger carers, but had a very limited response. In addition, we worked with a local voluntary sector organisation that supports migrants and refugees to help us engage with people who have English as a second language. To explore staff perspectives, we sent a short survey to NSFT staff and as part of the survey identified people who were willing to be interviewed. We spoke to 12 staff from NSFT.

Across all groups of carers, we found that being a carer of an adult with SMI has particular challenges due to the unpredictability of the illness and concern about serious self-harm or hospitalisation. This can mean that carers suffer with anxiety and struggle with their own wellbeing. Stigma around mental illness can act as a barrier to seeking support for fear of judgement from others.

Young carers are vulnerable, because they are not always recognised, especially by adult services and they do not always have the support they need. They also do not have any information about SMI to help them understand their parent’s behaviour.

Carers who are under the age of 45 years are often struggling with other responsibilities such as dependent children or employment. They often struggle financially and find it difficult to find non-judgemental support.

For those carers who have English as a second language, accessing benefits, such as Carers Allowance and emotional and practical support for them as carers can be difficult.

Staff told us that they want to work in partnership with carers and do their job well, but this is hindered by large caseloads, a lack of time and an IT system that makes recording onerous.

Progress on the action plan was slower than we had hoped, due mainly to restructuring and changes in the senior staff of NSFT. These made it difficult for carers to meet with staff to start implementing the action plan. These delays are hopefully now resolved, and more rapid progress can be made in year 3.

We made the following main recommendations, which can be found in full in the main body of the report:

1. Improve support and recognition of young carers
2. Improve consent procedures and communication with carers in crisis situations
3. Improve the electronic patient record system to make it easier to record and view carer details
4. Produce more written information for carers about SMIs
5. Staff should ensure that consideration is given to carers’ other responsibilities

Why we looked at this

This report is the second-year report for a three-year project, which Healthwatch Norfolk was commissioned to undertake by the Norfolk and Suffolk Foundation Trust (NSFT). The project aims 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. The project was initially commissioned following discussions with three carers of adults with SMI, whose experiences have helped to inform this piece of work. The project is due to be completed by the end of July 2026.

The project will have a particular focus on the information and resources available to carers, carers' health and wellbeing, carer involvement and whether carers feel their voices are being heard. This phase of the project report covers the period from July 2024 – June 2025 and focusses on three groups of carers and their experiences.

The first report, covering the period from July 2023-June 2024 can be found on our website here: https://healthwatchnorfolk.co.uk/wp-content/uploads/2024/10/Experiences-of-Carers-of-adults-with-SMI-report-June-2024.pdf (Healthwatch Norfolk, 2024).

Year One Findings

A number of themes were identified from the research in the first year of this project. We found that information was an issue for carers, and in particular there was a lack of information specifically about serious mental illness, medication and its side effects and on being a carer of someone with SMI. Carers told us that they wanted clearer, jargon-free information that should be given to carers as soon as possible.

We also found out that there was not enough specialised emotional or practical support for Carers and there are difficulties when trying to access support. Carers do not always recognise themselves as carers and it can take a number of years for this to happen, which can be a barrier to accessing both information and support.

Our findings suggest that most of all, Carers want to feel assured that the person they support receives good quality care. We found that there was a lack of trust in services, with improvements needed to mental health provision and services, particularly crisis services. There were also issues with continuity of care and disjointed services which need to be improved.

Lastly, we found that Carers felt that their voices were not heard and that they were often dismissed and ignored. Carers told us they would like to be communicated with more regularly, to be shown more respect and some would like to have more involvement in the care of the person they support.

The Plan for Year Two

Research

The Carers Steering Group has been a key driver of this project, and includes five carers. They identified three areas for further research as part of this project in year 2: young carers (up to 18 years old), carers who are between 18 and 45 years old and carers with English as a second language.

At a project meeting in October 2024, it was agreed to expand this to gather the views of those staff who directly work with adults with SMI and are responsible for coordinating their care.

Young Carers

A “young carer” is a person under 18 years who help looks after a relative, who might be ill, have a disability or mental health issues, or who may have an alcohol or drug problem and be unable to care for themselves or anyone else.

It is difficult to know how many young carers there are in England and there is a wide variation in the numbers reported. The 2021 Office for National Statistics (ONS) census reported that there are around 120,000 young carers aged 5-18 in England, however the school census in 2023 indicated there were 39,000 'known' young carers in the country. A survey undertaken by the BBC in 2018 found that there were as many as 820,000 young carers aged 11-15. (The Children's Society, n.d.)

The number of young carers In Norfolk is estimated at 1153 (from the 2022-2023 Norfolk School census). But research suggests that as many as 1 in 6 children or young people are a young carer at some stage in their life. (Norfolk County Council, n.d.)

Younger Carers (those under the age of 45 years)

The Carers Steering Group were aware that in the survey undertaken in year one, only 12% of respondents were aged 45 years or younger. We recognise that this is a group who may have other caring responsibilities, such as children, as well as working full or part time. The 2021 census found that 2.8 million carers in the UK were also working, and some analysts think that this is a significant under-estimate (Carers UK 2023a). Juggling these responsibilities has significant impacts on their mental and physical wellbeing, and also makes it harder for them to participate in projects such as this one.

People with English as a Second Language

The barriers that carers may face are likely to be exacerbated for those who have difficulty communicating in English because it is not their first language. The use of interpreting, translation and language support in British healthcare is limited (Jan Cambridge, 2012).

Care Coordinators

The Carers Steering Group had experienced a number of problems when trying to work with care co-ordinators. They had often found it difficult to contact them when the person they look after was having a mental health crisis (especially outside standard working hours), found that 'red flags' giving warning of crises were not always addressed by care co-ordinators, and that the contacts with care co-ordinators could sometimes seem very cursory in practice.

In addition, in our previous work on the Evaluation of Community Mental Health Transformation, people told us that the consistency of appointments / visits from their Care Coordinator had got worse (https://healthwatchnorfolk.co.uk/wp-content/uploads/2025/06/Community-mental-health-Y3-Report.pdf). We therefore felt it would be helpful to get feedback from Care Coordinators and Lead Professionals to seek their views about engaging with carers and whether they felt there were any barriers to ongoing visits.

Carers' action plan for change

At the beginning of year 1 of the project, in July 2023, a meeting was held bringing together carers of people with SMI, and leaders from health, social care, housing, voluntary organisations and councils. At this event, people discussed and wrote down a range of ideas for how the experiences of carers of adults with SMI could be improved. An action plan was created following these discussions, with the overarching aim of producing positive change for carers of adults with SMI and the people they look after. Progress was made on this action plan during year one, but at the beginning of year 2 the project carers steering group decided that the original plan had become unwieldy, having too many goals to be actionable within the life of the project. A new action plan was therefore produced by the carers, focusing on seven areas where they most wanted to see prompt action. These were:

1. Emergency and contingency planning
   Many Carers are ageing and concerned about what will happen to the person they look after when they are no longer around. Through this action point, carers wanted to ensure that contingency plans are in place for everyone with an SMI, and that this contingency plan should be included in care plan. People with SMI need a quick response and prompt support if their carer becomes unavailable, as many are very dependent on their carers. The carers wanted there to be a person named in the plan who would respond – whether from social care or NSFT. They also wanted NSFT or an independent body to report on how many contingency plans have been acted on, and within what timeframe.

2. Successful community living
   The carers wanted to know how the Trust actively evaluates whether someone with an SMI is living successfully in the community (or not). They wanted to know whether a process exists, and if so, whether it could be shared with carers. The carers felt that professionals at the Trust often relied on telephone conversations with people in the community, which were often not sufficient to understand whether someone is living well in the community. Their proposal, which they wanted to take forward through this action point, was that a professional from NSFT should visit people with SMI at home at least once a year, rather than relying only on phone calls. They would also like to co-produce a guide for these home visits, based on their lived experience.

3. Red flags and the escalation process
   The experience of carers in the steering group was that they have often raised concerns with staff about the person they look after, that have not been taken seriously, even though carers are often the best-placed people to recognise a red flag that should prompt urgent action. Through this action point, carers hoped to achieve a process where concerns raised by carers would be officially logged, with a guaranteed response, in which the carer would be told

what has or hasn't been done and why. They also hoped to see measures put in place to treat red flags with particular urgency, when they come from carers who live with the patient.

4. Police and court involvement

It is the view of carers in the steering group that people with SMI should not be criminalised when they are mentally unwell, but that this can all too easily happen under current arrangements. Through this action point, carers wanted to see a process established whereby the police contact NSFT when someone with an SMI is arrested, and that NSFT should provide information about the state of that person's mental health.

5. Named contact person

The carers had experienced difficulties staying in touch with professionals from the range of different health and care organisations who were providing different aspects of their loved-one's care. This prevented carers from having a full picture of what was going on with their cared-for person. Through this action point the carers hoped to establish a system whereby there would be a named contact who has an overview of the care someone is receiving from both health and social care organisations.

6. Annual physical health checks

The life expectancy of people with SMIs in England is significantly below that of the general population (Office for Health Improvement and Disparities 2023). At the same time, in Norfolk and Waveney, 54.3% of people with an SMI underwent an annual health check, with the target for 2024/25 being 75%. Through this action point carers wanted to understand what was being done to improve the health check completion rates, and what more could be done.

7. Annual mental health and medication reviews

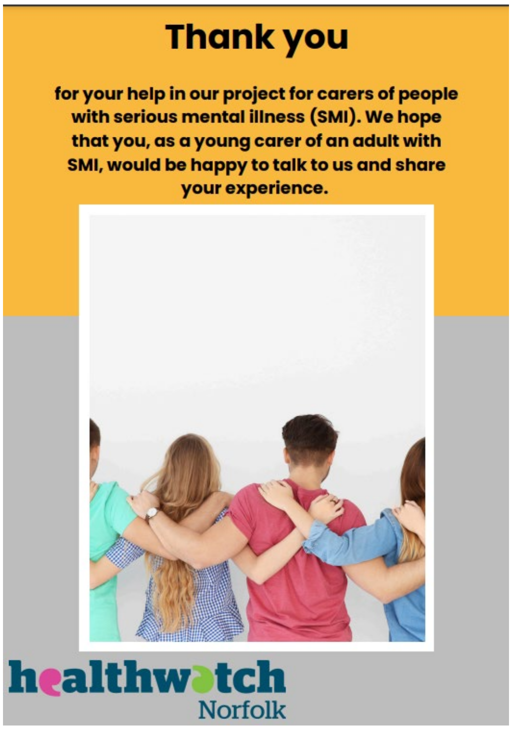
Carers in the project steering group had found that the people they look after went for long periods without having their medication reviewed, making it difficult to know whether their medication was still suitable. Through this action point, they wanted to make sure that all people under the care of NSFT have their medication reviewed every year to make sure it is still suitable and beneficial.

How we did this

We used various approaches to get information for this project, including desk-based research, reaching out to local VCSE organisations, one-to-one interviews, inviting people to share their experiences via social media and email, focus groups, and surveys. The approach used varied according to the population that we were trying to reach.

Young Carers

We contacted a number of young carers groups across the county to enlist their help with this project. The groups were all Voluntary, Community and Social Enterprise (VCSE) sector groups. We spoke to staff that worked directly with young carers to get their views. We also asked if they could support us in meeting with young carers so that we could interview them. Swan Youth Project in Downham Market and Great Yarmouth and Gorleston Young Carers organised meetings with a group of young carers. Information about the project was sent to the groups beforehand to explain to the organisation and the young people who were involved what the project was about and how their information would be used. A copy of the leaflet can be found in Appendix One.



Thank you

for your help in our project for carers of people with serious mental illness (SMI). We hope that you, as a young carer of an adult with SMI, would be happy to talk to us and share your experience.

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Figure 1. An image of the front cover of the information leaflet for young carers

We met with two groups of young carers. A member of staff from the project was present throughout the discussion. The interviewer had a list of questions to prompt discussion, but they were also able to be flexible and respond to what the young people were saying. In total nine young people took part in the two focus groups.

We interviewed five members of staff from five organisations that provide support to young carers. The interviews were semi-structured but with a focus on the difficulties encountered by young people who are carers for an adult with SMI.

We were also interested in the statutory support for young carers and spoke to the Head of Norfolk Safeguarding Children Partnership Business Delivery, the Strategy and Commissioning Projects Manager from Norfolk County Council and the Senior Carers Lead at NSFT.

Younger Carers (those under the age of 45 years)

We were aware that this may be a difficult group to reach, but thought that we would try to be creative in our approach to reaching out to this group. We designed a social media campaign, inviting people to share their story in a way that suited them – via Instagram, email or Facebook. We posted a video and poster to our social media platforms inviting people to share their experiences. We ran the campaign over Christmas and into the New Year, thinking that with time off over the festive period, working people might be able to find the time to respond. Previous experience of running campaigns during this time has shown that this can be a successful strategy.

If you would like to share your experiences by video or voice-note,
read more about we want to hear about and where to send them, by logging on to

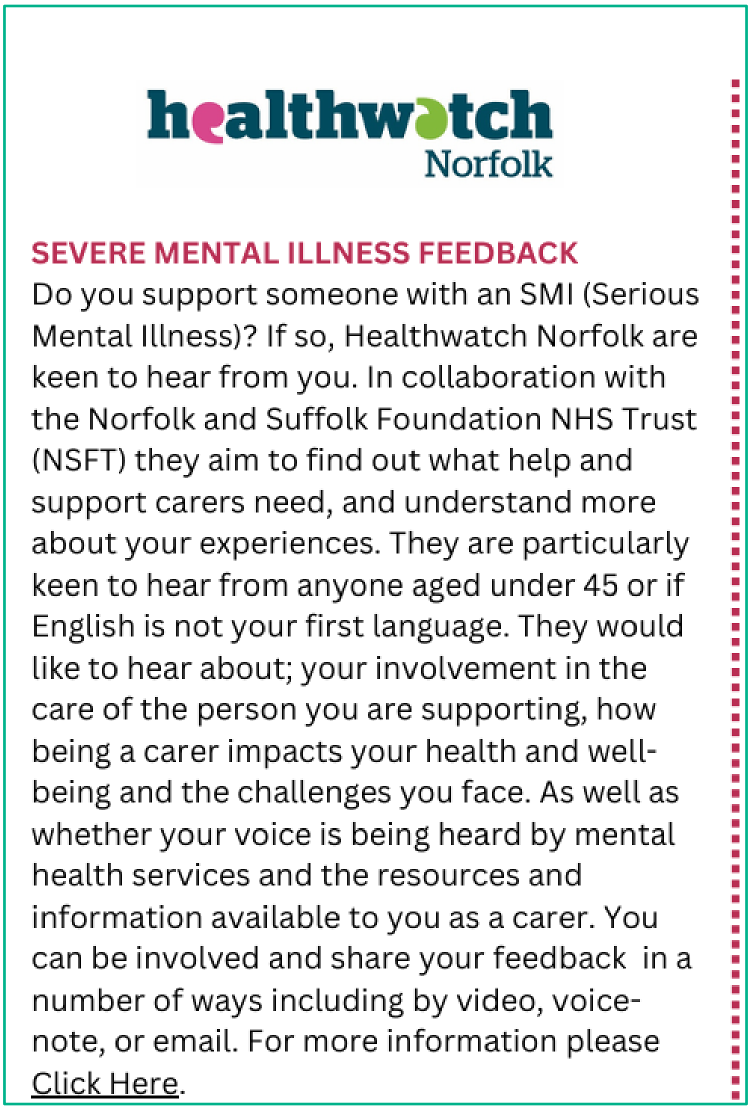
https://bit.ly/CaringForPeopleWIthSMI

or scan the QR code below

Experiences of those aged under 45 caring for an adult with SMI (Serious Mental Illness)

Figure 2. This picture shows the poster for the under 45s campaign
We were also mindful that in Year One of this project, only seven people that responded to our survey were aged 45 years or younger. Therefore, running another survey did not feel appropriate.

We also approached “Carers Voice”, a VCSE organisation that works with carers in Norfolk and Waveney. They included information about our work in their monthly newsletter and also invited us to attend their monthly locality-based online carers involvement meetings during February and early March, to give a short presentation about the project.



SEVERE MENTAL ILLNESS FEEDBACK

Do you support someone with an SMI (Serious Mental Illness)? If so, Healthwatch Norfolk are keen to hear from you. In collaboration with the Norfolk and Suffolk Foundation NHS Trust (NSFT) they aim to find out what help and support carers need, and understand more about your experiences. They are particularly keen to hear from anyone aged under 45 or if English is not your first language. They would like to hear about; your involvement in the care of the person you are supporting, how being a carer impacts your health and well-being and the challenges you face. As well as whether your voice is being heard by mental health services and the resources and information available to you as a carer. You can be involved and share your feedback in a number of ways including by video, voice-note, or email. For more information please Click Here.

Figure 3. A screenshot of the article included in the Carers voice newsletter

We also had articles in the local press and a short piece on local radio to promote the project and seek younger carers’ involvement.

We only received two responses to our campaign and appeals for support. One person that responded had misinterpreted the request and was a carer of an adult with SMI who was under the age of 45 years, but were themselves over 45.

