healthwatch
Norfolk

Experiences of Carers of adults with Serious Mental Illness (SMI)

June 2024

Contents

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Who we are and what we do

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

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

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

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

At Healthwatch Norfolk we have five main objectives:

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

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

Acknowledgements

Healthwatch Norfolk would like to thank all the Carers who took the time to share their feedback as part of this project. We would also like to thank all members of our project reference group (including the three Carers who helped to inform this project) for their feedback and expertise. Finally, we would like to thank all the organisations and individuals who have helped to promote the project and encourage participation.

Summary

Healthwatch Norfolk was Commissioned by the Norfolk and Suffolk Foundation Trust (NSFT) to find out more about the experiences of Carers of adults with Serious Mental Illness in Norfolk, and how they can be better supported.

The term Serious Mental Illness (SMI) is often used in healthcare settings (e.g. hospitals, community mental health settings and GP practices) to refer to psychological problems that are often so debilitating that people's ability to take part in *'functional and occupational activities'* (e.g. cooking, cleaning and going out) is severely affected (Healthy Surrey, 2024). Common diagnoses associated with SMI include schizophrenia, bipolar disorder, and psychosis. Research suggests that Carers of adults with SMI have had to fight for the person they support's treatment and care, had issues in being included in the person they support's care and felt that the voice of the Carer is not always being heard (Healthwatch Norfolk, 2024).

We gathered feedback through a variety of methods including a survey, interviews, and an online focus group. From these we were able to gain a greater understanding of the experiences of Carers of adults with SMI, particularly regarding: the information and resources available to Carers, Carer health and wellbeing, Carer involvement and whether Carers feel their voices are being heard.

Once we had identified the usable responses (those that met the project criteria) we received 64 responses to the survey. We also spoke with a focus group of six Carers and interviewed 13 people.

Just under half of survey respondents told us they were dissatisfied that their voice is heard by staff if they made a suggestion or gave them information about the person they support. This was a common theme throughout the survey and interviews, with Carers commenting that they felt their voices were not being heard and they were not given the recognition, respect, or value that they deserve. Interviewees commented that they have had to fight for the person they support's care and have generally encountered a range of communication issues which have left them feeling dismissed and not involved. This suggests there should be more staff training on the value of SMI Carers and how to involve them more in the care of the person they support.

Most Carers told us that caring has had a negative impact on their physical health, mental health, finances, and relationships. Almost half of survey respondents told us they have found it difficult to get support for their own health and wellbeing. Several Carers also commented that when they did receive support this was not appropriate or specialised enough for Carers of adults with SMI.

The majority of Carers would like more information about SMI, medication and side-effects and more specific information and resources on being a Carer for someone with SMI. This suggests that Carers should be given information specific to the diagnoses of the person they care for, and ideally tailored to the person so that Carers and staff can work together to support the adult with SMI.

Many Carers think that their experiences could be improved if there was more mental health provision and better care for the person they support. There are issues with continuity of care, communication, and crisis services. Some Carers also have a lack of trust in services, due to poor experiences.

Overall, the findings of this report suggest that Carers are not having their voices heard, with many not being involved in the person they support's care as much as they want to be. Carers' experiences can be improved by there being more support for them, an improvement in Care for adults with SMI and if Carers were listened to and involved more.

From the findings of this piece of work, the following recommendations can be made:

1. **More staff training to better value, support and involve Carers**- This includes delivering training to staff who care for adults with SMI, staff who provide psychological support (e.g. Wellbeing staff) and any members of staff involved in carrying out Carer's Assessments.

2. **Increase communication and information for Carers of adults with SMI** - Specialised information on SMI, Medication and side effects and information on being a Carer for an adult with SMI should be developed. There should also be reminders to staff to contact and reply to Carers.

3. **Increase Carer involvement and voice**- Explore the possibility of having Carer groups or Carer forums for each service of NSFT that cares for adults with SMI. Explore the possibility of employing Carer Champions at NSFT.

Please note that more details on these recommendations are provided at the end of the report.

Why we looked at this

Aims and objectives

Healthwatch Norfolk was commissioned by the Norfolk and Suffolk Foundation Trust (NSFT) to find out more about the experiences of Carers of adults with Serious Mental Illness (SMI) to see how their experiences can be improved and how Carers can be better supported. The project was commissioned following discussions with three Carers of adults with SMI, whose experiences have helped to inform this piece of work.

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 is a three-year project, which should be completed by the end of July 2026. This interim report covers the period from July 2023-July 2024.

Background

The term Serious Mental Illness (SMI) is often used in healthcare settings (e.g. hospitals, community mental health settings and GP practices) to refer to psychological problems that are often so debilitating that people's ability to take part in *'functional and occupational activities'* (e.g. cooking, cleaning and going out) is severely affected (Healthy Surrey, 2024). Common diagnoses associated with SMI include schizophrenia, bipolar disorder, and psychosis.

There are currently 9,194 people[1] on the SMI register in Norfolk & Waveney (NHS Norfolk and Waveney Integrated Care Board, 2024). Besides the mental health impact of their conditions, people with SMI also often have poorer physical health than the general population and can often develop chronic physical health conditions, such as obesity, asthma, diabetes, chronic obstructive pulmonary disease (COPD), coronary heart disease (CHD), stroke, heart failure and liver disease at a younger age than the general population (Office for Health Improvement and Disparities, 2023). Adults with schizophrenia, bipolar

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[1] As of 31/12/2023

disorder or psychosis should be invited by their GP surgery to have a free annual health check each year (Norfolk and Waveney Integrated Care System, 2024).

It is estimated that there are over 100,000 unpaid Carers in Norfolk (Norfolk Safeguarding Adults Board, 2024). The Carers Trust defines a Carer as *"anyone who cares, unpaid for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support"* (Carers Trust, 2024).

It is estimated that unpaid Carers in England and Wales contribute £445 million to the economy each day, which totals £162 billion in a year (Petrillo and Bennett, 2023). However, Carers are not always able to access support for their own health and wellbeing (The Kings Fund, 2023). Almost three quarters of Carers with 'bad' or 'very bad' mental health are continuing to provide care, despite feeling at 'breaking point'. Research suggests that one in three Carers with poor mental health have had thoughts relating to suicide or self-harm (Carers, UK, 2023). A key issue that affects many Carers' quality of life is making sure that the person they care for has access to good health and social care (The Kings Fund, 2023).

Carers of adults with SMI have described how they feel stigmatised and marginalised by professionals that provide services and how a lack of understanding and support can cause them an increase in anxiety and ill-health (Healthwatch Kent, 2015). Previous Healthwatch Norfolk work also suggests that Carers of adults with SMI have had to fight for the person they support's treatment and care, had issues in being included in the person they support's care and felt that the voice of the Carer is not always being heard (Healthwatch Norfolk, 2024).

Carer involvement in mental health treatment has consistently been supported by research and promoted by policies (Giacco *et al*, 2017). For example, the Mental Health Act Code of Practice for England (2015), states that Carers should be involved in decisions about care and treatment (when the patient wants this or if the patient does not have the capacity to understand) (NHS, 2018). Research also suggests that Carer involvement can help patients and staff to recognise and respond to early signs of relapse (Herz *et al*, 2000). When Carers are involved in treatment, patients are also more likely to experience improvements to their symptoms (Norman *et al*, 2005).

However, Carers are often not involved in practice (Giacco *et al,* 2017). This is particularly the case, when patients are treated in inpatient settings where

Carers often feel that they are not included in decisions about the care of the person they support (Wilkinson and McAndrew, 2008).

Therefore, it is important to gain a greater understanding of the experiences of Carers of adults with SMI and how they can be better supported.

How we did this

Methodology

The project aimed to collect feedback from Carers of adults with SMI to understand more about their experiences and how they can be better supported. We designed a public survey which was created using SmartSurvey, ran a focus group and conducted interviews with Carers.

We chose to conduct in-depth semi-structured interviews to get a detailed and nuanced idea of Carers perspectives. They also give people a chance to freely express their views because the questions are quite general and open. We also ran a survey as these help us to check our findings with a larger number of people and see whether they are more broadly applicable.

When analysing the interview and survey data we found that not many Carers had told us about their experiences of accessing information and resources. We then decided to run a focus group, to find out more about Carers' experiences of these. The target audience for this project are Carers of adults with SMI.

Participation in the survey, interviews and focus group was entirely voluntary and participants gave their consent for their answers and views to be shared in this report anonymously.

We wanted to know more about:

- The information and resources available to Carers
- Carers' perceptions of how being a Carer impacts on their health and wellbeing
- Carers' involvement in the person they support's care

- Whether Carers feel their voices are heard

Project Reference Group

As part of this project, we created a project reference group. The group consisted of Carers, a Mental Health Commissioning programme manager and staff from NSFT, the Integrated Care Board (ICB) and voluntary organisations such as Carers Voice and the Norfolk Integrated Housing & Community Support Service. The purpose of the reference group was for members to provide advice and guidance based on their experience and knowledge of the issues faced by Carers of adults with SMI. The group meets quarterly, and members gave feedback on the survey, interview discussion guide, Carer definition and definition of Serious Mental Illness used in this project.

Definition of Serious Mental Illness

There are varying definitions of Serious Mental Illness and the diagnoses that this includes. For this project, we have used the following definition, based on feedback from the project reference group:

Serious Mental Illness (SMI): *"is often used in healthcare settings and refers to psychological problems that are often so debilitating that people's ability to engage in functional and occupational activities is severely impaired"* (Healthy Surrey, 2024).

Common diagnoses associated with SMI include:

- schizophrenia/ schizoaffective disorder
- Bipolar Disorder
- Psychosis
- This can also include other diagnoses such as major depressive disorder, personality disorder and eating disorder, (when they are long-term and severely impact the person's life).

Throughout this report, there will be a focus on Carers of adults with schizophrenia, bipolar disorder, and psychosis. This is because these diagnoses are in the NICE guidance for physical health checks (NHS England, 2024). This focus should not be seen to imply that other diagnoses are not ‘serious’ or ‘severe’ or do not carry any other physical health risks.

We have also included responses from Carers of adults with other diagnoses such as personality disorder, Post-Traumatic Stress Disorder (PTSD) and obsessive-compulsive disorder (OCD), when these diagnoses are long-term and severely impact the person’s life. This was to ensure that anyone who identifies themself as a Carer of an adult with SMI had the opportunity to have their voice heard.

Definition of Carer

Based on feedback from the project reference group, we have used The Carers Trust definition of a Carer as *“anyone who cares, unpaid for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support”* (Carers Trust, 2024). We have also capitalised the word ‘Carer’ throughout the report to show the importance of Carers, this was based on the feedback from the project reference group.

Survey

Healthwatch Norfolk worked with NSFT to create a Carer survey with a series of questions to meet the aims and objectives of the project. To reach as many people as possible, both online and print surveys were used. There was also an option to call Healthwatch Norfolk and complete the survey over the telephone.

The survey ran from Monday 22nd January 2024 to Monday 11th March 2024 and all responses (n=72) were collected during this time frame. Once we had identified the usable responses (those that met the project criteria), there were 64 responses in total.

Interviews with Carers

We conducted in-depth semi-structured interviews with Carers of adults with SMI to gain more of an insight into their experiences. We conducted 13 interviews in total which were done using either telephone or Microsoft Teams. The interviews were thematically analysed using NVivo and some were turned into case studies.

We primarily recruited the Carers through the survey, although we also interviewed some Carers who wanted to take part but had not completed the survey. It should be noted that two of the Carers we interviewed were based in Suffolk. Whilst the focus of this project is on the experiences of Carers in Norfolk, we have included the Suffolk interviewees feedback as they still have valuable experience of being a Carer of an adult with SMI and the person they support being cared for by NSFT. However, any quotes from the Suffolk interviewees will be clearly labelled to avoid confusion.

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

Participant involvement and consent

To encourage people to take part in the survey, we developed a range of promotional materials, with a goal of reaching as many individuals and groups as possible, including seldom reached communities.

Healthwatch Norfolk promoted the survey through social media posts on the Healthwatch Norfolk website and in the Healthwatch Norfolk newsletter. We also created a video to encourage people to take part (Figure 1) which was promoted on YouTube and the Healthwatch Norfolk website.

Figure 1. A video shared on social media and our website to explain the Carers of adults with SMI piece of work

We contacted a range of local stakeholders (including organisations such as Carers Voice, Carers Matter and Caring Together) to promote engagement with the survey amongst their networks. The survey was also shared with the Norfolk and Waveney Mental Health Provider Forum to ask members to help to encourage participation. We also presented the project at a Norfolk 'Sharing & Learning event' where NSFT, Voluntary Community and Social Enterprise (VCSE) organisations and other services supporting mental health come together to talk about what they do. Participation in the interviews was promoted within the survey itself and through word of mouth.

To try to widen participation and offer opportunities for those who may be digitally excluded, the Healthwatch team attended a range of events to promote engagement in the survey and interviews. These included: Dereham Mental Health Carers group, Norwich Mental Health Carers group, Great Yarmouth Fire Station, and Banham Community Café. We also put some leaflets in the Kings Lynn Steam Café and the Norwich Mind Rest Hub.

We also contacted staff at NSFT and asked them to promote and encourage participation in the project. This included staff from the Early Intervention in psychosis service, complex psychosis team and the head of Carers participation and experience.

The sample size for the public survey and interviews was not set in advance as both were entirely voluntary and members of the public chose whether to provide feedback.

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SHARE YOUR STORY

Do you care for someone with an SMI (Serious Mental Illness)?

We would like to hear your experiences. You can do it by:

Scanning the QR code to fill in our survey

Logging on to bit.ly/SMICarers

Calling us on 0808 168 9669 to arrange a chat

An SMI can be:
Schizophrenia/Schizoaffective disorder
Bipolar disorder
Psychosis
Other long-term disorders that severely impact someone's life

Figure 2. An example of a poster used to promote the survey.

Survey data analysis

A range of analysis methods were used as the survey included a variety of question types, including open-ended, closed-ended and multiple-choice questions. The results and comments are reported on in the 'What we found out' section.

Answers that were closed-ended or multiple choice were exported from SmartSurvey and analysed in Excel. Percentages in this report are rounded to the nearest whole number. Answers where participants could write their own answers, were analysed using thematic analysis using NVivo. This enabled comments to be coded to establish themes, which are explored further in the 'What we found out' section of this report. Any comments used as direct quotes in this report have been left unchanged, this is to ensure originality. Any major grammatical or spelling errors will be marked with "[sic]."

Demographic data was also collected to gain a better understanding of the reach of the survey to help make sure we engage with people from different backgrounds and so that we can understand what needs different groups in our community have.

A copy of the survey questions can be found in Appendix 2. A summary of this demographic data can be found in Appendix 3.

Focus Group with Carers

We ran an online focus group with Carers, which was facilitated by Carers Voice. This allowed Carers to share their views on the information and resources available to Carers of adults with SMI. The number of participants was limited to a maximum of eight people, this is because it has been noted that focus groups with six to eight people, often work well (Office for Health Improvement and Disparities, 2020). The focus group consisted of six Carers, who were caring for adults with a range of diagnoses including paranoid schizophrenia, bipolar disorder, borderline personality disorder and episodes of psychosis.

A copy of the questions can be found in Appendix 4.

We asked Carers Voice to recruit Carers and facilitate the focus group. It should be noted that two participants had already taken part in an interview for this project and another Carer had to leave the focus group early due to other commitments. One Carer was also based in Suffolk.

The focus group and interviews were recorded and the data sent off for transcription. The focus group transcript and interview transcripts were then analysed using thematic analysis in NVivo. The themes are reported on in the 'What we found out' section of this report.

Other activities

Bi-monthly Carers meetings

We have continued to have regular bi-monthly meetings with the three Carers who helped to inform the project, to ensure that they have their voices heard.

Carers of adults with SMI Action Plan

Healthwatch Norfolk held an event in July 2023 where Carers of those with SMI and leaders in health, social care, housing, charities and voluntary organisations, and councils met to give an insight into the issues that Carers of adults with SMI are facing. There was an artist at the event who captured the key themes of discussions and Carer's experiences. The artwork produced is shown in Figure 3 below.

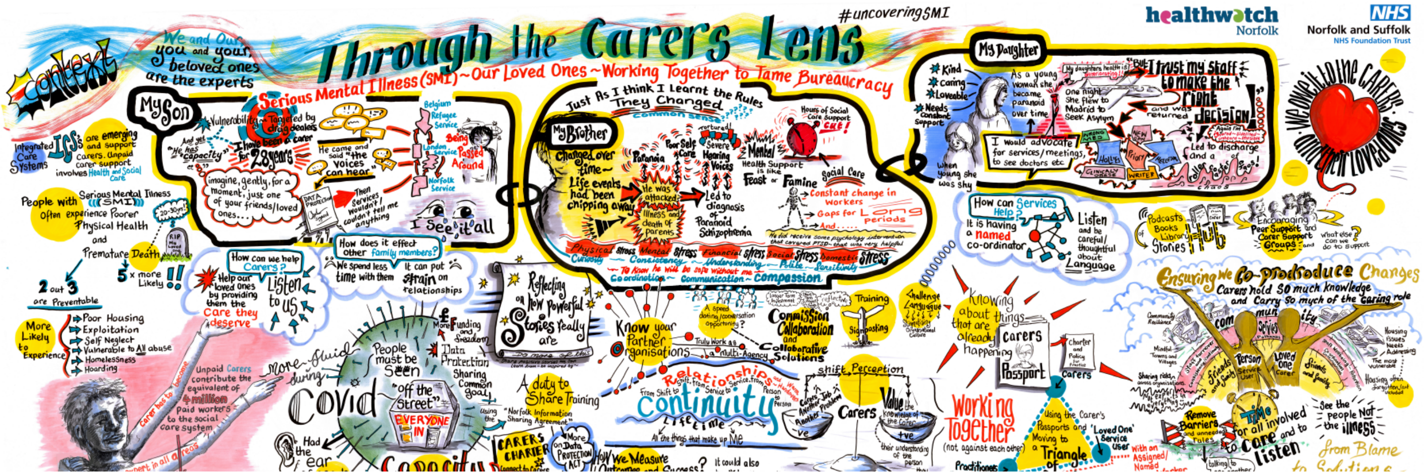

Figure 3. A photograph of the artwork that was created from the SMI Carers event in July 2023.

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. It was then decided that an action plan would be created following these discussions. Organisations at the event were assigned to various actions.

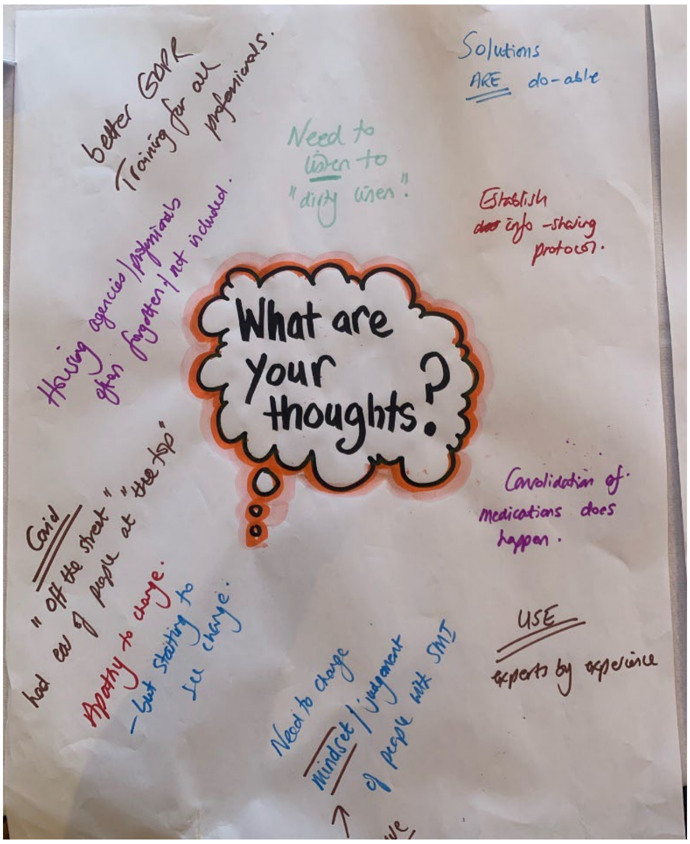

Figure 4. An example of some notes made at the July 2023 event on ideas of how the experiences of Carers of adults with SMI can be improved.

One of the main overarching goals of the action plan is for Carers of adults with SMI to experience positive changes. The actions have been refined throughout the project to ensure that they are clearer and more actionable to help make sure that changes are made. We will be holding another event in July 2024 where we will be following up on some of these actions and seeing what progress has been made. The details of the progress that has been made will be included in the Year two project report, which is due to be published in summer 2025.

Limitations

As there are 9,194 people[2] on the SMI register in Norfolk & Waveney (NHS Norfolk and Waveney Integrated Care Board, 2024), we cannot say that the sample size (n=64) of this work is representative of the entire population of Carers of adults with SMI in Norfolk. However, it does provide an insight into people's experiences of being a Carer of an adult with SMI.

We also cannot say that our responses are representative of the population of Carers of adults with SMI in Norfolk, as there were some areas of Norfolk that we did not receive any responses from including people living in NR13, NR15-NR17, NR23 and NR26 (e.g. Long Stratton, Acle and Sheringham). The majority of respondents were also women (50, 78%) which does not reflect the population as only around 59% of unpaid Carers are women (Census, 2021 cited in Carers UK, 2024a).

Whilst we tried to reach people who are digitally excluded, we only received one paper survey (once data was cleaned). Therefore, due to the small sample size we received, we cannot say that the responses are representative of this population. However, we will try to engage more with Carers who are digitally excluded in Year 2 or Year 3 of this work, to ensure their voices are heard.

We also may not have fully captured certain groups of people's views. For example, we only receive a small number of responses from people aged 16-25 (2, 3%) and 26-45 (5, 8%). These Carers may have had different views or experiences; therefore, we cannot say we have fully captured their views in this research.

The surveys, interviews and focus group were all completed by Carers who spoke English. Therefore, we have not reached Carers of adults with SMI who do not speak English. For example, most Carers that completed the survey were British, English, Northern Irish, Scottish or Welsh (57, 90%). These Carers may have had a different experience, especially when trying to access information, resources, and support.

There were several potential barriers to participation in this project, including Carers not having the time or energy to take part and people not viewing themselves as a Carer. Research suggests that it takes people an average of two years to view themselves as a Carer (Carers UK, 2024b).

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[2] As of 31/12/2023

What we found out

Carer stories

Throughout the interviews Carers shared their experiences of being a Carer of an adult with SMI. This allowed us to gain an insight into Carer's experiences of accessing information and resources, their involvement in the person they support's care, whether they feel their voice is heard and the impact this has on their own health and Wellbeing.

Some of these experiences have been presented in the case studies below. These were picked to show a range of diagnoses and relationships, and to show the impact on individual Carers of the issues discussed later on in the report. This does not mean that any experiences that have not been turned into a case study were any less important or valuable, and they form part of the broader analysis of data that follows the case studies.

Case Study 1: Rebecca's story

Rebecca* is 64 and cares for her adult son Jack who has psychosis and Severe Depression. Rebecca has been caring for him for around four and a half years, but in the last six months Jack's mental health has *"got a lot worse".* Jack had lived in London for years but had become paranoid and was experiencing delusions. This resulted in Jack coming home to live with Rebecca and her husband in Norfolk.

"He [Jack] became unable to carry on working and he was living with a girlfriend and the relationship broke down. So, then he didn't have anywhere to live either, although he was still living there [in London]. But in the end, he came to live with us, and he was very ill."

Rebecca explained how her son was angry with people who he felt were '*persecuting him*' and how she was worried he might hurt someone. *"We were afraid he might go out and hurt somebody, but he never did hurt anybody. But it was frightening really. It was frightening at the time."*

Rebecca has found it difficult to live with *"somebody who is always unhappy and also doesn't make eye contact and he doesn't say anything". She* described how caring for her son has impacted her mental health as she feels guilty and feels as though she was a bad mother because of her son's illness and because she feels that her son "*takes after*" her.

"Although, no, I've never been psychotic, but I've had the same kind of social anxiety that he had since he was a teenager. So, I think it's just like me. And then I think I haven't been a good enough mother, […], although possibly now I've come to the conclusion that I wasn't as bad as I think I was."

Caring for her son has also had a negative impact on Rebecca's relationship with her husband, as they both found it difficult to understand the situation they were in, which resulted in them getting angry with each other.

"This has been going like that for years and for a long time me and my husband just ended up getting angry with each other. I think it was just so difficult to understand the situation that we just didn't know what to make of it"

Since being a Carer, Rebecca has also lost her freedom as she is unable to go out and do what she wants. She also cannot go on holidays with her husband as going away for long periods makes her son's delusions worse. This has also resulted in Rebecca seeing her mother less, as she lives abroad. .

"And that's another thing, we couldn't go away together. We wouldn't want to leave him here for 10 days on his own. Now that would be terrible for him being on his own, being lonely."

Rebecca tried to get support for her own health and wellbeing and was *"desperately looking for support"* but all the things she found *"seemed quite distant or a bit irrelevant".*

Rebecca had a Carer's assessment and found this useful as she received counselling and *"was very happy with that and it helped"*, but she now does not receive any support other than the mental health Carers support group she attends and seeing her friends. Whilst Rebecca finds the group helpful, she notes that it does not help her situation of being a Carer of an adult with SMI.

"It doesn't help with this role that we still have and we don't want to have really, yeah, I want my son to be independent and able to live, not to live with us like this and in bed all day and not, not happy at all actually in a kind of constant hell"

Rebecca explained that she doesn't feel as involved in her son's care as much as she wants to be and whilst she feels the Psychiatrist has a *'deep understanding'* of her son's condition *"he doesn't make any suggestions or any plans with us as to how to proceed and there's nothing like that".*

Rebecca explained how she has had difficulties trying to talk to her son's therapist as her son does not want her to do this as he will think she is *"making a fuss over nothing"*. However, Rebecca explained that the Care Coordinator *"basically told me off for calling him without telling my son, I can't tell my son I'm going to call any of them there because he says, no, don't want you to."*

Overall, Rebecca has had mixed experiences communicating with the staff looking after her son. She felt that his care coordinator was not approachable, however, she described her son's current psychiatrist as a *'lovely man'* and said that he has *"been our strongest support really".*

Rebecca also described the difficulties of getting financial support for her son. She explained that she feels her son is entitled to PIP and council tax but has had challenges getting this as her son is not aware he is ill.

"And so [sic], *looks like I can't apply because it's a real symptom of psychosis, not knowing that you're ill. It's part of the illness, but of course it's not taken into account. [...] He has to be with me apparently if I ring about PIP, he has to be there to say he agrees with me making the phone call. And so, he is never going to do that."*

Rebecca explained that she feels that nobody can support her better than if her son is well looked after and cared for.

"I don't think anybody can support me very much other than in looking after him and talking to him in the right way and helping him if nobody could support me to help him. [...] I still need help to help him, but in the way that helps him and not in the way that just tells him it's all in his head"

Since taking part in the interview, Rebecca told us that she feels more hopeful now, since starting a course called Psychosis REACH. The course helps Carers of people with psychosis, to communicate with the person they care for. Rebecca explained how the course has helped her as she is now much more able to talk to Jack which has resulted in him agreeing to apply for PIP and increase his medication.

Rebecca explained that she now also feels differently towards the Carers group she attends and told us how she finds the group helpful and how she appreciates the group members *"a lot".*

"I still dip into depression and become unable to cope, but I come out of it again. The support group now really helps to lift me and keeps me going".

- *All identifying information has been removed*

Case Study 2: Sally's story

Sally cares for her son Max who has Paranoid Schizophrenia and has been caring for him for over 25 years.

When Max was 17 and studying for his A Levels his "*mental state changed dramatically*". Sally tried to get mental health support for her son but hit obstacles such as being labelled an "*over-anxious mum*". Sally did not initially have the confidence to confront this as she was frightened of upsetting any doctors or mental health professionals *"because you think that it will have a backlash on your loved one"*, which left her feeling sidelined.

Over the years, Sally has had experiences with three different mental health trusts and one private institution. She explained that none of these trusts ever *"gave caring and compassion to people with serious mental illness"*. Sally thinks this is because people who are seriously mentally ill have always *been "bottom of the pile"* in terms of funding, which has resulted in both staffing and care getting worse.

Sally explained how Max started taking drugs *"to try and help with the voices in his head and the hallucinations*" he was having. She explained that it is common for people with SMI to take alcohol or illicit drugs. The medication that people with SMI take can have a lot of unpleasant side effects, including overeating. Sally believes that her son's drug taking "*is as a result of coercion*" She now feels that her son is in a "*dangerous situation"* due to a *"lack of numbers of staff to actually run an efficient service"* with Sally often envisaging *"a police car coming up my drive to* *tell me that he's dead because he's drug overdosed. And that is a big reality for me".*

Sally explained how it is difficult being a parent of an adult with SMI as she questions whether her son has a serious mental illness because of something she has done *"in your heart you're thinking, is there anything I'd done that would make this happen?"*. She also explained that a lot of psychiatrists feel that serious mental illness is the result of abuse, but how this is hurtful and very difficult for Carers as she knows that her son *"came up in a household where he was loved and nurtured and there was no abuse".*

Caring for her son has had a negative impact on Sally's life. She told us that she does not have a life and instead has *"an existence because of Max's life"* and always has to be nearby. Sally tried going on holiday and paying for people to look after her son but then *"things have happened"* and she had to be on the phone trying to sort things out. Sally explained that caring has *"a huge impact in your life and the way your life goes"* explaining that at this stage of her life she thought she would be *"a grandmother with teenage grandchildren and he [Max] would be happy, but it didn't happen that way".*

Sally also feels anxious, depressed, and isolated and described how people will make judgements on her parenting.

