



Nottinghamshire Healthcare
NHS Foundation Trust

healthwatch

Nottingham & Nottinghamshire

Specialist Mental Health Services

November 2023

Trigger Warning: *This report contains direct quotes that make overt reference to self-harm, suicide, and experiences of mental health crisis.*

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We gather and represent the views of those who use health and social care services, particularly those whose voice is not often listened to. We use this information to make recommendations to those who have the power to make change happen.

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Executive Summary

Approximately 1 in 4 people in the UK will experience a mental health problem each year, while 1 in 6 people in England report experiencing common mental health conditions such as anxiety and depression in any given week. Closer to home, in Nottingham and Nottinghamshire, it is **estimated** that over 297,750 people between the ages of 16 to 74 are living with ‘any mental health disorder’, including common mental disorders (e.g., anxiety or depression), PTSD, eating disorders, and severe mental illnesses (including but not limited to, psychosis, bipolar disorder, or schizophrenia)¹ (Nottinghamshire County Council, 2014; Nottingham Insight, 2019). It is likely that a number of these individuals will be accessing services provided by Nottinghamshire Healthcare NHS Foundation Trust (NHFT).

NHFT is currently undertaking a transformation programme of the delivery of mental health services across adult pathways, including significant additional financial investment. The ethos of the transformation programme is ‘no wrong door’. This means that it aims to deliver integrated, personalised, place-based, and well-coordinated care, while also aiming to ensure that service users have a seamless journey if they need to move between services.

Healthwatch Nottingham & Nottinghamshire (HWNN) were commissioned by NHFT to undertake a project that aimed to understand people’s experiences of accessing and using Specialist and Community Mental Health Services in Nottingham & Nottinghamshire. In doing so, HWNN sought to ascertain what challenges people face when accessing mental health services, including what worked well for them and what can be improved. This project also explored people’s attitudes and behaviours when they, or someone close to them, had mental health concerns. To gain these insights, HWNN carried out a mixed-methods research project, gathering data from previous, existing, and prospective² service users via a survey, focus groups, and one-to-one interviews.

¹ This figure is based on national estimates, and a combination of figures produced by [Nottinghamshire County Council \(2014\)](#) and [Nottingham Insight \(2019\)](#). As these figures are somewhat outdated and pre-date the COVID19 pandemic, it is likely that the figures are higher, hence the emphasis on “estimated”.

² Some respondents were on the waiting list, following assessments or after they have been given a formal diagnosis of mental illness, and were therefore yet to access services.

We found that, whilst some people had positive experiences of mental health services, others saw the system as being a long way from achieving its aim of 'no wrong door'. Some respondents expressed deep dissatisfaction with services at all stages of the mental health pathway. Early intervention is not always happening, access is difficult with long waiting times, so that service users can deteriorate until they reach crisis point which puts pressure on crisis response services. The care offer can be time-limited, and some respondents felt that they were discharged too soon which can lead to re-referrals. Not all services provided holistic care, although some services were praised such as The Recovery College and some Voluntary, Community, and Social Enterprise (VCSE) organisations.

This report outlines our detailed findings and the dominant feedback received. This feedback covers various aspects, including the difficulties faced when trying to access services, (in)consistency in care, a need for improved staff knowledge and understanding, a desire for holistic, person-centred care and increased service user involvement. Informed by the feedback received, HWNN make these five key recommendations to NHFT:

- 1. Prioritise early intervention with the dual aim of reducing waiting times and providing clear guidance on how long waiting lists are, to ensure that service users are given information on how to 'wait well'.**
- 2. Examine and improve the way in which patients are identified to receive care from Primary Care Mental Health Practitioners, especially for those with long term mental health needs.**
- 3. Streamline referral processes and ensure that services are accessible to all.**
- 4. Implement centralised, co-produced, 'person centred care plans' to support consistency in care and ensure all service users receive holistic, person-centred support.**
- 5. Invest in more services to holistically support service-users, such as those offered by The Recovery College and Voluntary, Community and Social Enterprise (VCSE) organisations.**
- 6. Ensure that service users are given information about their condition(s), particularly following their first initial formal diagnosis.**
- 7. Review the current crisis provision with the dual aim of improving services and increasing the public's awareness of crisis services.**
- 8. Ensure that any further service evaluations engage with a sample that is representative of service users and the local population.**

Introduction

Informed and supported by the NHS Long Term Plan, NHFT is currently undertaking a large-scale transformation programme of the delivery of mental health services across adult pathways, including significant additional financial investment. The ethos of the transformation programme is 'no wrong door'. This means that it aims to deliver integrated, personalised, place-based, and well-coordinated care, while also aiming to ensure that service users have a seamless journey if they need to move between services. The programme also acknowledges that services are often hard to reach, particularly for those who experience mental health difficulties.