We attended an SMI Physical Health Check Roadshow, which was organised by Together for Mental Wellbeing. The event took place in King's Lynn at the end of January 2025. This gave us the opportunity to meet with carers and we were able to get feedback from some carers who were 45 years or younger. A carer from the Carer's Steering Group also introduced us to someone who is a carer aged under 45 years.

In total we spoke to four younger carers.

People with English as a second language

We undertook desk-based research to find any published research about the experience nationally of people who have English as a second language, before seeking the views of people locally.

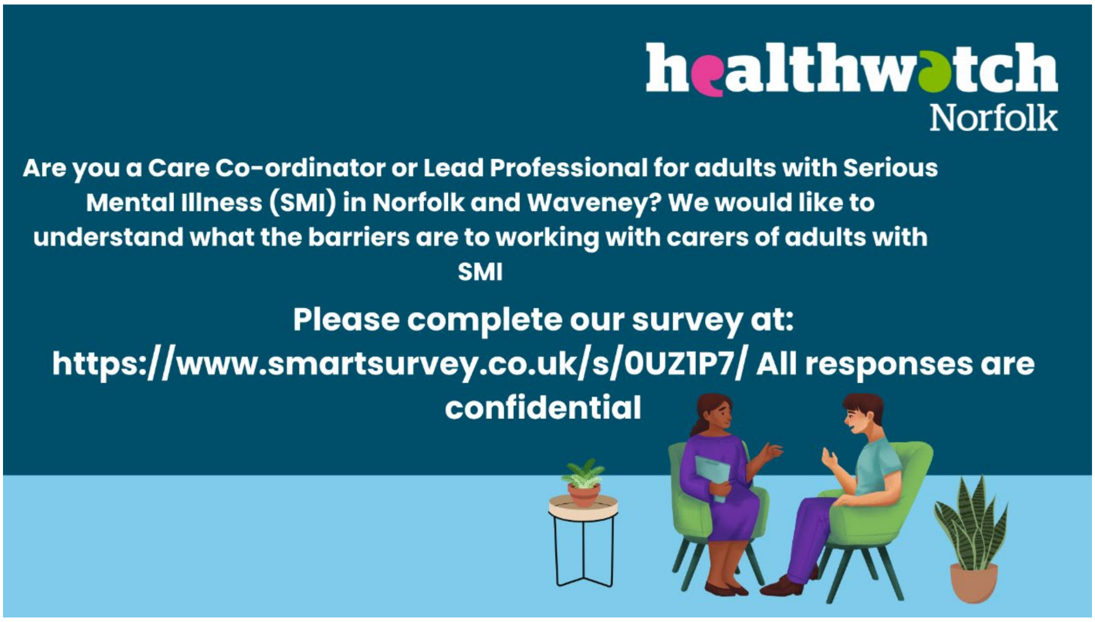
We wanted to use the expertise and contacts of organisations that support people who have English as a second language. We approached three organisations that work with migrants and refugees. One organisation, The Hanseatic Union in King's Lynn, responded positively to our request.

We interviewed key staff at the Hanseatic Union to get their feedback on the issues faced by carers of adults with SMI who have English as a second language. We contracted the Hanseatic Union to undertake interviews with carers and to provide us with some case studies using a format, which we provided. A copy of this can be found in Appendix Two. The Hanseatic Union provided us with four case studies.

Care Coordinators and Lead Care Professionals

We designed a short survey, which was sent to the Project Steering Group for feedback and suggested changes. We received advice that patients subject to a Care Plan Approach (CPA) should have a Care Co-ordinator, but those who are not subject to a CPA will have a Lead Care Professional. We therefore ensured that our communication and the survey referred to Care Coordinators and Lead Professionals.

It was agreed that the survey would be distributed through the NSFT Senior Internal Communications and Engagement Manager. The survey was open from mid-March to the end of April. We asked if NSFT could have an additional push to promote the survey at the beginning of April as there had only been a few responses in the first few weeks. Our experience shows that most people complete the survey when it is first published and promoted. We forwarded a poster, which could be used within any communication to promote the survey.



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Are you a Care Co-ordinator or Lead Professional for adults with Serious Mental Illness (SMI) in Norfolk and Waveney? We would like to understand what the barriers are to working with carers of adults with SMI

Please complete our survey at: https://www.smartsurvey.co.uk/s/0UZ1P7/ All responses are confidential

Figure 4. This image shows a poster promoting the survey to Care Coordinators and Lead Professionals

A copy of the survey can be found in Appendix Three. The survey was completed by 44 members of NSFT staff. As part of the survey, we asked people to leave their details if they would be happy to be interviewed. A total of 15 people gave permission for us to contact them for interview. We also contacted the Carers Leads for NSFT to find out more about their work and how they support engagement with carers.

We interviewed a total of 12 NSFT staff, which included three Carers Leads. The interview questions can be found in Appendix Four.

Action plan for carers

To try to achieve the objectives of the action plan, it was decided that each member of the carers group would select one or more points from the action plan that they were particularly interested in. We would then attempt to arrange regular meetings with senior members of NSFT staff, whose job roles were related to the point in question. An initial meeting was held between the project carers and senior staff of NSFT in October 2024 to discuss each part of the action plan, and attempts to arrange meetings began shortly after. The plan was to initially meet with only one or two NSFT staff members, and to involve professionals in time, if the particular action point demanded it. The objective was to produce tangible timetables for change on each of the action points, and to start working towards meaningful change. NSFT's Head of Participation, Involvement and Experience worked together on trying to keep the action plan on track in year 2.

Ethical Considerations

When working with carers under 18, it was important to provide information to the young people and the adults in their lives, information about the project and how we would use the information provided by the young people, so that they were able to give informed consent to participate. This information was sent in advance to the VCSE projects that had agreed to participate, so that the staff could go through the information with the young people and the adults in their family; they were all given a copy of the leaflet by the staff to keep.

When the interviewer met with the young people, she gave them another copy of the leaflet and explained again what the project was about and how their information would be used. We ensured that a member of the project staff was present during the focus group so that they could identify and respond to any potential safeguarding issues under the organisation's safeguarding policy and procedures.

We asked the young people if they would consent to the group discussion being recorded and explained that the recording would be written up into a transcript, which would help us to accurately recall what they had said. We told the young people that what they told us would be used in the report, but their details would remain confidential. The young people chose pseudonyms for themselves to be used in any case study. We explained that once the report had been completed the recordings and transcript would be destroyed.

All the young people who participated were given a shopping voucher of their choosing as a thank you for their participation. The vouchers were purchased after the focus group and sent to the project for distribution.

Our original intention was to write up case studies based on the young carers' experiences, however we were concerned that even with changing the names of the participants and some details, the young people would be identifiable. We therefore made the decision to produce a composite case study, which highlights some of the issues faced by the young carers, without basing it on any single young person.

When working with carers with English as a second language, we believed that it was important to work with an organisation that supported people with English as a second language as we were aware that the term “carer” may not be recognised within some cultures and there are different expectations of supporting family members. Following consultation with the Hanseatic Union they confirmed that it was important for people to talk to someone they trust and someone who understood the nuances of the culture of the interviewees.

We contracted the organisation for their time to find carers of people with SMI, to undertake the interviews and write up a case study. There was also some money to provide vouchers for the participants as a thank you for their involvement. All the case studies were anonymised.

The survey for Care Coordinators and Lead Practitioners was promoted through Norfolk and Suffolk Foundation Trust. We chose not to use our social media platforms to promote the survey as it was for certain NSFT employees only and not a public survey.

We wanted to keep the survey short and easy to complete, as we recognised that people have limited time. To reassure research participants that there would be no professional repercussions for sharing our viewed with us, we also ensured that the information about the survey clearly stated that any responses would be confidential and that individual responses would not be shared. People were able to review all the survey questions before they completed the survey. The only mandatory questions were the following initial questions:

1. Job role
2. Team and district
3. Do you have responsibility as a Lead Care Professional for adults with SMI? Yes / No
4. How long have you been in your role with Norfolk and Suffolk Foundation Trust?

At the end of the survey, we gave people the option to leave their name and contact details if they were happy to be contacted for interview and their preferred method of contact.

Analysis

The recordings from the individual interviews and group discussions were transcribed and these were analysed to identify key themes of most importance to the interviewees. They were analysed using NVivo, a software programme that helps us to identify themes. Any comments used as direct quotes in this report have been left unchanged, to preserve authenticity.

The survey for Care Coordinators and Lead Professionals included a variety of question types, including open-ended, closed-ended and multiple-choice questions. We therefore used a range of analysis methods. The results and comments are reported on in the 'What we found out' section.

We exported the closed-ended or multiple-choice answers from SmartSurvey and analysed them in Excel. Percentages in this report are rounded to the nearest whole number.

Open-ended responses, where participants could write their own answers, were analysed using NVivo. The themes are explored further in the 'What we found out' section of this report.

Limitations

Through our desk-based research we found that although there is a lot of information available about carers and young carers, there is limited information about carers of adults with SMI. We also struggled to find relevant information about carers for whom English is a second language.

We recognise that the sample numbers of people we reached for this project are low, but we also know that the percentage of the local population who are carers of adults with SMI is small, and the number of such carers who have English as a second language is even smaller. We understand that there are approximately 9,000 adults with SMIs in Norfolk and Waveney, based on data from the SMI register in Norfolk & Waveney (NHS Norfolk and Waveney Integrated Care Board, 2024).

We spoke to professionals working locally with carers who have English as a second language to get their views. We would have preferred to have engaged with more than one VCSE organisation working with migrants and refugees, but two of the organisations we reached out to did not respond to our requests for help.

One of the difficulties when working with organisations that do not specialise in mental health, is consensus of understanding of the term, severe mental illness. We were clear about the illnesses that we were referring to, such as bipolar disorder etc, but found that sometimes we were provided information about or put in contact with carers of people who may not have had one of the mental health conditions we had specified. However, these organisations were reliant on information provided by the carers and may not necessarily have had direct contact with the adult with SMI. They may also not have any record relating to the person being cared for as this is not the primary focus of the organisation; this is particularly the case for the organisation supporting migrants and refugees.

We had a low response from carers who were aged 45 years or younger despite extensive efforts. This is reflected in the low response to the previous year's survey.

As mentioned above, we received 44 survey responses from those staff employed by Norfolk and Suffolk NHS Foundation Trust (NSFT) who are Care Coordinators or Lead Professionals working in the Community Mental Health Teams. We are unable to state what percentage of the staff body this represents. This is because being a Care Co-ordinator or a Lead Care Professional, is not a job role in itself, rather it is a responsibility that different categories of professional will take on as a percentage of their workload. This makes it very difficult to measure how many people do this work.

We recognise that our report is unlikely to reflect the views of all carers of adults with SMI in the groups we targeted, but we have aimed to provide a rich portrait of some of the issues highlighted by those we have been able to reach and our recommendations are based on their feedback.

What we found out

Young Carers

> A young carer means a person under 18 who provides or intends to provide care for another person.
> (The Children Act, 1989)

Data from the 2021 Census shows there were approximately 120,000 young unpaid carers aged between five and 17 years in England, which equates to 1.4% of 5- to 17-year-olds (Office for National Statistics, 2023). Young carers can undertake a wide variety of tasks, such as practical help with cooking and housework, emotional support, personal care and looking after siblings.

Findings show that over a quarter of young carers who are aged between 11 and 15 years regularly miss school and just under a quarter of young carers found that their ability to make friends had been stopped by their caring responsibilities. Various studies show that young carers are more likely than their peers to be bullied at school, with more than two-thirds of young carers being taunted about the physical or learning disabilities or mental health problems of their parents (Williams, 2010)

There is also an emotional impact, with one in three young carers reporting that being a carer makes them feel stress (Action for Children, 2025). An international study of young carers found that in the UK 28% of adolescent young carers said they had thought about self-harming because of their caring role (Carers Trust, 2022). Young carers also have poorer educational and employment outcomes than their peers (Hounsell, 2013).

Research shows that many young carers remain “hidden” or difficult to reach, but those young people who are caring for those with mental illness can be especially hard to reach (Phelps, 2020). Norfolk Children’s Services have schemes in place to help identify and support young carers, which include the national initiative “Young Carers in Schools” (Carers Trust and The Children's Society, 2025). This provides information about young carers, a ten-step guide to identifying and supporting young carers, resources and an award scheme.

The law in England includes the right for every young carer to have a needs assessment to work out what support they need. Young Carers' Assessments should be carried out if a child or parent asks for an assessment, or if a young person appears to need help. (Carers Trust, 2024). In Norfolk if a young carer or their parent wants an assessment completed, they have to go through Children's Services' Child Advice and Duty Service, (CADS) which can be problematic: "*That can be quite challenging because sometimes they have to go through CADS and the problem sometimes we have with CADS, we have to keep training CADS is that if they [the young person] don't reach a criteria [for safeguarding], they might not be [assessed] and it shouldn't relate to the criteria*". It can also be a barrier to those who feel anxious about contacting Children's Services. Project workers from young carers organisations told us that there is a backlog of assessments waiting to be completed.

Data suggests that just under a third of young carers who are known to young carers projects are likely to be caring for parents or family members with a mental health problem (Becker, 2003).

Norfolk and Suffolk Foundation Trust, supported by local carers organisations, organise an annual residential festival for those young carers who are carers for an adult with SMI and young carers who are at risk of mental health issues themselves. Approximately 100 young people were invited to the last residential, with just over 60 young people participating. It is not known how many of the young people are carers of adults with SMI. (Norfolk and Suffolk Foundation Trust, 2024).

Safeguarding young carers

When we considered the potential risks to young carers from bullying, self-harm and sometimes living in a difficult environment, we felt that it was important to understand how young carers are kept safe and what referral processes are in place.

The All-Party Parliamentary Group for Young Carers and Young Adult Carers (All-Party Parliamentary Group for Young Carers and Young Adult Carers, 2024) heard from carer organisations that very few referrals are received from adult social care or health professionals. They also heard evidence that over 90% of local authorities did not appear to have arrangements for joint working between children and adult’s services for young carers. We spoke to the Head of Business Delivery for Norfolk Safeguarding Children Partnership, who told us that *“there's the procedures between adults and children's (services) and also parental mental health is an area of focus for our neglect strategy”*. Senior representatives from Norfolk and Suffolk Foundation Trust (NSFT) sit on the Norfolk Safeguarding Children’s Partnership.

We wanted to understand what was in place for young carers if their parent was beginning to go into crisis. We spoke to the Strategic Commissioner – Local Services for Children and Families, from Norfolk County Council. She explained that all young carers who have been assessed should have an emergency plan, which identifies who they should contact and how to contact them when they need help. “*There is an emergency plan, as we call it, and that's instigated either by the school or by a social worker or by a young carers group worker*”.

We also wanted to know what policies and procedures NSFT have around young carers of adults with SMI. We were told that there are no specific policy documents specific to young carers at Trust level. The current Electronic Patient Record (EPR) also makes it difficult to readily identify young carers. Although their date of birth can be recorded, the EPR does not have an option in the ‘related persons’ tab for ‘young carer’, which makes their status less visible to professionals. This option cannot now be added, because the supplier of the EPR is no longer making edits at that level. We were told that this has already been noted as something that needs to be brought up in the design of the new EPR system, which is currently being procured and is due to come into operation in around two years’ time.

Health professionals are not always aware that a young person is in the household – they may be at school when the professional visits – but it is important that health professionals maintain a curiosity about young people in the household and the impact of the parent’s mental health on them.
The Head of NSCP Business Delivery for Norfolk Safeguarding Children Partnership told us about a Serious Case Review (SCR) in Norfolk of a young man whose parents both had severe mental illness. The young man and his siblings had all struggled with their own mental health and following the unexpected death of his mother (from natural causes) he had died by suicide whilst in a state of acute grief.

A review of national SCRs highlighted the extreme vulnerability of young carers of adults with SMI, including criminal exploitation and risk-taking behaviour. Serious Case Reviews are undertaken if a child has died or been seriously harmed, and abuse or neglect is suspected. The review aims to learn from the incident to improve future safeguarding practices. The Norfolk SCR identified that, in that case, social workers did not fully recognise the young person or his siblings as young carers or reflect on how this impacted on them. A referral to a young carers group had been offered to a younger sister, but the parent refused the support. It was also highlighted in the review that none of the services that were supporting the parent had referred any of the children for young carer's assessment or support. Other national SCRs highlighted that there had been no recognition that the young people were carers or consideration given to the impact of their parents' mental health on them. (National Case Review Repository, 2025).

The views of professionals

We spoke to nine members of staff from six different VCSE organisations that work with young people, including young carers. We asked them about the particular challenges faced by young carers of adults with SMI.

Our interviews with project workers also highlighted that some parents do not want to recognise or accept that they are being cared for:

> *"We've had in the past a mum who had physical and I would say, mental health needs, and she had two children; I think we had them both down as young carers. She had a constant battle with herself because she really didn't want to ask her children for help and didn't necessarily see them as young carers because she didn't want to think of them as doing things".*

Research shows that this is a particular barrier among young carers caring for someone with mental ill health (Becker, 2003).