"Really, you're very isolated because everybody seems to know best about how things should be. I mean, I've had comments like, well, he just needs to go off his backside and get a job. And it's hurtful because people are making judgements on your parenting."

Sally noted that staff need to be aware of how *"fragile"* Carers really are.

"Sometimes, I suppose the name Carer implies that the big strong, hearty person that nothing touches. And yes, we all have this mask, but underneath it all we're not so strong".

Despite the impact that caring has had on her life and her own health and wellbeing, Sally feels that that money spent on Carer organisations would be better spent having staff to look after her son. Sally explained that if her son got better care, it would make her feel better.

"Our broken hearts can be better mended, glued together by better care for our loved ones.".

Sally explained that her life would be totally different, if her son did not have an SMI and if he was happy and working and believes that Carers can be helped is if the person they care for is helped.

“I'd probably be doing quilting or cross stitching or talking about the price of eggs. I wouldn't be the person I am now […] Life would be very different if so, the only way that you can actually help Carers is to help the loved ones because they are, stress is directly proportional to their illness”

Sally described some of the poor experiences of care her son has received, including when he ran away from Southwest London and was found in a refugee centre in Belgium.

“And when asked how he got there, he travelled by spaceship and instead this is where we were still in Europe. And instead of mental health professionals going to get him, he was put on a ferry and then a train to get back to London. So, there's been some horrendous experiences”

Sally also described how Max was arrested three or four years ago but a manager at NSFT would not tell her where her son was, which resulted in Sally being unable to get information and she later discovered that Max was due in court, but she was unable to get the date of this, so could not arrange legal representation for her son.

Max was under the influence of illicit drugs *“and was arrested by the police and went to court and the safeguarding at NSFT, the manager who I won't name, but he would not tell me where my son was. He wouldn't answer the question, data protection. And I was there for completely shut out. So, I couldn't even get a legal representation from my son.”*

Sally explained how *“you are forever fighting to be involved”*. She described how she has been trying to find out information about what is going on with the care of her son, but this has been *like “trying to get blood out of a stone”*. Sally explained that *“the lack of communication is a very serious issue”* and that generally Carers are not informed or kept updated.

“I feel that we’re not involved, we’re not seen as equal partners, which makes the triangle of care look like the Bermuda Triangle”. Sally also explained that Carers “have no status”.

Sally also described a poor experience with the mental health team and how she finds that the system is disjointed and how she has had to contact a variety of teams such as social services and the psychiatrist to try to find out information as “*nothing’s coming to me*”. She explained that the lack of communication and coordination has left her thinking “the worst”.

Sally feels that Carers are not respected, involved, or listened to and have no power or voice.

"Carers have no control, they have no authority, they've got no power. The power lies within the trust. Social services, GPs, supported accommodations. We have no power; we have no voice."

- *All identifying information has been removed*

Case Study 3: Alfie's story

Alfie is 55 a Carer for both of his adult children with serious mental illness. Alfie's children Alex and Rose have a range of diagnoses including psychosis, Personality Disorder, an Eating Disorder, Severe depression, PTSD, OCD and severe anxiety.

It took Alfie a while to view himself as a Carer and he has only been identifying as a Carer for the last few years as he just saw himself as a dad *"taking that language of carer onto myself took me a while. It's only been the last sort of two, three years I've really done that."*

Alfie found it difficult to find information on the diagnoses that his children had received and felt that the information available was not accessible to the *'lay user'*. He explained that whenever a diagnosis is made, there should be an assumption that the patient has a Carer, and they should be given information on the condition.

"I think that whenever a diagnosis of such an issue is made, there should be an assumption that there's a carer in the picture. So that carer should maybe have offered a conversation at that point just to say, have you ever heard of personality disorder? Cause I really haven't. Have you heard of personality disorder? This is what it is. Here's some information."

Alfie has found being a Carer constantly demanding and it has had a negative impact on his life: *"So it is pretty relentless. And so, you'd be with one all day and then you're just lying down and then the other one pops up because one of them has sleep issues"*

Alfie has not been able to stay at his partner's house and feels he has no control of what he does. He has also had to give up his job due to caring, so his only income is Carers allowance, which he has found "tough".

"So, I used to have a relatively senior job, so there are parts of my brain which are not being exercised, not being used, which is frustrating. I have no agency, none. I have no control over what I do any given day. And that is day in, day out, seven days a week, 52 weeks and a year."

Alfie had a Carer's Assessment and found this useful as he was able to get some psychological support which was *"really helpful and really valuable"* as he has had difficulties trying to access support and falling through the gaps. He was also able to get help *"fixing some things"* in the house.

Alfie explained that he would have a Carer's Assessment again as he felt that Carers Matter were trying to help him, unlike his experiences with other services which made him feel '*dismissed*' and *'patronised'*. He also explained how he had tried to *"go through the GP to seek help"* but *"there isn't help, which is tough"*.

Alfie explained that his daughter Rose was once at "the front of the queue" for a service, but she told them she did not want help so was dismissed from the service. Alfie feels that this is an excuse not to treat her and services should *"maybe ask why they're saying that rather than just chuck them out"*.

Alfie also described how when his son had taken an overdose a member of staff told him "*You haven't taken enough, typical borderline go away and take more. You'll probably succeed next time"*.

Alfie explained how it is difficult to get crisis support at night, yet this is the time when "issues most often arise". He explained that his son has found the Crisis Team variable and sometimes will not contact them, and his daughter is "not open to them at all". Alfie has tried calling 111 option 2 but *"in practice the last three times I've used it I've had waits of 90 minutes or so"*.

Alfie feels that he does not need to know all the details of meetings as he thinks his children should still have some privacy.

"I don't know any of the detail of the stuff that's discussed. Neither should I, that's not my stuff to know. But it's around safety or just general direction of travel. We do just touch base and that's appropriate and it's good."

Alfie feels that sometimes his voice is heard by individuals, such as his son's former care coordinator but generally feels unheard in relation to the needs and conditions of his children and in terms of his own health and the lack of support available when he is struggling to manage his own mood and general physical and mental health.

Alfie described a number of the challenges he has faced being a Carer of an adult with SMI, including the relentlessness, lack of information and lack of acknowledgement and support.

"The relentlessness is a big one […] But it's just the challenging, the lack of information, the lack of acknowledgement or support from the trust really. They just assume that because the trust actually has a duty of care to my kids and I'm discharging a large chunk of that for free and not getting any help from them for me while I'm doing it […]. And it would be nice to have some proper support from the trust either through supervision or through taking my own mental health because I defy anybody to be in this situation, not have their own mental health suffer."

- *All identifying information has been removed*

Case Study 4: Emma’s story

Emma is 58 and cares for her younger sister Claire, who has bipolar disorder and is awaiting an autism diagnosis. Emma has been caring for her sister for most of her life and cares for her sister’s youngest daughter, Megan.

Claire *“started having problems in her teenage years”* and was first referred to a North Wales Psychiatrist in 1995, but this was not followed up as she did not want this.

It has taken around 26 years for Claire to receive a diagnosis of bipolar disorder. Emma explained that when her sister was diagnosed with bipolar disorder at Chatterton House in 2021, this was one of the first times she has felt listen to as a Carer and felt relieved at her sister’s diagnosis, as she was previously told that her sister was *“just a bit anxious”.*

“I felt for the first time, I as the main supporter and carer was listened to, taken seriously. I wasn't overreacting.”

Claires referral to Chatterton House was not her first connection with mental health services in Norfolk. *“She'd had five previous referrals and on the very last time she was referred, it followed an incident during lockdown, which the police were called to.”*

Emma explained how the staff at Chatterton House had taken the time to look at her sister’s medical background and had noticed a number of professional referrals and letters from Emma saying how she was worried about her sister’s behaviour and asking for referrals.

“So, they had done the research, they had gone into some background, and it was the very first time I felt that had been done”

Emma explained that her sister receiving a diagnosis of bipolar disorder helped her to be kinder and *"more accepting"* of her sister as she was able to understand why her sister was behaving in the way she was.

Emma explained that *"although my sister did, the usual thing"* of not wanting her to go to the appointment. The staff asked her *"can we talk to your sister"* because Emma was constantly writing her concerns about her sister. Staff at Chatterton house also developed a 'traffic light system' to make it easier for Emma to communicate with her sister.

However, Emma feels that if her sister had received a diagnosis earlier, then her sister's daughter, Megan would have had more support as Emma feels that *"having to live separately from her mother"* has harmed her.

Before her sister was diagnosed, Emma felt that her voice was not heard and that she was seen as a *"troublemaker"* and a problem. When she tried to express her views, she felt that social workers and psychologists *"didn't want to hear an alternative narrative".* She also explained that she feels she should be treated with more respect and *"kept in the loop".*

"It was like I was no relevance. I was a troublemaker. They wanted just to get Claire to say, no, I'm fine. I can cope and off the [sic] go".

Emma described how being a Carer has impacted her life. Emma has had financial worries due to bailing her sister out to stop her being evicted and has been called by neighbours and friends because her sister has *"done something really quite odd".* She is also unable to go out of the country on holidays as she needs to be able to get back quickly if her sister *"gets tired and deteriorates".*

Emma told us that her and her husband are *"beholden to my sister's illness"* and there have been times where she worries that her husband would walk away. She told us they both *“want a simpler life”* and that she sometimes thinks about walking away but would not do this to Megan.

“If my sister's mental health deteriorates, there's dementia in the family and we don't get support, maybe I will just walk away and then somebody else will have to do it. So, I think sometimes they need to look after carers and give us respect”

Emma accessed the Wellbeing service and was offered classes for mindfulness. Whilst Emma took part in these classes, she explained that this was not the type of support she needed, as during this time she was also caring for her dad with vascular dementia as well as Claire and Megan. Emma was not aware of the Carers Identity Passport or Carer’s Assessments.

Emma told us that she would *“give anything” for her* sister *“to be mentally well”* and how this has negatively impacted her life, Claire’s life and her children’s lives.

“I would've given absolutely anything. I would rather be the one with an illness to live with than her. It has blighted her life. It has blighted our lives. It has blighted her children's lives.”

- *All identifying information has been removed*

Survey results

Please note that none of the questions were compulsory so the number of responses will vary by question.

Who we received responses from

The survey received responses from 72 people. Once we had identified the usable responses (those that met the criteria), there were 64 responses.

Figure 5 below displays where people who completed our survey live based on the first half of their postcode. As the map shows, we heard from people across Norfolk, with more responses received around Norwich.

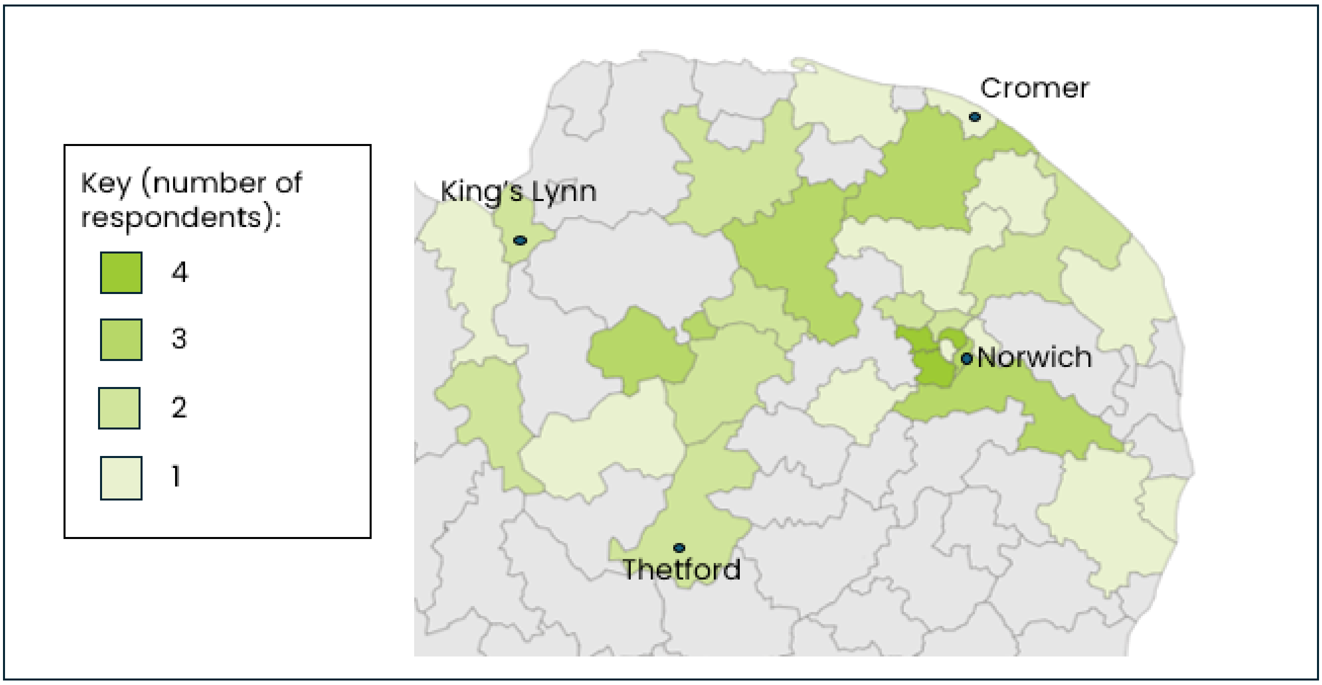

Figure 5. A map of Norfolk showing where survey respondents live based on the first half of their postcode (e.g. NR18). The darker areas on the map show where the highest number of responses came from.

Most respondents told us they:

- Were women (50, 78%)
- Were White British/ English/ Northern Irish (57, 90%)

Around one third of respondents were aged 56-65 years old (20, 34%). Two in five respondents told us they have a long-term condition (25, 39%) and 10 (16%) told us they have a disability. The age of respondents is displayed in Figure 6 below.

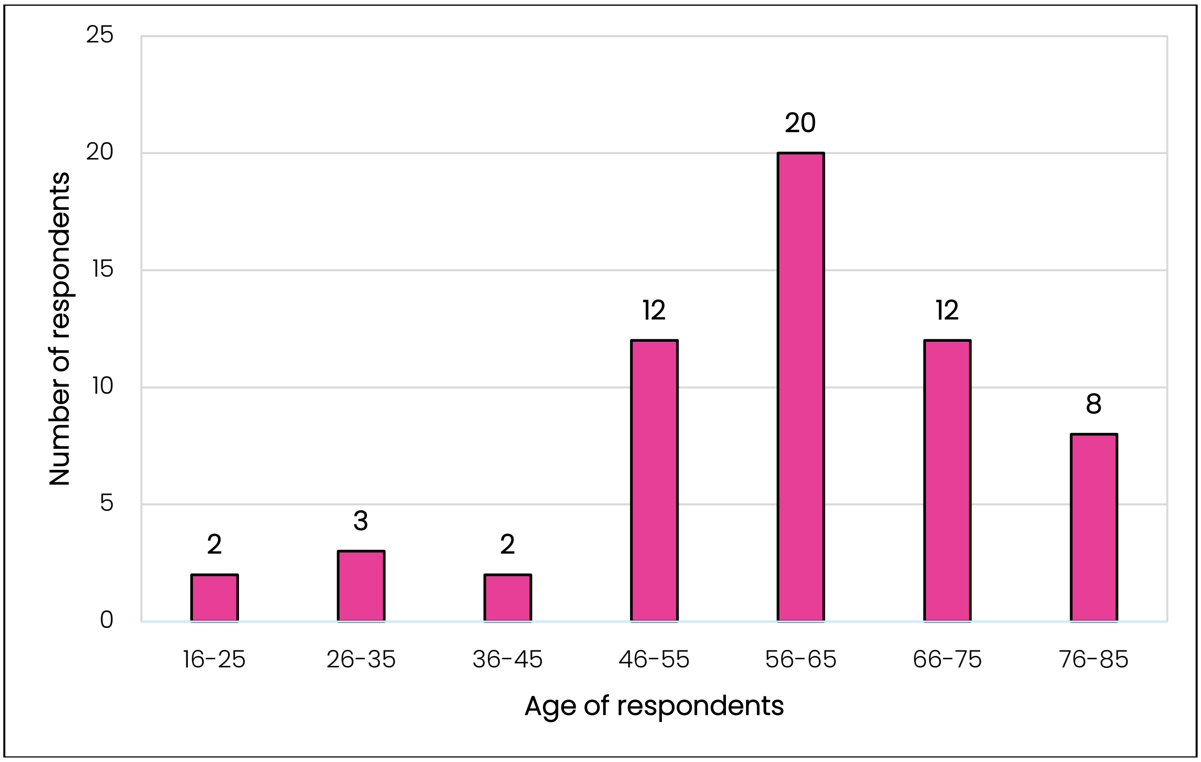

Figure 6. A graph to show the age of respondents.

Around half of Carers do not live with the person they care for (31, 49%) and just under half live with the person they care for (29, 46%).

One in five respondents told us they care for someone with severe depression (26,41%). Nineteen respondents care for someone with psychosis (30%), 16 care for someone with schizophrenia/ schizoaffective disorder (25%) and 12 (19%) care for someone with bipolar disorder. The diagnoses of the person the Carer cares for is displayed in Figure 7.

Two in five Carers (24, 38%) selected the ‘Other’ option. This included a range of other diagnoses including obsessive compulsive disorder (OCD), anxiety disorders and Post-Traumatic Stress Disorder (PTSD).

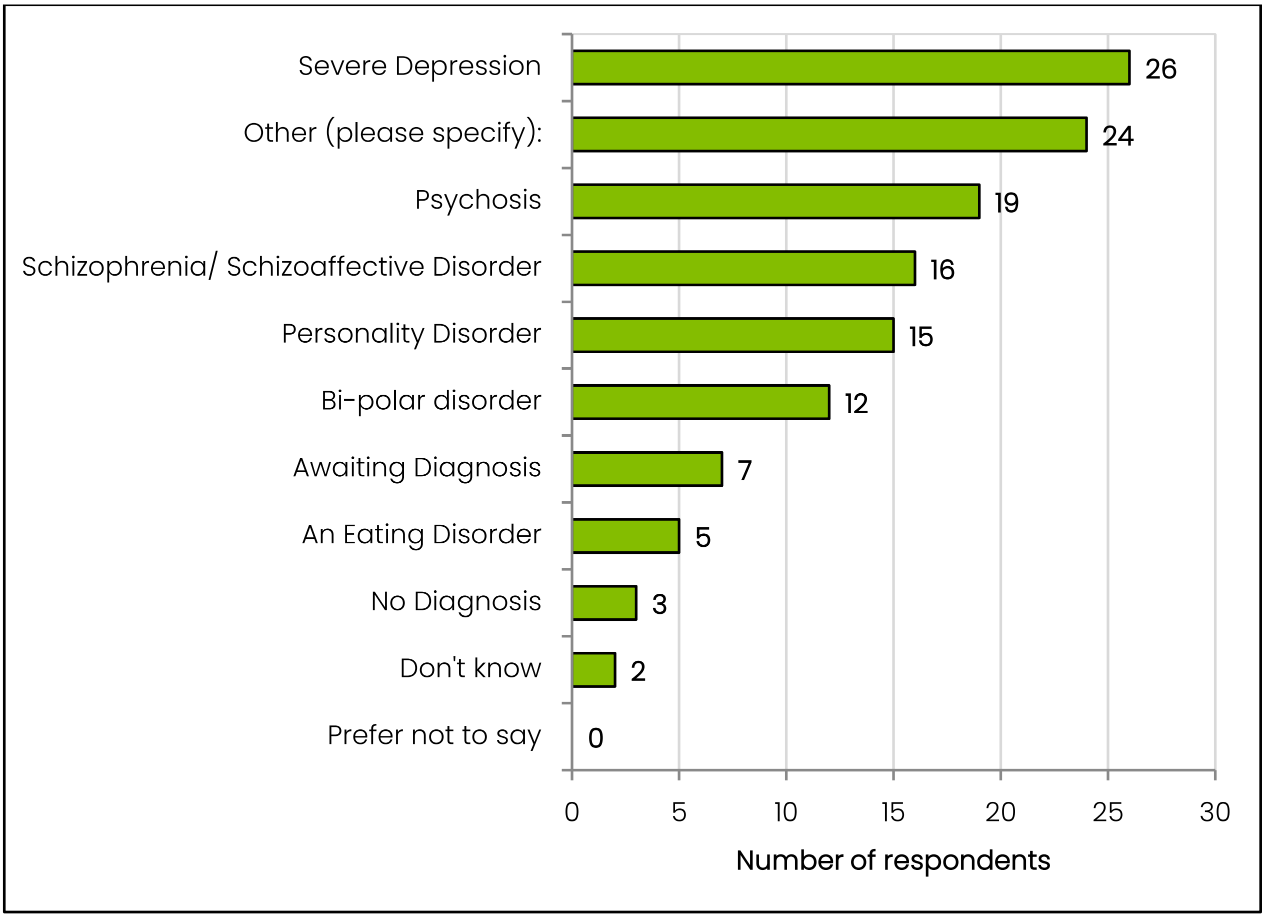

Figure 7. Responses to the question 'Does the person you are caring for have any of the following diagnoses? Please select all that apply'

Information and resources

As part of this project, we conducted desk-based research into what resources and information is available to Carers of adults with SMI in Norfolk. The purpose of this was to gain a general overview of the types of information and resources available to Carers. It should be noted that the information below is not a directory of services.

Information available for Carers

Carers Matter Norfolk
0800 083 1148

Carers Matter Norfolk

"Carers Matter Norfolk is the countywide service funded by Norfolk County Council and the NHS to provide support to unpaid Carers. All services are free and available to people aged 16+ caring for someone aged 18+" (Carers Matter, 2024a). Through the Carers Matter website, there are some online learning courses on mental health which can be accessed (run by open learn create). Carers Matter also developed a Carers Handbook which includes information and contacts for practical help with caring, money matters, health and wellbeing, planning ahead and young Carers and families. The handbook was last updated in 2021 and is due to be updated again. Link to the Carers Matter Norfolk website: https://carersmatternorfolk.org.uk/

Mind

Mind have information online about Caring for someone with a mental health problem. They also have separate pages with more information on different diagnoses such as bipolar disorder and Schizophrenia (Mind, 2024). Link to the Mind website: https://www.mind.org.uk/

Norfolk and Waveney Mind also have a Carers Service for Carers aged over 16 caring for people living with or recovering from mental ill health, in Great Yarmouth and Waveney (Norfolk and Waveney Mind, 2024).

Carers Rights Guide (Healthwatch England)

Healthwatch England have put together a webpage with information about some of the help and support which is available for Carers (Healthwatch England, 2023). Link to the Healthwatch England Carers Rights Guide: https://www.healthwatch.co.uk/advice-and-information/2023-06-07/what-support-can-i-get-carer

Carers UK

"Carers UK is the leading national charity for unpaid Carers. We support, advocate for, champion and connect Carers across the UK, so that no one has to Care alone" (Carers UK, 2024c). The website has general information on being a Carer and help and advice with financial support, practical support, work and career and health and wellbeing. Link to the Carers UK website: https://www.carersuk.org/

Caring Together

"Caring Together is a leading charity supporting Carers of all ages across Norfolk, Peterborough and Cambridgeshire" (Caring Together, 2024). They provide information and advice, run services in local communities and campaign so that Carers have choices. The website has general help and advice for Carers including information on Carer's rights, financial support, Carer's Assessments and the Care Act 2014. Link to the Caring Together website: https://www.caringtogether.org/

Rethink Mental Illness

Rethink Mental Illness have a 'Carers' hub' on their website This includes a variety of information, such as supporting someone with a mental illness, confidentiality, Carer's Assessments and responding to unusual behaviour linked to mental illness. The site also has information on different mental illnesses such as schizophrenia, bipolar disorder, and psychosis (Rethink Mental Illness, 2024a). Link to the Rethink Mental Illness website: https://www.rethink.org/

Carers Trust

The Carers Trust has a page on caring for someone with a mental health condition and taking care of your own mental health. This includes a variety of links to other sites such as Mind and Rethink Mental Illness. The site also has general information on Money and Benefits and Health and Wellbeing (Carers Trust, 2024). Link to the Carers Trust website: https://carers.org/

Royal College of Psychiatrists

The Royal College of Psychiatrists website has a page on 'Caring for someone with a mental illness.' This includes information on how much you can be involved in someone's medical care, the benefits you are entitled to, the challenges that come with being a Carer and how to support yourself. (Royal College of Psychiatrists, 2023). Link to the Royal College of Psychiatrists website: https://www.rcpsych.ac.uk/

Information and Resources from NSFT

We contacted a Carers Lead at NSFT to find out more about the information and resources available to Carers. This includes NSFT having a designated Carers Lead Team, that host online drop-in sessions for Carers and having a designated email service for Carers.

"Within NSFT we have a small Carer Lead Team that works strategically across the Trust supporting the implementation of Triangle of Care and use their expertise to support all staff. The Carer Lead Team hosts regular on-line drop-in sessions for carers or anyone wishing to speak with the team and also manages a dedicated carer Q&A email service, which is open to carers, professionals, and the public."

The Triangle of Care is *"an alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing."* (NSFT, 2024).

The Carer's Lead also explained that when Carers are identified, they should be offered an information pack. Whilst the contents of the pack may vary, they should all contain:

"The details of the team working with the service user, the contact details for the team, the carer support available within the team and NSFT in general, including our dedicated carer Q&A email service and our online-drop-in sessions. Packs should also contain information about local community services and the carers right to request a Carer's Assessment and how to do this."

NSFT also offers Psychoeducation workshops for Carers and Carers are welcome to attend any of their courses in the Recovery College. NSFT are also currently working on a *"Trust-wide generic Carer information booklet"* which they hope will be available in June 2024.

Practical Resources

Carers Identity Passport

The Carers Identity Passport from Carers Voice has been co-produced with Carers and staff across Norfolk's health and care system to ensure unpaid Carers are identified and recognised in healthcare settings. It is available in both a digital and physical version (Carers Voice, 2024).

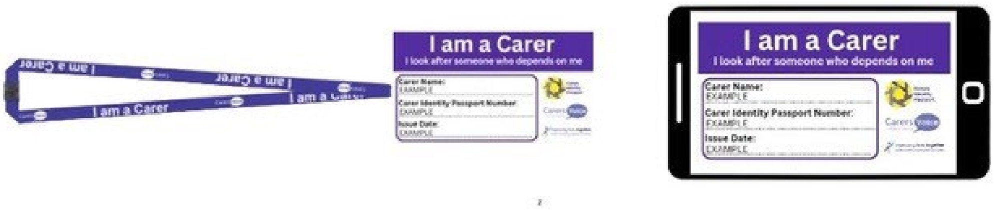

Figure 8. An example of a physical copy of a Carers Identity Passport (left) and a digital version displayed on a smartphone (right).

Carer’s Assessment

A Carer’s Assessment is a chance for Carers to let their local council or trust know about their caring responsibilities and how these affect them physically and emotionally. Carer’s Assessments are used to find out what support Carers need and whether they are willing or able to continue caring (Carers UK, 2024d).

Carers emergency card

Norfolk County Council offers people the opportunity to create and register an emergency plan with them. If someone cares for someone over 18, they can get a free Carer’s emergency card to ensure that the person they care for will be safe if they are in an emergency (Norfolk County Council, 2024).

Respite options

Rethink mental illness have a webpage with information on respite and options for Carers of adults with mental illness. Carers can get respite through social services, who can do an assessment to see if this is something they need (Rethink Mental Illness, 2024).

Carers Groups

There are a variety of Carers groups in Norfolk. For example, Carers Matter run a range of Mental Health Carers Groups, including in-person groups in Norwich, Dereham and Diss. However, it should be noted that when we tried contacting several groups that were advertised on the Carers Matter website some of the contact details were outdated.

Norfolk and Waveney Mind also have a range of support groups running across their Rest Hubs, and although these are not specific for Carers, Carers are welcome to attend. There are also a variety of online groups that Carers can join. For example, one Carer we interviewed, told us about an online Facebook group called ‘POPS’, which is for family members of people with psychosis and schizophrenia.

As mentioned, NSFT also run a range of groups including NSFT virtual coffee morning, Early Intervention in psychosis Support Groups and ‘Stepping back safely workshop for carers', which is psychoeducation for family members and Carers of people who are at risk of suicide or self-harm.

Voice organisations

Carers Voice

Carers Voice is an independent charity representing Carers in Norfolk and Waveney. They *"give unpaid Carers a voice in the way their services in Norfolk and Waveney are designed, developed and delivered"* (Carers Voice, 2024). They work in partnership with Carers Matter Norfolk. Link to the Carers Voice website: https://www.carersvoice.org/

Carers Voice also run online Carer Involvement Meetings, which are an opportunity for Carers to come together with people and organisations working in the area and give feedback on services. They are also an opportunity for Carers to connect with other Carers and find out more information about support and activities in the area.

Survey results

Have you been able to find information and resources to support you?

Carers were asked whether they have been able to find information and resources to support them. Over half of respondents answered ‘somewhat’ (36, 60%). Around two in five respondents answered, ‘Not at all’ (38%) and only one person answered ‘completely’ (2%). This is displayed in Figure 9.