As part of this work, the Trust commissioned HWNN to engage service users, carers, families, and stakeholders in the development of mental health services in Nottingham & Nottinghamshire. For this purpose, Healthwatch conducted a research project to engage with previous, current, and prospective service users, to explore and answer the following questions:

1. What is people's awareness of the availability of community mental health services? And where would they go if they have mental health concerns?
2. What are people's experiences of the barriers to accessing mental health services?
3. What are people's experiences of community mental health services and how can their experiences be improved?

This report, therefore, seeks to answer the aforementioned questions, drawing upon the dominant sixteen themes that arose from service users' feedback, all of which are broad and intersecting.

Background

In early 2019, the NHS launched its Long-Term Plan outlining steps and actions to improve health services, bring about positive changes, and ensure that the NHS is continually moving forward 'so that in ten years' time we have a service fit for the future' (NHS, 2019). The plan also aims to ensure that the NHS is getting 'the most value for patients out of every pound of taxpayers investment' (NHS, 2019:1). It is committed to improving mental health services and expanding accessibility for both adults and children, with the aim that by 2023/24 it would be delivering community-based 'mental health care for 370,000 people with severe mental illness' (ibid:1). By 'doing things differently', the plan aims to give people 'more control over their health and the care they

receive', encourage 'more collaboration between GPs, their teams and community services', make 'better use of data and digital technology', and provide more 'convenient access to services and health information for patients' (ibid.:2).

In the same year as the publication of the NHS Long-Term Plan, Nottingham and Nottinghamshire Integrated Care System (ICS) collaborated with other stakeholders and community engagement groups to develop a new Integrated Mental Health and Social Care Strategy (N&N ICS, 2019). The aim of this strategy was to transform and improve mental health and wellbeing in Nottingham and Nottinghamshire in alignment with their commitment to reshape services and other interventions 'so that they can better respond to the mental health and care needs of the population' (N&N ICS, 2019:2).

As stated in the strategy, the vision is:

'a whole system, all-age, person-centred approach, driven by access to physical and mental health and social care in the same place at the same time, with no wrong door, where prevention is at the heart of all we do. We will reduce inequalities and narrow the gap between Serious Mental Illness (SMI) life expectancy and the rest of the population by 3 years and increase healthy life expectancy by 3 years' (2019:2).

The aim of this strategy is thus to improve service users' experiences of services by ensuring easier accessibility and developing pathways to mental health services, while also tackling factors associated with health inequalities and reducing gaps in life expectancies.

In alignment with the new Nottingham & Nottinghamshire Integrated Mental Health and Social Care Strategy, and in accordance with the NHS Long-Term Plan, Nottinghamshire Healthcare NHS Foundation Trust (NHFT) is currently undertaking a large-scale transformation programme of the delivery of its mental health services across adult pathways. A significant component of this involves engaging and consulting with service users, carers, families, and stakeholders in the development of the services. The aim of this is to ensure that their voices are heard through the scoping, design, and implementation of a new landscape for mental health, rather than merely providing 'tokenistic'

involvement. As stated earlier, the ethos of the transformation programme is 'no wrong door' which means that it aims to deliver integrated, personalised, place-based, and well-coordinated care, as well as focusing on ensuring that service users have a seamless journey if they need to move between services. The programme also acknowledges that services are often hard to reach, particularly for those who experience mental health difficulties.

To support the implementation of this strategy, NHFT commissioned HWNN to conduct a research project on people's experiences of using Adult Specialist and/or Community Mental Health Services. The aim of this project, as agreed by HWNN and the commissioner, was to find out about people's experiences of mental health services and care within NHFT, including the barriers people face to accessing services, how well services communicate what is on offer to potential and existing service users, how inclusive services are of the diverse range of service users and what is working well and where improvements could be made. Hence, our role was to gather feedback from individuals who have accessed these services in the past two years through surveys, interviews, and focus groups and provide a report and recommendations. This report will be used to inform the way in which Specialist Mental Health Services are developed in order to create care that is holistic, person-centred and meets the needs of all service users.