The workers we spoke to told us that the young people themselves do not always recognise that their parent has support needs, they feel their experience is similar to other children and young people "*I think sometimes some of the young carers don't necessarily recognise that they deal with mental health, that their parents actually struggle quite seriously with their mental health*". A report by the Carers Trust and the National Centre for Research (Carers Trust and National Centre for Research [NatCen], 2019) found that young carers under the age of 11 years who have grown up with caring responsibilities often perceive that what they are doing is normal. It is only as they reach secondary school age, when most young people are beginning to become independent from their parents, that they begin to perceive the differences between themselves and their peers.

Project workers talked to us about the anxiety that young carers of an adult with SMI struggle with if they go out and leave their parent at home “*there is definitely separation anxiety there. So, for that young person going away and leaving that adult is frightening, they’re not sure what's going to happen”.* Whilst this is true of most young carers, anxiety for those who have a parent with SMI is often greater due to the unpredictability of mental illness and the concern about serious outcomes, such as self-harm or hospitalisation when the child is absent (Becker, 2003). This anxiety can lead to problems with school attendance:

“we've definitely seen young carers who have sort of refused to go to school in the morning and have had meltdowns and things, and at the heart of that is that they're worried about leaving, they don't want to leave that parent”.

We also heard that young carers are at risk of exclusion or dropping out from school, particularly once they get to secondary school age and if they have a history of poor attendance. Young carers also struggle if they do not feel their situation is understood or supported by the school:

“I have seen that if schools say they will support them [the young carer] but don’t follow through, it can mean that they don’t finish their education - they ‘re either taken out [excluded] or vote with their feet”

Project workers also identified that the parent can also be anxious about being separated from their child and stop them from attending activities “*the parent with the mental health challenges, not letting young people leave them, taking the young person away from a session due to separation anxiety, stopping the young person attending at last minute”.*

Project workers also talked about the difficulties and frustrations around obtaining parental consent and support for the young carers to attend activities or access services. “*But when there's when there's a mental illness and they've still got parental responsibility, that's really hard. The kind of home visit, the repeated phone calls, the ‘I've sent you this information four times now’”.* If a parent is struggling to keep on top of things, this can mean that the young people miss out on services or support. One worker told us that if a parent is facing escalating mental health issues, then “*everything becomes dysfunctional*”. Another project worker told us that some of their young carers are not officially recognised because the registration process was too much for the parent to complete and their schools may not be aware of the young carer’s family situation.

Stigma is also an issue for families with a mental health condition as they tend to fear judgement from others to a greater extent when compared to those with physical disabilities (Becker, 2003). Fear of engagement with Children’s Services is also a barrier to support. We heard of a number of occasions where parents had previous involvement with Children's Services, which meant they were reluctant for their children to be registered as young carers as they were concerned that their children would be removed. One project worker expressed concern about those young carers who have not had an assessment or been recognised as a young carer because they do not want to talk about their home situation:

> *“It's the unidentified [young people] that I would really worry about and particularly in the mental health scenario because actually a lot of that is not admitted to. Nobody wants to go in and go ‘my mum's got deep depression and my house is full of rubbish and all of that’. Nobody wants to say that at school.”*

The views of young carers

> I'm a young carer for my mum. She has anxiety, depression, schizophrenia, agoraphobia; a lot of things.

We spoke to two groups of young carers. One group was five young people aged between nine and eleven years old and the other group was four young people aged between 15 and 16 years old. They told us that their parents had a range of mental illnesses and physical disabilities. All the young people were caring for parents with an SMI, which included bipolar disorder, schizophrenia, personality disorder, and two of the young people also had older siblings who had SMI. “*I* *care for my mum and my sister, and my mum's got bipolar and personality disorder and my sister's got bipolar"* and *"I care for my dad, my mum and my sister".*

The younger group of young carers focussed on the physical disabilities of their parents, but did not talk about their mental illness. The project staff confirmed that the parents had mental health issues including depression and trauma, however it is unclear whether these would fall into the category of severe mental illness. We have included the contributions of the younger group as their experiences were similar to those in the older group.

We asked the young people what being a carer for their parent looked like. They told us that they had taken on the parenting role "*Sometimes it's like you act the parent, that's my mum, but I'm parenting her"* and *"You have to reassure them it's going to be okay".*

> You can't just think for yourself. You've got to think for them as well, but they're meant to be the parent. So it's like in a way you've just got to think for them

But the young people also told us that this doesn't mean that they have control and can find it frustrating when their parent makes a decision that they don't agree with. This was confirmed by the project worker "*I've known that when mum wants to parent, someone can get stroppy sometimes".* It can be frustrating for the young carers to have so much responsibility but not have any power.

We asked the young people what sort of things they do for their parent as their carer. Most of the young people we spoke to, talked about the physical tasks they undertook. "*I have to go make food and drinks*" and "*I help her cook or something, or I clean my room. Wash up".* Responsibilities increased as the young people got older: "*I'm nearly in high school, so there's lots of things I can do now".*

Sometimes when they have a bad day, you've got to help them and either help them by doing what they need to get done or try to make sure they can do it themselves or something.

The young people also told us about how their parents used technology *"she knows that if I go downstairs, we have an 'Alexa' so she can call me through it and say I want to a cup of tea, make me one".*

We asked the young people if there was anyone that helped them. They talked about project workers from the young carers group and social workers "*I have somebody who used to come to my school*" and "*my social worker still comes*". Friends also played an important role "*my mates. They just make me have a laugh*" and "*I like it when my friends go round or when I come around theirs, it just feels a little bit more calm*". One young person told us that they had support from someone coming into school to help them manage their emotions "*I did have someone that helped me…a girl…who would help me with my stress because I used to get very mad for no reason".*

The young people did not have many experiences of people who visited their parent at home checking that the young person was okay "*I think sometimes when they used to come, they'd sometimes ask*". One young person told us about the support her parent had received "*every now and again, my mum goes to this person that sits her down and talk through what's gone throughout these months and calm her down".*

The other parent can be a support for the young person: "*I suppose my dad, he's quite helpful*" but sometimes there is a lack of understanding from the other parent "*He sees it as an easy option. My mum goes, if she goes to the mental hospital, well she's just getting away from doing this working or he doesn't see it as that she's actually in pain*" and:

"..my dad, he's helped a lot because he sees a lot, but he doesn't have the best understanding of mental health. He just thinks it's an excuse to be naughty or horrible. So, it's more like I'm trying to explain to him, 'no, it's not like that, you can't help it' but he doesn't see it. But he is always there for me"

The young people told us about some of the difficulties of living with an adult with serious mental illness: “*I just have to be really careful with what I say as well because a lot of the times they always get triggered*”. They also talked about the things that worried them. “*[My worry is] just that she gets really suicidal. The amount of attempts she has had, it's just always in the back of my mind. I know she's doing better now, but it's just always in the back of my mind. You never know what's going on in someone's head*”.

> Sometimes you feel like you're walking on eggshells because you, sometimes you can do the littlest thing and they'll just flip at nothing and just start going mad. It's like I knocked a drink over and they're going nuts. It's just like ‘what?’ sometimes. But then you just think they can't help it. It just is what it is.

They also told us about the times when their parent was stressed or angry. “*He gets really cross about things that perhaps aren't that big a deal,*” and “*Sometimes people fight, sometimes they put it on other people. Sometimes he puts it on me because I accidentally dropped a pillow and he rushed to pick it up and said, go to your room*”. The young people have learned to recognise the signs when their parent is starting to get angry. “*She goes outside for a fag,*” and “*I know my mom, I can tell because she gives me, she looks down and then just stares at me until I go and I'm like, yep, I know. And then my dad, he just close his eyes for very long and just stares at me and then he gets red and then I'm like, yep, time to leave*”.

> Normally she says if I'm in the kitchen, I'm annoying her. She just says, ‘can you go away please?’ Or she'll start going like this [shows a particular gesture]. And that's how I know…

Some young people talked about upsetting experiences when their parent had been horrible to them “*Sometimes when my mom gets stressed, she sometimes calls me names*”. The young people tried to make allowances “*Sometimes they might say things they don't mean and you have to be able to be like, right, this is not them talking, this is this someone else. I need to not take that personally*”.

> Sometimes my mum's having a moment, she'll say nasty things to me. And the struggle is, you have to remember this isn't them talking. This isn't her, this is a different person.

One young person told us that the times when they were told off were reasonable “*we get told off by doing something naughty. But not getting told off for no reason*”.

Some young people were unable to continue living with their parent “*It got really bad and she got moved into a mental health facility and she's sort of been in and out for the past few years, so couldn't really live her anymore”.*

When we spoke with the young people, we asked them if they had an emergency plan. One young person told us about a time when her parent was sectioned after the young carer’s adult sister contacted the mental health team with concerns about their parent. We asked her if she was worried about her parent, would she know what to do. She told us:

> *“I wouldn't even know who to go to in the first place. And I think if I was to go to someone and say something to someone, I don't think they'd act on it the way they did to my older sister. I think just because we're younger, we don't really understand, but sometimes you understand more than people that are older than us”.*

One young person told us about her experiences of being worried about her parent, but not getting assistance from her school to support her parent or manage her own anxiety about what was happening:

“I don't go to that school anymore, but when I was there, there'd be days where I'm like, what if something is happening to mum? Because I know she had a bad recent day, like the day before or the day before that. And then she'd like, I know that she's probably going to have a bad day that day. And I'd be like, ‘miss [to the teacher], can I call my mom please?’ Sometimes they would tell me, ‘no, you can't’. And I would just like, sorry. And I would just start going off saying like, ‘oh miss, please let me call my mum because if something’s happened to her and I don't know, I'm going to have, I don't even know. I'm just going to rage’. But no-one would listen until I got home and told my mum.

I also told [the project worker] and they and my mum had all that sorted it. Then they would let me call my mum at break and lunch, every so often. It was supposed to be every day, but every time I asked, they'd be like ‘no, you can't do this’ and then they'd say ‘come back at the end of lunch’. Then when I'd go back to them at the end of lunch, they'd be like ‘you should have come to me at lunch. I was in my office this whole time around that’. But if things happened at home, I would call my dad and he would listen, and he would sort it and speak to the people that needed to be spoken to.”

This young woman was no longer in mainstream education as she had been excluded from her school following an altercation with a teacher. Another young person had been excluded after taking retaliatory action against another pupil following months of bullying. Although the bullying had been flagged up to the school by the young carers project, the school had not dealt with it but focussed on the young person’s attendance issues.

One young person told us that because her parents were concerned about professionals there was no-one she could contact *“I don't really tell anyone… my parents, I think they just kind of sort it out themselves. Obviously, they don't like having people knowing our business as well”*. She had a previous bad experience, which made her very reluctant to talk to anyone outside the family: “*I kind of said some stuff before to some people at school and social services ended up coming, which it was not really helpful. So, I just don't like talking to people*”. Another young person told us that her parent did not have any support from external services “*My mum has trauma or something from past things, so she won't let people in*”.

Another young person told us that she had to stop living with her mum and move in with her dad, but she was not involved in the decision about this. “*They* *[social services] spoke to my dad and various other people around me and they made the decision that I would live with him".*

The young people who talked to us told us that they were not given any explanation about why things were happening *"I didn't really understand why I was getting taken away from her. That was her norm to me. That was who she normally is. So, it was weird. But I guess after a while I just learned that they made that decision because they thought that was best"*.

They also told us that it would have been helpful to have received information about their parents' mental illness *"No one ever told me what these things were that she had. I just learned from seeing her"* and *"I guess she's always kind of from when I was born, she's had various mental illnesses before that. Obviously when it got worse, I saw it happen, but I didn't know what it was, so it was hard to report it."*

The young people were empathetic toward their parents and wanted to improve things for them. *"Honestly, all you want to do is make them feel better. I suppose you should bring them back to normal, but you can't, obviously"*.

> I just think it's quite hard to be around someone all the time and to watch them suffer, not being able to help them because after seeing it for such a long time, you sort of start to understand the way they feel, but you still don't understand how you can help them...

We asked some of the young people what their biggest worry was. A couple of the young people talked about their fears around dying. *"Probably my family dies"* and *"Probably just dying. Also, my mom's trying to find love, but either somebody keeps on leaving or somebody last time cheated on her"*. One young carer felt unable to express her worries *"I can't say because it's too big. Too scary. Private. It's private family problems"*.

Learning from the focus groups

The staff who supported us in meeting the children and young people and were present during the focus group, fed back to us that it had been a valuable experience for them, as they had become more aware of some of the issues those young carers were experiencing. They said that they would think about how they could provide similar opportunities in the future because they felt there were benefits for the young people. A few months after the focus group one of the staff informed us that as a result of the group, two of the young people have since developed a more supportive friendship - they were previously unaware of the similarity of their circumstances.

Younger Carers

> There's so many factors that I don't think people truly take into consideration if someone's on the ward and they live in Ipswich and they're placed in Bury and they're [the carer] constantly back and forward. They're trying to fit in part time work gets kids to school, go and do mum’s shopping, collect meds.
>
> NSFT staff member

There is little information available about the experience of those carers who are under the age of 45 years and caring for someone with a mental illness. However, we were able to find some information that related to younger carers. Carers who have dependent children and care for an adult relative, can be described as ‘sandwich carers’. Whilst this does not specifically relate to those caring for an adult with SMI, the challenges for these carers are still relevant.

The key issue for these carers is the impact on their ability to work. The Carers Trust found that 45% of those younger carers 18-25 year-olds who work, say that they always or usually struggle to balance caring with paid work (Carers Trust, 2023).

A report published by the Office for National Statistics looked at the data relating to sandwich carers (Public Policy and Social Insights Team, 2024) who were aged between 16 years and 64 years of age. Just under half (49%) were aged under 45 years. The main findings for all the carers were that just over half (53%) were unable to work as much as they would like, or were unable to work at all, due to their caring responsibilities. This percentage increased for those who were caring for over 20 hours per week.

Sandwich carers are also more likely to have struggled financially (16%) and have run out of food in the last twelve months (8%) compared to the general adult population who struggle financially (9%) and run out of food (5%). For those who are caring for over 20 hours per week this increases to 25% who struggle financially and 17% who have run out of food in the last twelve months (Public Policy and Social Insights Team, 2024).

They are also at greater risk of depression and anxiety (31%) (GHQ-12 score of 4 or more) compared with all adults (24%), with almost a fifth (19%) of carers reporting that they were currently diagnosed with depression.

A study in the UK compared a group of approximately 2,000 carers with an average age of 37 years, who looked after children and older people with similar aged people living with a child under the age of 16 years, but not caring for children. The researchers found that the mental health of the sandwich carers, who were typically aged between 30 and 49 years old, had poorer mental health than their counterparts (Peel, January). The impact was greater on those who provided more than 20 hours care a week, negatively affecting both their mental and physical health.

The views of younger carers

We were able to interview four younger carers who told us about their experience of caring for an adult with SMI. The main themes from those we spoke to were the impact on the carer's ability to work – two of those we spoke to were unable to work due to their caring responsibilities and the other two talked about the pressure of trying to maintain employment when trying to support someone with an SMI, especially when they are depending attention. "*I have to say, look, I'm at work today. I'm not going to be able to talk. So, drop me a text if you've got a problem. That way I can read it and if I think I need to reply urgently then I can step away. She sent me loads of texts, not saying what had happened, but saying I needed to talk to her there and then*".

One carer told us that when their wife, who has bipolar disorder and underlying schizophrenia, is struggling, she has night-time agitation, which means the carer is up until 4am and then has to get up again to go to work. Others have taken time off with stress "*I ended up being off with my mental health for quite a long time because of the impact that has*".

Those that are not working find it difficult to manage financially, which also creates pressure for them: *"I'm not sleeping very well. Financially, it's not brilliant being on sick leave".*

The carers also talked about trying to manage the adult the care for and to be aware of when things are deteriorating *"I can see when things are coming, she starts to hear things or see things. Her eyes change"*. This need for vigilance takes its toll on the carer and all the carers talked about the need to express their own frustrations and anxieties, but this needed to be to someone who would not be judgemental and understood severe mental illness. One carer had a mixed response when she attended her local Rest Hub for support. Initially it was helpful, but the person that was there did not understand bipolar disorder and in the end their responses became unhelpful *"they kept telling me that I should leave my wife".*

Some of the carers expressed frustration that staff from the mental health services did not communicate with them. *"I've complained because they really only speak to my partner and there should be a triangle of care. I've mentioned this a few times and I'm still in the dark,"* and *"Well, they definitely don't work with the family".*

All the carers talked about the need for additional support for them. *"I need someone to go to when things are bad"* and *"I'm on the waiting list to get support from the talking therapies or whatever they're called"*.

Case Study - Lionel and Betty

Lionel is a carer for his partner, Betty, who had postpartum psychosis following the birth of their son. They are both in their thirties. Over the following years Betty has continued to have relapses. During a relapse Betty can become violent and unpredictable.