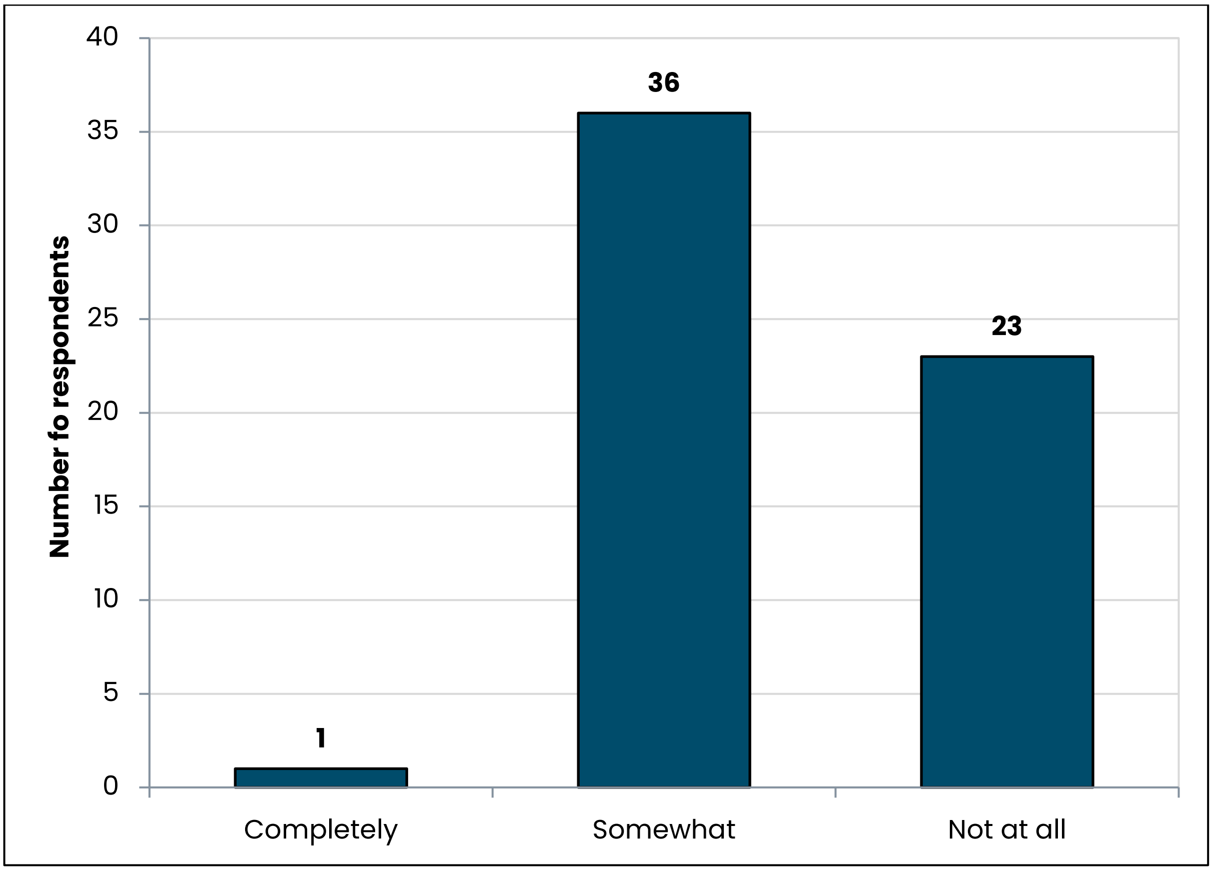

Figure 9. Responses to the question 'Have you been able to find information and resources to support you?'

Answers varied across the age range with those aged 46-55 (10, 83%) the most likely to say they had ‘somewhat’ been able to find information and resources to support them.

There were some differences between Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, or psychosis. Carers of adults with bipolar disorder were the most likely to say they have not been able to find information and resources available to them (5, 42%). Whereas Carers of adults with schizophrenia/ schizoaffective disorder were the most likely to answer ‘somewhat’ (10, 77%). This is displayed in Figure 10 below.

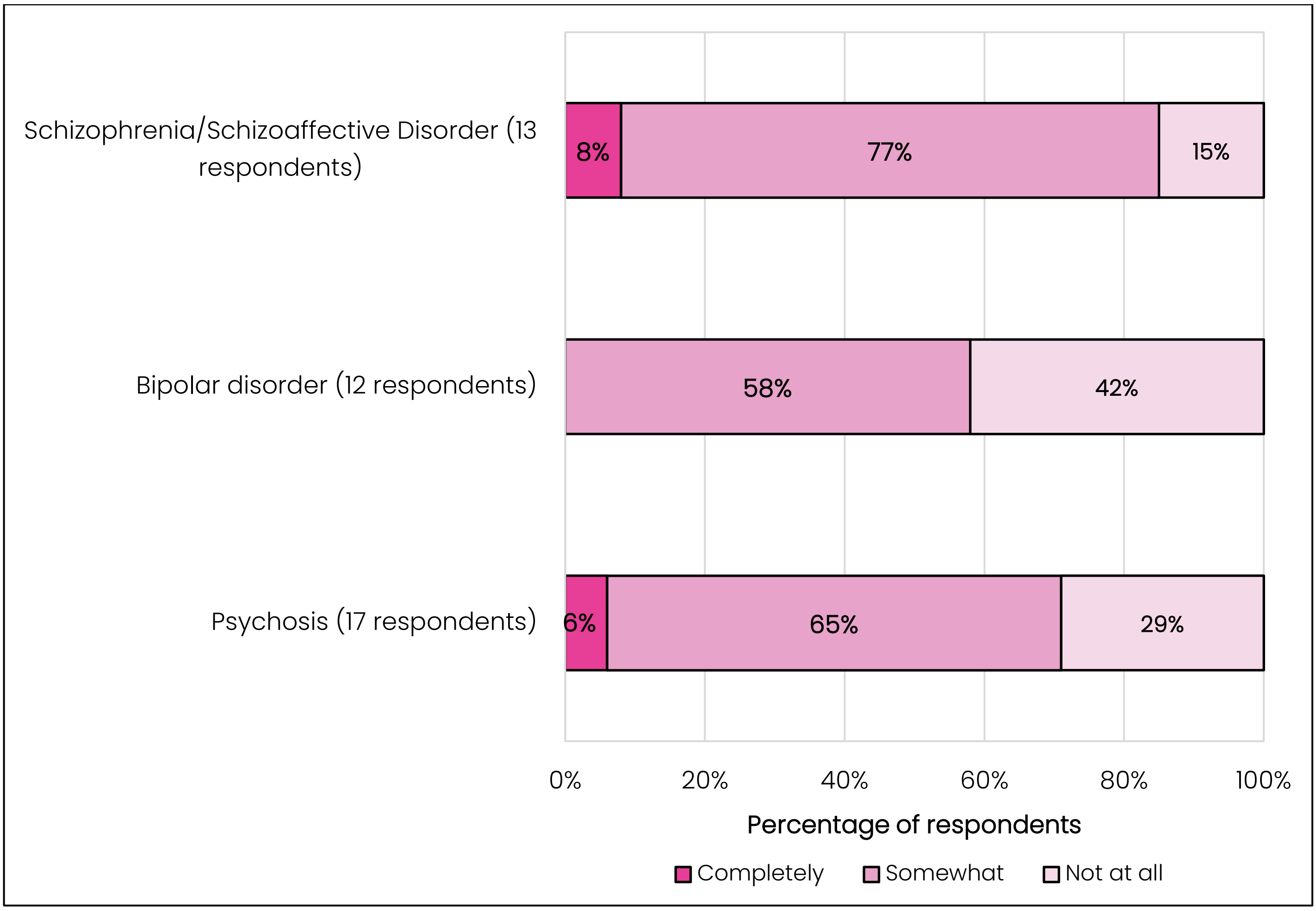

Figure 10. Responses to the question 'Have you been able to find information and resources to support you?'. A comparison between Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, and psychosis.

As part of this question, Carers were asked to share what information and resources they have found helpful. Several Carers mentioned that they have found Carers Matter helpful. A few Carers also mentioned that they have found information from Mind helpful. For example, one Carer told us: “*Mind have useful resources as do Carer's Matter* [Sic] *but I have found that most support comes from friends.,”* whilst another commented *“online information from MIND”.*

Carers also mentioned finding information online, such as *“Online information and links related to groups for carers”* and *“Information on Bipolar online and the medication.”* Other answers included Carers groups, Carers Voice, and books: *“I tend to find out information myself. This is either through work colleagues or buying books which allows me to understand schizophrenia.”*

Focus group members also told us about resources they have found helpful, including the Recovery College courses ran by NSFT and information from Mind and Rethink Mental Illness. For example, One Carer told us how they found the 'Living Well with voices' course ran by the Recovery College helpful as it provided information on hearing voices and was led by someone with lived experience. However, the Carer explained that it is not always promoted as something Carers can benefit from.

> "So, I think that that [Recovery College] is a good resource, but it's not always sold as something that carers can tap into."

The Carer also told us about an American website called 'SMI advisor' which they have found helpful because it was easy to understand and had useful information about caring for an adult with SMI, including whether or not to make eye contact and how to talk to someone who is hearing voices. They told us that this is a resource they wished they had had years ago: *"So it's that kind of resource that I feel that people need really, or I would've needed* [sic] *still need even after 35 years."*

Another Carer told us about how they have been attending an American online course run by 'Psychosis Reach' for families and Carers of people with psychosis. The course has six sessions and is led by a Carer who has undertaken additional training, in order to lead the course. The Carer explained that *"It's brilliant"* and that the course is about the everyday conversations that you might have with someone *"who is delusional and who has severe mental illness and how to improve your relationship with them."* The Carer explained that the course goes into every detail of a conversation.

What information and resources would you find useful?

When asked, "What information and resources would you find useful?" the majority of Carers told us they would like more information about serious mental illness, medication, and side effects (43,72%). Seven in ten (41, 68%) said they would find wellbeing support useful, and half of respondents told us that information about Carer support organisations would be useful (31%, 52%).

Nearly half of Carers told us they would find it useful to have more information about Carer's Assessments (28, 47%) or information about the Carers Identity Passport (29, 48%). Around two in five respondents (25, 42%) said they would find respite options useful, and 21 Carers (35%) said they would find Voice Organisations (e.g. Carers Voice) useful. This is shown in Figure 11.

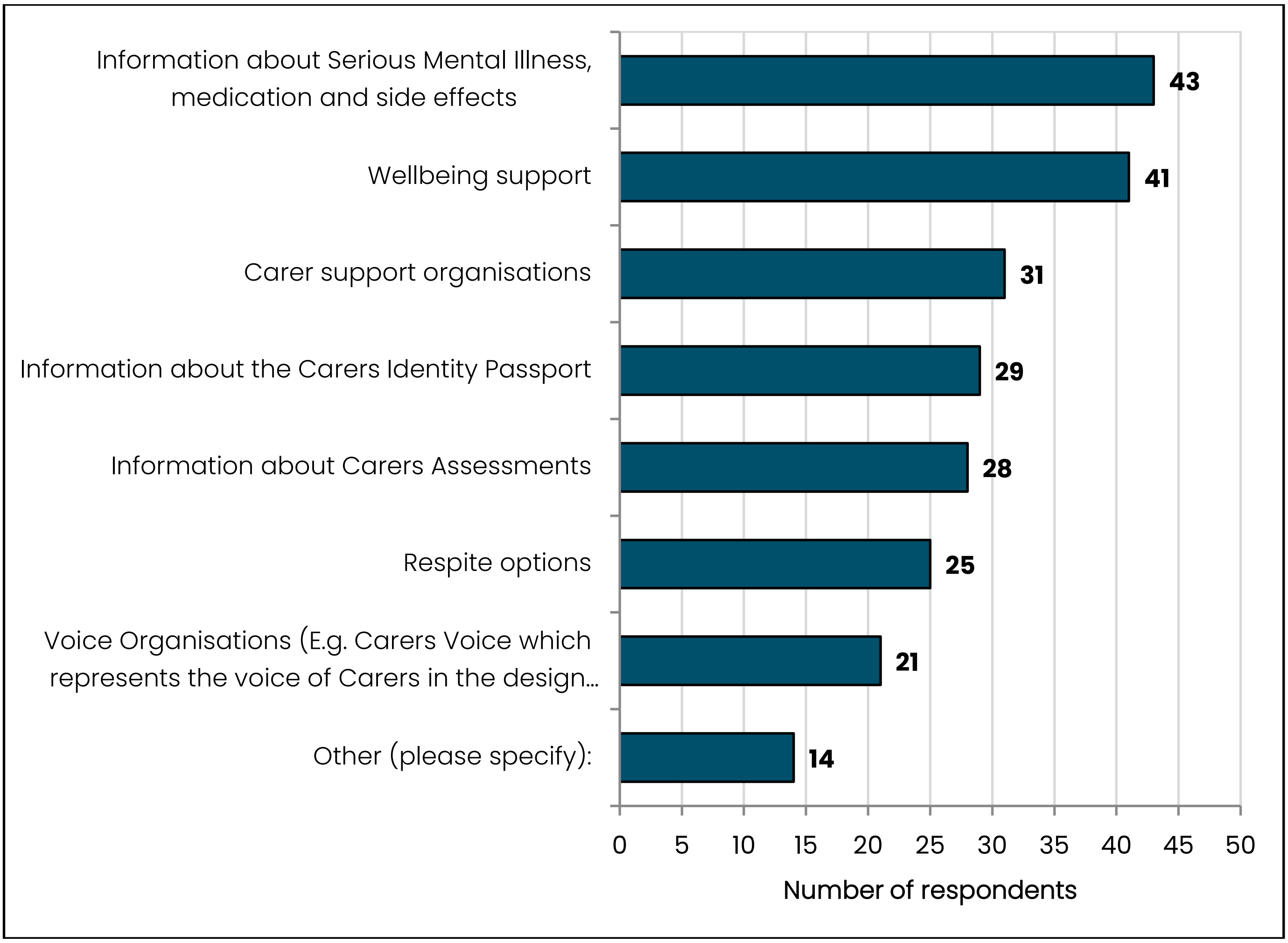

Figure 11. Responses to the question 'What information and resources would you find useful?'. Respondents could select more than one option.

Around a quarter of respondents (14, 23%) chose the ‘other’ option. This included receiving more information on how to help and support someone with SMI and how Carers can deal with their behaviour. This is illustrated in the comments below:

- *“Information about how to help and support my daughter with her MH* [Mental Health]*”*
- *“Help on how to cope when the person you're caring for doesn't want to get help or help themselves…”*
- *“How to deal with psychotic episodes and how to de-escalate when the person affected is in a state of high arousal.”*

Of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder or psychosis, Carers of adults with schizophrenia/ schizoaffective disorder (10, 21%) and bipolar disorder (10, 20%,) were most likely to say they would find information on wellbeing support useful. Whereas Carers of adults with psychosis were equally likely to say they would find information on wellbeing support (12, 17%) or Carer support organisations useful (12, 17%).

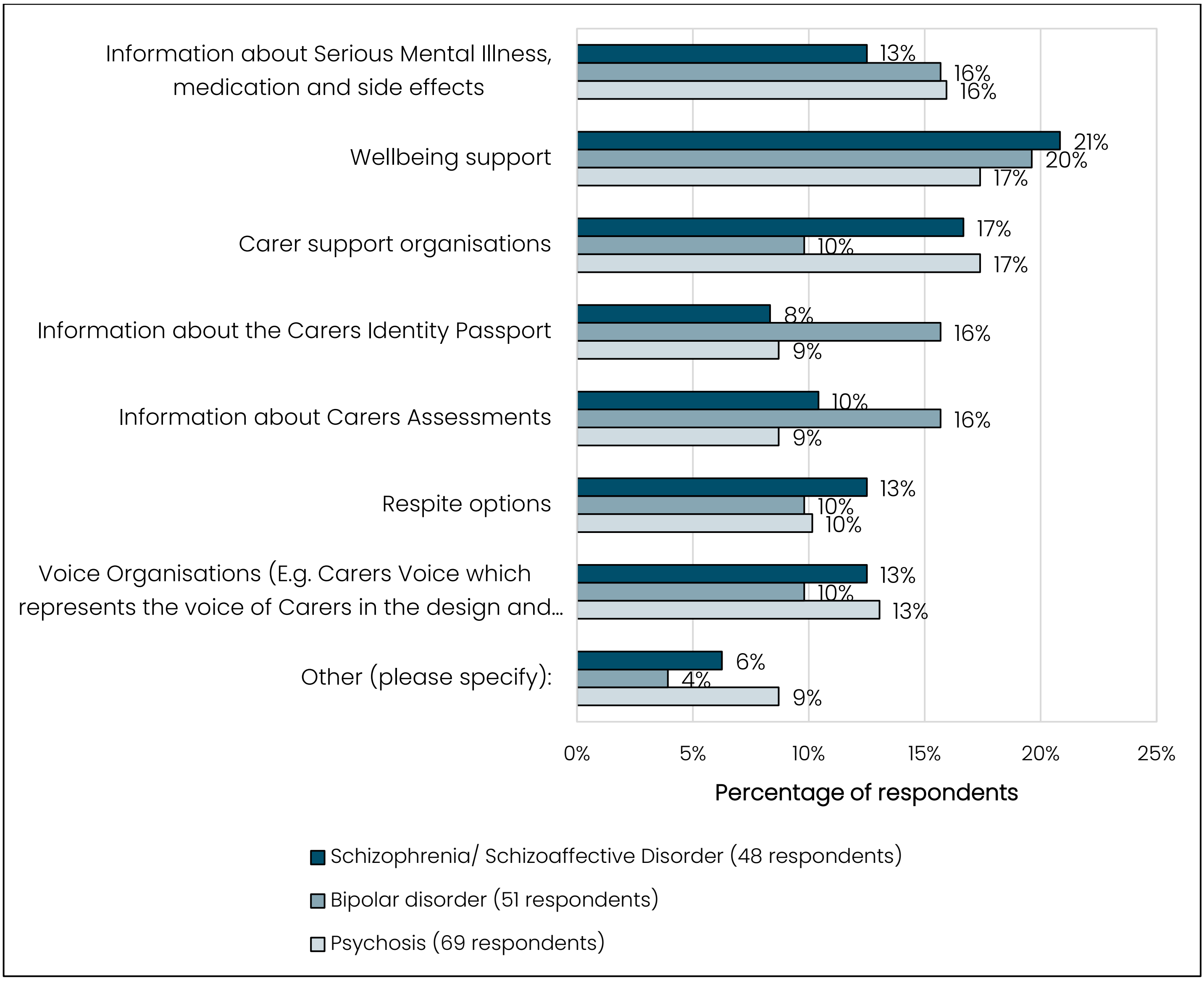

Figure 12. Responses to the question 'What information and resources would you find useful?'. A comparison between Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, and psychosis. Respondents *could select more than one option.*

One Carer in the focus group explained how they would like more information on SMI, such as information about the physical effects of medication for people with SMI, therapy types and how Carers can help the person with SMI. Focus group participants also told us they would find it useful to have more information on Carers groups, benefits, financial support, and more information on what happens if a Carer dies.

> "So, I would like to see more information about the physical effects of medications for people with SMI also, what needs to be done, what has to be done and who coordinates it because it involves GPs as well."

Is there anything that would make you more likely to access the information and resources available to you as a Carer?

Most Carers told us they would be more likely to access the information and resources available to them, if there was more specific information and resources on being a Carer for someone with SMI (45, 74%). Over half of respondents said they would be more likely to access information and resources if these were easier to find (34, 56%).

Around half of respondents told us they would be more likely access information and resources, if there were more available (29,48%). Eighteen (30%) Carers told us they would be more likely to access these if they had more time and one in ten Carers (7, 11%) told us they would be more likely to access these if they were easier to understand.

Ten people selected the 'Other' option (16%). This included a variety of answers, including if staff members could make Carers more aware of the information available and if Carers did not have to look in so many different areas to find information. This is illustrated in the following quotes:

- *"If I didn't have to look in so many different areas to find information."*
- *"If someone involved in the person's care could make this information obvious to me."*

The majority of Carers would be more likely to access information, if there was more specific information and resources on being a Carer for someone with SMI

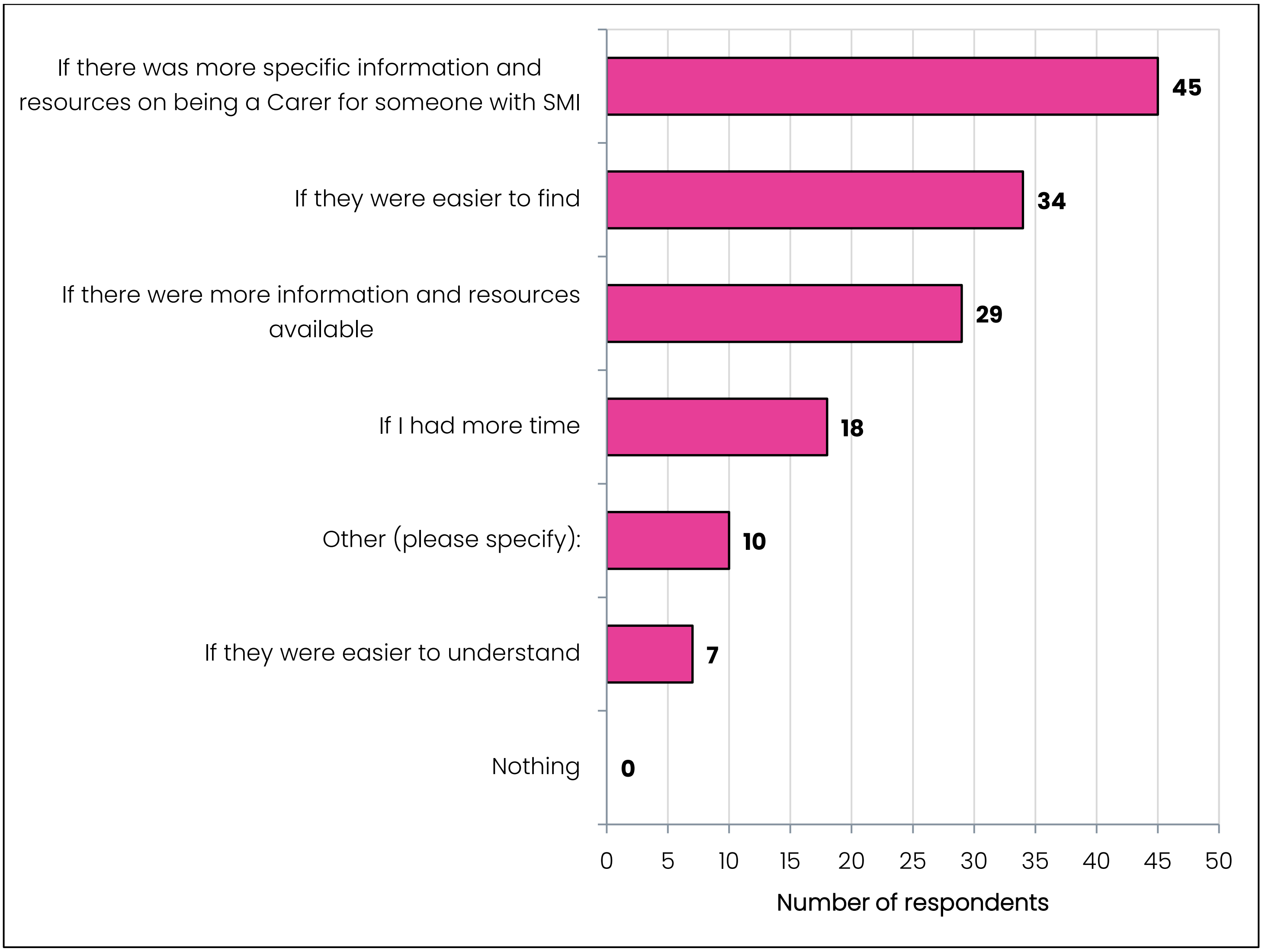

Figure 13. Responses to the question 'Is there anything that would make you more likely to access the information and resources available to you as a Carer?'. Respondents could select more than one option.

Of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder or psychosis, Carers of adults with psychosis (16, 39%) or schizophrenia/ schizoaffective disorder (10, 37%) were the most likely to say that they would be more likely to access information if there was more specific information available on being a Carer of an adult with SMI (Figure 14).

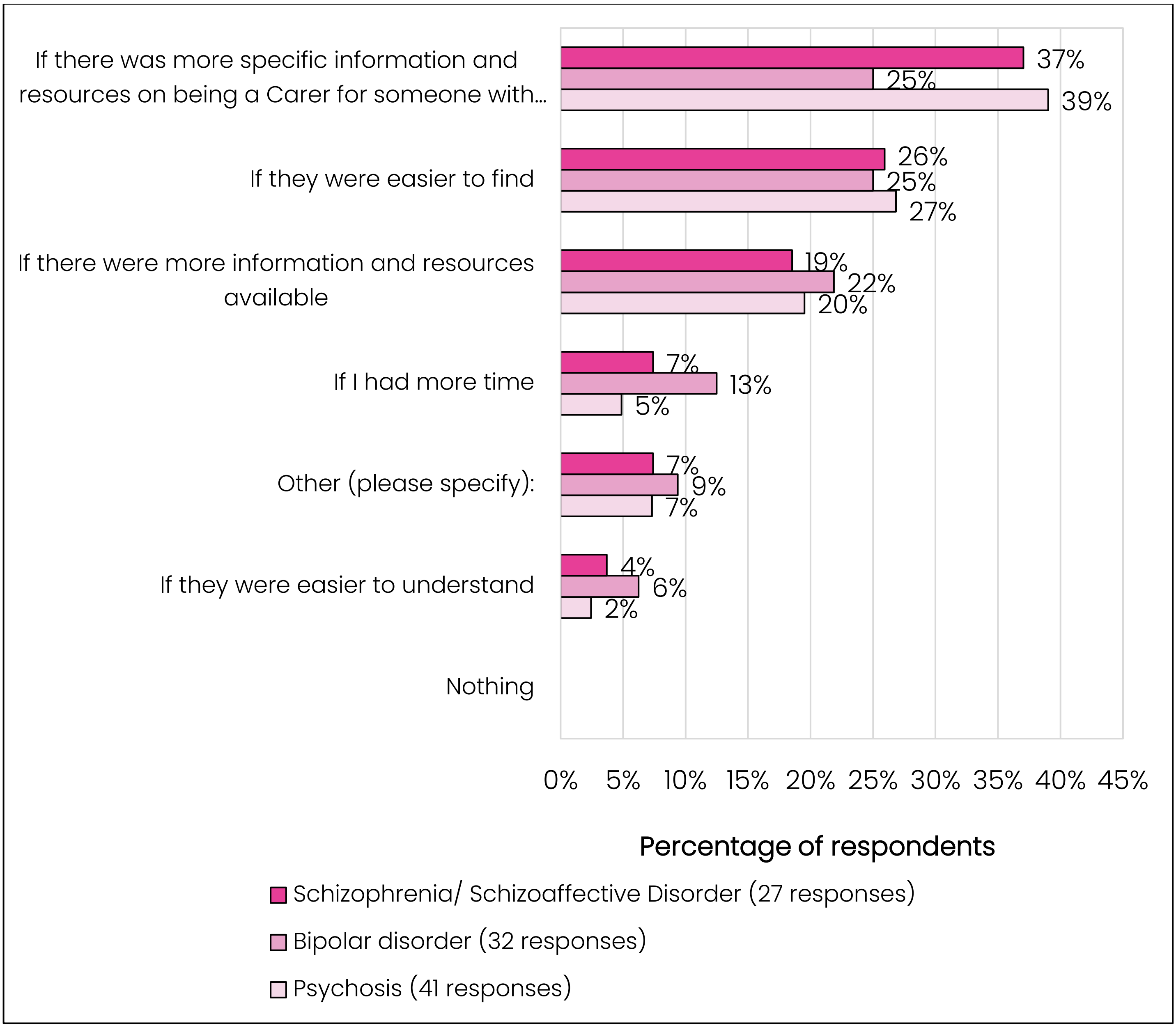

Figure 14. Responses to the question 'Is there anything that would make you more likely to access the information and resources available to you as a Carer?'. A comparison of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar and psychosis

Throughout the survey, a few Carers also commented on how they have had difficulty finding information and have had to learn about SMI themselves. For example, one Carer told us: "*Learning on my own as to why things are happening*" and another added: "*Originally 25 years ago it was very difficult to get any information let alone support. With the rise of the internet, it has been easier to find out information.*"

Specialised information

Carers were also asked about the information and resources available to them as part of the interviews. One of the key themes from the interviews was that Carers wanted specialised information about the person they were caring for. Carers commented that they would like personalised information on the person they are caring for and to know what to expect regarding the symptoms and behaviour. This is illustrated in the comments below:

- *"In an ideal world, you would have a personalised care plan that isn't about what care [the person they support] needs, but it's about how to avoid him needing care in the first place."*
- *"I think it is kind of almost the same sort of information resources that patients need [...] As the person living with SMI, here's a bunch of stuff for you to read as the carer rather than here's our massive website"*

One Carer mentioned that they would like to be told this information at the point of diagnosis. For example:

> "I think actually to be told at diagnosis what the possible likelihood outcomes are going to be going forward or at any stage based on what we know at this point we think X, Y, Z, but we're not sure. And it could be this, but you're not really told anything."

Receiving information sooner was also mentioned by a few Carers in the focus group, with one Carer explaining that they think Carers should receive information *"as soon as possible"* because they did not receive much information and had to research it all themselves which was *"quite exhausting."* Another Carer explained that despite their brother having Schizophrenia since 1987, their brother was only recently given information about the issues of taking Clozapine and caffeine *"It's that kind of thing that needs to be really seriously sorted out."*

The format of information

During the interviews, Carers told us that they mostly preferred to receive physical information (e.g. booklets and leaflets) and information without jargon. One Carer mentioned that they would prefer physical copies as *“you've got it there”*, whilst another explained how they were given a *“massive wad’* of papers but think it would be better to have a conversation and receive resources that are *“concise and really directed”* as Carers have limited energy and are often short of time.