As a part of initiating this project, we conducted a literature review of several primary studies related to people's experiences of mental health services in England, including the NICE guidelines on ***Improving the Experience of Care for People Using Adult NHS Mental Health Services*** (NICE, 2011), as well as other NHS publications. Through these reviews, we identified nine areas that, if addressed nationally, would improve people's experiences of mental health services. These themes subsequently guided our data analysis. However, we expanded the categories in response to additional themes found in the responses. The themes initially identified were:

- Assessment, diagnosis, and referrals
- Equitable accessibility
- Healthcare professionals' communication skills and relationship with service users
- Healthcare professionals' knowledge and understanding
- Communicating information to service users
- Stigma and discrimination
- Service users' involvement
- Holistic support
- Transfer between, and discharge from, service

Our Approach

We adopted a mixed, multi-method approach to data collection, which included online and in-person surveys, focus groups, and one-to-one interviews conducted over an eight-month period. 328 surveys were conducted with the general population, as well as 3 focus groups and 16 one-to-one interviews with current and/or recent³ service users. We also collected feedback in the form of a case study, totalling responses from 367 individuals.

We conducted an online survey which was distributed to the general public through HWNN networks, including social media, staff, volunteers, and partner organisations. Paper copies of the survey were also made available and shared with the general public in community and public settings. Through this survey, HWNN gathered feedback from people who have either tried to access mental health services for themselves, or people who have attempted to access services on behalf of someone they have a close relationship with or care for, as well as prospective service users, i.e., *'what would you do if'*. The aim was to understand the general public's experiences of accessing these services and to explore the barriers they faced. HWNN also sought to inquire into people's awareness of the mental health services available and to understand what individuals would do if they had mental health concerns. It is important to note, however, that the responses received were not all necessarily relevant to Severe Mental Illness Services and thus offer a general and wider insight into mental health services. Hence, although 328 people responded to this survey, it is difficult to ascertain how many of this number had accessed Specialist Mental Illness services. On the other hand, respondents who took part in the Focus Groups and one to one-to-one interviews, were people who accessed or are accessing specialist mental health services.

Through focus group discussions and one-to-one interviews, HWNN sought to understand service users' experiences of speciality Mental Health Services and mental health pathways, including where they went for help and what their experience of this was in Nottingham City and Nottinghamshire County. HWNN also sought to understand service users' experiences of using Community Mental Health Services, what is working well, and where improvements could be made. Through our partnership work with different community organisations, focus group participants were identified from Turning Point, Improving Lives, The Recovery College, and The Bipolar Lift. Subsequently HWNN conducted three focus groups with three of these organisations

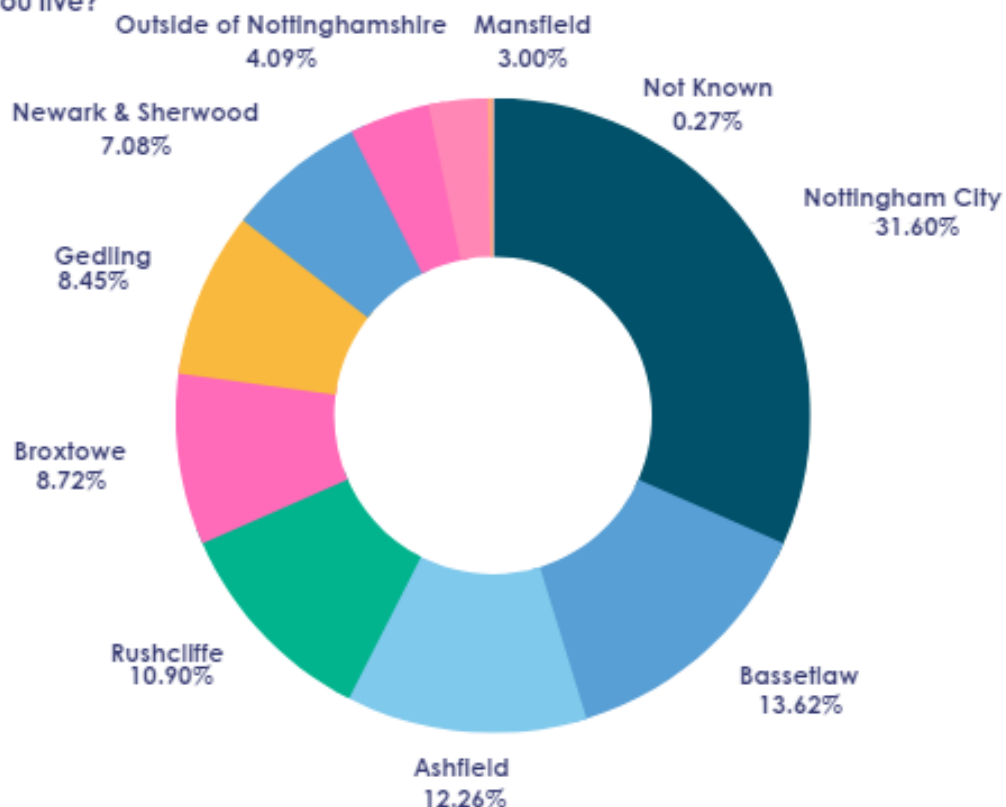
³ By recent, we are referring to individuals who have used, were referred to and/or discharged from services in the past two years.