Lionel and Betty have one dependent child, who Lionel is also looking after *"We try our utmost best to look after, look after our child. It's tricky though".*

Betty's last relapse was in Autumn 2023 and since then, she has been waiting for a Care Coordinator to be allocated to her *"We've been waiting for over a year for a Care Coordinator and no one seems to be taking much responsibility at [the Community Mental Health Team] for my partner's care. And she's a bit stuck, we find them a bit useless, to be honest"*.

Lionel is frustrated by the slow progress in appointing a Care Coordinator and has tried numerous avenues to get Betty the help she needs. *"Before this started, I was a shy person. I was stuck in the corner. Now it's become nature to air my views now, because you don't get anywhere otherwise."*

He is especially frustrated as it was his understanding that Betty would receive urgent support, but this has not been the reality *"she got discharged from the Priory on the assumption that she'd get an assessment from the Crisis Team and Community Mental Health Team within 48 hours or 72 hours after being discharged. The Crisis Team came out 48 hours after she got discharged. He said that you'll be under [the Community Mental Health Team] … He said two weeks max… he said before Christmas 2023. [They] didn't turn up until two months late; and then she was an hour late. She [the mental health worker] was an hour late. She didn't have all the information. Half her information was incorrect."*

Lionel has been told that until Betty has a Care Coordinator, she can't receive any therapy, including access to a consultant, despite the fact that she has previously seen one. *"I got told that you're not allowed to have a consultant appointment until you get a care coordinator. I said, 'well that's funny because we've already had one'"*.

Lionel had contacted the mental health team to explain his frustration and compared Betty's wait for support to his experience of an NHS waiting list *"Christmas 23, she was on the urgent waiting list for a Care Coordinator. I said, 'we're now 12 months later." And I said, 'I've been on the urgent waiting referral waiting list at Norfolk and Norwich [University Hospital] for an ENT [ear, nose and throat] appointment. I said, I've been referred, been on the waiting list and seen the consultant in the time it's managed for Betty to get nowhere'. I said, 'how urgent is this waiting list?"*

He has had support from the Mental Health Practitioner at his GP surgery and has had Cognitive Behavioural Therapy (CBT), but he feels that until Betty gets the support she needs that he is going to struggle *"I'm constantly living in that fear and anxiety of when he's going to happen again, what's going to happen?"*

This has had a negative impact on Lionel, who is currently signed off sick from his job with anxiety *"I told my work, my employer that last year, I said, looking after a small one, looking after someone who's got a mental health problem and doing full-time work is unsustainable long term."*

Lionel feels at the point of despair as none of his efforts to get the support for Betty have achieved anything. “*It's just got to me, how many more years are we going to be like this?”*

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

Case study - Penelope

Penelope is carer for her husband Ernest. They also have dependent children. Ernest has paranoid schizophrenia - he was already diagnosed and receiving treatment when they first met. Ernest is as well as he can be, but his mental illness does impact on their lives “*Day-to-day life is allowing him to have his weird quirky routines that get him through knowing when to take the pressure off, when to come home, when to not ask of any jobs of him to do just when to have some quiet time. Sometimes it's being mindful what you say to not trigger off any paranoia”*. Penelope’s support for Ernest is emotional and practical “*Just being there for him, talking to him, allowing him to release, encourage him to look after himself. Hygiene wise, shaving wise. Just trying to get him out of the house, getting him to engage with his own family, which he doesn't always want to do”*.

When Ernest is struggling, he becomes more inward focussed and struggles to engage with others. Penelope describes his behaviour “*he is just laying down, trying to sleep, trying to get away from everybody, not engaging in any conversation with you; maybe just totally disengaged from everyone, getting more frustrated with the children and whatever they're doing. He's quite inward with it, if you know what I mean, rather than showing everyone. So, he just wants to curl up in a ball and hide*”.

Ernest no longer receives support from the Community Mental Health Team, but attends the clozapine clinic for his medication “*He lost his care coordinator last year. I think they were cutting back and he had me, so I think they thought ‘well, don't worry about that then’.*” Penelope tried to argue for continued support, but this was rejected.

Ernest has used the Rest Hub, but the service there is only for those in crisis, and Penelope feels that the opportunity for Ernest to meet up with someone and talk about the things that are worrying him would help him, but would also help her *"If he had somebody to talk to once a month, someone to off-load to, because he actually feels much better afterwards and it takes the pressure off of me"*.

Penelope has found that although family and friends try to be supportive and well-meaning, they do not fully appreciate the balancing act of trying to support someone with an SMI *"they say, can't you just push him a bit more? It's like you don't understand, if I push him, he's going to go into psychosis and then not able to do anything then. It is finding that balance"*.

She feels that her opportunities to be able to express her own frustrations are limited *"even if I see my mum or my friends, even if I vent, they won't understand and I think they'll look at Ernest in a poor light"* and feels that if she expresses some of her frustrations that people will only see the negatives *"I worry about, that people think that I shouldn't be with him because it's hard. Well, it is hard, but it doesn't mean I don't love him and it doesn't mean we don't have good times. It's just extra things to think about"*. Penelope is now linked with a Carers Support group, which has helped.

Neither Penelope or Ernest are in employment and are therefore dependent on benefits, including Carers Allowance, which means their income is limited. This is difficult for Penelope. *"I don't know how to better my family. We are where we are. I see all my friends around me getting better jobs or buying houses."* The staff at the Clozapine clinic have been helpful and provided food vouchers when things have been difficult. *"We really like the Clozapine clinic staff…they're really helpful. If Ernest says, can I talk to anybody? We'd always find that they say 'Yes, give me five minutes' and take him to a little side room. They've helped us out with food bank vouchers and they're actually the first people we think to call because we know them. Whereas if we call up the general line, you just speak to any random person that you don't know of"*.

One of the things that Penelope had found frustrating about mental health services was that Ernest's access to therapy was cancelled after he missed two sessions *"Ernest did have some therapy, I can't remember what it was, but he missed two sessions because he didn't feel up to going because of his own mental health. And then that was it. He was knocked off the books because he didn't go. And it's like, do you not realise that people with mental health [illness], you are seeing for therapy, they can't always face it? So that just seemed a bit ridiculous for someone who's struggling to knock 'em off [stop their therapy].*

One of the things that Penelope feels would be really helpful would be someone to support Ernest in spending time with the children *"I'd like it if there could be someone who could come with Ernest to the park one day with the children and just give him that support, he worries about it all the time and he won't go to the park with the children on his own, not even one of them. Whereas if he just had someone who could support him to do that, build his confidence, that's not always me".*

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

One younger carer we spoke to is a carer for her parent, who has a borderline personality disorder *"She has had eating disorders in the past, she has what's called borderline personality disorder, depression, anxiety. She self-harms pretty much constantly. She she's overdosed regularly"*. This carer was also a young carer, and despite leaving home at a young age, she has continued to provide care for her parent.

For her, caring is a huge burden that has severely impacted on her life. *"I don't know how people cope if they have to live with the person they care for sometimes because I'd had enough of it, you know, to be fair, growing up with it. But yeah, it's just, it's horrible, honestly"*.

She tries hard to put in boundaries to protect herself from her parent's constant demands but feels guilty about how her parent makes her feel *"If you saw me when I was with my mum, you would probably not recognise me because I don't think I'm a nice person. But I can't help it because when it's just got into my headspace for so long that you just kind of start to lose your patience, you know?"*.

Carers with English as a second language

According to the 2021 Census there are approximately 4.7 million unpaid carers in England (Office for National Statistics, 2023). The census identified that the most common ethnic group of unpaid carers in England (78.3%) was 'White: English, Welsh, Scottish, Northern Irish or British'.

In Norfolk, there is estimated to be just over 81,500 unpaid adult carers who look after a family member or friend (Caring Together, 2023).

Norfolk has a much less ethnically diverse population than England as a whole. Norfolk's population is an estimated 931,900, with a predominantly white (aggregated ethnic group) population of 94.7%, compared with 81.0% for England. The proportion of people from all other ethnic groups combined is 5.3%, compared with 19.0% for England (Norfolk County Council, 2020).

English is the main language for 95% of Norfolk residents. Those people who do not have English as their main language, 1% do not speak English very well or are unable to speak English. Polish, Lithuanian and Portuguese are the most widely spoken other main languages (Norfolk County Council, 2020)

Carers Trust and NatCen (Carers Trust and National Centre for Research [NatCen], 2019) report that service providers found it more difficult to support families who did not speak fluent English (for example, those with an additional language or where parents were deaf or hearing impaired).

Research undertaken by Carers UK indicates that Black, Asian and Minority Ethnic (BAME) carers are less likely to receive practical and financial support for their caring role and more likely to have a longer period of time where they are unable to access support, usually because of a lack of advice and information and difficulty accessing culturally appropriate services (Carers UK, 2019).

Research shows that people from ethnic minority groups in the UK have poorer mental health and their access to mental healthcare is poorer, with more negative experiences and outcomes compared to those who are white British. Findings show that assessment and treatment of mental illness for those in ethnic minority groups are a major barrier to care that is appropriate and person-centred, as it is felt that these do not recognise the everyday experience of people's lives, which include racism, complex trauma and spirituality and how these impact (both negatively and positively) on people's mental illness (N Bansal, 2022).

One study involving carers, patients and clinicians in the UK identified that differing cultural understandings of mental illness can lead to misinterpretation between carers and healthcare providers. For instance, certain behaviours or symptoms might be interpreted differently across cultures, potentially leading to misdiagnosis or inappropriate care strategies (Giacco D, 2017)

Carers UK recommend that good practice should consist of the provision of information and advice, culturally sensitive services, creating a workplace that is diverse and inclusive and the involvement of Black, Asian and minority ethnic carers in policy and practice (Carers UK, 2023).

The views of professionals

When we spoke to the Project Lead from the Hanseatic Union about carers who have English as a second language. She told us that in her experience carers with English as a second language have a low awareness of benefits and services that might be available to them and their eligibility for these.

She told us about the specific issues presented by the language barrier, from different definitions of some terms, including the term 'carer'. She also explained that as people grew older, they often lost their confidence in speaking a second language and therefore need more support and understanding if they are struggling to communicate. She is also aware of instances when people have faced prejudice from services because English is their second language.

Face-to-face communication is easier than conversations conducted over the telephone, as talking on the phone can make it harder to understand what the person is saying. It also helps if people can refer to a leaflet or something written so they can look at the information later. People also rely on their children to translate paperwork or make phone calls on their behalf, which is not always appropriate. Family and friends are a source of support and help, but they are not always available when needed.

We asked the Project Lead what changes would be useful for carers, she told us that the Carers Allowance is too low and should be equal to the minimum wage. She feels that it is important that there should be more in-person support to apply for benefits and support staff who are bilingual need to have a clearer understanding of the benefits system, so that they can better advise carers. She also said that more translated materials should be available, but that it is important to check with people whose first language it is translated into that the meaning is right. Lastly, she felt that there should be more translated information about benefits and support available in public spaces, such as libraries, GP surgeries and religious centres.

We discussed the most appropriate way to get the views of those carers who have English as a second language. The Project Lead stressed the importance of interviews being undertaken by someone who both understands the language and the cultural norms of the interviewee. She explained that many of those who may be in a caring role would not recognise the term 'carer' or see themselves as a carer, and that there may be a difference in understanding of terminology. These barriers are recognised nationally (James, 2019).

She also identified that for some cultures there is a stigma around mental illness and the interviewer would need to be sensitive to this. "*It is a difficult subject for our client group as they find it impossible to talk about or accept a mental health issue due to their cultural beliefs*". This stigma can also mean that people from some communities may feel stigma and shame about seeking support (Mental Health Foundation, 2024).

We therefore agreed that it was most appropriate for the Hanseatic Union to undertake the interviews on our behalf, using their own staff to undertake the interviews and provide us with case studies.

The Project Lead at the Hanseatic Union told us about an experience they had trying to get help for a young man in mental distress:

Professional's experience

In our local Lithuanian community, we became aware of a young man, in his mid-20's who had previously been doing well – he was living independently and in employment. For a few weeks he had been seen just standing still in the town centre – for what seemed like a few hours at a time. I asked my team to see what they could find out about him.

The Lithuanian community said he was a lad who had become ill and was now living on a bench. They were leaving food for him. We sent a Lithuanian staff member to talk to him when he was standing still – but he became frightened. We spoke to a homeless organisation and asked what they knew about him. They knew he was homeless but because he didn't respond when they spoke to him, they thought he didn't understand.

He was doubly incontinent and still just stood still for hours at a time. We contacted local GP surgeries once we had learned his name (again from the Lithuanian community). Even though he was registered with one they refused to come out to him – and only suggested that we took him to Accident and Emergency (A&E). However, he wouldn't get in a car. He would barely respond and continued just standing still.

We rang a whole range of organisations, including Adult Social Services. No-one would help for various reasons, we didn't have five pieces of information about him or he wouldn't go to them for help. We tried Community Nurses, we tried just asking around for anyone medical who would just come and see him with us.

When we went and offered him food and tried to talk – we could smell something was infected – so we thought we could maybe use this to get him help, as we could get nowhere asking for help with his mental health. We tried all the same places again – still no one would help – even though we said it was probably infected and going septic. There were stains on the front of his trousers so we thought it might be his leg.

Through the Lithuanian community we managed to find his brother – who was abroad and talk to him. He begged us to try to help him – he said he would come and get him but we knew he couldn't get on a plane.

One day we just decided that if we didn't do something extreme, he would most likely die of the infection. At 9am we rang for an ambulance stating that he had an infection in his leg and waited with him by his bench in a local park. It took six hours for the ambulance to agree to come – and when they arrived, we said he had mental health issues and they refused to see him. We then said he had an infected leg – and they looked, saw it was infected and tried to get him into an ambulance. He was still doubly incontinent, not moving or talking. He was taken to A&E for treatment.

We did what we could to keep in touch and after about ten days he was moved to a mental health ward – he was there for approximately five months and then released into supported accommodation.

He came into get advice about universal credit the other week – and he was back to his old self – looking good, talking and texting his brother daily. His medication had worked and lifted whatever blackness he was living in.

It should not be this hard to get such an ill person the help they needed.

The views of people with English as a second language

The staff at Hanseatic Union interviewed three people who had caring responsibilities for someone with mental ill health. As identified in the limitations section of this report it is difficult to know whether these difficulties would be recognised as serious mental illness, but their experiences reflect some of the challenges faced by carers who do not have English as their first language, and who look after people with severely debilitating mental illnesses.

Case Study - Misha

Misha is a 62 year old woman. She cares for her friend, Katia, who is 63 years old. Katia has no relatives in the UK and Misha is her only source of support. Misha did not identify the exact nature of Katia's mental illness, but her biggest challenges were supporting Katia with her physical needs *"I take care of Katia, and it's really difficult for me. She is very capricious and refuses to do anything to improve her emotional and physical condition. I have no personal time and cannot get away from her anywhere. I started helping her because I felt sorry for her when I saw the state of her house and her condition. Now she is in a wheelchair, but she could walk if she wanted to. However, she does nothing because she is in pain. We argue often because I try to do what's best for her, but she refuses to accept it".*

Misha has received help from her GP with her caring role and has been given leaflets and the GP has made referrals for additional help for Katia. Katia has had some input from the NHS for her mobility issues and equipment *"They have provided us with helpful equipment, such as a pill organiser (as my friend takes around 30 pills a day), a special table for eating, and a special bed".* Social Services has had limited contact. *"Unfortunately, they have visited our house only once".*

Misha does not feel that she has support in her role as a carer from health services *"I don't really feel supported. They only pretend to want to help".* Her experience of support from social services has been mixed. *"Social services try to listen, but they don't do what they promised. In 2017, we asked social services for help. They suggested that we return to our home country and even offered us £1,000 for this. In the end, we didn't receive any support from them at all".*

The NHS have been good at providing interpreters for Misha and Katia, but Misha feels that they have not provided the support needed *"It is easy to talk to them because they always provide an interpreter. However, they still don't follow through on their promises. I don't feel that the people from health services truly know how to help with the problem I come for. They listen and sometimes offer general advice or provide basic support, but they don't fully understand the complexity of the situation. Even when they make promises, they often don't* *follow through. I don't feel like they have a real solution or a clear plan to address the challenges we are facing".* When asked what was good about social services' support, Misha was unable to think of anything "*There is nothing for me to say, unfortunately*".

Misha was asked what changes should be made to support those in a caring role for people with mental health problems. "*If I could change something about caring for people with mental health problems overall, I would focus on ensuring that the support provided is consistent and reliable. Health services should follow through on their promises and offer real, long-term solutions, not just temporary or vague help. I would also make sure there are more trained caregivers available to provide daily support, especially for people who need assistance with mobility or daily tasks. Emergency response systems should be more efficient so that individuals don't have to wait for hours for help, as I often have to do when calling the SOS line or ambulance*".
Names and identifying details have been changed to protect the individual's anonymity.

The above and following case study show how meeting the physical needs of the individual can be more of a challenge than responding to their mental health issues.

Case Study - Lena

Lena is a carer for her mother who is 76 years old. Her mother has depression and has been suicidal. She has a physical disability and dementia.