> “You never reduce it [information] to one side of A4, but if you can just keep it concise because people are likely to be low on energy, low on resources, and very short on time. So just keeping it concise and really directed.”

The need for direct and clear information was also highlighted by a focus group participant who explained that the information they have received from NSFT could be “more *coordinated thought through and clear under different headings”.* They suggested that there needs to be three types of information displayed: Information about the person you are caring for and their condition, how you care for someone with their condition and how you look after yourself as a Carer of someone with SMI.

> “And for us as the people living with the people with serious mental health conditions, just information on things that can help us to help them”

Carers Identity Passport

Carers in Norfolk are entitled to a free identity card supplied by Carers Voice Norfolk and Waveney. Carers Voice co-produced a Carers Identity Passport to ensure Carers are recognised and can get the help and support they need in healthcare settings. The passport is for Carers of all ages and should be recognised within East Coast Community Healthcare, James Paget University Hospitals, Queen Elizabeth Hospital King's Lynn, Norfolk and Norwich University Hospitals, Norfolk and Suffolk Foundation Trust and Norfolk Community Health and Care Trust, (Carers Voice, 2024). There is a physical and digital version of the Carers Identity Passport available. The Carers Identity Passport launched in November 2022.

Survey respondents were asked about their awareness and experience of the Carers Identity Passport. More than half of survey respondents told us they were not aware of the Carers Identity Passport (35, 57%). Around one in four participants told us they were already aware of the Carers Identity Passport and own one (14, 23%).

Nine people were aware of the Carers Identity Passport but do not own one (9, 15%) and around two in five Carers told us they would apply to get a Carers Identity Passport (26, 43%). Only a small minority of Carers told us they would not apply to get a Carers Identity Passport (4, 7%). There were no respondents aged 45 and under who own a Carers Identity Passport.

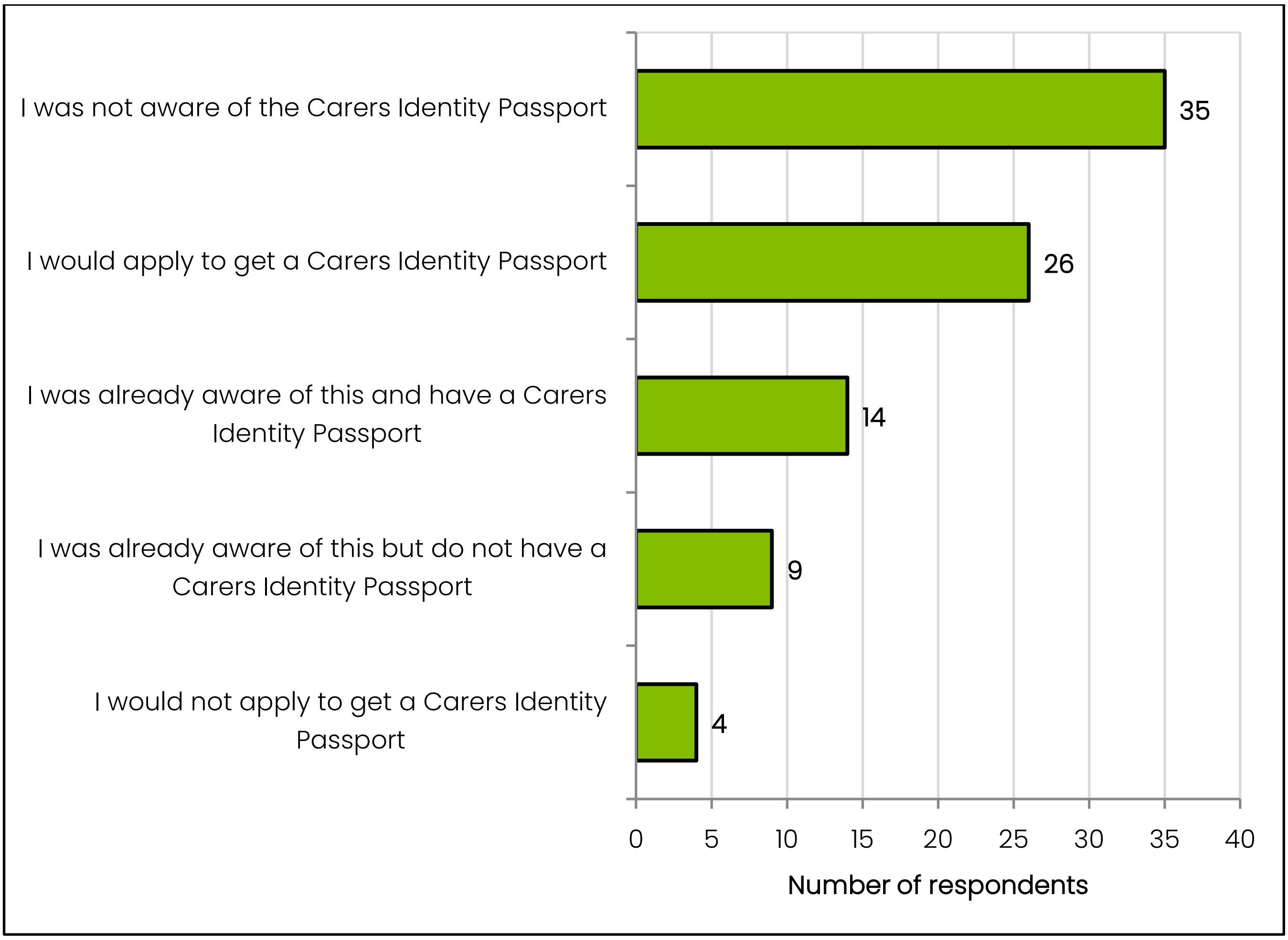

Figure 15. Responses to the question 'Please select all that apply to you'.

Carers who live with the person they care for were slightly more likely to own a Carers Identity Passport (7, 18%) than Carers who do not live with the person they care for (5, 11%). Whereas people who do not live with the person they care (19, 42%) for were slightly more likely than people who live with the person they care for (14, 37%) to say they are not aware of the Carers Identity Passport.

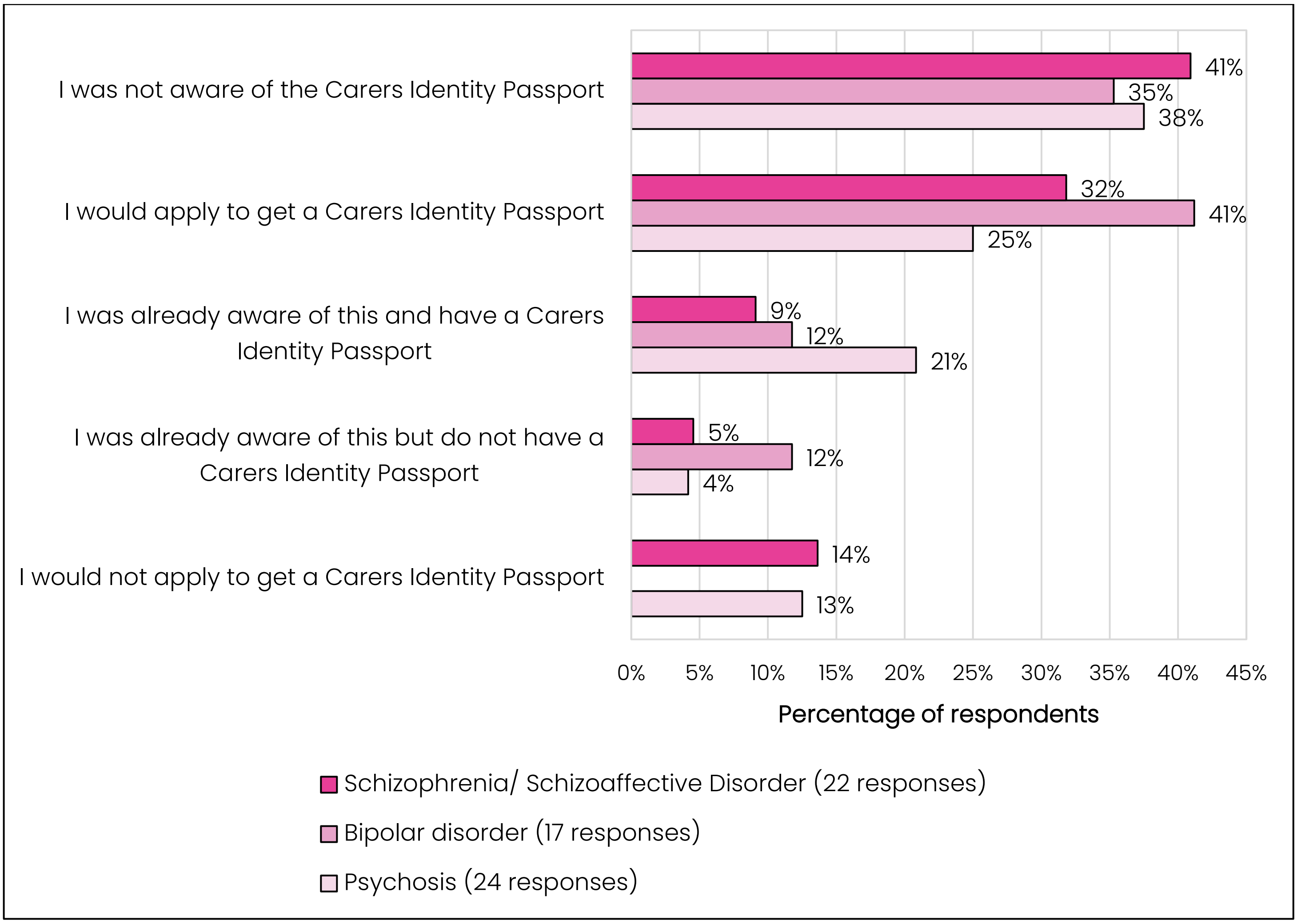

Figure 16. Responses to the question 'Please select all that apply to you'. A comparison of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, or psychosis.

Of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder or psychosis, Carers of adults with bipolar were the most likely to say they would apply to get a Carers Identity Passport (7, 41%). Whereas Carers of adults with psychosis were the most likely to already be aware of the Carers Identity Passport and own one (5, 21%). This is shown in Figure 16.

Carers who own a Carers Identity Passport were asked to tell us more about their experience. Several Carers noted that whilst they have a Carers Identity Passport, they have not had to use it yet and a few Carers mentioned that they did not find the passport very useful or beneficial.

Carers who do not have a Carers Identity Passport were then asked why they do not have one. There were a variety of answers including not being aware of the passport, not needing one and not wanting to wear one. This is illustrated in the comments below:

- *"Didn't know there was one or what it is for. No one in mental health team has mentioned it."*
- *"I don't feel I need one. We haven't been admitted to hospital so doesn't feel appropriate for me."*
- *"My cared for person would not like me showing this so it's not h* [sic.] *getting one."*

Interviews with Carers

The Carers we interviewed generally thought the Carers Identity Passport was a good idea, but many did not have much knowledge or experience of it. For example, one interviewee told us that whilst they own a Carer's Identity Passport, they have not used it yet but think it *"is wonderful because you don't have to be telling people you're a carer."*.

Another Carer commented that whilst they do not own a Carers Identity Passport and do not think it would help them, they acknowledged that it could still be helpful for other people: *"If I thought it would be valuable to me, I would get one. But for me personally it's not valuable, for other people, it will be, and I would actively encourage that."*

Two Carers told us about their experiences of owning and using the Carers Identity Passport, and these experiences were varied. One Carer told us that whilst the passport was useful during the Covid pandemic when visiting A&E with the people they care for, they have not needed to use it since:

> "And once I had the passport it was easy to say, look, I'm a carer. This person cannot tolerate this environment unless I'm sat here, I am jabbed to the max.[…] Since the restrictions have eased, honestly it is nice to have it in the back of my mind, in my mental back pocket as it were. I've never actually needed to use it because everyone goes to A and E these days with somebody else usually."

Another Carer explained that when they wore the Carers Identity Passport to an appointment with the person they care for, the consultant still questioned why they were there and gave them a 'grilling':

> “[The consultant] gave me a grilling as to why I was there. It's interesting, even though I was wearing it saying I am a carer, it should have been down on my brother's notes because again, he gave permission..”

Focus group participants also discussed the Carers Identity Passport and covered many of the themes from the interviews and survey, including people generally thinking it was a good idea, but there was varied awareness and experiences. One Carer in the focus group questioned how serious NSFT are about recognising the Carers Identity Passport and suggested that staff need more training in recognising the passport.

> “How serious NSFT about recognising the carer's passport because in mental health things are a little different to physical health when all of the things about confidentiality and everything else kicking and sometimes their reluctance to share information. So, I think there needs to be a bit of learning training if you like”

Carer’s Assessment

Carers were then asked about their awareness and experience of Carer’s Assessments. Anyone aged over 18 who provides unpaid care for someone can have a Carer’s Assessment (Carers UK, 2024d). Carers are entitled to a Carer’s Assessment regardless of their financial situation, the amount of care they provide or level of need for support. A Carer’s Assessment is an opportunity for Carers to have a discussion about what support or services they need. The assessment looks at how caring affects the Carer’s life, including their physical health, mental health, work, study, whether they are willing or able to continue caring and what they would like to achieve (Carers Matter, 2024b).

Nine survey respondents (14%) told us they have had a Carer’s Assessment within the last 12 months and 14 (22%) have had a Carer’s Assessment more than 12 months ago. No Carers told us they were on the waiting list for a Carer’s Assessment.

Ten respondents (16%) told us they have never been offered a Carer’s Assessment but would like one and 14 (22%) Carers told us they have never been offered a Carer’s Assessment, but do not want one. A small minority of Carers told us they have been offered a Carer's Assessment but did not want one (3, 5%).

Some Carers (9, 14%) were not aware of Carer's Assessments but would like one. This is displayed in Figure 17 below.

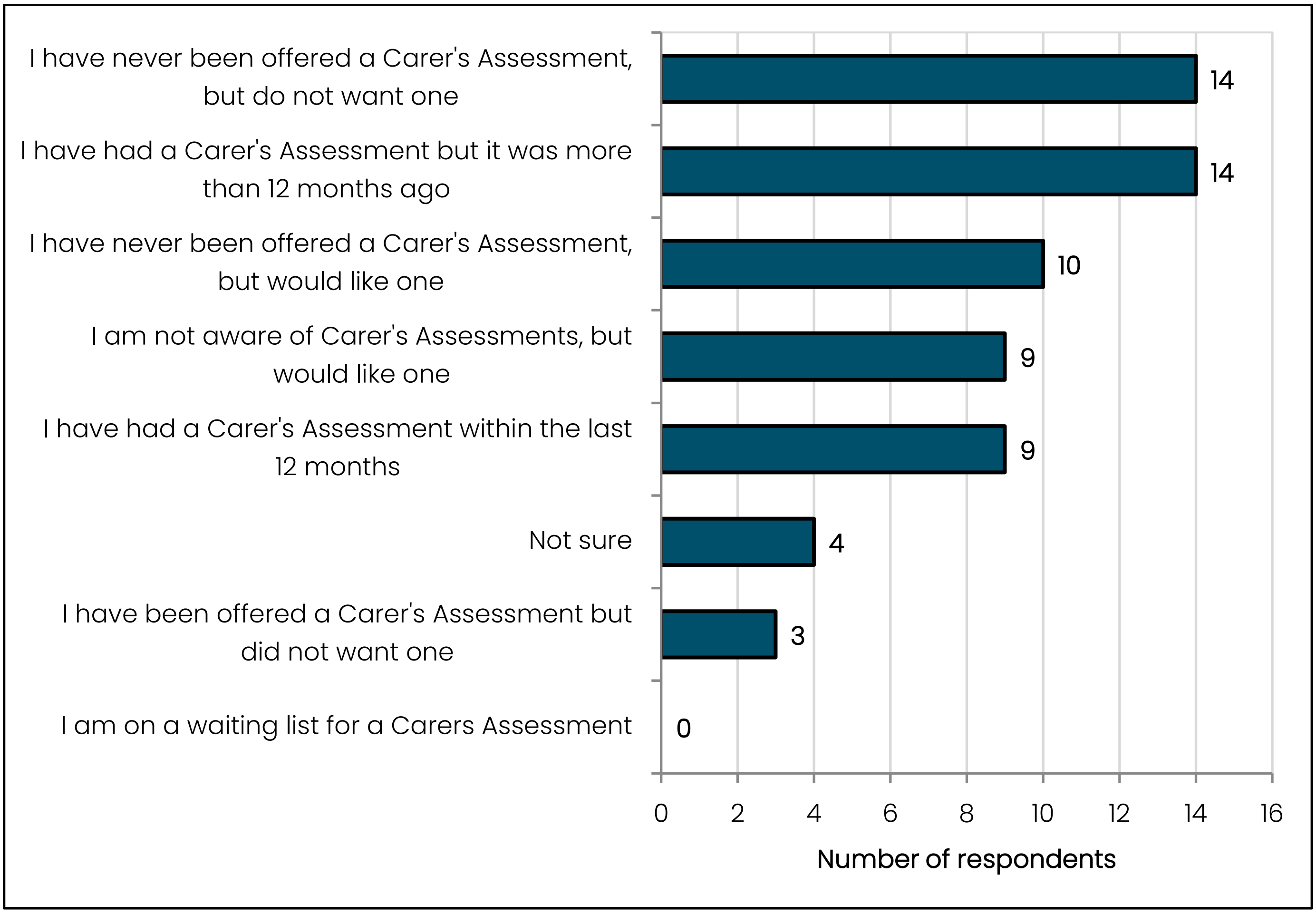

Figure 17. Responses to the question 'Which of these statements applies to you?'. Respondents could select more than one option.

Carers that do not live with the person they care for, were more likely to say they have never been offered a Carer's Assessment, but do not want one (12, 39%) than Carers who live with the person they support (2, 7%). Carers that live with the person they support were more likely to have had a Carer's Assessment in the last 12 months (7, 25%) than Carers that do not live with the person they support (1, 3%).

There were some variations in answers between Carers of adults with schizophrenia/ schizoaffective disorder, bipolar or psychosis. Carers of adults with psychosis were the most likely to have had a Carer's Assessment in the last

12 months (4, 21%). Carers of adults with Schizophrenia were the most likely to have had a Carer's Assessment but it was more than 12 months ago (5, 31%) or to have never been offered Carer's Assessment, but would like one (5, 31%). Carers of adults with bipolar disorder were the most likely to not be aware of Carer's Assessment but would like one (3, 25%).

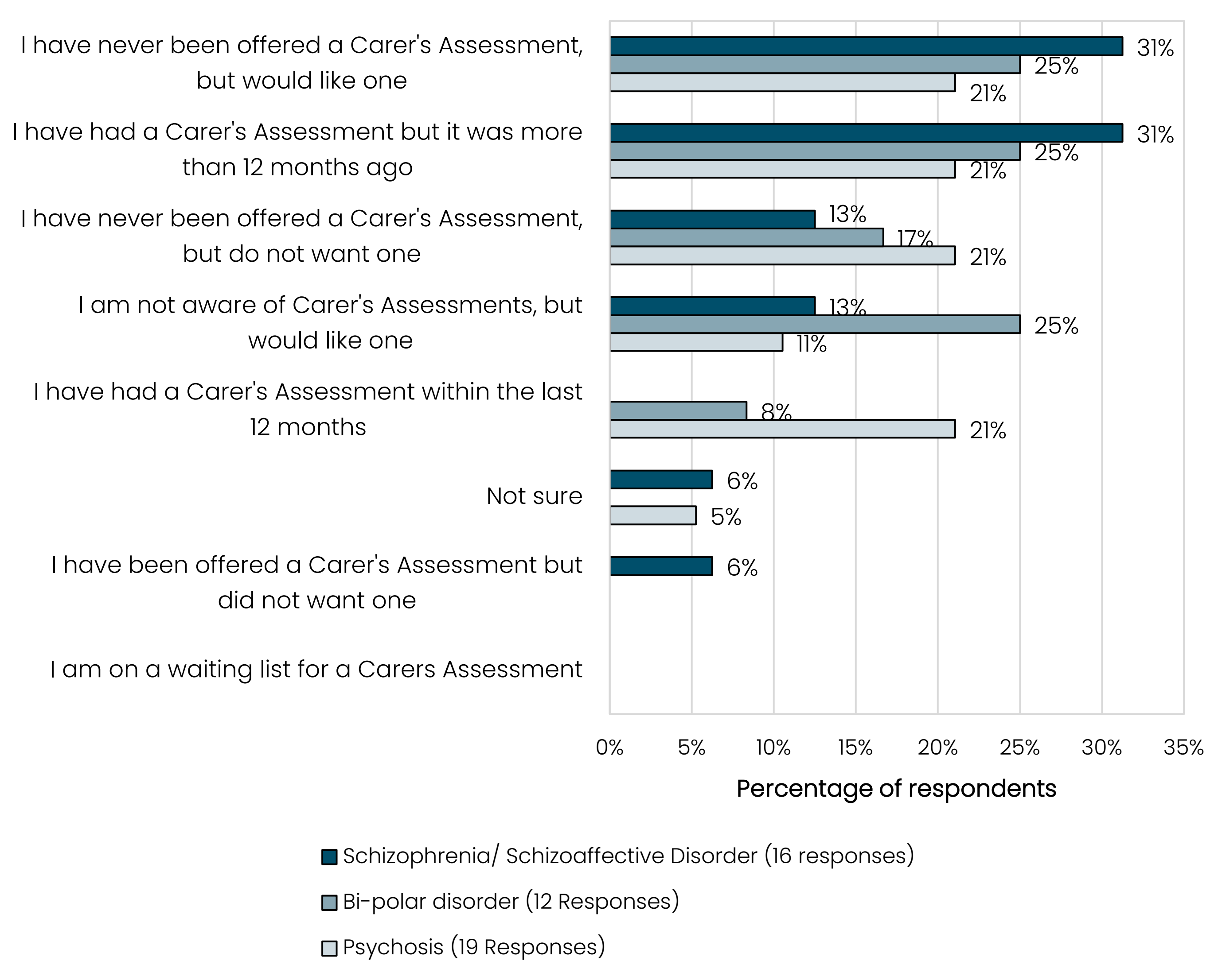

Figure 18. Responses to the question 'Which of these statements applies to you?'. A comparison of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, and psychosis.

Some interviewees told us that they have never heard of Carer's Assessments. For example, one Carer explained that they did not know about Carer's Assessments until completing the survey for this project:

> “I didn't know about them again until I did the questionnaire online […] So until very recently I didn't know. And an awful lot of other people dunno about it.”

Experiences of Carer’s Assessments

Across the interviews and focus group, there were varied experiences of having a Carer’s Assessment, although many Carers did not find it helpful. Carers described having Carer’s Assessments from Adult Social Care, Carers Matter and NSFT.

Of interviewees who have had a Carer’s Assessment, two commented that they did not find the assessment very helpful. One Carer explained that whilst they have had a Carer’s Assessment, they would not have one again as they felt *“it was a bit of a tick box exercise.”*

A few focus group participants also told us that whilst they found it easy to get a Carer’s Assessment, they did not find it useful *“I didn't get anything out of it at all.”* One Carer told us that whilst the assessment itself was ok, there was very little follow up, which left them wondering *“where the assessment went to, whether it was put on a shelf and forgotten or whether it was tied up with the information that they had about my daughter”.*

Positive experiences

Several interviewees told us that they got help from the Carer’s Assessment, but some did not view it as something that they would repeat every year. A few Carers mentioned the psychological support they received as a result of the assessment and how they found this helpful. For example, one Carer explained how the counselling they received helped them to see things less negatively:

> “I mean the lady was very kind […] She referred me for counselling, so that was very helpful. And then I actually got the counselling sooner than I expected and it was 12 sessions, so it's a lot. I was expecting only six. So, I was very happy with that, and it helped. It seemed to just help while it was

happening, although I think it helped me to see things in a less pessimistic way about myself, the way that I have been with my son"

Similarly, some focus group members also spoke about their positive experiences of having a Carer's Assessment, including receiving access to courses, Cognitive Behavioural Therapy, speaking to someone from Mind and how having an assessment helped themselves and the person they care for.

"The person on the phone I spoke to was very helpful and got access for me for courses. There was a course about not sleeping. I had some CBT therapy, so that was very good."

Carer Health and Wellbeing

Carers were asked what impact (if any) does being a Carer of an adult with SMI have on their own health and wellbeing. This included any impact on physical health, mental health, employment/ education and training, finances, relationships, and housing. Each topic is explored in more depth below.

Physical Health

The majority of respondents told us their physical health has got worse (40, 63%) since being a Carer of an adult with SMI. Eleven Carers said their physical health has got both better and worse (11, 17%) and only two Carers told us their physical health has got better (3%). This is shown in Figure 19.

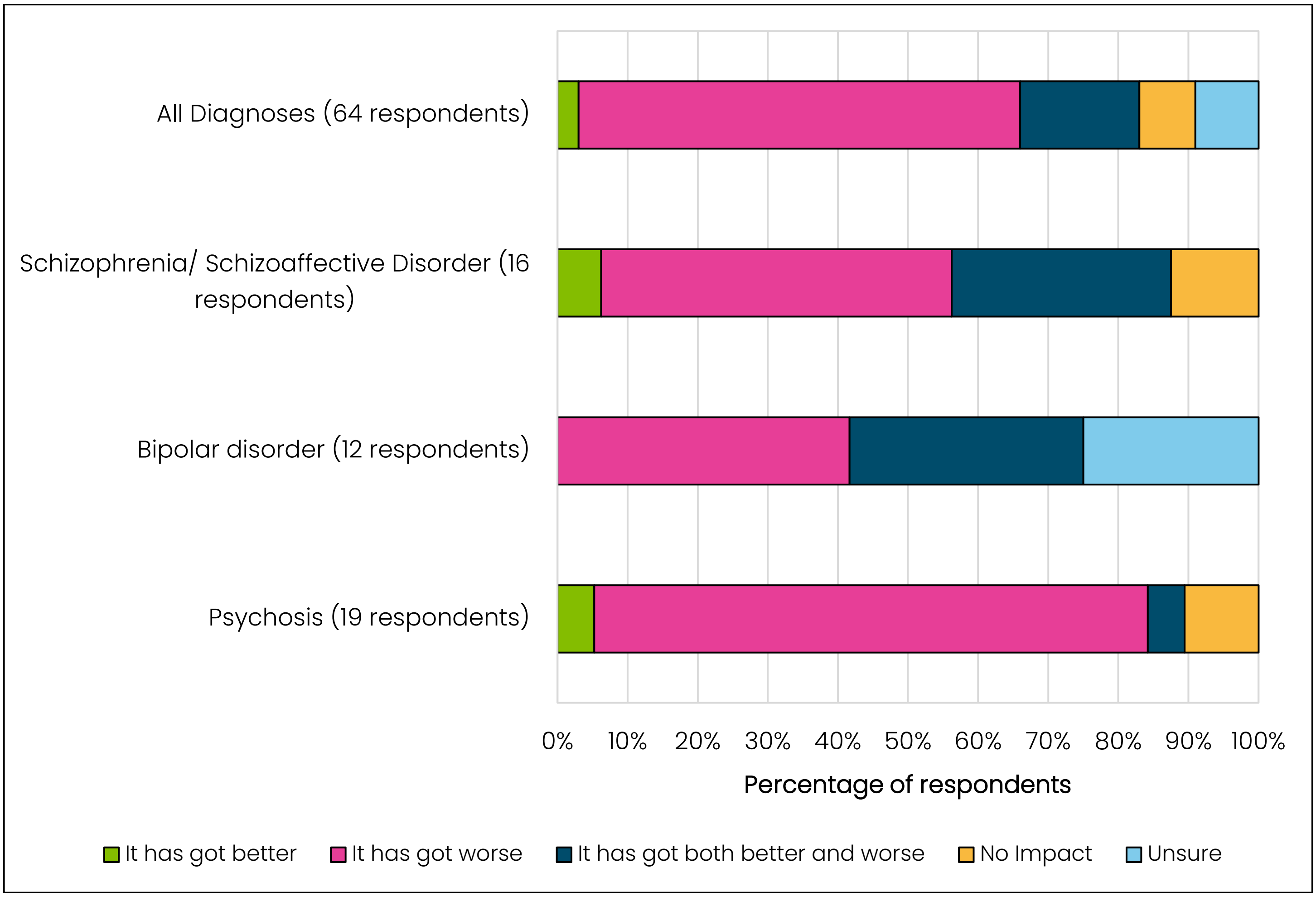

Figure 19. Responses to the question 'What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing? Physical Health.

Of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder or psychosis, Carers of adults with psychosis were the most likely to say their physical health has got worse (15 ,79%).

Carers who live with the person they care for were more likely to say their physical health has got worse (23, 79%) than those who do not live with the person they support (14, 45%). Carers that do not live with the person they care for, were more likely to say their physical health has got both better and worse (9, 29%) than Carers who live with the person they support (2, 7%).

Carers who have a disability (8, 80%) or a long-term condition (18, 72%) were more likely than those without these conditions (15, 60%) to say their physical health has got worse since being a Carer of an adult with SMI.

Throughout the survey, several Carers commented on how their physical health has got worse since caring for an adult with SMI: *"Physical health poorer especially fatigue" and "It's very hard - emotionally and physically draining."*

Mental Health

Most respondents told us that their mental health has got worse (48, 75%) since caring for an adult with SMI. This was a common theme throughout the survey and interviews. Only a small minority of respondents told us that their mental health has got better (2, 3%) or got both better and worse (6,9%). Four Carers told us that there has been no impact on their mental health (4, 6%), and a further four were unsure of the impact that caring has had on their mental health (4, 6%).

Carers who live with the person they care for were more likely to say their mental health has got worse (25, 82%) than Carers who do not live with the person they care for (20, 65%). Women (39, 78%) were more likely than men (7, 64%) to say their mental health has got worse.

Of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder or psychosis, Carers of adults with psychosis reported the most negative mental health impacts being the most likely to say their mental health has got worse (16, 84%), whereas Carers of adults with bipolar were the most likely to say it has got both better and worse (7, 25%).

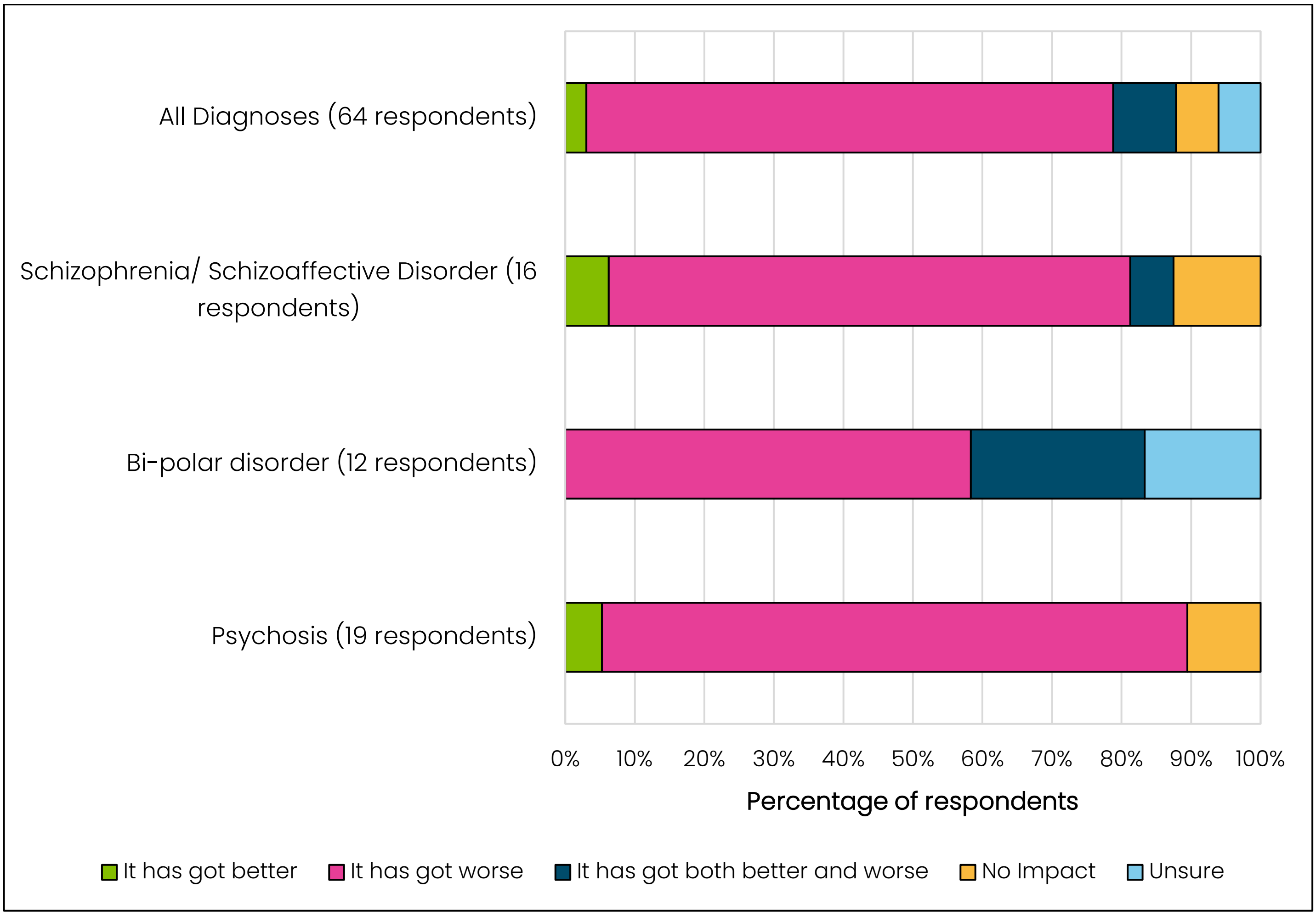

Figure 20. What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing? Mental health.

Throughout the survey, Carers mentioned the emotional impact of caring, with many commenting on how unrelenting caring is, with little time for themselves:

> "I mean [sic] isn't a minute of the day that goes by where he's not on your mind or you are worried about him or you are waiting for him to call because he calls constantly throughout the days whether he's good, bad, so you are constantly worrying about him."

One Carer also described how challenging it is to maintain their own wellbeing, which has had an impact on their social life and marriage.

> “Emotional challenges to be able to support them and to try and maintain my well-being is challenging. Impact on my life especially social life and impact on my marriage.”

Emotional impact of Caring

The impact of caring on Carers’ mental health was a common theme throughout the interviews. The biggest impact that Carers spoke about was the emotional impact of caring for an adult with SMI. Carers spoke about the constant and relentless feelings of guilt, responsibility, and fear.

For example, one Carer described how they are in a state of stress most of the time: *“Well, I think that you're almost in a state of stress almost all the time because you don't know what's going to come down the road at you.”* Whilst another commented how they feel guilty that they cannot do more to support the person they care for:

> “Yeah, I couldn't do anymore, and we've all stepped up to do what we can. I've said I feel guilty I don't do more, but I work full time, and I've got my own family and my mum and my children and the others. “

Several Carers also mentioned that they live in constant fear, with one Carer explaining how they fear that if they do something wrong, the person they are caring for will end their life: “*you have this constant fear of am I going to do something wrong? Is that going to then mean they're going to take their own life?”*

Some Carers also spoke about being on anti-depressants, needing counselling and feeling suicidal. For example, one Carer described how they found it difficult when their brother deteriorated and how this was one of the closest times, they have had to feeling suicidal:

> “But as time went on and services deteriorated, so did my brother and his living conditions deteriorated, and I found it very difficult. I became desperate because I just couldn't, I honestly is one of the closest times to me probably being feeling suicidal.”

Carers were also worried about what would happen if they were no longer around to look after the person they care for and some raised concerns that services would not look after them: *“But then you think, well, what's going to happen when I'm gone?”*

One Carer mentioned that they had heard some older Carers say that they wish the person they Care for dies before them, because they are worried that the person, they care for will become homeless or be *‘on the street’* if the Carer dies.

Isolation

Some Carers spoke about feeling isolated, with a few explaining that this is because of the stigma around SMI and how it is viewed by society:

> “It has been very lonely and isolating for much of the time, particularly in the light of serious incidents in the media in which SMI people have been labelled.”

Asking Carers how they are

A few Carers told us that they would like to be asked how they are. For example, one Carer explained how they were grateful when a consultant asked them how they were: *“she actually asked me, how are you and how are you coping? And I was so grateful that showed.”* And another Carer added:

> “That's the biggest single change actually, and it's a really simple change. Are you their carer? Yes or no? Are you okay? Yeah. Are you aware of support of the support that's available for you?”

Employment/ Education and training

Around two in five Carers told us their employment/ education and training has got worse (41%, 24) since caring for an adult with SMI. Ten (17%) Carers told us their employment/ education and training has got both better and worse and only one person said it has got better (2%).

Three in ten Carers said caring has had no impact on their employment/ education and training (17, 29%) and seven Carers (12%) were unsure of the impact caring has had.

Of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, or psychosis, those caring for someone with psychosis were the mostly likely to say their employment/ education and training has got worse (8, 44%). Carers of adults with bipolar were the most likely to say caring has had no impact on their employment/ education and training (4, 33%).

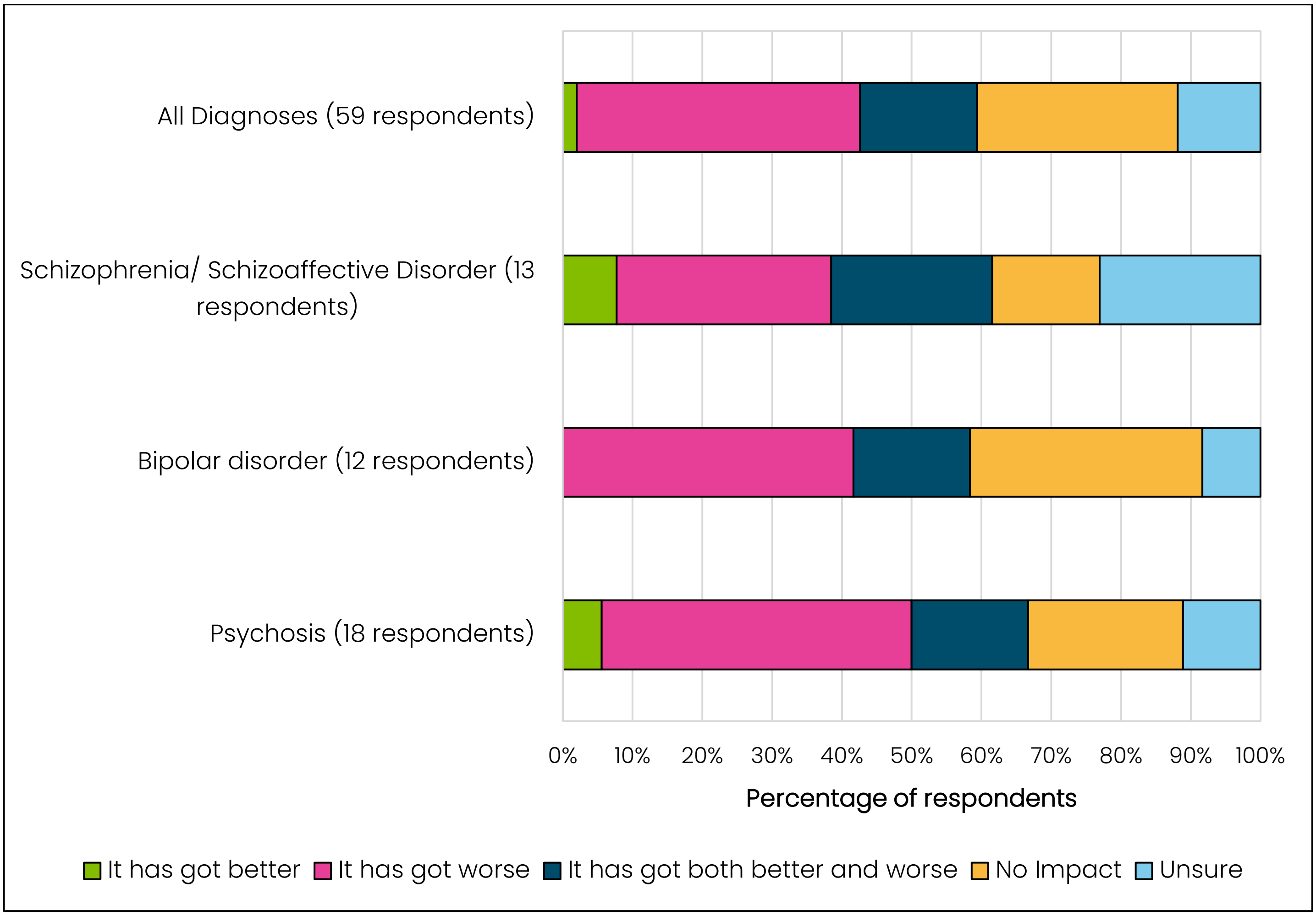

Figure 21. What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing? Employment/ education and training.

There is little difference in answers between Carers who live with the person they care for and those who don't.

Throughout the survey and interviews, Carers commented on the impact that caring has had on their employment, including being unable to work and needing to take time off to support the person they care for. One Carer explained that as their work involved a lot of travel, they had to give this up to look after their son: *"And as my work involved a lot of travel, I had to withdraw from it as a lot of carers have to do."* Another Carer told us that they cannot work because they cannot guarantee that they will be in a meeting or office at a particular time, due to their caring role:

> "I used to earn quite a high salary doing a fairly senior job. However, I cannot work because of the needs of "my people". I am unpredicatbly [sic] called on to spend a morning, a day, an overnight with one or other of them so can't guarantee to be in any meeting or in any office at any given time."

Finances

Over half of survey respondents told us their finances have got worse (56%, 34) since caring for an adult with SMI. Eight Carers told us their finances have got both better and worse (13%) and only two people told us their finances have got better (3%). One in five Cares said that caring had no impact on their finances (13, 21%) and four Carers were unsure of the impact caring had on their finances (7%) (Figure 22).

There were some small variations between Carers of adults with Schizophrenia, bipolar or psychosis. For example, Carers of adults with bipolar were the most likely to say their finances have got worse (8, 67%), Whereas Carers of adults with Schizophrenia were the most likely to say their finances have got both better and worse (3, 21%).

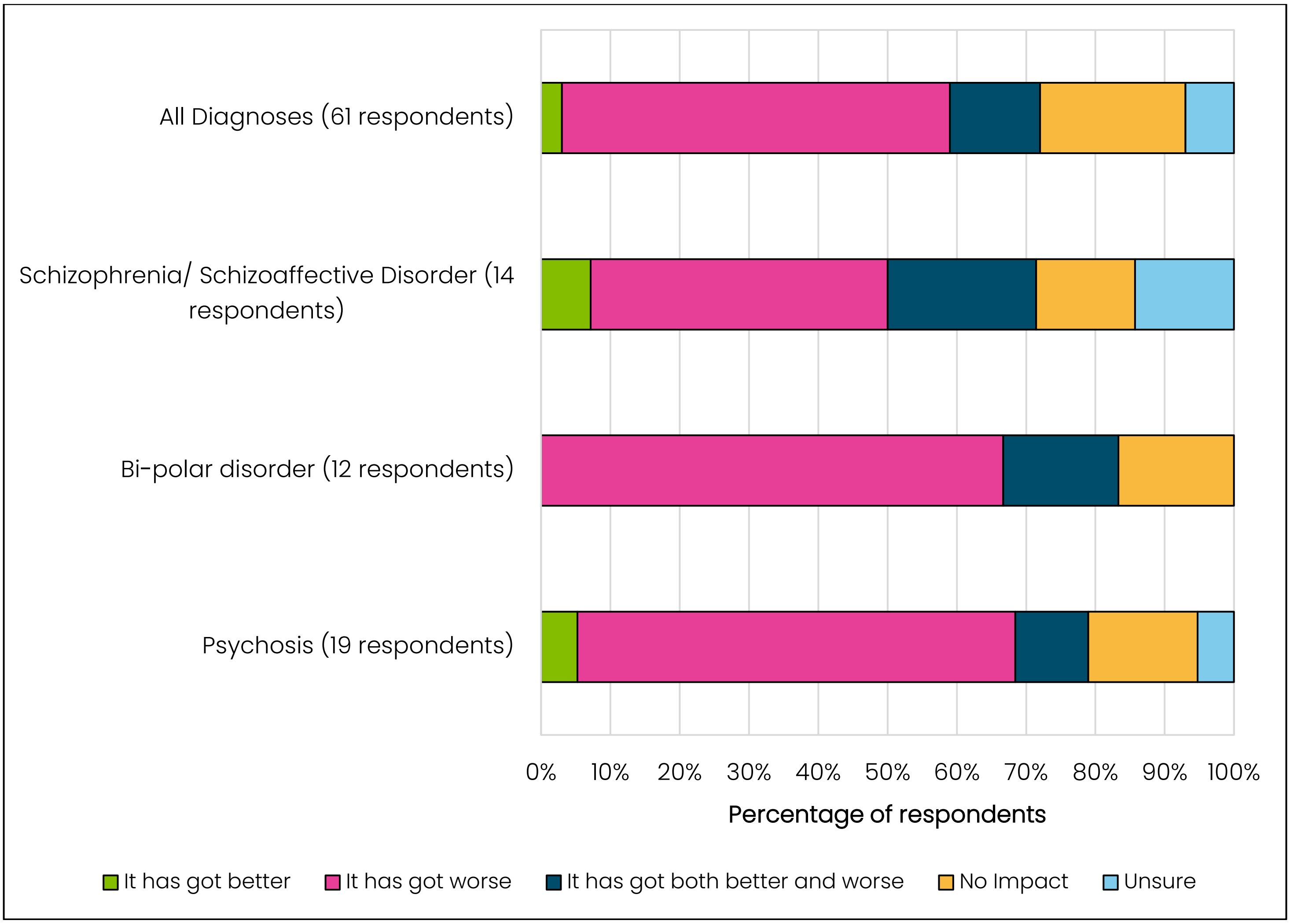

Figure 22. Responses to the question 'What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing?' Finances.

There was little difference between Carers who live with the person they care for and those who do not.

Throughout the survey, a few Carers mentioned the financial impact of Caring for an adult with SMI. Carers spoke about how caring has impacted their employment and has then impacted their finances as a result. For example, one Carer told us that the loss of employment is *"putting a strain on finances"*, whilst another commented that they have not been able to *"increase working hours and income to cope with rising cost of living due to caring."*

The financial impact of caring was also mentioned in the interviews, with one Carer explaining that their entire income is Carers allowance which they have found *'quite tough'*. Another Carer explained the financial worries they have had caring for their sister with bipolar disorder and how they have had to *"bail her out"*:

> “With bipolar, we've had the extreme highs and the extreme lows, and we've had the financial worries and having to bail her out to stop her being evicted.”

Relationships (Friends and Family)

Over half of survey respondents told us their relationships have got worse (58%, 36) since Caring for an adult with SMI. Ten Carers told us their relationships have got both better and worse (16%) and four (6%) told us their relationships have got better. Seven Carers told us there was no impact on their relationships (11%) and five were unsure of the impact caring has had on their relationships (8%) (Figure 23)

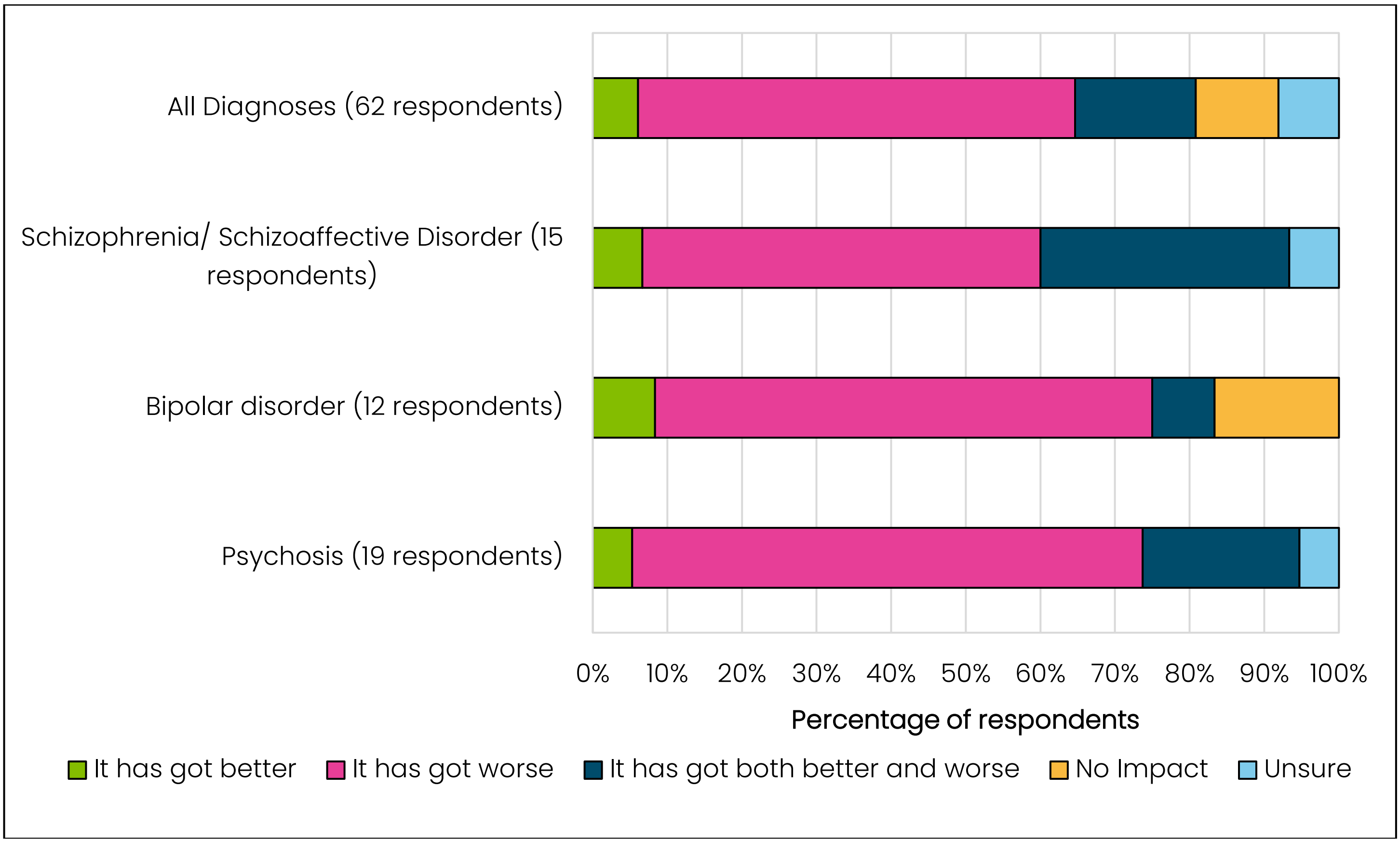

Figure 23. Responses to the question 'What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing? Relationships.

There were only small variations in answers between Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, or psychosis. Carers of adults with psychosis (13, 68%) or bipolar disorder (8 ,67%) were the most likely to say their relationships have got worse.

Carers that live with the person they care for were more likely to say their relationships have got worse (19, 66%) compared to those who do not live with the person (15, 50%). Women (31, 65%) were also more likely than men (4, 36%) to say their relationships have got worse.

Throughout the survey, some Carers mentioned the negative impact that caring has had on their relationships. For example, one Carer commented that their whole family had been affected and that they: *"Live on the edge"* whilst another Carer told us that they cannot go out with their husband unless their daughter can stay with the person they care for *as "he won't tolerate other Carers in our home."*

The negative impact that caring has on relationships, was also a common theme in the interviews, with Carers describing how caring has negatively impacted their relationship with the person they care for and other people, such as family members and partners.

Carers spoke about not wanting to be a Carer anymore, needing a break and that they just wanted to have a relationship with the person that they felt they should have, such as being the person's sibling, friend, or partner. One Carer explained how being a Carer changes the dynamic of relationships, noting that they feel that they have lost their friend as the friendship no longer works both ways. They described the sadness, frustration and bereavement that have occurred as a result of this:

> "So it's sad. I think that, and I feel I've lost her. I feel my friend that was a fully functioning and reciprocal friend because friendship works both ways. I feel that's gone. So, there's a loss there. There's a bereavement and a sadness and a frustration that I can't change it more than I've been able to."

As well as impacting their relationships with the person they care for, Carers also spoke about the impact that caring has had on their relationships with other people, such as family members and partners. One Carer told us that since caring for her son, she has seen her mother less as she lives abroad. Another

Carer explained how caring for her brother with paranoid Schizophrenia has put a strain on her relationship with her husband:

> “Well, they've had a huge impact on my life and also my relationship, which I will, I think I'd like to say it is really affected my relationship with my husband over the years. We've had some very difficult times. I have to accept that he is kind of cynical, I suppose. I don't know, he just doesn't want to engage very much with my brother. He's better than he was, but that has caused me huge emotional problems because I've been torn between the two really.”

Housing

Most respondents told us that being a Carer of an adult with SMI has had no impact on their housing (37, 62%). Around one in five Carers told us their housing has got worse (22%, 13) and five Carers (8%,) said their housing has got both better and worse. Only one Carer told us their housing has got better (2%). This is displayed in Figure 24.

Of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder or psychosis, Carers of adults with schizophrenia/ schizoaffective disorder were the most likely to say caring has no impact on their housing (7, 54%). Whereas Carers of adults with psychosis (6, 33%) or bipolar disorder (4, 33%) were the most likely to say their housing has got worse.

Carers who do not live with the person they care for were more likely to say there has been no impact on their housing (20, 71%) than those that live with the person (16, 55%). Whereas Carers that live with the person were more likely to say that their housing has got worse (9, 31%).

Throughout the survey and interviews, there was very little mention of the impact the caring has on housing.

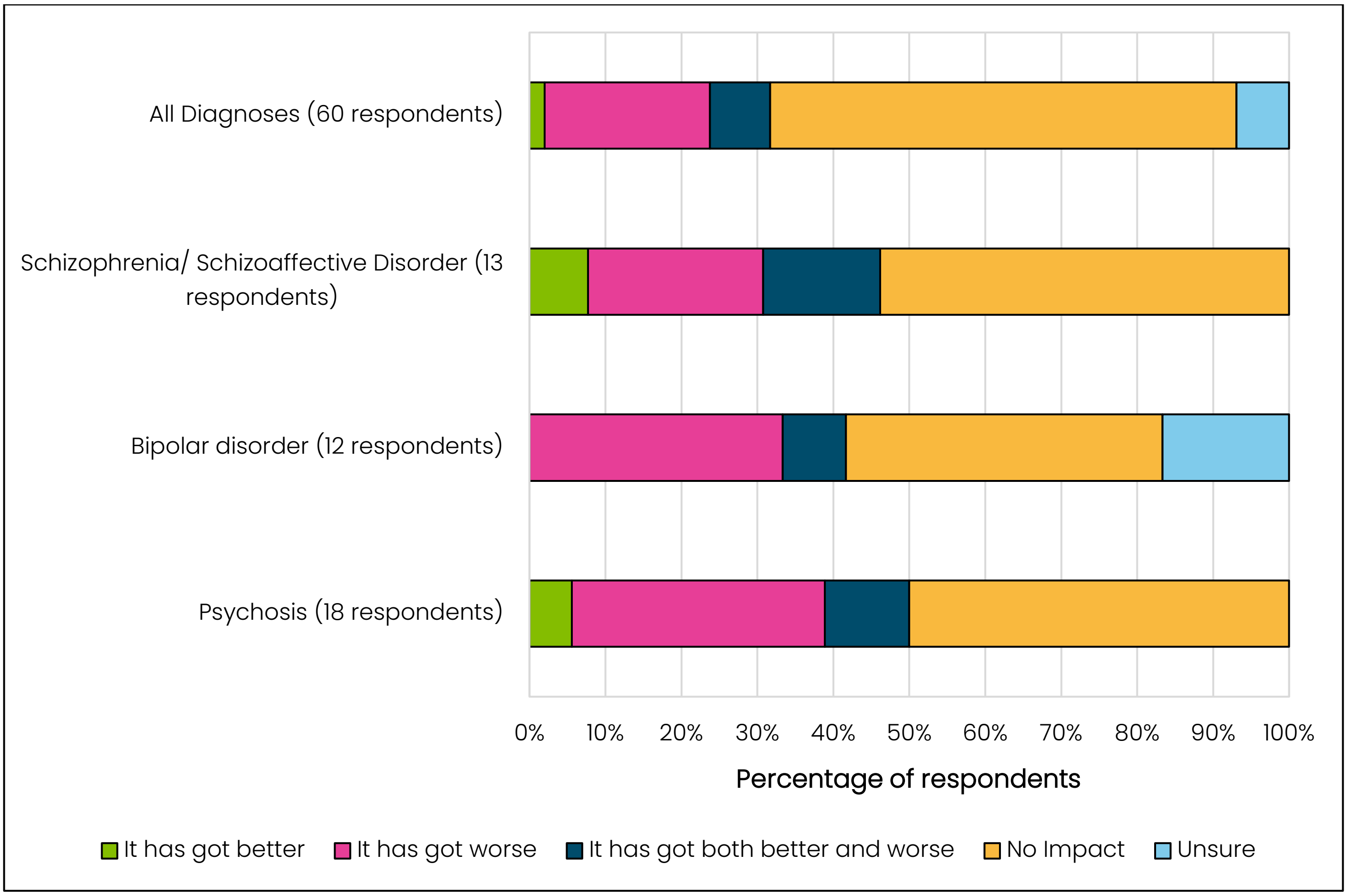

Figure 24. Responses to the question 'What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing? Housing.

Comparison of different impacts

Overall, over half of Carers told us their physical health, mental health, finances, and relationships have got worse since caring for an adult with SMI. Carers were most likely to say that their mental health has got worse. A comparison of the different impacts is displayed in Figure 25 below.