One of the challenges that Lena has is around managing appointments, especially if they conflict with her work. "*Due to my mum's illness, she can't come for an appointment by herself. Also, it's not easy to get an appointment on the day when I do not work. Usually, I get a notification about an appointment at the last minute. I had to postpone appointments because of my work*".

Lena and her mother also have housing difficulties: "*the apartment has become unsafe due to the mum's condition. I applied for the housing register and had to wait over 4 months and there weren't any available houses to vote for. I had to abandon the idea because the wait was too long*".

Lena identified the support she has had in caring for her mother, including with her mental health issues. She feels that the services are responsive to her requests for help. Her main sources of support are the GP (who "*provides leaflets* *and makes referrals for my mum")*, the stroke team, social services (who "*explained how to apply for safe housing*"), the VCSE sector, including the Hanseatic Union who assisted with applying for social housing.

Lena feels that she is listened to and that the health services are helpful and respond quickly to her requests for help. "*They help and are sympathetic,*" however she feels that she needs more support, so that she can continue to work. "*They expect me to take care of my mum and not go to work. They only offered help for one hour a day, which is not enough, as I usually work 12-hour night shifts".*

Lena talked about receiving good support with her mother's mental health "*My mother wanted to commit suicide. She is suffering from depression due to the situation in Ukraine and because she sees how difficult it is for me to take care of her. I contacted the GP immediately, and they made a referral to the Older People West team. They came to our home, spoke with my mother, and now visit regularly to provide support. Since their involvement, things have become a little easier".*

Her biggest frustration is support around her mother's physical disabilities, particularly in relation to appropriate housing "*There should be more social adapted housing available for people with disabilities. Currently, we live in a two-bedroom apartment with my mum and 8-year-old son. My mum has to sleep in the living room. It has taken us a year to get a shower installed instead of a bathtub and we are still waiting. Housing associations should reconsider their timelines for people with disabilities".* She would also like support that would enable her to work "*It would be great if social services could provide us with a caregiver who could look after my mother while I am at work".*

Lena talked about how things could be improved: "*we have to wait too long for appointments, and we have had to attend many. It would be great if we could get appointments more quickly, especially in emergency situations*".

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

One carer talked about the isolation and struggle of being the sole carer of someone with mental health issues and how her mother's lack of English means that support services continue to rely on her as a carer, even when she has her own health issues.

Case study - Renata

Renata is a carer for her mother, who has mental health issues, which is compounded by dementia. Renata has health issues herself. Renata talked about the challenge she has in finding appropriate support for her mother "*It is extremely difficult to get timely support. Finding the right person to contact is a struggle, as social services often prioritise caregivers rather than the individuals in need. My mother has severe mental health issues, but she has yet to receive a proper diagnosis. She has dementia, but when we had an appointment with a nurse, they only asked her simple questions. Since my mother could answer them, they concluded she had no mental health problems. A proper diagnosis should involve more thorough assessments. Instead, we were offered a phone appointment to diagnose dementia, which is completely inadequate*".

Renata doesn't feel listened to "*My mother cannot stay alone, yet after describing all her difficulties, we were only given an appointment a month later for some checks. At that appointment, they only offered a blood test. We are still waiting for a diagnosis, and she still cannot access proper support".*

She has also been frustrated that she has not been given full information about services "*Social services suggested a club for my mother, and she attended for a while, but later, I received an unexpected bill for £1,500. Nobody informed us that this service was not free*".

The support from NHS services has not been helpful to Renata and she believes that her mother is not getting the care she needs "*Our GP only focuses on my mother's high blood pressure and ignores her real issues. Emergency help is also inaccessible—I once called an ambulance because I thought my mother had a stroke, but it never arrived. Ten hours later, a doctor called and told me to bring her in myself. However, I physically cannot lift her".*

Renata feels that services rely on her to intervene with her mother when her lack of English is a barrier *"When my mother was in a sheltered housing facility, I frequently received calls from the staff because they did not know how to care for her, particularly because she does not speak English*". She is also frustrated by the services that are provided. "*Social care workers do not prepare meals for my mother. If she refuses to take her medication, they immediately call me instead of handling the situation themselves*".

Renata’s mother’s health has deteriorated and she is now in hospital. This has created a challenge for Renata *“Currently, my mother is in the hospital. She cannot walk or stand. However, our appointment for a dementia diagnosis is scheduled for March 23rd, and the doctor insists I bring her in, or else the appointment will be postponed for months”*.

Renata’s own health issues have not resulted in any additional support and she has been left to struggle on her own. *“On top of all this, I was diagnosed with cancer and had surgery. Afterwards, I contacted social services for help, but I did not receive proper support. I had to care for my mother immediately after my surgery”*. This has had a negative impact on Renata’s own wellbeing *“I am under immense stress because I am facing all these challenges alone. I feel bullied and overwhelmed by social services”.*

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

The findings in this section identify some issues which seem to apply more broadly than just communities with English as a second language. A perceived lack of responsiveness by urgent services across different statutory bodies is common to all of these accounts, with services either responding slowly, or refusing to help people who do not exactly fit their remit. The mixture of physical mental and social problems seem to pose challenges not only for caring, but also for seeking help from services. The quality of services that people receive also seems to be uneven, and professionals are perceived to not always follow through on their commitments.

More specifically to people in this community, there also seem to be language and communication difficulties related to being carers (and patients) with English as a second language. Partly this is related to a lack of translated materials explaining how services and benefits work, as well as a felt lack of in-person support to access services, which can be particularly difficult for non-native English speakers. Also, while the carers in the case studies did not encounter problems with the availability or effectiveness of interpreting services, in day-to-day caring services a lack of confidence in dealing with people with English as a second language seems to have made carers’ lives more difficult.

Care Coordinators and Lead Professionals

The objective of this part of the research was to understand from the perspective of frontline staff, what some of the barriers to working with carers might be. This should help us to gain a more rounded perspective on the causes of the problems that carers face, and a more informed idea of how these problems might be addressed.

Who responded to our survey

Norfolk and Suffolk Foundation Trust employs approximately 5,000 people, although not all of those will be clinicians or those working directly with people with serious mental illness. We were unable to find out how many people within NSFT are a Care Coordinator or Lead Professional. A total of 44 people completed our survey. Of these, 32 (73%) told us that they had lead responsibility for an adult with SMI.

We had a response from various teams within NSFT. The largest response was from those in the Community Mental Health Teams with 13 (41%) people from these teams, 6 (19%) people just stated the district they worked in, so these could also be from Community Mental Health Teams. 5 (16%) of people were in the Early Intervention Team, with 3 (9%) people from the youth team and 2 (6%) people from the Rehab Team. There were also a number of individuals from three different teams, which we have put as 'other named teams'.

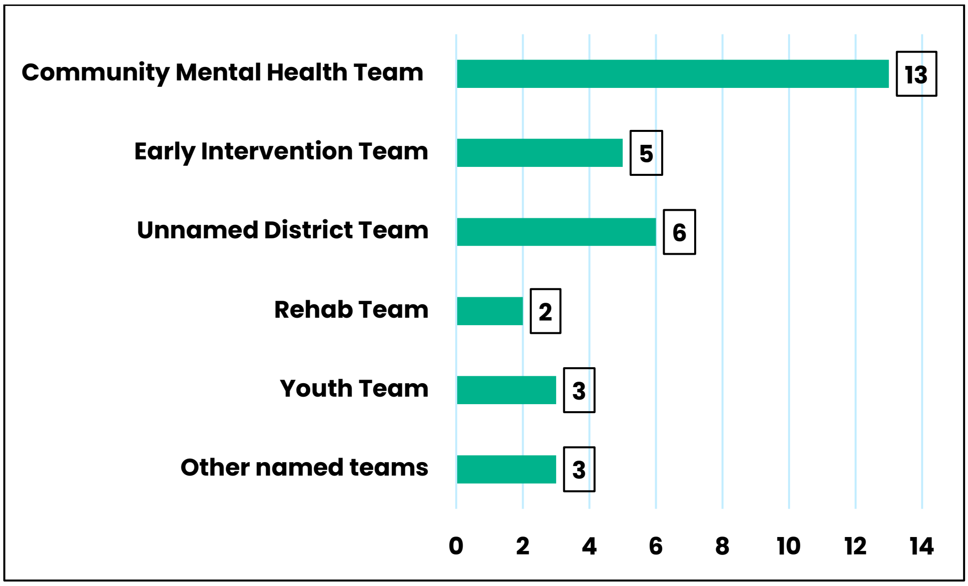

Figure 5. This graph shows the teams that the respondents work in

The length of time that people had been in their role ranged from less than a year to over 30 years.

We asked people what their gender is (giving eight options including self-describe). The gender split of respondents was mostly female 23 (72%), with 4 (13%) male and 5 (16%) people chose not to say.

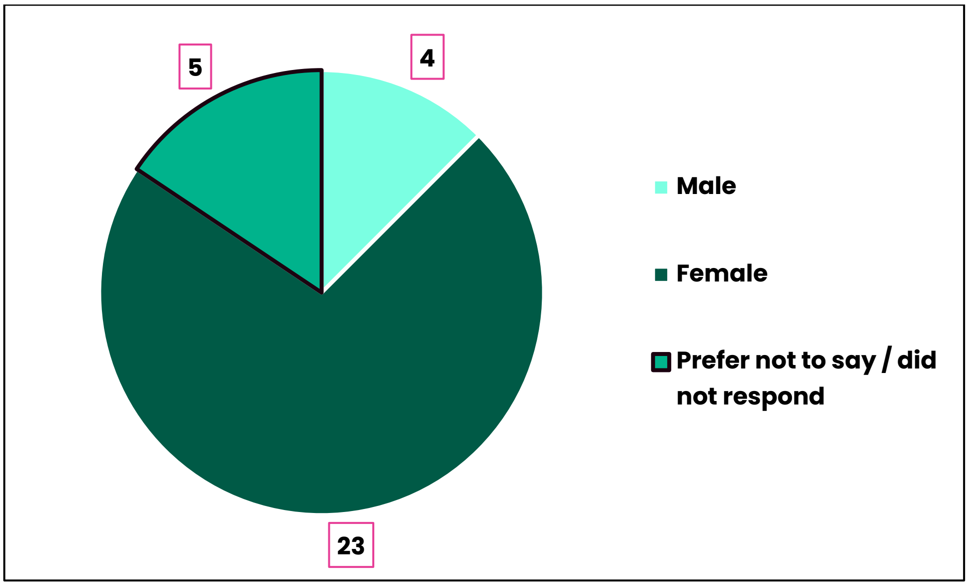

Figure 6. This graph shows the gender of the respondents

At the end of the survey, we gave people the option to leave their details so that we could contact them to arrange to talk with them and find out more about their responses. 12 respondents left their details and were contacted for interview. We were able to interview 10 people in total. We have included the comments from the interviews within this section.

Engagement with carers

We asked the question "How well would you rate your engagement with carers of adults with SMI?". Of the 32 responses received in response to this question 18 (56%) told us that it was good, 11 (34%) said it was fair and 3 (9%) said it was poor.

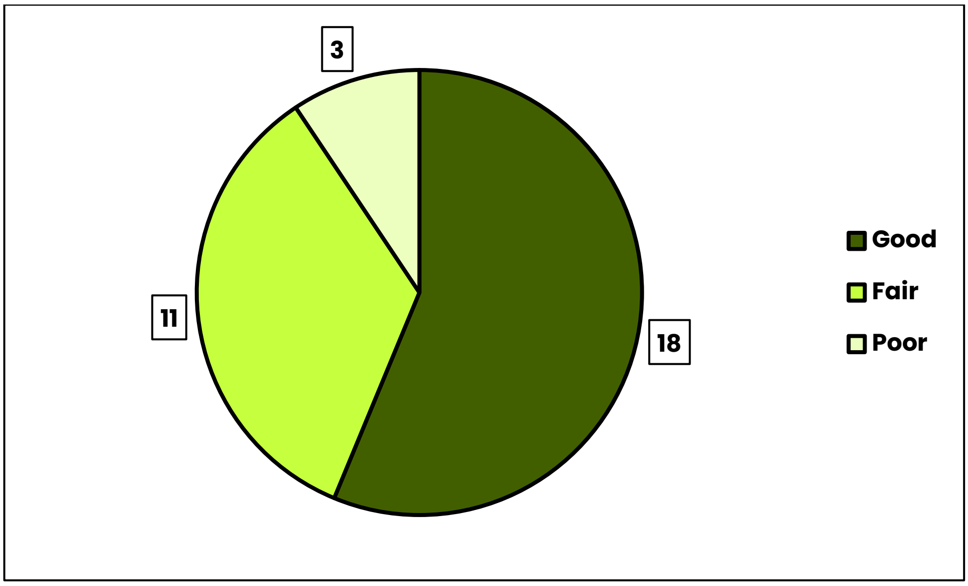

Figure 7. This graph shows how well respondents rated their engagement with carers of adults with SMI

Recognition and support for carers

We asked survey respondents to tell us whether they agreed or disagreed with the statement “Carers of adults with serious mental illness have told us that they struggle to get recognition and support from the Trust”. Of the 43 people who responded to the question, 17 (53%) people agreed, 10 (31%) disagreed, 4 (13%) strongly agreed and no one strongly disagreed and 1 person (3%) did not respond.

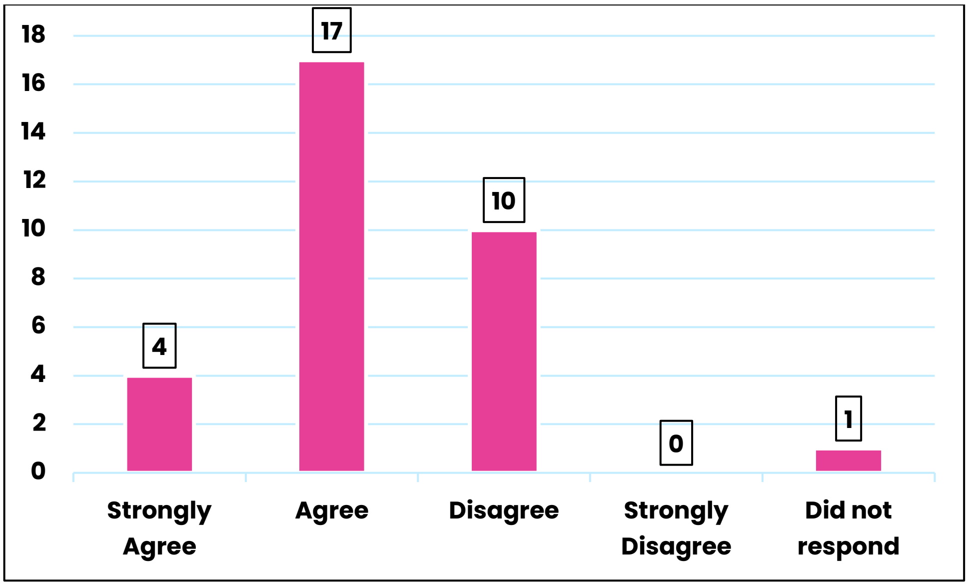

Figure 8. This graph shows whether people disagreed or agreed with the statement “carers of adults with SMI struggle to get recognition and support from the Trust

We asked people what the reasons for their response were, and the table below gives some examples of comments by people agreeing and disagreeing with the statement:

Agreeing with the statement	Disagreeing with the statement
"I've met carers that haven't been able to access support or have been let down at first hurdle of trying to gain the right information".	"Once the GDPR has been signed by the patient we are more than happy as professionals to include carers in any recovery plan/discussion".
"Services are already overwhelmed so practitioners don't have cognitive space or time for carers as well. Staff are unsure of how to support carers. Carers sometimes put staff under pressure to provide services that don't exist or to visit more often than the staff member can".	"Individual Carers Assessment are offered and referrals to other agencies. We also offer Carers Events - there is has been no uptake but we hope the engagement will grow".
"Practitioners do not always feel confident around information sharing and patient rights".	"We try to involve carers of our patients were we have consent. Also we will share information when relevant risk has been disclosed".
"Parents and carers can be made to feel that they are the problem. They feel they are seen to over or under care".	"There are carers leads, carer support, signposting to MIND carer and carers matters. Carers can be included in patient reviews".
"Whilst with in Early Intervention Services we have dedicated support groups for carers, family and loved ones of adults with SMI, they often tell me that when their relative transfer to other services (e.g. Youth, CMHT), they have less contact and are offered less engagement. I think the support available to carers are not well publicised and I am not sure whether support groups are always available at the times carers would like to access these".	"I can only comment on the SU [service users] and carers I visit I always ensure carers are involved in patient care when appropriate and offered carers support".

Barriers to working in partnership with carers

> It would be great to be able to involve carers... but again due to time this is seldom done.

We wanted to understand what the key barriers are to working in partnership with carers. Respondents could select from a list of multiple options, which included 'other'. The biggest issue identified, with a total of 22 (69%) respondents, was a lack of time to engage with carers, with the second main issue, identified by 19 (59%) people, was a lack of consent from the adult with mental illness.