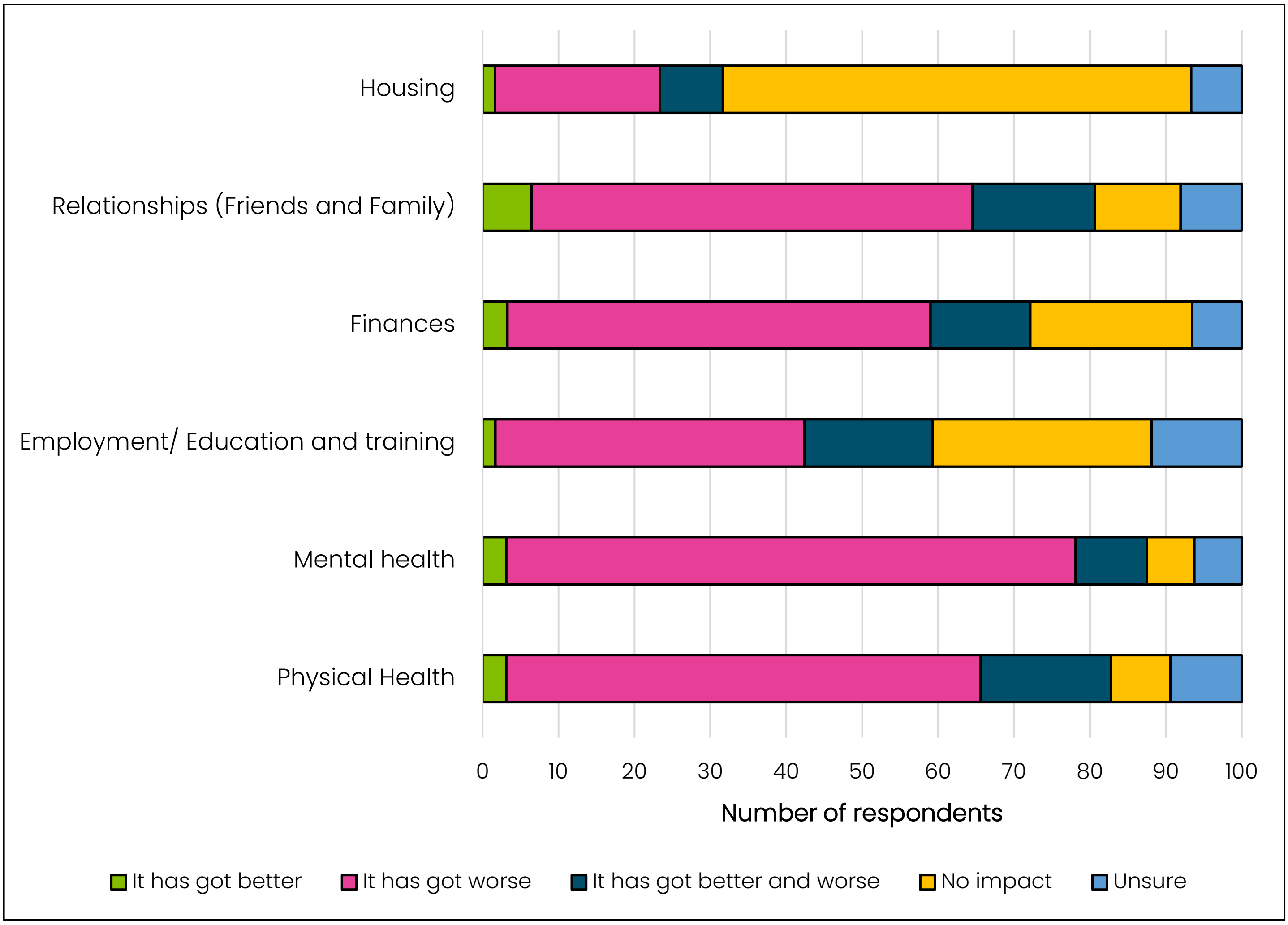

Figure 25. A comparison of answers to the question 'What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing?

> "It's exhausting. it has taken a physical, mental, and emotional toll on my life, health and relationships and has, at times, sent me into despair. Crushing. I am reluctant to make plans for myself and have had to stop thinking about the potential future because it is too painful."

Other impacts of caring for an adult with SMI

As well as the impact on physical health, mental health, employment, relationships, finances and housing, Carers also mentioned the practical impact of being a Carer, such as not being able to go on holiday. Several Carers commented that they were unable to go on holiday due to their caring responsibilities and a lack of trust that the services would support the person they care for. For example, one Carer told us:

> "I don't get to take holidays that I would like to take as a retired person. I mean, we have a caravan on the coast because we thought that was probably the best way to actually get away at all because we're still just only an hour away. But obviously I'm very fortunate that I'm able to do that. But further holidays are quite limited because obviously it's always a case of worrying about what's got happen."

Support for Carer’s health and wellbeing

How easy have you found it to get support for your own health and wellbeing?

Almost half of respondents told us they have found it difficult to get support for their own health and wellbeing (30, 47%). Seventeen (27%) Carers told us it was neither easy nor difficult to get support and only one person told us they found it easy to get support (2%).

One in four respondents (16, 25%) have not tried to get support.

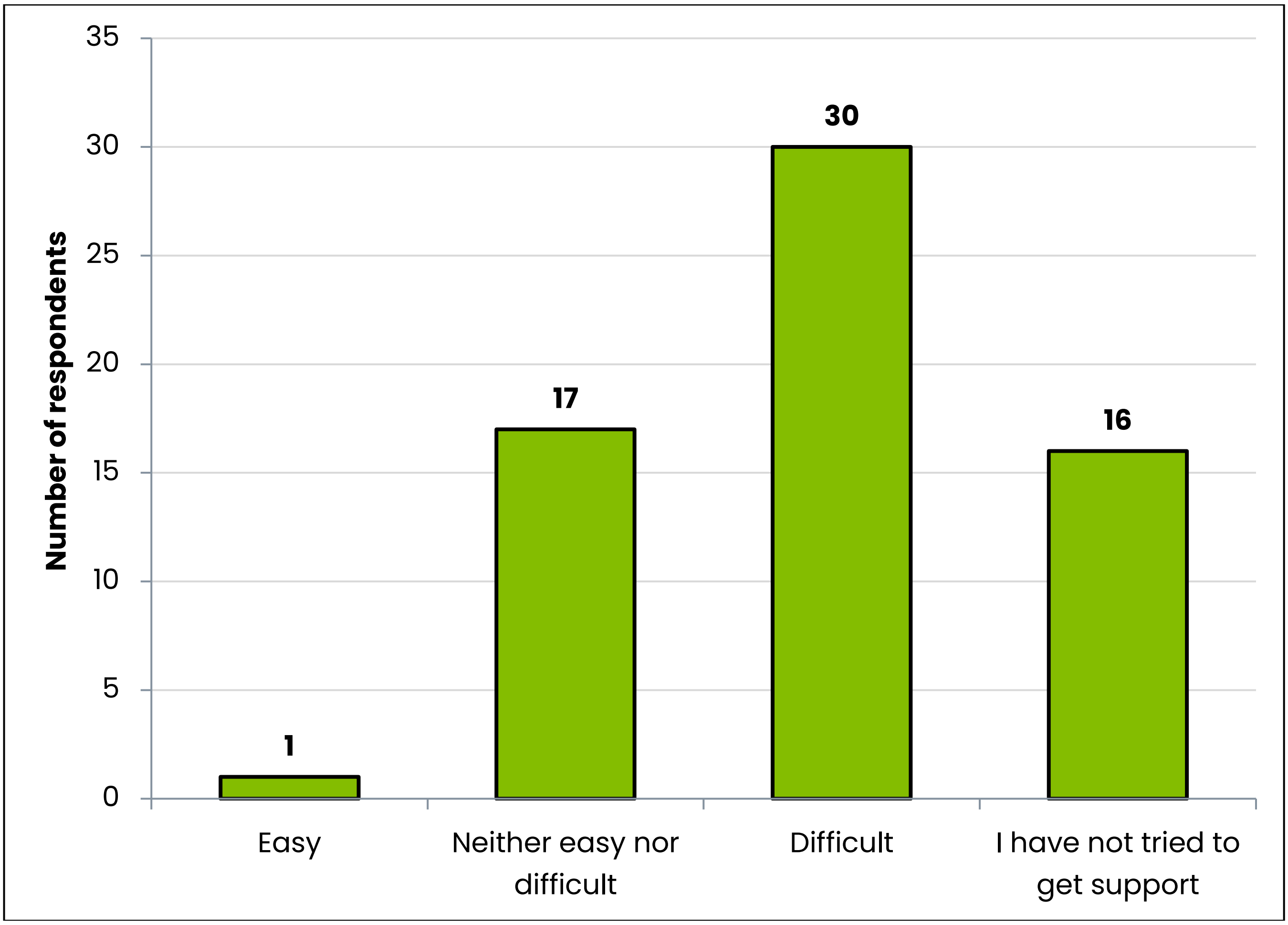

Figure 26. Responses to the question 'How easy have you found it to get support for your own health and wellbeing?'

Women (23, 46%) were slightly more likely than men (4, 36%) to say they found it difficult to get support for their health and wellbeing.

Carers who live with the person they care for were more likely to say it was difficult to get support for their own health and wellbeing (18, 62%) than those who do not live with the person they care for (9, 29%). Carers who do not live with the person they care for, were more likely to say they have not tried to get support (12, 39%).

Most Carers that live with the person they care for have found it difficult to get support for their own health and wellbeing.

Of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, or psychosis, none said they found it easy to get support for their own health and wellbeing. Carers of adults with psychosis were the most likely to say they had found it difficult to get support (10, 53%) and Carers of adults with schizophrenia/ schizoaffective disorder were the most likely to say they have not tried to get support (6, 38%). This is displayed in Figure 27 below.

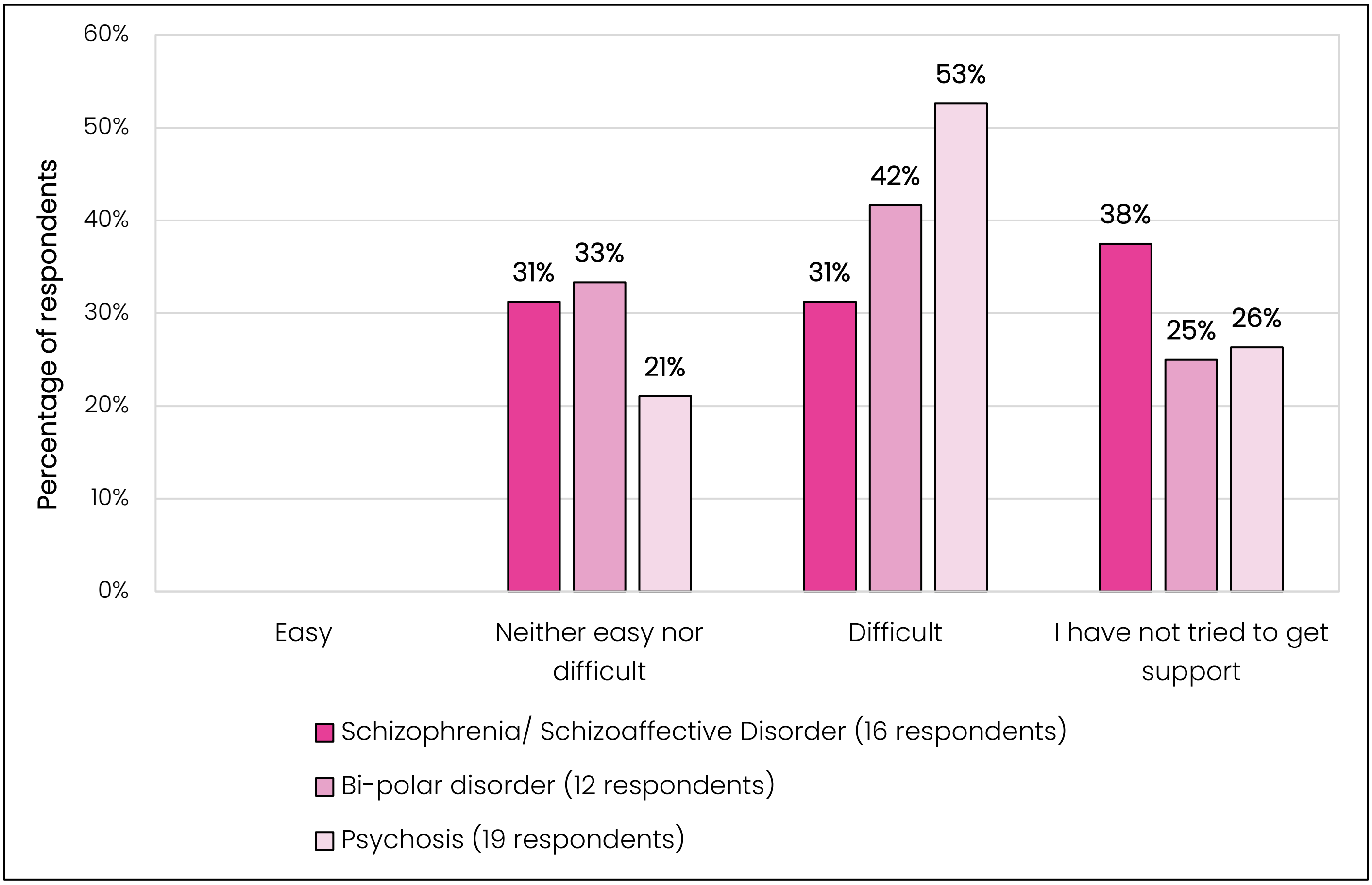

Figure 27. Responses to the question 'How easy have you found it to get support for your own health and wellbeing?'. A comparison between Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, and psychosis

Throughout the survey, a few Carers commented that there is *"No support"* for Carers and how *"It is hard emotionally and physically with absolutely no support".* Another Carer described how they found it challenging to get support and they do not think they will receive any counselling through the NHS.

> "It can be challenging to get support such as courses, resources [sic] and counselling. I do not think it's realistic that I will receive any counselling or therapy through the NHS, since the service user I care for hasn't received that yet either."

One Carer we interviewed also described the difficulties they have faced trying to get support, falling through gaps in services and asking for help and not receiving it. They explained how they have *a "history of poor mental health"* and find it *"quite challenging getting help for me from the system."* They view the health system as being split into 'red,' 'amber' and 'green' where they explained that *"there's sort of provision at the green level"* where people are given CBT or antidepressants, but these do not work for them. However, as they are not a current risk to themselves or anybody else, they are *"not a red"* and they feel that services *"just aren't interested unless you're red,"* so has found it difficult to get support.

If you received support, what type of support did you receive?

Carers were then asked, if they received support, what type of support they received (Figure 28). Three in ten respondents told us they had received support from local organisations (e.g. Carers Matter, Carers Voice) (16, 30%) or through a GP appointment (15, 28%). Nearly one in five Carers told us, they did not know where to go (9, 17%) to get support.

Around a quarter of respondents selected the 'Other' option (14, 26%). This included a variety of answers, such as receiving no support, going on a course, and having *"a couple of days break."*

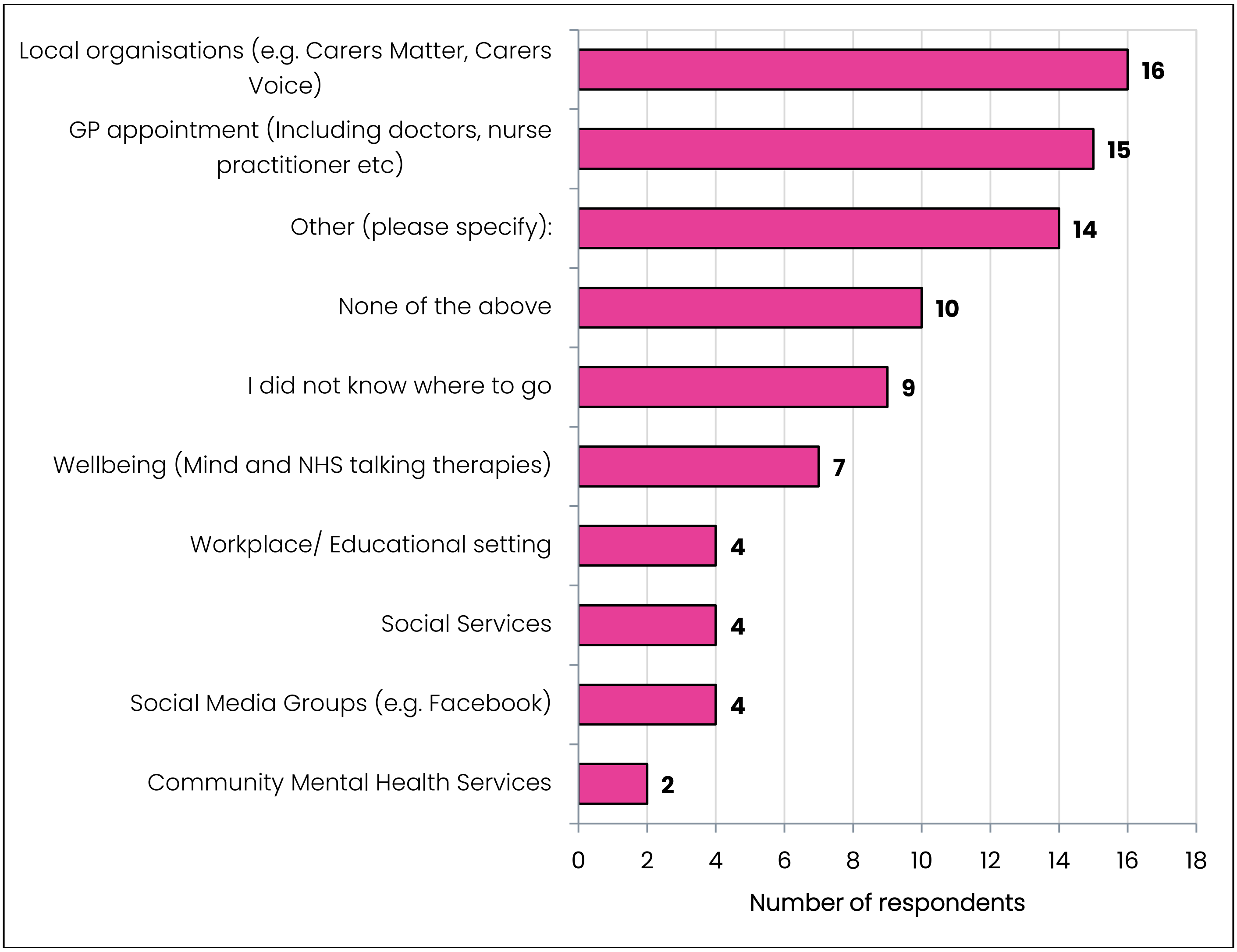

Figure 28. Responses to the question 'If you received support, what type of support did you receive?'. Respondents could select more than one option.

There were only small differences between Carers of adults with schizophrenia/ schizoaffective disorder, bipolar or psychosis.

There were some differences between Carers who live with the person they care for and those who do not live with the person they care for. Carers who live with the person they care for were more likely to have received support from local organisations (11, 22%), than people who do not live with the person they care for (5, 16%). Carers who do not live with the person they care for were slightly more likely to have received support from a GP appointment (6, 19%) than Carers who live with the person they care for (8, 16%)

Men were far more likely to have received support from a local organisation (7, 44%) than women (9, 14%). Whereas women (11, 17%) were slightly more likely than men (2, 13%) to have received support through a GP appointment.

Support was not appropriate or specialised enough

In the interviews Carers were also asked about the support they have received. Several Carers spoke about how the support they received was not appropriate and not specialised enough for Carers of adults with SMI. One Carer explained how they received a *"patronising letter"* telling them to *"carve out some time for yourself. Yeah, but how exactly am I to do this."* Another Carer told us that they had a phone call with Carers Matter but were not offered any support and felt that the person they spoke to did not understand the impact of Caring for someone with serious mental illness:

> "I found getting support through Carers matter [sic] very difficult.[…] I had a phone call and I wasn't offered support. Essentially with the triage, the person who was speaking to me, I felt didn't understand the impact of looking after someone with a serious mental illness. […] And because my state of mind at the time anyway, I found that really quite damaging in a way because it made me feel, it upsets me."

Another Carer explained that they have PTSD due to events that occurred from their brother having paranoid Schizophrenia. However, they found that the support they received from the Wellbeing service was making them feel worse. When they told the service that they could not continue having counselling due to this, they were not offered an alternative and the support was stopped *"They just didn't find me an alternative or anything, just stopped it and I haven't had anything."*

Positive experiences of support

Whilst several Carers explained that they did not receive appropriate support from services, a few Carers highlighted the positive experiences they have had such as receiving counselling through the Carer’s Assessment and how this was helpful. One Carer also told us they had received therapy through Caring Together *“which was also really, really helpful to me.”*

Carers not seeing themselves as Carers

A small theme from the interviews, was that some Carers do not always see themselves as a Carer, with some people mentioning that it took them a while to identify themselves as a Carer. This could be a barrier to accessing the support, information, and resources available to Carers because these people may not even think to look for this support.

> “I just always thought, that's my job. I'm a sister. He'd do it for me. If it was the other way around. We are very, I mean our family, we are a very close family and I've just never ever thought of it as a carer.”

Carer involvement and having their voice heard

Involvement in care

Carers were asked whether they are involved in the person they support's care as much as they want to be. The majority of respondents answered 'yes' (44, 72%). Twelve Carers said 'No' (20%), they are not involved in the person they support's care as much as they want to be and only a small minority said they 'Don't know' (5, 8%).

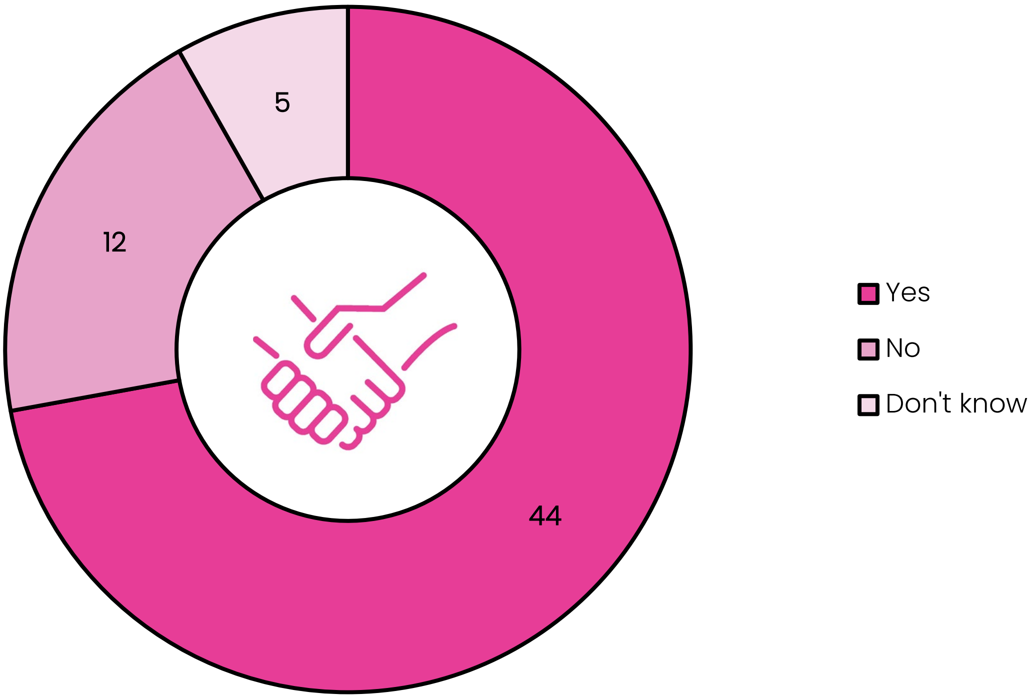

Figure 29. Responses to the question 'Are you involved in the person you support's care as much as you want to be?'

Of Carers of someone with schizophrenia/ schizoaffective disorder, bipolar or psychosis, people caring for someone with bipolar disorder were the most likely to say they are involved in the person's care as much as they want to be (9, 75%), compared to just over half of those caring for someone with psychosis (10, 56%) or schizophrenia/ schizoaffective disorder (8, 53%).

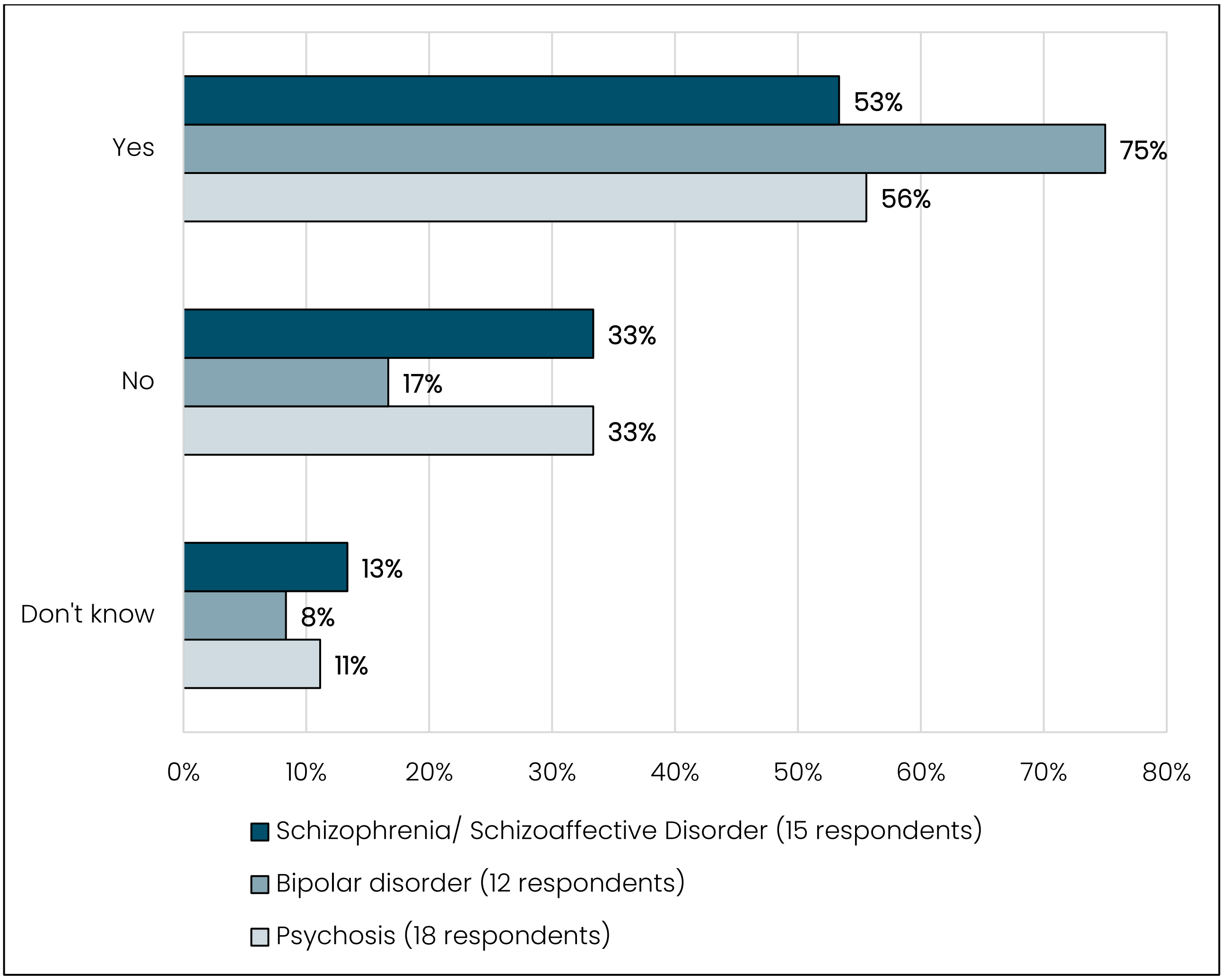

Figure 30. Responses to the question 'Are you involved in the person you support's care as much as you want to be?'. A comparison of Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, and psychosis.

Carers who live with the person they care for were more likely to say they are involved in the person's care as much as they want to be (22, 81%) than those who do not live with the person they care for (20, 65%).

Being involved in the person they support's care

People were then asked to expand on their answer. Carers who answered 'Yes,' they are involved in the person they support's care as much as they want to be, gave examples of their involvement. This included helping financially, being with the person most of the time, doing things for the person such as taking them shopping and viewing their medical records. This is illustrated in the comments below:

- *“I am involved in all the appointments.”*
- *“I really support my mum and live with her.”*
- *“As I help with all his financial and social activities there is not much left.”*

Some Carers told us that whilst they are involved in the person they support’s care as much as they want to be, this is because they feel that they need to be involved in the care as they do not receive any other support. For example, one Carer told us *“I am the only carer he has, I do everything for him”* whilst another added:

> “I'm with him all the time. So, I have no choice but to be involved. If I was not, he would not access care or be able to and I fear that mental health team would not contact him.”

A few Carers commented that whilst they are involved in the person they support’s care, they *“would appreciate even a little outside support”*.

Not being involved in the person they support’s care

Carers that answered ‘No’ they are not as involved in the person they support’s care as much as they want to be, were asked to give reason(s) for their answer. Carers mentioned that this is because they do not feel listened to or involved in the person they support’s care, including not being involved in assessments or meetings:

> “Although my son is doing well at the moment, when he has assessments or meetings I am not involved. Therefore, I am totally reliant on what he tells me. I still feel that if he has a relapse then I will once again be completely unprepared on how to support and deal with his illness.”

Fighting for support for the person they care for

During the interviews, Carers were also asked about their involvement in the person they support’s care. Carers spoke about having to fight for support for the person they care for, having to chase for information, and being dismissed, ignored, and seen as a troublemaker by some service providers. A few interviewees also commented that they think adults with SMI should be asked if there is someone trusted they would like involved. This is illustrated in the comments below:

- *"Well, their communication with me is if I contact them, it's not them contacting me"*
- *"So, this is quite common to sort of push them on somewhere else. Problem parents equals problem patients. We don't want Goby parents asking too many questions."*
- *"You are forever fighting to be involved. The professionals keep you out."*

> "I pleaded with them and kept telling them things she had said and the way she was, but they didn't listen basically."

Communication issues from services

Carers also spoke about communication issues from services, including there being a lack of communication. For example, one Carer told us that there has been no coordination and a lack of communication, leaving Carers thinking *'the worst'*:

> "There is no coordination. And because of the lack of communication, your mind, you just go here, there and everywhere. Your mind, you think the worst, hope for the best, but think the worst. So, the big thing in all of this is communication."

One Carer told us that they feel *"there's been a huge lack of communication from the Mental Health Trust"*, which made them feel *'left in the dark'*, not knowing what should be happening with the person they care for.

“We feel in the dark is this what should happen? Should she be sent home after five weeks on this antipsychotic and just left at home forever? Is that, and we've had to go back though, is she not going to be reviewed? And then when she's reviewed, she isn't reviewed very well and then she declines further and then they go, oh actually she shouldn't be on all that. So, I think for us it's been a pretty poor show from communication from the mental health Trust.”

Some Carers mentioned how it they would find it helpful for Carers to have regular check ins and updates with staff. For example, one Carer suggested that there should be more collaboration with Carers from mental health staff and how they should check in with Carers to see how things are going so they can work together in the treatment of the person they care for. *“And I think really there should be something where they keep in touch with us and ask us how is it going? And we could say, we've tried this, we don't think it worked, what can we do?”*

Another Carer noted how they would like to receive reports *“on what’s happening and what has been done”* rather than “*two-line emails saying, this one's on holiday, I'm seeing him next week. Safeguarding said this, it's not a full picture”.* However, they acknowledged that if staff had more time, then they may do this. One Carer also explained how they were not told by the care team that they would be having meetings with the manager and only found out by coincidence when they visited their daughter.

“The manager of the home happened to be in office with her door open. She just spoke to me and said, you come in [...]. And I said, what for? And she said, for the meeting [...] But the team hadn't told me.”

Communication issues and not feeling involved, was also a theme in the focus group. Carers told us how they have not been kept informed by NSFT, do not feel involved, have received ‘broken promises’ and have not been contacted back. For example, one Carer who cares for their daughter with bipolar told us how they were promised by NSFT that they would be kept *‘in the loop’* but that this has not happened.

> “And I've been promised that I will be kept in the loop either by phone calls or emails, whatever communication means they like to use, but it doesn't happen. So, we are given assurances that we will be kept informed as much as the person that you are caring for wants you to be kept informed, but in reality, it doesn't happen.”

Another Carer in the focus group described the difficulties of supporting their daughter when she is in crisis, because of receiving some inadequate information, being passed from place to place and not getting *“any answers and not getting any responses to what I should be trying to do in order to help my daughter to cope with her crisis.”*

A few Carers in the focus group also highlighted the importance of Carer involvement. For example, one Carer explained that if Carers are not involved then information becomes *“quite meaningless”*:

> “The information comes with involvement, whereas you can have information without involvement and it becomes quite meaningless really, it's just reading leaflets on your own and it's not very helpful.”

Having their voice heard

Carers were then asked how satisfied they feel that their voice is heard by staff if they make a suggestion or give them information about the person they care for. Just under half of survey respondents told us they were dissatisfied (29, 45%) that their voice is heard by staff if they make a suggestion or give them information about the person they support. Around a quarter of respondents were neither satisfied nor dissatisfied (16, 25%) and only two in five Carers (13, 20%) told us they were satisfied that their voice was heard.

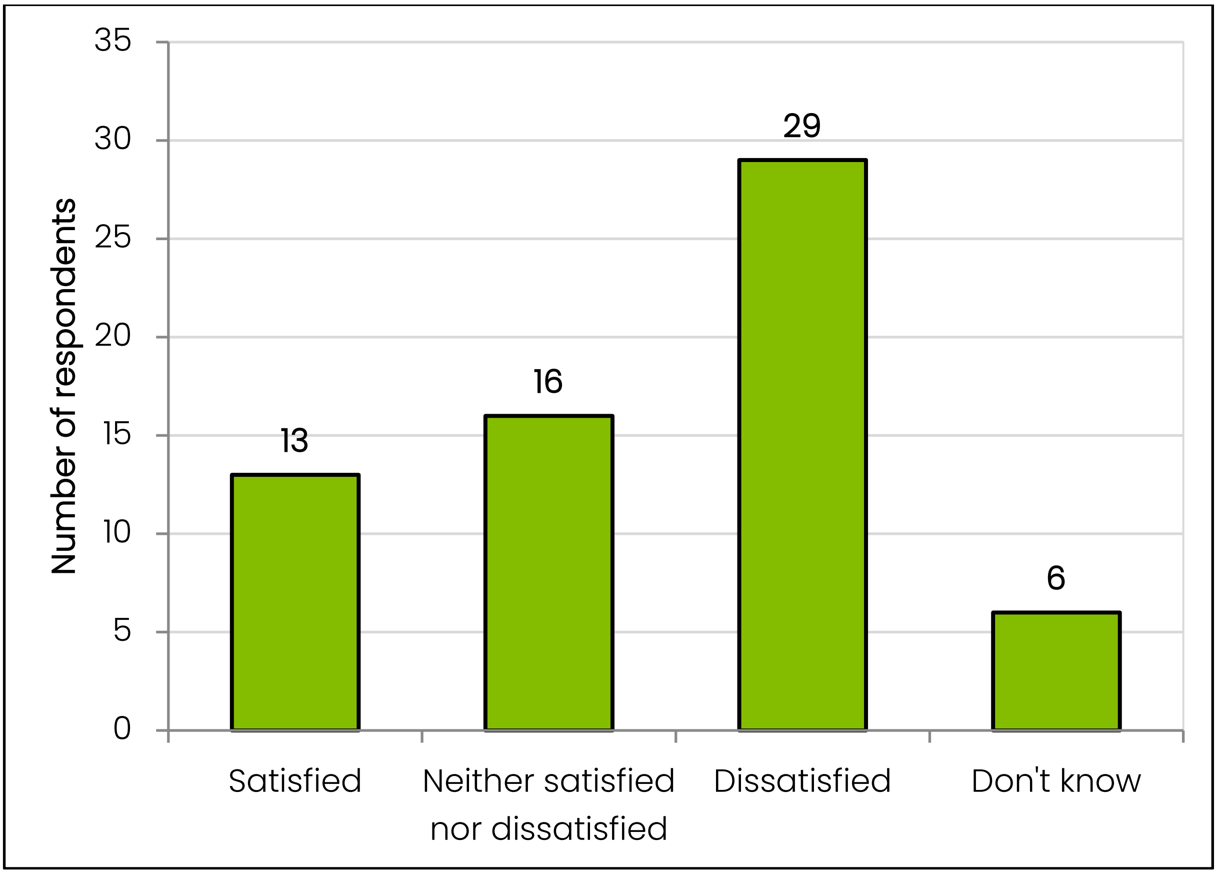

Figure 31. Responses to the question 'How satisfied do you feel that your voice is heard by staff if you make a suggestion or give them information about the person you support?'

There were some variations in answers between Carers of adults with schizophrenia/ schizoaffective disorder, bipolar disorder, or psychosis. Carers of adults with psychosis were the most likely to be dissatisfied (11, 58%) but were also the most likely to be satisfied (5, 26%). This is illustrated in Figure 32 below:

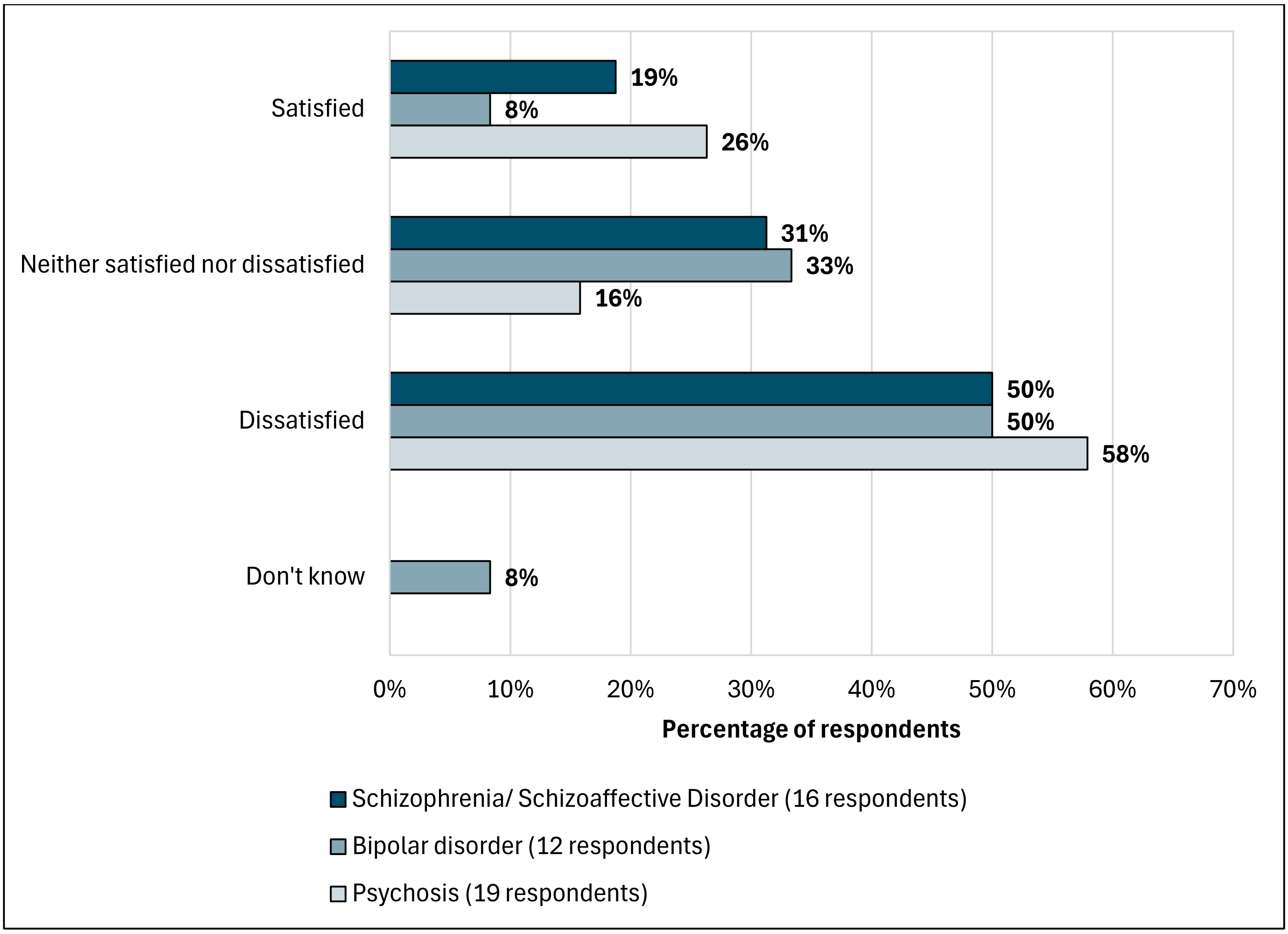

Figure 32. Responses to the question 'How satisfied do you feel that your voice is heard by staff if you make a suggestion or give them information about the person you support?'

Carers who live with the person they support were more likely to say they are satisfied that their voice was heard (8 ,28%), than those who do not live with the person they support (5, 16%). Women (10, 48%) were also more likely to feel dissatisfied that their voice is heard than men (3, 27%).

Having their voice heard

Carers were then asked why they have chosen their answer. Of respondents who told us they were satisfied that their voice is heard by staff if they make a suggestion or give them information, there were a variety of answers, including staff speaking to the Carer and acting on their concerns. For example, a Carer told us that their son’s psychiatrist responds promptly: *“My son's psychiatrist responds very promptly to my emails and acts on my concerns.”*

Carers who were neither satisfied nor dissatisfied that their voice is heard, commented that their experiences can be varied. One Carer explained that *"The response and how seriously my concerns have been taken has varied".* Another Carer mentioned that whilst they feel they are being listened to at the moment this has not always been the case:

> "At the moment we feel we are being listened to. In the past staff at the mental health services have been unsupportive and lacking in understanding, even senior members of staff".

Not having their voice heard

Carers who were dissatisfied that their voice is heard, told us that they are not listened to, are dismissed and their knowledge is not taken into consideration. This was a common theme throughout the survey, interviews and focus group.

One survey respondent told us that their concerns are often dismissed *"I have raised concerns about communication and listening to me as a carer. Often it is dismissed if in a higher clinical role as if they know best.".* One Carer we interviewed also told us that when they try to *"speak up"* for the person they care for, they are seen as an irritation.

> "In the past staff at the mental health services have been unsupportive and lacking in understanding, even senior members of staff".

Carers in the interviews and focus group, also highlighted the importance of Carers being valued and given the recognition they deserve. Carers in the interviews spoke about how they wanted to make sure professionals understood the role that they play and how essential it is because they know the person they care for more than anyone else. For example, one Carer explained how they feel that they are not respected and are excluded from their son's care:

> "I would say that carers are not respected. We are seen as lesser. We're referred to as the person's mum. Well, we're a person as well as the mum. We are a person. And it's very condescending to just, oh, Max's* mum. And to not be listened to, excluded is a constant theme throughout caring, not

> just caring for seriously mentally ill, but caring in general. It has no status."
> * Name changed

Carers also commented that staff were dismissive of their knowledge and that their voice is not taken into consideration: *"I felt that the psychiatrist was really dismissive of my knowledge and yeah, and I have raised that further."* Another Carer also emphasized how having their voice heard and being involved is even more essential in a disjointed system.

One Carer in the focus group described how they were not listened to when they moved from Suffolk to Norfolk. The Carer told staff that her and her husband needed support, but instead her husband was discharged, which result in him going into crisis and getting a lot worse.

> "I think it's really important obviously for carers to be listened to and everything and respected [...] I just feel like I wasn't listened to and they discharged him. Then obviously because of that we had no support when we did move and at all we just had nothing. Then obviously went into crisis and got a lot worse."

"I think the most important thing for me is that I'm listened to because I know her and I know her better than anybody else"

Having Carer's voices heard in decision making levels

A few Carers highlighted the value of the Carer's voice in decision making levels. One Carer suggested that senior members of staff should go out with the community mental health team and see the reality of Carers of adults with SMI as "*you can't make decisions. I feel if you don't see the reality of what you're making decisions about*." They also told us they think Carers should have *"a seat at the decision-making table"*, because if Carers "*had a qualification for the years of experience we have in caring, we would be professors us."*

Examples of good communication

Whilst many Carers commented on the lack of communication they have received and have generally felt ignored and dismissed. A few Carers told us about examples of good communication they have received amongst these negative experiences and explained what made these good. Comments generally focused on feeling involved, listened to, and valued. One Carer described how an administrator they encountered took the time to listen to them and acknowledged them even though they could not help. This is illustrated in the quote below:

> "She [an administrator] just seemed that she was listening to me rather than trying to fob me off. She took the time, which I know she didn't have. She took the time to listen to what I had to say, and then she was like, okay, I can't deal with this, but this is how we can deal with it. So, if you put all of that in an email, put this in the subject line, I will get it. I will then be able to send it off to a team manager or somebody more senior to look at. And she did exactly that and she responded with or received thanks. And just that actual acknowledgement that she'd seen my email and was doing something with it was brilliant."

Another Carer (*based in Suffolk) told us they have found it '*amazing*' to have multidisciplinary meetings with their brother's psychiatrist, psychologist, occupational therapist, and doctor. They explained that it was *'powerful'* to finish a meeting where all voices had been heard and decisions were made together. They also commented that it was nice for the person they care for to have the Carer at the meeting as "*he knows I was always there to almost kind of holding* *his hands if he's needed so I could calm him down because sometimes those kind of meetings can be a bit overwhelming."*

Improving the experience of Carers of adults with SMI

In the survey, Carers were asked what (if anything) they think could be done to help improve their experience of being a Carer of an adult with SMI. The answers to this question continued to highlight some of the main themes of this piece of work, including more support needed for Carers, improving services and the care of the adult with SMI, and listening to and involving Carers. The answers to this question are explored in more depth below.

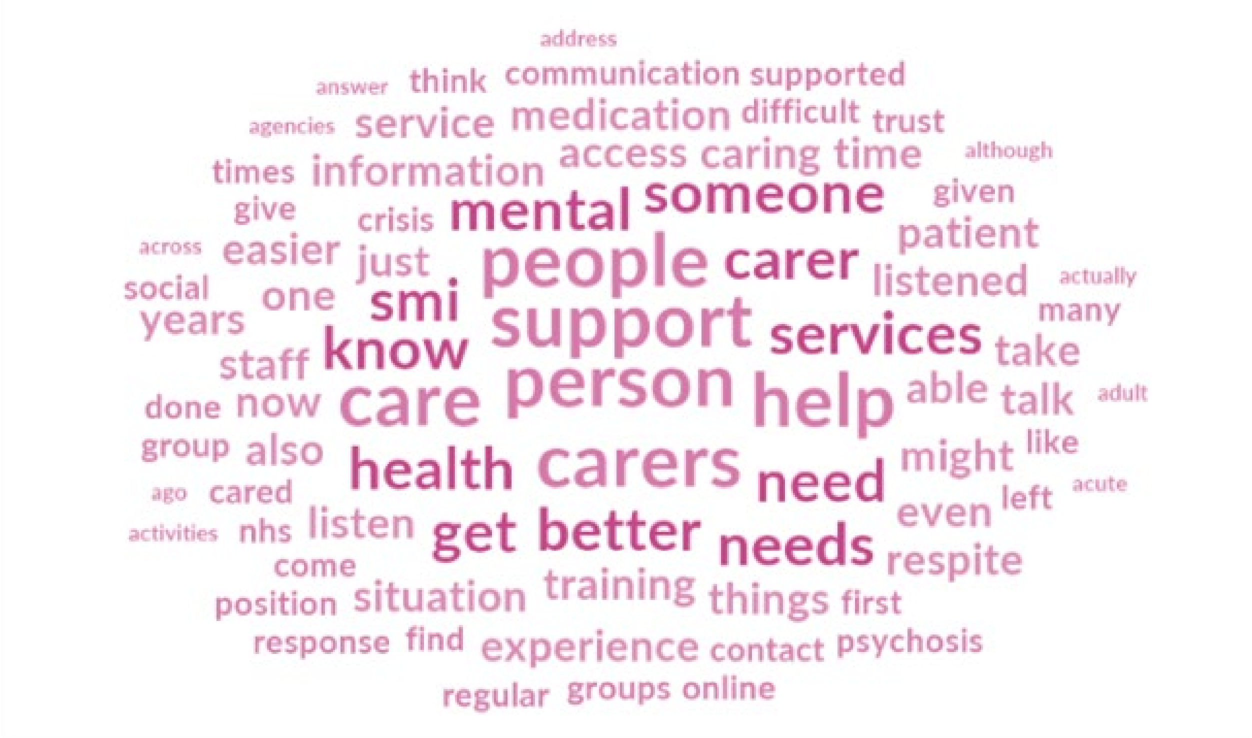

Figure 33. A word cloud for responses to the question 'What (if anything) do you think could be done to improve your experience of being a Carer of an adult with SMI?'. The larger the word the more commonly it was used.

More support needed for Carers

The largest theme in responses to this question, was that there needs to be more support and better care for Carers. Carers spoke about the types of support they think could help to improve their experience. This included practical support, emotional support, respite, and more training for staff.

Practical Support

Many Carers gave examples of the practical support that they would find helpful, including financial support or advice and receiving more information on SMI. One Carer explained that they would like more information on *"my person's diagnosis and what to expect"*, whilst another commented that they would find signposting support helpful as the person they care for is too unwell to contact HM Revenue and Customs (HMRC):

> "I need practical support such as being signposted to charities that can address the problems encountered by the person I care for. For example, the SMI person is so ill to deal with HMRC."

Carers also gave a variety of other examples of practical support, including more support from mental health teams and social services, having a recognised ID for Carers, training for Carers and physical assistance. These are illustrated in the comments below:

- *"More support from the mental health teams an* [sic] *where to access information from"*
- *"Some form of recognised and official ID the* [sic] *specifically links me to my sister and her daughter."*
- *"Training: there *is* some training out there if you know where to look.* […] *The more I know, the better care I can provide."*

Emotional Support

Carers also mentioned examples of the emotional support they think would improve their experience. Several Carers told us that they would like someone they can talk to *"Knowing that there is someone you can talk to and get help* *from when you need it."* and *"Being able to vent to other people experiencing the same problem"*

A few Carers also told us how they would like more Carers groups or events. One Carer explained how they would like more groups as they have found it beneficial to meet other people with a similar experience to them:

> "More groups. I attend a carers support group, but it would be nice if there was a social group of some kind. I have found that support from people with no experience of psychosis is not very helpful. It has been of immeasurable help meeting people who have had similar experiences"

The importance of Carers groups and the positive impact they can have emotionally was also discussed in the focus group.

Other answers included a Carers helpline, more support for Carers online, by telephone and in person and the mental health of Carers to be taken more seriously: *"The MH [Mental Health] of carers themselves should be taken much more seriously than it is."*.

Staff improvements

Carers also spoke about how more training for staff and a better understanding of Carers of adults with SMI, could improve their experience. For example, one Carer told us that staff should be trained to communicate with Carers as staff's lack of understanding has stopped them from trying to get help.

> "Better training for officials when dealing with carers. It can be really difficult at times- I have come across those with common sense and those who have not. The stress of 'here we go again - they think I'm not telling the truth' again sometimes stops me even bothering to contact help".

Respite options

A few Carers specifically mentioned that improved respite opportunities are needed: *"Respite that actually is what the carer needs and when."*

No support for Carers

Some Carers told us that there is no support for Carers, with one explaining that they were *"begging for support"* and another commenting that everything has been left to them to sort out *"The reality is that this has fallen completely on my shoulders".*

Improving services and care for the adult with SMI

Another theme in responses to this question was around improving services and care for the adult with SMI. This included: better care for the person with SMI, better access to services, improvements to staffing, service provision and using the Triangle of Care.

Carers told us that their experience could be improved if the person they care for received better care and if access to services was improved, such as *"easier routes to acute services",* joined up services, and groups *"for people with SMI to attend with transport".* A few Carers specifically mentioned that NSFT services need to be improved, for example, one Carer told us their experience could be improved if they felt that the person they care for "*is cared for and not neglected by the Trust"*

Some Carers commented that improvements to staffing could help to better support the person they care for. For example, one Carer told commented that there needs to be: "*Better recruitment and retention of staff."* Whilst another explained that there needs to be someone to co-ordinate the care: "*There needs to be a person responsible for the coordination of support and services in all areas for my cared-for person."*

Carers also told us that there needs to be more services and funding for adults with SMI. This included more residential care and more emergency mental health responders.

A small number of Carers specifically mentioned the Triangle of Care and how this should be better implemented. This is illustrated in the comments below:

- *"Proper implementation of the Triangle of Care throughout the Trust and across all delivery arms"*

- *The 'triangle of care' being a reality”.*

A few Carers in the focus group also spoke about continuity of care and how improvements could be made to make sure there is support available. For example, one Carer explained how their brother was ignored and *‘dropped’* due to staff changes.

> “We know that people leave services and so on and that's going to happen, but people just talk. My brother was ignored, he was just dropped. He was like a lambing being dropped from the top of a cliff. He doesn't seem to exist anymore to other people in the trust.”

The impact of Mental Health provision

The impact of mental health provision and better care for adults with SMI was also a theme in the interviews. Carers generally felt that the priority was not them, it was the people they care for who need the support. They felt that if that was addressed then things would be easier for them as Carers.

Carers spoke about how if the person they care for was better supported, then it would make their life easier. For example, one Carer explained that the most important thing for them is their daughter being looked after properly:

> “If I knew my daughter was properly looked after for life, that would be the biggest relief. [...] Because that's the most important thing is, I mean, if she was, well, I wouldn't be a carer”.

Another Carer explained that they do not want support for themselves, other than people to look after their son *“I don't want support. I don't think anybody can support me very much other than in looking after him and talking to him in the right way and helping him if nobody could support me to help him.”*

Carers spoke about the impact of gaps in crisis services: *“what would be useful would be an improvement in services, particularly the crisis service.”* One Carer explained that there needs to be more beds for people in *“acute phases of SMI”* as despite “*begging*” for her husband to be admitted, he was put on a waiting list as there were not enough beds. However, this resulted in the police being called and he was admitted to hospital just ten days later.

> “They need more beds for people in acute phases of SMI at one point, between the suicide and having to call the police out on actually two occasions, Jack sat and begged to be admitted to hospital because he felt unsafe twice. I begged at the same time. And they were like, we've only got 19 beds. Sorry, there's a waiting list. Oh, that's okay then. And 10 days later we had to get the police out and if Jack had been admitted at that point, that whole thing could have been avoided.” *Names changed

Another Carer, who cares for their sister with bipolar disorder told us that they feel very isolated now that *“999 aren't responding with this Right Care Right Person.”.* They explained that they have *“always had a good response from police”* and if it wasn’t for them, their sister would not be here, but *“now that's been taken away. You really do feel deserted.”*

Carers also spoke about continuity of care and the impact of disjointed care. One Carer told us that when their son was admitted to a psychiatric hospital, they had to give his medical history 22 times:

> “When Alex was admitted to a psychiatric hospital in the week between a particular bout of self harm and him being admitted, I gave his full medical history 22 times, 22 times I gave the same information to different people. That just shouldn't happen.” *Names Changed

Carer involvement and having their voice heard

Another theme in responses to the question of how Carers’ experiences could be improved, was around Carer involvement and having their voices heard. As already mentioned, this was a common theme throughout the survey and interviews. Carers re-emphasised how they should be listened to, involved, and valued.

Some Carers told us that they would like better communication, including making it easier for Carers to contact services, regular contact with professionals and better communication between Carers and services. This is illustrated in the comment below:

> “Better lines of communication between carers and the service and for concerns around patient safety to be taken more seriously because we notice those little changes that can't be picked up on during an appointment which is a somewhat artificial situation in the first place.”

A few Carers specifically told us that they would like to be included more in the person they support’s care. For example, one Carer told us that their experience would be improved if they were *“included in care planning”.*

Any other comments

Carers were asked whether they have any other comments about being a Carer of an adult with SMI, these comments mainly centred around the themes already mentioned including: The difficulties of being a Carer (the emotional and physical impact of this), problems with services (including feeling let down and having difficulties with access and lack of trust in services), Carer involvement and having their voice heard and more support needed for Carers. A few Carers also commented that they are concerned what will happen to the person they support if they become unwell.

> “It’s hell on earth. A nightmare trying to get help for person cared for in an inadequate, failing service.”

Other Models of Care

We also researched other models of care that have helped to involve Carers and improve the experiences of both patients with Serious Mental Illness and their Carers. Examples of these are explored below.

Case Study: Open Dialogue Approach

The Open Dialogue approach comes from Finland and is a different approach to mental health crisis and organising care.

Open Dialogue brings together people’s professional and social networks to provide continuity of care for people who use the services. Open Dialogue is different to other treatments and has some unique features, such as: consistency of staff, the belief that all voices are equal and avoiding quick treatment decisions or labels. It is hoped that Open Dialogue will *“create space for new understandings of difficulties in the context of the individual’s own life”* (KMPT, 2024). The Open Dialogue Approach focuses on helping people’s families and networks to use their *“own resources in their recovery and take more control”* (UCL, 2024).

There are seven key principles to Open Dialogue

1. Immediate help
2. Social network perspective
3. Flexibility and mobility
4. Responsibility
5. Psychological continuity
6. Tolerating uncertainty
7. Dialogue (KMPT, 2024).

One Carer we interviewed told us that they wished that Norfolk services would take on the Open Dialogue Approach’.

“Well, I wish they would take on this open dialogue approach, […]. I've heard about it, I mentioned it to the psychiatrist and he said that where he worked before in Devon, they did actually, they implemented it and it just said it did have good results, but here in Norfolk we don't have it.”

The Carer explained that Open Dialogue involves a system where anyone who is concerned can call a member of staff and they involve people who *"are closest to the person that they're concerned about."* And then continue with these meetings frequently.

The Carer told us that they thought this was a *"very promising approach"* and seemed to have good results with hospitals being closed as a result. However, they questioned how hospitals could close, if people who were already ill, have not got better.

"But the thing that wasn't very clear was somebody asked what about the people who have already been ill for a long time? […] But I still can't understand how they close the hospitals if the people who were already ill haven't got better."

Several mental health trusts in the UK have used the Open Dialogue approach, including Kent and Medway NHS and Social Care Trust (KMPT, 2024).

Carer Champions

Several Trusts across the UK have employed Carer Champions to enable Carers to have their voices heard.

A Carer Champion is someone whose role is to *"promote, role model and stand up for Carer collaboration and involvement across the care pathway. To enable Carers to have a voice and their experience and knowledge to be valued"* (Devon Partnership Trust, 2023).

Most of the teams at Devon Partnership Trust have at least one Carer Champion. Carer Champions also provide Carers with access to information and resources to help support them in their Caring role (Devon Partnership Trust, 2023).

Carer involvement at the Dragonfly Unit at NSFT

The Dragonfly Unit is a general adolescent psychiatric unit. The service is for young people aged 13-18 who are experiencing a serious mental health disorder *"that cannot be safely managed in a community setting"* (Norfolk and Suffolk Foundation Trust, 2024b).

The Dragonfly Unit hold a regular Carers Forum, where Carers can talk to staff and ask them questions. The forum focuses on education, information, and support for Carers. Staff also contact Carers and parents with a weekly update on the progress of the patient (when there is consent for this).