Caseloads, unrealistic expectations of carers and the priority of the adult with SMI were equally selected by 13 (41%) people. Not knowing what support is available to carers was identified by 6 (19%) people. Wider data protection issues and carers not wanting to engage were each identified by 5 (16%) of people.

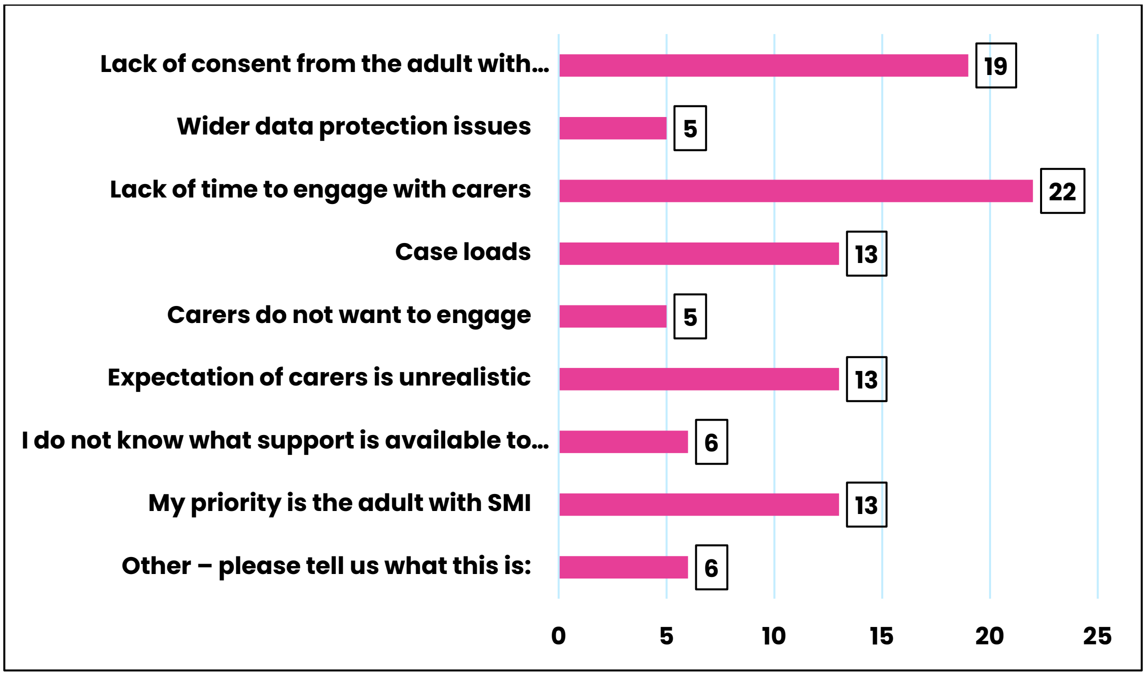

Figure 9. A graph showing the key barriers to working in partnership with carers

Of the 6 (19%) of people who responded other, there were a few reasons identified within this. People mentioned issues relating to the carers themselves "*Some carers may be causing some issues*" and "*Lack of contact details or known carers*". One person mentioned a lack of knowledge "*Staff are ignorant of the legal requirement to support carers under the Care Act and focus too much on the consent issues without understanding consent properly or using the Caldecott Guardian when in doubt*".

The staff we interviewed saw carers as essential partners, but felt there were challenges involving them due to patient confidentiality and lack of consent to share information or due to organisational issues such as workload and time.

Some of the staff we were interviewed were very clear that lack of consent from the individual with SMI should not mean that carers cannot be supported

"Even if the individual doesn't want their family involved, we can still support the carer without sharing information… part of our work is making contact with carers and family members, letting them know that they can call us and offer support."

One person talked about the conflicting legislation "*the Care Act and the Mental Health Act both say carers need enough information to enable them to care… and law that says if you don't want someone to share your information, they can't. I would be very interested in a case coming to court where those two pieces of law had to battle it out*".

The Trust Carer Leads told us that issues around consent have become a barrier for carers seeking help through NHS 111, when the person the care for is having a crisis:

"We were under the assumption when the system was first set up, the 111 system answer to that they would speak to carers, but they're not, they're being told that they can't speak to them and they've got to speak to the police, the service user without the permission. So when a carer is having a crisis, because the service user obviously is, then they are not able to access that system and get some support themselves".

People also talked about organisational issues making it difficult to work with carers "*Workload, too much admin, too much training, too many meetings, too many computer processes! Low staffing*".

“[The] Main barrier is teams not having sufficient man hours to support this type of contact in a meaningful way, and/or team culture and training not supporting this type of contact. If the former is the case, the latter will often develop, I guess.”

“Getting additional support for carers is difficult…we are 9 to 5 service often carers themselves are working so speaking to them can be hard as they have to prioritise understandably all their caring and other responsibilities. They can't be available just because we are.”

One member of staff wrote in the survey about the difficulties that they had encountered in engaging with carers:

“It is very hard to manage carer expectations at times. I have experienced more verbal abuse from carers of our service users than from the service users themselves. I understand they get frustrated that they perceive their loved one is not getting adequate support but being abusive/obstructive to us is not helping.”

A member of staff we interviewed told us about how carers can be frustrated by the lack of support they have had:

“By the time people come to our team, have probably already been trying to cope with their person that they're caring for probably over a number of years and are probably quite frustrated and burnt out by the time they get to a secondary mental health service”.

People we interviewed acknowledged that the service relied on carers. “*We do of rely on them to let us know if things are going a little bit awry so we can get in there early to prevent hospital admission or prevent relapses*”.

Being able to do your job

> Sometimes carrying high caseloads and dealing with urgent care, I am mostly working unpaid over my hours.

We asked respondents to tell us if they can do their job as well as they would like and their reasons for this. 14 (44%) people said that they were less able to do their job than they would like, 13 (41%) people told us that they were mostly able to do their job, 3 (9%) people said that they were not really able to do their job and 2 (6%) people felt completely able to do their job.

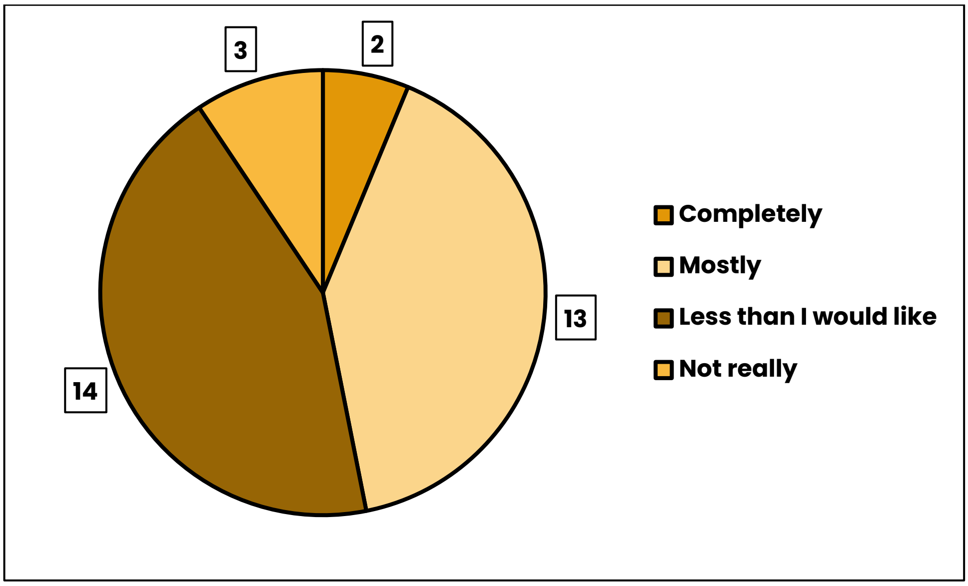

Figure 10. This graph shows how well people felt able to do their job

We asked respondents to state the reason for their response. A number of themes emerged from the comments, which were also raised in the interviews.

Caseloads and staffing

> Lack of staff and large caseloads. Too much time spent on doing paperwork.

One of the key themes that emerged from the survey and in the interviews was that high caseloads, staffing issues and a lack of time had an impact on their ability to do their job as well as they would like. *"Caseloads are too large to be able to give comprehensive care to patients"* and, *"more time and less caseload numbers".* Admin tasks and meetings were also identified as an issue reducing the time available to work on core tasks: *"The amount of documentation, meetings, and low staffing levels".*

One person identified their commitment to trying to do a good job:

"I work sometimes without a break to ensure all service users get the care and time they need to ensure recovery, volunteer and put forward more ideas on how we can support people."

Trying to fulfil the role properly means that some staff are working over their hours *"Sometimes carrying high caseloads and dealing with urgent care, I am mostly working unpaid over my hours"*, which can contribute to staff being off sick *"I don't feel I have adequate time to complete my job as well as I'd like to. There are too many pressures in general and a lot of burnout".*

One member of staff talked to us about the challenges they face in doing their job: *"time and capacity to do what you kind of need to do for people or what we would like to be able to do to support people".*

The IT system

The IT system we use, Lorenzo, for recording patients notes and care plans, is awful.

Interviewees and survey respondents expressed dissatisfaction with the Lorenzo IT system. Their feedback focussed on the poor usability and how it led to duplication of work. *"Our Lorenzo system's just clunky and…it's just really slow as well. Frustrating at times really, which just makes things take longer than they* *need to"* and *"it's quite repetitive. You kind of duplicate a lot of information, a lot of the time on different documents and it's just not so user friendly".*

There was also frustration that using the system takes a lot of time, which can mean that staff have less contact time with service users, or work additional hours in order to undertake all their tasks:

"We have excessive administration tasks that are very time consuming. What isn't understood is the time it takes to use systems - often they are not user friendly and you have to rely on everything working seamlessly, even to get the bare minimum completed."

"Writing the patient note on the system can be a very long task and often takes longer than the actual contact with the patient, it takes away time spent with patients and it is common to be working after hours to put the notes on the patient records. The expectations to do this all in 9-5 is very unrealistic."

The system has a series of tabs that contain information, but this can make trying to find key information difficult *"on Lorenzo you have to look all over the place for different bits of information".*

"I have worked on different IT systems and Lorenzo is the worst I have ever encountered; it makes adding carer details or care provider details difficult. I pointed out to a member of staff, the care provider and carers tab the other day and although they have worked with the Trust for years (longer than me) they had no idea about the use of these tabs".

One person suggested that having a 'front sheet' with all the key information on it would be invaluable:

"I just think a one page, [a] front page. It's not their combined assessment; it's not their care plan. It is just a one page – 'these are the things that I want you to know about me.' It would make so much more sense. You can change it. You can put their telephone number in it. You're not searching around for different things all the time".

Another staff member reinforced how this would be useful and referred to the IT system that Children's Services use: *"on a child's record on the front screen, it's really clear; at the top it tells you their legal status, so [for example] you'd know if someone's been detained or not.. it's a much more user-friendly way of and* *there's a kind of basic summary on that front screen that says these are the issues"*.

The IT system was also seen as a barrier to collaborative, person-centred care. Staff told us that they were unable to complete care plans in the community and had to resort to printing forms off to complete by hand, and then typing them onto the IT system "*we don't take laptops out and do it [care plan]*" and "*I generally kind of print it, print off a blank copy and then take that to the patient and then we'll go through it. But then I then have to come back and put it on to Lorenzo".* The result of this can be that the resulting document is not as good as it could be:

"…taking your laptop out to a patient to do a care plan, or a carer to go through a carer's assessment, you're kind of relying on everything working and it doesn't always work or it takes a long time to make it work. So sometimes you end up with a document that isn't really as good as you would like it to be".

Another staff member echoed the need for IT that is easier to use in the community:

"..maybe if we had I-Pads or something that we could take out with us. So, a bit less invasive than a massive great big laptop, taking that into some visits just wouldn't be appropriate…if we had like something like that, that we could take and actually do with our patients at that time, that would save a good amount of time".

When we spoke to the Carers Leads, they told us that they do not have issues with Lorenzo "*I have found Lorenzo for us, for what we do right, fine. We, as three have managed Lorenzo*". However, they did concede that there were some issues:

"Lorenzo was never created to have carers in. It was only service users. So then they had to find a way of recording the carer stuff, which it doesn't. You have to go into the service user's box to be able to get access the carers".

Limited resources

People also expressed frustration with how reduced resources over time has had a negative impact. "*Increased demand with less resources adversely impact directly on service delivery*" and "*teams are overwhelmed and continuously expected to provide for with fewer resources*".

"I am a sole practitioner within my team although we have a newly appointed Therapy Assistant to help, but we could still do with another OT [Occupational Therapist] as I have responsibility of running the service on my own and doing everything."

One member of staff made a plea for increased resourcing:

"We just need more funds for more staff and support staff (AHPs!!!), more money for therapies, less admin, more help with admin would be fantastic, less processes would give us more time for 1:1 contact and more meaningful, timely and safer outcomes for our patients. This would mean staff would feel more fulfilled with their work and would help with staff retention and reduce staff sickness".

Cancelled appointments

> Staff retention, responding to chaos and crisis, and staff sickness are probably the main reasons why people cancel. Care Co's(coordinators) don't want to cancel; they don't want to let the service users down.

We wanted to gain a better understanding of the frequency of cancelled appointments and the main reasons for cancellations. We asked whether, from the respondents' experience, appointments were cancelled frequently, sometimes, infrequently or rarely. 16 (50%) respondents told us that appointments were rarely cancelled, 7 (22%) saying they were infrequently cancelled, and 9 (28%) saying they were sometimes cancelled. No-one stated that they were frequently cancelled.

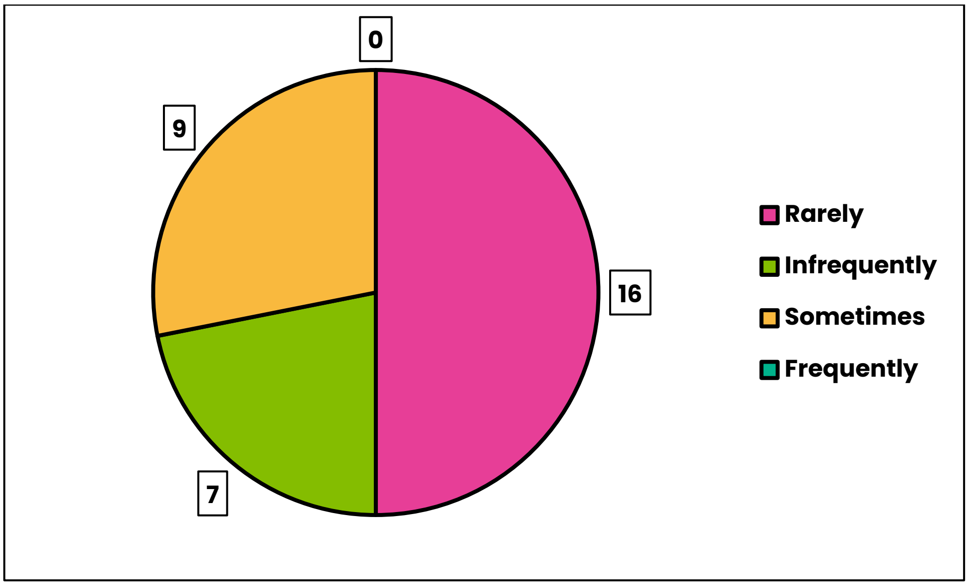

Figure 11. This graph shows whether respondents felt that appointments were cancelled rarely, infrequently, sometimes or frequently.

We asked what respondents felt were the main reasons for appointments being cancelled. Respondents were given a list of options and they could choose multiple options. People were also able to input their own reason. The most identified issue was staff sickness, with 27 (84%) respondents selecting this. Having to respond to a crisis was the second highest response with 22 (69%) of people choosing this. 13 (41%) people felt that appointments were cancelled due to caseloads being too large. Staff turnover was an issue for four (13%) people, with no-one stating it was due to restructuring.