Whilst this service is for young people, the Carers Forum and regular updates is a good example of how Carers can be involved in the care of the person they support.

What this means

Our analysis and recommendations are based on the survey, focus group and interview responses that we received and whilst the sample has its limitations, clear themes have been identified.

The information available to Carers could be more specialised. What Carers have told us suggests that there is a lack of information on SMI, Medication and side effects and being a Carer of someone with SMI. Carers would like more information on this that is clear and concise with no jargon. There is also a sense that this information should be given to Carers as soon as possible.

There is also not enough specialised emotional or practical support for Carers and there are difficulties when trying to access support. It can take people several years to identify themselves as a Carer, which can be a barrier to accessing both information and support.

The findings suggest that Carers want to feel assured that the person they support receives good quality care. There is a lack of trust in services, with improvements needed to mental health provision and services, this is particularly the case for crisis services. There are also issues with continuity of care and disjointed services which need to be improved.

There are also communication issues, with Carers feeling that their voices are not heard and that they are often dismissed and ignored. Carers would like to be communicated with more regularly, shown more respect and some would like to be involved more in the care of the person they support. There is a need for staff to be more aware of the value of Carers and how to involve them in the care of the person they support.

Recommendations

From the findings of this piece of work several recommendations to NSFT and local Carer organisations can be made to improve the experiences of Carers of adults with SMI.

More staff training to better value, support and involve Carers

1. All staff involved in the care of an adult with SMI (including admin/reception staff) should receive training on the value of SMI Carers and how to involve them more in the care of the person they support. If possible, the training should be delivered by a Carer of an adult with SMI. This training should also include information on Carers' rights and data protection, so staff can find ways to reassure Carers and involve them (even if the person they are Caring for does not want them involved). This training should also be delivered to any member of staff carrying out Carer's Assessments or providing psychological support.
2. When staff have any contact with Carers, they should ask them how they are and whether they need any support.
3. Staff who deliver psychological support (e.g. staff at Wellbeing) and those who triage these services, should receive specific training on the experiences of Carers of adults with SMI and how support can be tailored to their specific situation.
4. Staff should ask adults with SMI whether they have someone that cares for them.
5. Staff should receive awareness training on the Carers Identity Passport and how to recognise this.

Increase communication and information for Carers of adults with SMI

1. Develop specialised information on SMI, Medication and Side effects and information on being a Carer for an adult of SMI. This should be given to

Carers at the point of diagnosis and personalised to the person they care for, if possible. This information should be available in a range of formats, including physical copies and it should be clear and concise.

2. Updates to systems to remind staff to contact Carers and implement processes/ policies to ensure that when a Carer contacts a staff member, they receive an acknowledgement from the member of staff member to say that they have received this and reply to the Carer in a set amount of time.
3. There should be an increase in communication to Carers to increase awareness of the information, resources (including Carer's Assessments) and Carer groups that are currently available to Carers. This should be in a variety of formats to make them more accessible (e.g. online, leaflets, in local magazines etc).

Increase Carer involvement and voice

1. Explore the possibility of having Carers groups or Carers forums for each service of NSFT that cares for adults with SMI, to help Carers gain support from other Carers in a similar situation and allow them to have their voice heard.
2. Explore the possibility of employing Carer Champions at NSFT to promote Carer collaboration and involvement and provide Carers with access to information and resources.

Improving mental health service provision and better care

Many Carers told us their experiences could be improved if there was more mental health provision and better care for the person they support. NSFT are currently doing a variety of work to help to improve this, including ongoing work to ensure more continuity of care for patients of SMI and lived experience (of Carers and adults with SMI) being embedded into staff training.

Formal response

The response below comes from the Norfolk and Suffolk NHS Foundation Trust.

Thank you for sharing your comprehensive SMI Carer Event Report, which highlights the key challenges faced by carers of individuals with Severe Mental Illness (SMI). We appreciate your ongoing partnership, and the valuable insights gained from the survey and interviews conducted.

We acknowledge the findings that reveal concerns about carers not feeling heard, recognised, or adequately supported. At NSFT, we are committed to improving carer involvement and addressing the areas highlighted in your report. Below is a detailed response to each of the concerns raised, alongside the steps we are taking to improve the experience for carers.

Response to Key Findings:

Carers Feeling Unheard and Unrecognised. We understand that many carers feel that their voices are not sufficiently acknowledged or valued by staff. We are actively working to improve this through:

- Established a Carer Champions Network, with over 60 Carer Champions throughout the Trust. These champions are embedded in local teams and act as advocates, ensuring that carers' voices are heard. We hold monthly forums to provide updates and support to our champions.
- Developed a Trust-wide Carer Booklet, now in circulation, which offers comprehensive guidance and support for carers of individuals with SMI.

Training for Staff on Carer Value and Involvement. We are committed to ensuring that staff understand the crucial role carers play in supporting individuals with SMI. To enhance staff understanding, we have:

- Introduced Carer Awareness Training, available as an e-learning module, monitored by our Carer Leads to track compliance. Following this report, we will refresh this training to include specific modules on carers of SMI, their rights, and how to involve them in care planning.

- We acknowledge that not all individuals have a next of kin (NOK), but the goal is to ensure staff are consistently asking and recording this information. As part of the "Think Family" initiative, we are working to ensure that all carers and next of kin (where applicable) are documented in service users' records. The project aims to achieve 90% documentation of carers and 100% documentation of next of kin by October 2025.

Support for Carers' Emotional and Physical Wellbeing We recognise the need to provide more targeted support for carers' emotional and physical wellbeing. We are addressing this by:

Continuing to work on a Carers Strategy, part of our wider Service User and Carer strategy, which has a dedicated priority focused on carers. Our goal is to ensure carers feel supported and can say:

  - "I have felt supported, and my voice is listened to."
  - "I was identified as a carer early on and contributed to assessment, care, and discharge planning."
  - "I have access to a named person who is responsible for supporting carers."

- Offering carers access to a range of services to support their wellbeing and providing clear communication about confidentiality and their rights.
- Continuing to promote the Think Family initiative, which ensures that carers and next of kin are documented in service users' records, so that carers can be supported and included in care planning.

Communication and Information for Carers. We understand that carers require more comprehensive and accessible information about SMI, medication, and side effects. To address this, we are:

- Developing specialised information on SMI and related medication to be provided to carers at the point of diagnosis. This information will be available in various formats, including physical copies, and personalised to the individual being cared for.
- Improving communication systems to ensure that when carers contact staff, they receive timely acknowledgements and responses. This will help build trust and improve transparency between carers and the Trust.

Carer Involvement and Voice Carers have expressed a desire to have a stronger voice and more involvement in the care of their loved ones. In response, we are:

- Exploring the creation of Carers Forums for each service within NSFT that supports adults with SMI. These forums will provide an opportunity for carers to share their experiences, connect with others in similar situations, and provide feedback on services.
- Set up the Network for Carer Champions across the Trust, who will serve as key contacts for carers, promoting collaboration, involvement, and access to information and resources.

Improving Mental Health Services and Continuity of Care We are committed to improving the overall provision of mental health services, including better continuity of care for those with SMI. As part of this, we are embedding lived experiences, both from carers and individuals with SMI into our staff training programmes, through our participation team. We are also making strides through Quality Improvement and Listening into Action initiatives, ensuring formal service user and carer input in all our service improvement efforts.

Ongoing and Future Actions:

We recognise that the concerns raised in the Healthwatch report represent significant areas where we must improve. We are fully committed to:

- Continuing to build on our Carers Strategy, which outlines clear objectives to support carers in their roles.
- Offering more opportunities for feedback from carers, ensuring that their insights contribute to ongoing service improvements.
- Expanding our Think Family project, which will roll out Trust-wide by October 2025, ensuring that carers are identified early, supported, and included in care decisions.
- We are grateful for the ongoing partnership with Healthwatch and the valuable feedback provided by carers. Together, we will continue to work towards ensuring that carers of individuals with SMI feel respected, supported, and fully engaged in their loved ones' care.

A significant advancement our improvement plan, is the establishment of a new Patient Experience Directorate. This directorate will be spearheaded by a newly appointed Chief Patient Experience Officer and a Director of Patient Experience. A primary focus of this directorate will be to enhance our engagement with service users and carers, ensuring that their needs are effectively addressed.

The creation of these roles is vital for amplifying the voices of the individuals we serve on a daily basis. The Chief Patient Experience Officer and Director of Patient Experience will not only oversee initiatives aimed at improving support for service users and carers but will also take the lead in forming our new service user and carer councils across our five localities.
Additionally, these positions will play a crucial role in collaborating with our system partners to tackle health inequalities within the populations we serve. By prioritising these efforts, we aim to foster a more inclusive and responsive healthcare environment.

The Chief Patient Experience Officer will also lead on tackling health inequalities, which we know are particularly prevalent amongst people with SMI, and as a consequence feature as a significant concern for carers. The CPEO will work in partnership with organisations and systems to influence the barriers and promoting equity of access to services that improve health outcomes for people that require it.

We appreciate the feedback provided in the SMI Carer Report and the event where this was shared with our system partners and remain fully committed to improving the experience of carers at NSFT. Your collaboration and the perspectives of carers are essential to helping us achieve this goal.

We look forward to continuing to work with Healthwatch Norfolk and carers to improve the support and services offered by NSFT.

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Appendix

Appendix 1: Interview Guide Questions

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

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Interview Questions for Carers of adults with SMI

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

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

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

Anything mentioned within this discussion will be private and confidential unless there is a genuine and urgent concern for your safety or wellbeing. Any feedback from this discussion will be anonymised and any potential identifying information will be removed.

Opening questions

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

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

Information and resources

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

2. *Do you know what information and resources are available to you as a Carer?*
3. How do you feel about the information and resources available to you as a Carer?

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

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

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

Carers Identity Passport

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

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

Carer's Assessment

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

9. If you **have had** a Carer's Assessment:

Please could you tell us a bit more about your experience of having a Carer's Assessment:

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

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

- If you do not want one, why not?

- If you have never been offered one but would like one, how would you want to be offered one? Do you know how to access one/ who to contact?
- Is there anything that would make you more likely to have a Carer's Assessment?

Carers Health and Wellbeing

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

If you have **received support:**

11. How easy did you find it to get support for your own health and wellbeing? Why was this?
12. Please could you tell us more about your experience of the support you received? (e.g. how did you find the support, how long ago was this experience, how would you rate this experience? What was good and what could be improved?)

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

Carers involvement and your Voice being heard

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

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

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

Thank you and debrief

Appendix 2: Survey questions

This survey is aimed at people who care for an adult (18+) with Serious Mental Illness (SMI). If you are struggling with your own mental health or would like information about support for Carers please visit the following links for organisations that can help you.

Support for Carers: https://healthwatchnorfolk.co.uk/information-and-advice/information-and-advice-services/carer/

Support for mental health: https://healthwatchnorfolk.co.uk/information-and-advice/information-and-advice-services/mental-health/

Who is Healthwatch Norfolk?

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

What is this survey about?

Healthwatch Norfolk is currently working with the Norfolk and Suffolk NHS Foundation Trust (NSFT) to find out more about the experiences of Carers of Adults with Serious Mental Illness (SMI). Hearing directly from Carers of adults with SMI will allow NSFT to gain a better understanding of their experiences and will help us to provide NSFT with recommendations on how the experiences of Carers can be improved.

Not everyone sees themselves as a Carer and some people may not be sure whether or not they are a Carer. The Carers Trust defines a Carer as *"anyone who cares, unpaid for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support".*

The term Serious Mental Illness (SMI) "*is often used in healthcare settings and refers to psychological problems that are often so debilitating that people's ability to engage in functional and occupational activities is severely impaired*" (Healthy Surrey, 2023).

Common diagnoses associated with SMI include:
- schizophrenia/ schizoaffective disorder
- bipolar disorder
- psychosis

- This can also include other diagnoses such as major depressive disorder, personality disorder and eating disorder, (when they are long-term and severely impact the person's life).

If you are aged 16+ living in Norfolk and care for an adult (18+) with SMI we would like to hear about your experiences, as your views are important to us. All responses are anonymous and will be used by Healthwatch Norfolk to make recommendations to service providers as part of a project report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

The survey will take around 15 minutes to complete, although some questions are optional.

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

How the survey results will be used

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

All responses will be anonymous. The survey results will be used to make recommendations to NSFT and health and social care providers as part of a project report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Want to keep in touch?

To stay up to date with what we are doing at Healthwatch, you can sign up to our newsletter via our website: www.healthwatchnorfolk.co.uk

If you do not use email, you can call Healthwatch Norfolk on 01953 856029 to ask to receive our newsletter via post.

Survey closing date: Monday 11th March 2024

Please note that questions marked with an asterisk (*) require responses.

1. Please tick to confirm *

☐ I have read and understood the above statement

2. Please tick to confirm *

☐ I live in Norfolk. I am aged 16+ and the person I am caring for is an adult (18+) with a Serious Mental Illness (SMI)

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

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

Throughout this survey "*The person you care for*" | "*your cared for person*" or "*the person you support*" refers to the adult with SMI that you care for and who cannot manage without your support. The caring role towards them is not always doing physical jobs but it can also include giving them mental support as well.

Information and Resources

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

5. Have you been able to find information and resources to support you?

☐ Completely
☐ Somewhat
☐ Not at all

☐ Not Applicable

If you have found resources and information, what information and resources have you found helpful?

6. What information and resources would you find useful?

☐ Voice Organisations (E.g. Carers Voice which represents the voice of Carers in the design and delivery of services for Carers in Norfolk and Waveney)
☐ Carer support organisations
☐ Information about Serious Mental Illness, medication, and side effects
☐ Respite options
☐ Wellbeing support
☐ Information about Carer's Assessments
☐ Information about the Carers Identity Passport
☐ Other (please specify):

7. Is there anything that would make you more likely to access the information and resources available to you as a Carer?
Please select all that apply:

☐ If they were easier to understand
☐ If they were easier to find
☐ If there was more specific information and resources on being a Carer for someone with SMI
☐ If there were more information and resources available
☐ If I had more time
☐ Nothing

☐ Other (please specify):

8. Carers Identity Passport

You can apply for a 'Carers Identity Passport':

"Unpaid Carers have told us that they wish to be identified as Carers, in a healthcare setting. In order to help support this, Carers Voice have co-produced a Carers Identity Passport, to ensure Carers are recognised and can get the help and support they require. The Carers Identity Passport is for all age Carers, including Young Carers and Parent Carers in Norfolk and Waveney" – Carers Voice

This is recognised by healthcare settings in Norfolk. More details are available here: https://www.carersvoice.org/carers-identity-passport-leaflet/

Please select all that apply to you:

☐ I was already aware of this and **have** a Carers Identity Passport
☐ I was already aware of this but **do not** have a Carers Identity Passport
☐ I was **not aware** of the Carers Identity Passport
☐ I **would apply** to get a Carers Identity Passport
☐ I **would not** apply to get a Carers Identity Passport

If you have a Carers Identity Passport, please tell us more about your experience. If you do not have one, why not?

9. Carer's Assessments

As a Carer you are entitled to a Carer's Assessment.

Definition of a Carer's Assessment: *"It's a chance to let your local council or trust know how your caring responsibilities affect you physically and emotionally. They will use the assessment to find out what support you need, whether you're willing or able to carry on caring, what you want to achieve in your daily life and whether you qualify for help."*- CarersUK

Which of these statements applies to you?

- ☐ I **have** had a Carer's Assessment **within the last 12 months**
- ☐ I **have** had a Carer's Assessment but it **was more than 12 months ago**
- ☐ I am on a waiting list for a Carer's Assessment
- ☐ I have **been offered** a Carer's Assessment but **did not want one**
- ☐ I have **never been offered** a Carer's Assessment, but **would like one**
- ☐ I have **never been offered** a Carer's Assessment, but **do not want one**
- ☐ I am not aware of Carer's Assessments, but would like one
- ☐ Not sure

Carer Health and Wellbeing

10. What impact (if any), does being a Carer of an adult with SMI have on your health and wellbeing?

	It has got better	It has got worse	It has got both better and worse	No Impact	Unsure
Physical Health	☐	☐	☐	☐	☐
Mental health	☐	☐	☐	☐	☐
Employment/ Education and training	☐	☐	☐	☐	☐
Finances	☐	☐	☐	☐	☐
Relationships (Friends and Family)	☐	☐	☐	☐	☐
Housing	☐	☐	☐	☐	☐

11. How easy have you found it to get support for your own health and wellbeing?

☐ Easy
☐ Neither easy nor difficult
☐ Difficult
☐ I have not tried to get support

12. If you received support, what type of support did you receive?
Please select all that apply:

☐ Community Mental Health Services
☐ Local organisations (e.g. Carers Matter, Carers Voice)
☐ GP appointment (Including doctors, nurse practitioner etc)
☐ Wellbeing (Mind and NHS talking therapies)
☐ Social Media Groups (e.g. Facebook)
☐ Social Services
☐ Workplace/ Educational setting
☐ I did not know where to go
☐ None of the above
☐ Other (please specify):

Carer Involvement and Voice

13. Are you involved in the person you support's care as much as you want to be?

☐ Yes
☐ No
☐ Don't know

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

14. How satisfied do you feel that your voice is heard by staff if you make a suggestion or give them information about the person you support?

☐ Satisfied
☐ Neither satisfied nor dissatisfied
☐ Dissatisfied
☐ Don't know

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

Improvements and other comments

15. What challenges (if any) have you faced as a Carer for an adult with SMI?

16. What (if anything) do you think could be done to help improve your experience of being a Carer of an adult with SMI?

17. Have you seen any changes to Community Mental Health services in the last 3 years?

☐ Yes
☐ No
☐ Don't know

If yes, what changes have you seen? (Were they positive or negative changes?) If no, what changes would you like to see?

18. Do you have any other comments about your experience of being a Carer of an adult with SMI?

19. Healthwatch Norfolk would like to interview people to find out more about their experiences of being a Carer of an adult with SMI. If you would like to be interviewed for this project, please leave your first name and preferred contact details here and we will be in contact.

Demographics

In this next section we will be asking you some questions about yourself and your life. <u>All these questions are optional.</u>

Why we ask these questions
Your answers help us make sure that we hear from people from different backgrounds and that we understand the needs of different groups in our community. Remember: all your answers are strictly confidential and the survey is anonymous.

20. When did you first start caring for someone with SMI? (If you don't remember the year, please give an estimate)

21. Does the person you are caring for have any of the following diagnoses:
Please select all that apply

☐ psychosis
☐ bipolar disorder

☐ schizophrenia/ schizoaffective disorder
☐ Personality Disorder
☐ An Eating Disorder
☐ Severe Depression
☐ Awaiting Diagnosis
☐ No Diagnosis
☐ Don't know
☐ Prefer not to say
☐ Other (please specify):

22. Please select one of the following:

The person I am caring for is my:

☐ Child (inc step children)
☐ Neighbour/ Friend
☐ Grandchild
☐ Partner
☐ Parent (inc step parents, guardians etc)
☐ Sibling
☐ Any other family member
☐ Prefer not to say
☐ Other (please specify):

23. Do you live with the person you care for?

☐ Yes
☐ No
☐ Prefer not to say

24. What is your ethnic group?

Arab:

☐ Arab

Asian / Asian British:

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

Black / Black British:

☐ African
☐ Caribbean
☐ Any other Black / Black British background

Mixed / Multiple ethnic groups:

☐ Asian and White
☐ Black African and White
☐ Black Caribbean and White
☐ Any other Mixed / Multiple ethnic groups background

White:

☐ British / English / Northern Irish / Scottish / Welsh
☐ Irish
☐ Gypsy, Traveller, or Irish Traveller
☐ Roma
☐ Any other White background

Other:

☐ Any other Ethnic Group
☐ Prefer not to say

If other, please specify:

25. How old are you?

☐

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

☐ I have a disability
☐ I have a long-term condition
☐ None of the above
☐ I prefer not to say

27. What is the first half of your postcode? (e.g NR18)

☐

28. What is your gender?

☐ Man
☐ Woman
☐ Non-binary
☐ Genderfluid
☐ Questioning
☐ Prefer not to say
☐ Prefer to self-describe:

29. Where did you hear about this survey?

☐ GP website
☐ Healthwatch Norfolk Event
☐ Healthwatch Norfolk Newsletter
☐ Healthwatch Norfolk Website
☐ News (website / radio / local newspaper)
☐ Search Engine (e.g. Google)

☐ Social media (e.g. Facebook / Instagram / Twitter)
☐ Through a friend or co-worker
☐ YouTube
☐ Other (please specify):

Appendix 3: Demographics of respondents

Demographic data of survey respondents (including interviewees and focus group participants who completed the survey).

		Number of respondents	Percentage of respondents
Age	16-25	2	3%
	26-35	3	5%
	36-45	2	3%
	46-55	12	20%
	56-65	20	34%
	66-75	12	20%
	76-85	8	14%
Gender	Woman	50	78%
	Man	11	17%
	Non-binary	1	3%
	Prefer not to say	2	2%
Ethnicity	British/ English/ Northern Irish/ Scottish/ Welsh	57	90%
	Any other White background	2	3%
	Indian	1	2%
	Irish	1	2%
	Any other Mixed/ Multiple ethnic groups background	1	2%
	Prefer not to say	1	2%

Please select any of the following that apply to you	I have a disability	10	16%
	I have a long-term condition	25	39%
	None of the above	25	29%
	Prefer not to say	8	13%
Does the person you are caring for have any of the following diagnoses	Severe Depression	26	41%
	Other	24	38%
	psychosis	19	30%
	schizophrenia/ schizoaffective disorder	16	25%
	Personality Disorder	15	24%
	bipolar Disorder	12	19%
	Awaiting Diagnosis	7	11%
	An Eating Disorder	5	8%
	No Diagnosis	3	5%
	Don’t know	2	3%
	Prefer not to say	0	0%

Appendix 4: Focus Group Discussion Guide

Project: Carers of adults with Serious Mental Illness (SMI)

Focus Group Date:	Thursday 16th May
Focus Group Time:	10:30am
HWN Staff:	Jess Hickin
Focus Group Priority Area	
To develop a greater understanding of the experiences of Carers of adults with Serious Mental Illness and how they can be better supported. The focus group will specifically focus on the information and resources available to Carers.	

Question	Notes	Complete
Welcome and start recording	Confirm attendees are happy for session to be recorded for transcription purposes. Recording will be deleted once the write up is complete and any direct quotes will be anonymised.	
Introductions (all attendees)	'Healthwatch Norfolk is the independent voice for patients, Carers 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. 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.'	
Purpose of focus group	The focus group will last around 1.5 to 2 hours.	

	There are no right or wrong answers at this session, we are just really interested in hearing peoples’ personal experiences and opinions. The information we take away from the discussion will be anonymised and will be used in a report to be given to service providers, so they can gain a greater understanding of the experiences of Carers of adults with SMI and how they can be better supported. We ask that attendees share with us what they feel happy and comfortable doing so and respect the privacy of other attendees by treating information confidentially. Thank you for your time today.	
Any Questions?	If you have any questions about the focus group and the Healthwatch Norfolk ‘Experiences of Carers of adults with Serious Mental Illness’ piece of work, please let us know. If we can’t answer them today, we will look into it and feed the answers back to you.	
Focus Group Discussion		
Information		

Focus group questions	**What information and resources for Carers are you aware of?** *- Have you used any of these information and resources? (How useful did you find these? What was good about them and what could be improved?)* ***[Ranking question activity]*** *- What information and resources would you find useful?* *- Are there any information/ resources missing?* **[Participants to be shown a list or cards of a variety of different information and resources for Carers].**	
	What (if anything) would make it easier to access the information and resources available to Carers? *-E.g. the format, length of resource, type of information, a glossary, language used, timing of receiving the information.* **[Flipchart or similar activity]**	
	Most Carers in our survey, told us that they would find it useful to have more information about Serious Mental Illness, medication, and side effects. Most Carers also told us they would be more likely to access information and resources if there was more specific information and resources on being a Carer for someone with Serious Mental Illness. *-What (if anything) would you like to know about Serious Mental Illness, Medication, and side effects?* *-What (if anything) would you like to know about being a Carer for someone with Serious Mental Illness?* *- When would it be most helpful to receive this information?*	

Resources		
	Have you ever had a Carer's Assessment? *-What was your initial contact like?* *-How easy did you find it to access the Carer's Assessment?* *-Were you given any information at the point of the assessment? (e.g. information about being a Carer of an adult with SMI and information on the resources available)* *- Did you receive any support after receiving the Carer's Assessment? If yes, how did you find this?* *-What was good about the assessment and what could be improved?* ***[Ask these questions if most of the group have had a Carer's Assessment].***	
	Have you ever had a Carer's Assessment? *If no:* *-Why is this?* *- Is there anything that would make you more likely to have one?* ***[Ask these questions if most of the group have not had a Carer's Assessment].***	
	Do you own a Carers Identity Passport? - *How did you find out about it?* - *How easy did you find it to get the Carers Identity Passport?*	

	- *What are you hoping the passport will do?* - Have you used it? How was this experience? (How did clinicians or care staff respond to it? Do you think you were taken more seriously because of it? Did it help you get the support you needed?). - *What was good about the passport and what could be improved?* - *If you do not own a Carers Identity Passport, why is this? Is there anything that would make you more likely to own one?*	
	Is there anything else you would like to say about the information and resources available to you as a Carer of an adult with SMI?	
Focus Group wrap up and conclusion		
Additional Feedback	Do any attendees wish to share anything else you would like to say before the end of the session?	
Summary of themes	Feedback themes to group	
Thank you and gift vouchers	Thank you to attendees and staff that have helped with this focus group today.	

Appendix 5: List of information and resources shown to Focus Group Participants

Information on being a Carer and Caring for someone with Serious Mental Illness (SMI)

Carers Matter Norfolk

"Carers Matter Norfolk is the countywide service funded by Norfolk County Council and the NHS to provide support to unpaid Carers. All services are free and available to people aged 16+ caring for someone aged 18+"- Carers Matter Norfolk. Through the Carers Matter website, there are some online learning courses on mental health which can be accessed (run by open learn create).

Mind

Mind have information online about Caring for someone with a mental health problem. They also have separate pages with more information on different diagnoses such as bipolar disorder and Schizophrenia.

Carers Rights Guide (Healthwatch England)

Healthwatch England have put together a webpage with information about some of the help and support which is available for Carers.

Carers UK

"Carers UK is the leading national charity for unpaid Carers. We support, advocate for, champion and connect Carers across the UK, so that no one has to Care alone"- Carers UK. The site has general information on being a Carer and help and advice with financial support, practical support, work and career and health and wellbeing.

Caring Together.

"Caring Together is a leading charity supporting Carers of all ages across Norfolk, Peterborough and Cambridgeshire"- Caring Together. They provide information and advice, run services in our local communities and campaign so that Carers have choices. The website has general help and advice for

Carers including information on Carer's rights, financial support Carer's assessments and the Care Act 2014.

Rethink Mental Illness.

Rethink Mental Illness have a 'Carers' hub' on their website This includes a variety of information, such as support someone with a mental illness, confidentiality, Carers assessments and responding to unusual behaviour linked to mental illness. The site also has information on different mental illnesses such as Schizophrenia, bipolar disorder, and psychosis.

Norfolk and Suffolk Foundation Trust

NSFT have a webpage on 'Help with your caring role'. This includes a video library and information on the Care Act 2024, Money and benefits, Young Carers, and the Triangle of care. There is also a dedicated email address for carers where they can ask questions about anything causing them concern.

Carers Trust

The Carers Trust has a page on caring for someone with a mental health condition and taking care of your own mental health. This includes variety of links to other sites such as Mind and Rethink Mental Illness. The site also has general information on Money and Benefits and Health and Wellbeing.

Royal College of Psychiatrists

The Royal College of Psychiatrists website has a page on 'Caring for someone with a mental illness. This includes information on how much you can be involved in someone's medical care, the benefits you are entitled to, the challenges that come with being a Carer and how to support yourself.

Practical Resources

- Carers Identity Passport
  The Carers Identity Passport from Carers Voice has been co-produced with Carers and staff across Norfolk's health and care system to ensure unpaid Carers are identified and recognised in healthcare settings. It is available in both a digital and physical version.

- Carer’s Assessment

  A Carer’s Assessment is “*a chance to let your local council or trust know how your caring responsibilities affect you physically and emotionally. They will use the assessment to find out what support you need, whether you’re willing or able to carry on caring, what you want to achieve in your daily life and whether you qualify for help."- CarersUK*

- Carers emergency Card

  Norfolk County Council offers people the opportunity to create and register an emergency plan with them. If you are a Carer for someone over 18 you can get a free Carer’s emergency card to ensure that the person you care for, will be safe if you are in an emergency.

Respite options

- Rethink mental illness have a page about respite and options for Carers of adults with mental illness. *[Respite is sorted through the Carer’s Assessment].*

Carers Groups

- Carers Matter Norfolk Groups (Specific Mental Health Carers Groups).
- POPS (online, global Facebook group for family members of people with psychosis and schizophrenia).
- Carers Voice groups

Norfolk and Suffolk Foundation Trust (NSFT) Groups:

- NSFT Virtual coffee morning
- NSFT Virtual Family and friends’ support
- Family and Friends Support Group
- Great Yarmouth and Waveney carers group
- Early Intervention in psychosis Support Groups
- ‘Stepping back safely workshop for carers’ (psychoeducation for family members and carers of people who are at risk of suicide or self-harm).

Voice organisations

Carers’ Voice

Carers Voice is an independent charity representing Carers in Norfolk and Waveney.

Other

- Carers Service- Great Yarmouth and Waveney (Mind).

healthwatch
Norfolk

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