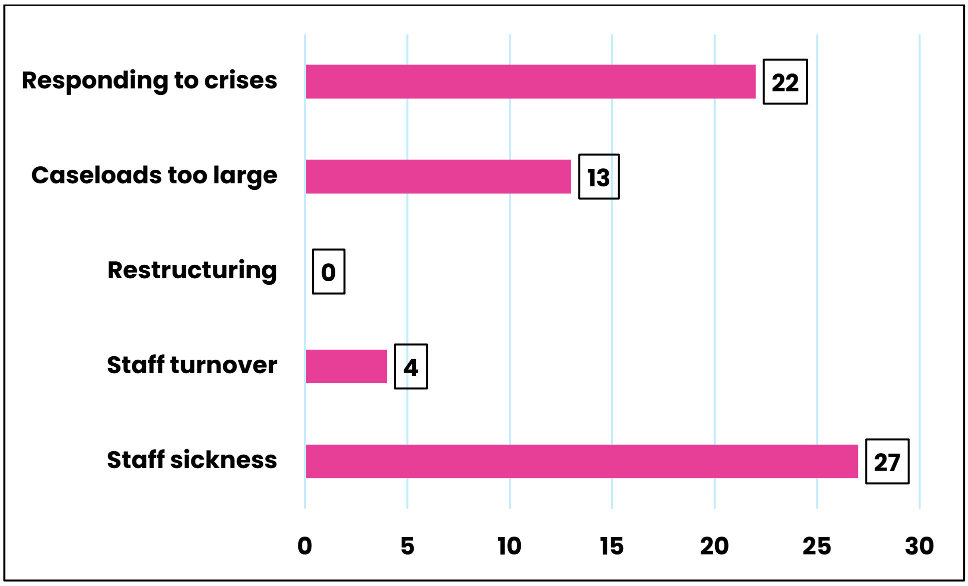

Figure 12. This graph shows the reasons for cancelled appointments

Six (19%) people gave other reasons, which included two people who said that the patients cancelled the meetings. *"Patient or carer cancelling a meeting or re-arranging. We are flexible about rearranging though"* and, *"Patients either call to cancel appointment or fail to attend the meeting"*. The other four people talked about the measures in their teams to ensure that appointments were not cancelled *"the Early Intervention Team is fortunately to have more equitable resources available, albeit we're over our commissioned caseloads. As a service we rarely / infrequently cancel meetings"* and *"Staff cover to make sure our community clozapine clinic remains operational and service users are able to get their medication"*.

Interviewees also reinforced that it is not the norm to cancel appointments, but when it does happen it is usually down to issues such as staff sickness *"Appointments do sometimes get cancelled and it's usually down to staff sickness, caseloads and crises… cancellations are unavoidable"*. One staff member told us that cancelling appointments can negatively affect the relationship with the service-user: *"It's a real shame when appointments have to be cancelled, particularly for these chaotic caseloads because the trust is difficult to build… I've heard lots of people say 'what's the point of telling you about it anyway, because you're probably just going to leave'"*.

One interviewee talked about the difficulties of trying to prioritise the work within teams and the need to respond to crisis situations *"I'm aware of teams that have been under pressure, people have gone off sick, long term sick… They may have even had the number of people in their service increased through service transformation changes. They're forever prioritising…there may be someone who is really more suicidal, for example"*.

When staff are on long term sick leave there is limited capacity to pick up additional work within the teams, which means that the quality of support is affected. We asked one member of staff what would happen if she went on long term sick *"my cases would be reviewed by my line manager. She'd go through my caseloads, she'd maybe allocate some people to do some follow-ups for my cases, but they certainly wouldn't be seen as much as I'm seeing them and managing them"*.

Improving working in partnership with carers

> To have a dedicated carer, family & friend lead within each service; where the job role is not on top of their existing role, but either their whole role or they have clearly job planned and dedicated time to undertake this important function.

We wanted to understand if the respondents could identify any things that could make working in partnership with carers easier; 24 people (75%) left comments about what they thought could improve working in partnership. Half of those who replied talked about the need for improved carer support: *"Separate support available for carers*" and "*…clear pathways of support for carer".* People also stated that there should be support for carers offered within NSFT "*an NSFT carers team to refer to"* and "*specific carer support worker in the team, would provide a more joined up approach for us….".* Four people (13%) talked about time: "*Allocated time / protected time for carers rather than 'added' on to our caseload which I what has happened currently"* and "*More time, smaller caseload".*

Other things that people felt could improve working in partnership with carers included being able to identify carers earlier, and improved assessment of carers: "*Having a straightforward assessment and an easy way for them to be seen*" and improved training, especially around consent. "*Robust staff training around our duty to provide support with carers, refer to carer organisations. We do not need to have patient permission to discuss a carer's needs".*

It was acknowledged by two members of staff that we interviewed that the Trust is less good at engaging with some groups of carers "*We're not good at identifying carers from different minority groups or young carers*" and, "*Where are our carers from minority ethnic backgrounds, they might need something different. Where are they represented in a predominantly very white trust?*"

When carers are involved, outcomes were said to be generally better, but involvement is inconsistent across teams.

Lastly, we asked people if there was anything that they wished to add or tell us about. Two people talked about training: "*I attended two sets of online carer courses run by different people within the NSFT and I thought they were both really good so hope these - and more - are still running"* and, "*Consider supporting staff to undertake the Maudsley Delivering Support for Carers of*

People with Psychosis: a train the trainer programme; or the King's College CBT informed & Carer Support Practice in Psychosis".

Carers Leads within the Trust

Norfolk and Suffolk Foundation Trust has three Carers Leads (2.5 full time equivalent), who work across the Trust. Originally, they had provided carer support for the Trust, but their roles have evolved, and they now play a strategic role in trying to ensure that carers are recognised and supported within the Trust.

There is a structure of Carers Ambassadors whose role it is to ensure that their teams maintain a focus on carers. The Carers Ambassadors should have protected time to undertake this task

"They [Carers Ambassadors] are people who are enthusiastic about carers and say that to their teams and their managers. They have an agreement in that team for some protected time to do that role, in the same way as a green light champion, a safeguarding champion and all the other champions or specialists roles in the Trust".

There are approximately 60 Carers Ambassadors within the Trust, however there is variation across the teams about how much time they are given to undertake the role:

"A lot of teams and services manage to give some ambassadors whole days, several hours. They are teams who actually value carers and are willing to invest in carers; that is decided at team and management level wherever their staff and budget is decided."

There are also many teams that do not have a Carers Ambassador. The Leads play an important role in supporting the Ambassadors: "*those Ambassadors need us. They need leadership, they need support, our skills, our experience*". A key part of the support to Ambassadors is to ensure that their role is to provide expertise to the colleagues, not to pick up everything related to carers within the team as this would be impossible: "*when you're working in a team where they've got 600 service users at least, how many carers do they have*?"

The Carer Leads have created a data dashboard "*we now collect carers data. We have a huge dashboard and report that shows us how many carers* *are identified, how many carers have been sent information packs, how many carers have had a contact visit*". The hope is that this will help to further embed carer involvement in the Trust's work: "*the board are now going to start having that…they're going to know their numbers are down on carers identified and carers packs being sent out and they're going to have to focus on that".* However, the accuracy of the data is dependent on mental health practitioners inputting the correct information onto the IT system: "*you might have teams that are working with carers, but because they haven't filled the data that's triggered the right thing in the computer system, we can't measure that that person saw that carer that day or that week".* The Leads feel that this is an issue that needs to be addressed through training. "*When we go to teams and we say your data could be much more up to date if you recorded things on Lorenzo in this way. Some of the feedback we had over the years is, well, we didn't know we had to do it like that".*

For the Leads 'Carer Awareness' training is essential for all staff: "*we are still fighting very passionately that carer awareness training should be mandatory for everybody in this Trust; managers, board, receptionists, everybody".*

Now the Carers' Charter has been finalised there are plans to work on a charter for young carers. The Leads acknowledged that the Trust has not been good at identifying young carers. "*Staff should identify those children as being young carers, from my years of experience in this Trust, we're not great at doing that*".

The Leads are passionate about the difference that it makes when carers are fully involved as partners in the patient's care "*Having carers and informal supporters on board reduces admissions and relapses. It helps to keep people more in favour of taking their medication because they get positive feedback from others about how well they're doing".* They are also optimistic that there are positive changes happening: "*we have the strategy and we have a board that I believe are very carer-focused and are listening to our voices*".

Action plan for carers

Progress on the action plan in year 2 was disappointing, and slower than we had hoped it would be. It often took a long time to get responses from the staff allocated to each action point. In large part, this was due to a restructuring of senior staff at the Trust, which resulted in new people being hired at board and director level, while others were in the process of leaving while we were trying to work with them. Staff who were leaving were reluctant to get involved in a process which they would not see through to completion, and new people arriving in their role found it difficult to find the time to meet us.

The restructure of the Trust's board and directorate should now be complete, and we hope to make more progress in year 3. Below, we detail the current status of each of the action points.

1. Emergency and Contingency Planning
4. Police and court involvement

The new interim Chief Operating Officer will be the main staff contact for these action points, and meetings are due to commence in the summer of 2025.

2. Successful Community Living
3. Red flags and the escalation process
7. Annual mental health and medication reviews

A preliminary meeting on these action points has been held between carers and two transformation project managers, with more substantive meetings to follow. Subsequent meetings should also include the Chief Transformation Officer and Director of Transformation.

5. Named contact person

The main staff contact for this point is the Director of Nursing and Quality in Suffolk, and the first meeting took place in April 2025. Discussions on this point have also covered the related point of the content of care plans, which touch on this point, as well as the emergency and contingency planning point. There is a strong desire for care plans to be meaningful documents that involve family members and include contingency planning in case the carer is unavailable, and include contact details for a staff member with an overview of all of a person's care. It was agreed that carers will take part in delivering training for

NSFT staff on what should be involved in care plans. Future meetings will also tackle more substantively the establishment of named contact persons.

6. Annual physical health checks

The main staff contact for this point is the Director of Nursing. An initial, productive meeting took place in April 2025 to discuss current progress on SMI health checks in Norfolk and Suffolk. It was discussed that there is a significant gap between progress on this point in Norfolk and Suffolk. In Norfolk the rate of completed health checks for people with SMIs is 58% (close to the England average), whereas in Suffolk and North East Essex it is 86.9%. This seems to be due to two very different commissioning models. In Norfolk SMI health checks are carried out by GP surgeries, whereas in Suffolk there is a dedicated programme including assertive outreach to people with SMI in the community. Next steps on this action point will include trying to engage Norfolk and Waveney Integrated Care Board in discussions about how this commissioning model could be changed.

What this means

All carers face challenges. However, carers of adults with a serious mental illness have an additional challenge due to the nature of the adult's illness. When considering the issues for young carers, younger carers and those with English as a second language we found that there were some overlaps in the challenges that these groups of carers face. The unpredictability of the individual due to their illness and concern about them self-harming or needing to be hospitalised is a cause of anxiety for both young carers and younger carers.

Young carers and younger carers told us about the need to be vigilant to the mood of the adult with SMI and to look for indicators that things are deteriorating with that person and trying hard not to "trigger" them. Most carers reported that their own mental health was suffering as a result of their caring responsibilities.

Stigma about mental illness and fear of judgement is a barrier to support for each group of carers. The younger children we spoke to and those who had English as a second language, were more focussed on the physical disabilities of the person they were caring for. Carers also talked about the lack of understanding from wider family, which affected their ability to seek support.

Although in Norfolk there is a link between NSFT and the Norfolk Safeguarding Children Partnership, NSFT does not have a system in place to record young carers or policies about recognising, assessing or supporting young carers.

The issue about a lack of information from year one has been confirmed with both carers and NSFT staff. Young carers would find information about SMI useful. Having a translated information sheet in different languages would allow patients and carers from different language communities to absorb the information in their own time. NSFT staff would also like information sheets about SMI to share with patients and their carers.

The majority of NSFT staff who completed the survey and those we interviewed try to engage with carers and recognise that carers did not always get support and recognition from the Trust. A lack of time, caseloads and resources are barriers to engagements with carers and impact on staff ability to do their job as well as they would like. Reducing resources and an IT system that people find difficult have a negative impact. Although crisis situations and staff sickness can lead to cancelled appointments, staff did not feel that appointments were frequently cancelled. Although the Trust has a commitment to carers – the Carers Lead and Carers Ambassadors are evidence of this – the Trust could be bolder in promoting the vital importance that carers play and how truly working in partnership with them can make a difference.

The Carers Leads advocate for mandatory carer awareness training for staff and protected time for carer ambassadors in teams as a way of improving the support to carers.

Recommendations

1. Norfolk and Suffolk Foundation Trust

1. Improve support and recognition of young carers
    - Develop and implement a policy specifically recognising young carers of adults with SMI, including procedures for identifying them and recording their status in clinical systems. Update the Electronic Patient Record (EPR) system to include a "young carer" option under "related persons."
    - Ensure NSFT clinicians are trained to identify potential young carers and understand the safeguarding implications, especially during home visits or care planning.
2. Improve consent and communication in crisis situations
    - Clarify and communicate consent protocols with carers to improve information sharing, especially in crisis situations.
    - Ensure that staff training gives a clear understanding that if a patient says they do not want their carer to be kept informed, this should not mean that the carer is denied support, or the opportunity to share important details with staff about the person they look after.
    - Provide carers with contact details for urgent support, including a clear pathway to raise concerns during out-of-hours crises.
3. Improve the electronic patient record system
    - Engage frontline staff and carers in the redesign of NSFT's IT and electronic patient records system. Prioritise ease of recording carer involvement and concerns and making relevant carer information accessible during crisis response.
    - In the meantime, measures should be taken to make it easier for staff to record and view carers' details on Lorenzo.
4. Produce more written information about SMI for carers
    - Develop and distribute jargon-free information about SMI conditions tailored to carers, particularly young carers and those supporting people with schizophrenia, bipolar disorder, or personality disorders.
    - Develop translated materials on carers' rights and available support, prioritising languages most spoken locally (e.g. Polish, Lithuanian, Portuguese).

    - Work with VCSE partners like Hanseatic Union to ensure information is culturally appropriate and to co-deliver outreach and benefits advice.
5. **Staff should ensure that consideration is given to carers' other responsibilities**
    - Many carers struggle to work, but last-minute scheduling of appointments make it difficult for those that do work to attend.
    - Staff should be aware of 'sandwich' carers and the additional pressure that this creates, and look for additional support for these carers.

2. NSFT and Norfolk County Council

1. **Establish a clear referral pathway** for adult mental health professionals to notify Children's Services when a parent's condition is likely to be impacting a young person.
2. **Create multi-agency guidance for recognising and supporting young carers** in families affected by SMI, incorporating learning from this report and local Serious Case Reviews. This should include guidance on collaboration between schools and other services.
3. **Fund and deliver peer support groups specifically for young carers**, to allow them to talk about their experiences and share their frustrations and worries.

3. Norfolk County Council

1. **Resource and monitor completion rates of Young Carers' Assessments**, ensuring emergency plans are consistently put in place and reviewed annually.
2. **Review and reform the referral process to CADS** (Children's Advice and Duty Service) so that young carers can access assessments without requiring a safeguarding threshold.
3. **Steps should be taken by children's services to reassure young carers** that coming forward as a young carer will not cause them to be removed from their parents.
4. **Schools which have young carers policies should make sure that these policies are honoured in practice**
    - Schools should also allow young carers of people with SMI to call home at break and lunch times, if a young person is anxious about their relative's wellbeing.

Response from Norfolk and Suffolk Foundation Trust

We would like to extend our sincere and heartfelt thanks to Healthwatch and to all the individuals, carers, young people and families who so generously shared their experiences and insights as part of the Year Two report. Your contributions help us understand the realities of caring for adults with serious mental illness, and they have shaped the actions we are taking as a trust to support carers better.

Caring roles make a profound difference, not only in the lives of those receiving support but also in the way services are shaped and delivered. The report clearly shows that caring responsibilities can have a significant impact on carers, with carers often facing anxiety, stigma, and isolation, especially during crises or when support systems fall short. Young carers, carers under 45, and those with English as a second language face additional barriers to recognition and support.

These voices have highlighted the urgent need to improve how carers are identified, involved and supported. In direct response to this need, the Trust has taken considerable action to address this. This includes working collaboratively to produce a Trust plan for 'Improving the Identification and Recording of Carers within the Clinical Record'. This sets out a comprehensive plan to ensure carers are recognised, recorded within the clinical record, valued and included across NSFT services.

This ambitious plan includes improvements to better capture carer information; establishing a group to oversee progress, setting clear targets for carer identification; working with partners to better support young carers and ensure they are recorded correctly in the electronic patient record, working with young people and those groups identified in the Healthwatch report to co-produce solutions to the issues identified. Our plan has the full support of the Trust Board of Directors and reflects our firm commitment to supporting our carers and families through the leadership of Cath Byford, chief patient experience officer and deputy chief executive officer.

The Trust has formally launched our Carers Charter at our Annual General Meeting held on 9 October which was co-produced with carers. We are very proud of this and delighted that the Carers Charter was initiated from a meeting facilitated by our partnership on this programme with Healthwatch Norfolk.

At our Trust Listening Into Action event this month, we have launched our 'Common Sense Confidentiality' document as part of our revised Confidentiality Policy. This will strongly enhance the importance of communicating effectively with families and carers and provide support for colleagues in doing so.

The experiences and expertise of carers shared within the report will also influence the transformation of community mental health services that is currently underway which includes the caseloads that our teams hold. As part of the design of the future clinical record system, we will also be ensuring that how carers and families are identified and captured within the clinical record will be improved and streamlined.

The actions set out address the recommendations in the Healthwatch report and reflect our significant commitment to improving carer involvement and support and to provide safer, kinder and better care for our service users, carers and families.

Acknowledgements

Thank you to the project staff from the following VCSE organisations that gave us their perspective on young carers of adults with SMI. We are especially grateful to the staff who facilitated the focus groups with the young people:

- Swan Youth Project
- Great Yarmouth and Gorleston Young Carers
- MTM Youth Services
- Caring Together
- The Benjamin Foundation
- Holt Youth Project

We would like to say a very big thank to the young people from the two projects that told us about their experiences of being young carers. When we met with the young people, we asked them to choose a pseudonym for themselves. Hopefully they will recognise themselves from the pseudonyms below:

Swan Youth Project
- Bella
- Rose
- Edith
- Jacob
- Ellie

Great Yarmouth and Gorleston Young Carers
- Deidre
- Lottie
- May
- Lucy

Also our thanks to the Head of NSCP Business Delivery for Norfolk Safeguarding Children Partnership and the Strategic Commissioner – Local Services for Children and Families, from Norfolk County Council for their time.

Many thanks to those people who are carers under the age of 45 years, who gave their feedback and were willing to be interviewed for this project.

Hanseatic Union

We would also like to extend our thanks to the staff from the Hanseatic Union and their service users who were willing to share their experience of having English as a second language and being a carer for an adult with SMI.

Staff at Norfolk and Suffolk Foundation Trust

Thank you to those who helped facilitate the distribution and promotion of our survey for Care Coordinators and Lead Professionals and for those who completed the survey and agreed to be interviewed.

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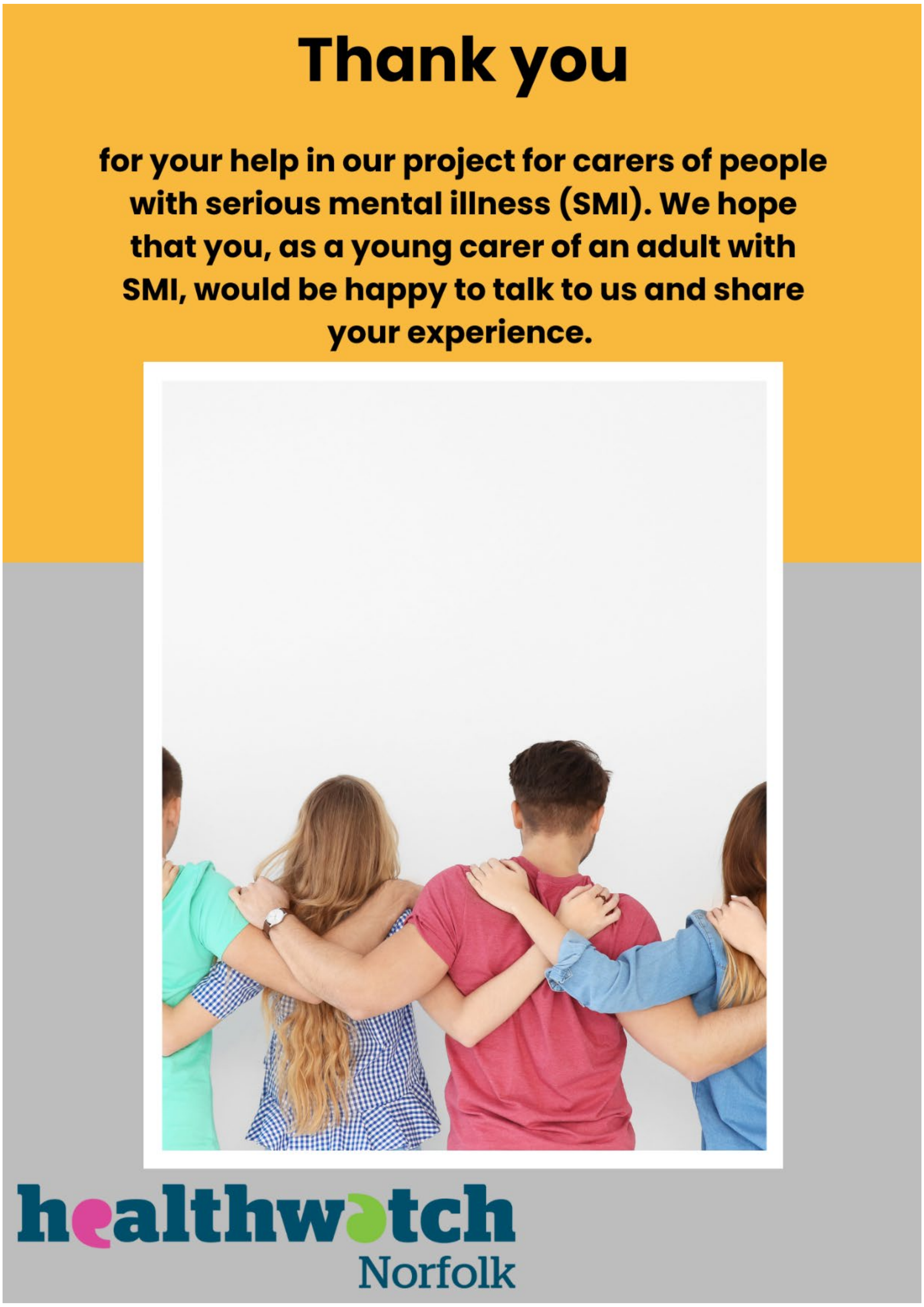
Appendices

Appendix One – Information leaflet for young carers



Thank you

for your help in our project for carers of people with serious mental illness (SMI). We hope that you, as a young carer of an adult with SMI, would be happy to talk to us and share your experience.

healthwatch
Norfolk

Who are Healthwatch Norfolk?

Healthwatch Norfolk is the local health and social care champion for the county. We make sure NHS leaders and other decision makers hear your voice, and use this feedback to improve care. We can also help people find reliable and trustworthy information and advice.

Your feedback is used to better understand the challenges facing the NHS and other care providers, and your experiences can help improve health and care for everyone.

To find out more, click the link below:

CLICK HERE TO FIND MORE ABOUT HEALTHWATCH NORFOLK

What is this project about?

This is a three-year project that looks at the support and help that carers of adults with serious mental illness (SMI) get from mental health services. Carers have told us that they do not feel that they are listened to and that they do not get enough information and support.

In this second year of the project, we want to try to understand what it is like for young carers of adults with SMI. We know some of the challenges faced by young carers, but we are interested to learn if there are particular difficulties that you face when you are supporting an adult with SMI.

At the end of this year of the project, we will produce a report with our findings and recommendations of how things could be improved. It will go to the community mental health services (Norfolk and Suffolk Foundation Trust) and will be available to the public.

healthwatch
Norfolk

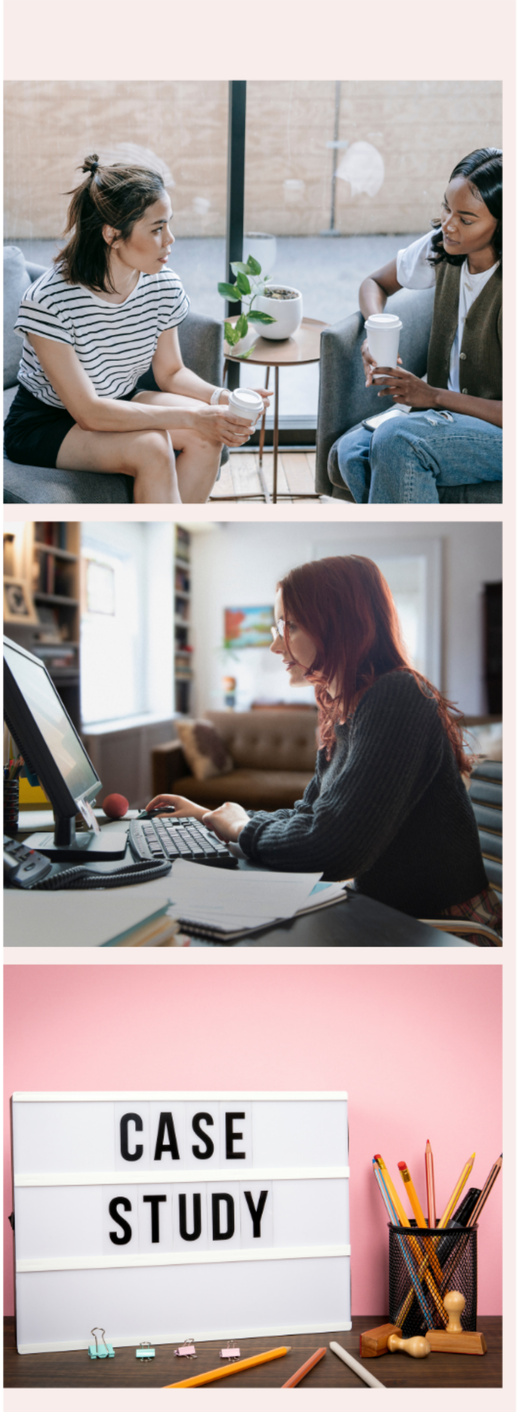
How will we use the information you give us?

With your permission on the day, we would like to record our interview with you. This makes it easier for us to make sure that we are accurate when writing up.

We will look to see if young carers are telling us similar things and if so, we will highlight these issues in our report and perhaps make recommendations about what could be improved.

We would also like to use some of young carers stories as case studies (changing the names and any information that would allow someone to recognise you). This is a good way of helping people have a better understanding of the challenges that people face.

After the report has been written, we will delete the recording and any notes we have made from this. We will also remove your details from our systems.



Appendix Two - Case Study Template

The case study should ideally be one side of A4 in size 12 font and should be telling the story of the carer and their experience of caring for someone with an SMI. It should identify key challenges and suggestions to how things could be improved.

- Please provide a pseudonym for the individual – preferably one that they have chosen for themselves.
- Their gender and age
- The person they care for / support (pseudonym again please) their gender and age. What is their relationship – partner, sibling, child etc.
- The nature of the person's mental illness and how long they have lived with this.
- Their experiences of being a carer for an adult with SMI
- The support the person with SMI has had from mental health services.
- The support the carer has had.
- The information they have had about the loved one's illness or support for them as carers.
- Challenges they have encountered because English is not their first language.
- The things that have really helped them in the role as carer.
- What improvements the carer feels could be made to help them in their role.
- What improvements could be made to improve the support to their loved one.

<u>Prompts that may be helpful.</u>

- What type of things do you have to do to support your loved one – practical tasks, keeping them safe, financial etc?

- When things are bad, what does this look like - if I was a fly on the wall what behaviours would I see? (this is really helpful as it helps to paint a picture of what the carer is dealing with).

- Does the person you support see any professional about their mental illness? A doctor, mental health worker, social worker.

- Have you ever been given any information about your loved one's condition – was it written or did someone tell you?

- Have you had any support for you as a carer? What support have you had and who from?

- What are the things that you find most difficult as a carer of someone with SMI?
- What are the main challenges you face as a carer for someone with an SMI?
- Has there been anything that has been really helpful to you as a carer? Have you been told about the carers passport?
- What changes would you make that could improve things for you as a carer and for the person you care for?
- Is there anything that you think we should know that we haven't asked about?

Appendix Three - Survey for Care Coordinators / Lead Practitioners

Introduction

Healthwatch Norfolk has been commissioned by Norfolk and Suffolk Foundation Trust to undertake a piece of research on the experience of carers of adults with serious mental illness. This is a three-year project.

We are keen to understand from a mental health practitioner's perspective what challenges you face in working with carers and adults with serious mental illness, whether there are issues with the system that create barriers to good practice and whether there are any solutions that could make things better for you.

We hope that you will be willing to give us five minutes of your time to give us your feedback. Your individual responses will remain confidential to Healthwatch Norfolk; we will use the responses to identify themes and may include some anonymous direct quotes within our report.

We may be keen to speak to some of you to find out a bit more. If you would be willing to be interviewed, please leave us your contact details via the survey so that we can follow up with you. This would also be confidential.

Thank you for your help.

Survey

1. Job role
2. Team and district
3. Do you have responsibility as a Lead Care Professional for adults with SMI? Yes / No
4. How long have you been in your role with Norfolk and Suffolk Foundation Trust?

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5. How well would you rate your engagement with carers of adults with SMI?

Excellent / good / fair / poor

6. Carers of adults with serious mental illness have told us that they struggle to get recognition and support from the Trust. From your experience do you agree or disagree with this?

   Strongly Disagree / Disagree / Agree / Strongly Agree

   - Can you tell us your reasons for this?

7. What are the key barriers to working in partnership with carers? (Please select all that apply)

   - Lack of consent from the adult with serious mental illness
   - Wider data protection issues
   - Lack of time to engage with carers
   - Case loads
   - Carers do not want to engage
   - Expectation of carers is unrealistic
   - I do not know what support is available to carers
   - My priority is the adult with SMI
   - Other – please tell us what this is

8. Are you able to do your job as well as you would like?

   Completely / mostly /less than I would like / not really

   - Please tell us your reasons for this response.

9. People have told us that appointments with their Care Coordinator / Lead Care Professional frequently get cancelled. From your experience do appointments get cancelled:

   Rarely / Infrequently / Sometimes / Frequently

10. What would you say are the key causes of cancelled meetings? (select all that apply)

    - Staff sickness
    - Staff turnover
    - Restructuring

- Caseloads too large
- Having to respond to crisis situations
- Other – please tell is what this is

11. Are there things that you feel could make working in partnership with carers easier?

12. Is there anything else you wish to tell us?

If you are happy for us to contact you to find out more about your responses then please leave your contact details below. Again, this will be in confidence.

Name:

Email Address:

Contact telephone number:

How would you prefer us to contact you to arrange a short interview?

When are the best days and time to do this?

Anything else you wish to add:

Appendix Four - Interview Questions for Care Coordinators / Lead Professionals

Thank you for your time today. We have been commissioned to undertake this work with carers of adults with SMI by NSFT. It is a three-year programme and this is the second year. This year we have a focus on young carers, carers under the age of 45 years and carers for whom English is not their first language. Last years findings identified a lack of information for carers, a lack of practical and emotional support for carers, a lack of trust in services – particularly the crisis service. Carers did not feel that their voices were heard and wanted more involvement in the care of the person.

Do you have any questions?

With your consent I would like to record this interview. As I mentioned in my email, this allows us to more accurately report on what people are saying and to use direct quotes where appropriate (these would be anonymous). The recording and transcript will be destroyed once the report ha been published. Are you happy for me to record our interview?

- Can you start by confirming your name, job role and how long you have been employed by the Trust?
- Can you tell me a bit about your role and the work you do with adults with SMI?
- Can you tell me a bit about the responsibilities of being a Lead Professional? Are there particular roles within the Trust that can have this responsibility?
- What are the main challenges to you in your role?
- Are there things that you think could be done to make it easier for you to undertake your role?

- What responsibilities does the Trust have toward carers?

- Can you tell me about the Carers Assessment and what it entails? Who has responsibility for undertaking this?
- Can you tell me about the Carers Identity Passport and how it is meant to work?

- What support is available to carers?
- What do you consider to be the main challenges faced by carers of adults with SMI?
- Do you think there are any changes that could be made to improve things for carers?

- Last year's report highlighted that carers felt that training for NSFT staff could be improved – to all staff – on Carers rights, and data protection. Are you aware of training that is available to staff on identifying and supporting carers?

- The report also recommended that communication and information for carers is increased, including specialised information about SMI, medications and side effects. Can you tell me if there is anything in place around this? Carers also requested that any contact with Trust staff should be acknowledged and a reply received within a set amount of time. What are your views on this?

- We recommended an increase in carer involvement and voice through carers groups or Forums and Carers Champions at NSFT.

- The final recommendation was focussed on the care of adults with SMI – looking at continuity of care and training delivered by those with lived experience. From another project looking at the transformation of community mental health services a key theme from adults with SMI was about cancelled appointments and frequent changes in personnel, which was why we were keen to hear from Lead Professionals to understand their experience. I'd be grateful if you could let me have your thoughts about this and help me to understand how it is for those professionals trying to support adults with SMI.

- Is there anything else that you would like to add?

Thank you so much for your time today. We will be in contact to let you know when our report is published.

Appendix Five – Resources

During our research we were informed about some resources that we thought would be useful to highlight.

The Recovery College

A local provider of free educational courses on wellbeing and mental health recovery, run by Norfolk and Suffolk Foundation Trust. The courses are open to anyone over the age of 16 and living in Norfolk or Suffolk who is interested in mental health recovery.

You can find more information about the Recovery College on their website: https://www.nsft.nhs.uk/recovery-college/

The National Hearing Voices Network

Resources and information for people who hear voices, see visions or have similar sensory experiences. They also have details of groups that are run to support people

More information can be found on their website: National Hearing Voices Network – For people who hear voices, see visions or have other unusual perceptions

Caring for People with Psychosis and Schizophrenia

A free online course for people caring for a relative with psychosis or schizophrenia provided by King's College, London. The course does not run all the time.

Details can be found here: https://www.futurelearn.com/courses/caring-psychosis-schizophrenia

Psychosis Reach

A US Cognitive Behavioural Therapy based training programme that provides evidence-based skills for relatives and friends of individuals with psychotic disorders. UK carers can attend the online courses.

Details can be found via the website: https://www.psychosisreach.org/

Mind

The national charity has helpful information sheets about different types of mental health issues, including severe mental illnesses, such as bipolar disorder and personality disorder.

The information sheets can be found here: https://www.mind.org.uk/information-support/types-of-mental-health-problems/

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