(excluding Turning Point) to gather service users' views in group sessions, including suggestions for service improvements. Interview information and opportunities were promoted through HWNN's and NHFT's social media accounts, stakeholder networks and the organisations mentioned above.

We prepared and provided information sheets describing the project, which were distributed prior to and on the day of interviews and focus groups. Interview questions were sent to the interviewees 24 hours in advance to alleviate any anxieties or concerns that participants may have had regarding the interviews. Focus group guidance and information was sent to the lead of the hosting organisation ahead of any focus group sessions. Participants were asked to read these documents and were given an opportunity to ask any questions about the project before providing HWNN with informed consent to record their anonymised data and responses.

To contextualise the sample, respondents were spread across Nottingham and Nottinghamshire, with Nottingham City comprising the greatest proportion of respondents, as expected, at 31.6% [112 of 367]. A small number of participants lived outside of Nottinghamshire (4.1% [15 of 367]), but all were accessing services in Nottingham and Nottinghamshire, hence their inclusion. Full geographical data can be found in Figure 1 below.

In which area do you live?



Of the people we heard from, 70.3% [258] identified as female, 25.3% [93] as male, and 1.1% [4] as non-binary, with the remaining 12 either declining to say or self-describing under a different category. Their ages ranged from 16 to 88⁴; however, the majority were aged between 25-49 (38% - [140]) and 50-64 (25% - [93]). The median age was 47 years old. In terms of ethnicity, the majority of participants were White (82.3% - [302]), describing their nationality as British and/or English (84.9% - [312]). Please see Appendix A – Demographics and Appendix B – Demographic Graphs for detailed demographic data.

This was a mixed-methods project, wherein the questions posed to survey respondents, interviewees, and focus group participants all differed⁵. HWNN and NHFT tailored the questions to different audiences, and the report synthesises those responses into a coherent analysis. It is therefore worth pointing out that all discussion in this report is based on a thematic analysis of the whole dataset – 367 people's stories and feedback. Throughout this data set, participants not only highlighted problems but also provided possible, viable solutions, all of which fall under sixteen broad and intersecting themes.

This report does not cover all of the feedback received but focuses on the most dominant themes drawn from detailed thematic analysis. Any direct or paraphrased quotes used are anonymised, with no personal identifiers used. The gender and age range of the participants are noted, however, to illustrate the broad range of participants engaged, while also contextualising the feedback discussed. Any quotes are ***italicised and boldened*** to differentiate feedback from HWNN's analysis and broader discussion.

⁴ Please note, individuals under the age of 18 were only able to participate in the online survey. Nine people aged between 15 and 17 participated, however, the 15-year-old had not tried to access services.

⁵ Each cohort of participants answered a different set of questions; however, all recounted their experiences of accessing (or failing to access) Specialist Mental Health Services in Nottingham and Nottinghamshire.

Findings and Discussion

Throughout the feedback collected, some respondents expressed deep dissatisfaction with the services they had accessed or failed to access. They noted flaws present in most services and at all stages of the mental health pathway, not only within Specialist and/or Community services. For instance, where survey respondents provided details about their experiences ($n = 180$), 65% [117 of 180] of the responses were negative in sentiment, 19% [35 of 180] were mixed in sentiment, and 16% [28 of 180] were positive in sentiment⁶.

Throughout this report, there are many examples of service users expressing dissatisfaction with services and/or lack of faith in the system:

"I don't feel it's a safe service to use. I think it's unreliable. It's stressful, and I think it's poorly run from top down" (woman, forties)

'I've been constantly trying to manage my own life whilst almost begging for help with it. I feel like I've done more of the work than the people who are actually paid to do it' (man, late teens)

'I'm here despite mental health services, not because of them' (woman, forties)

'I'd rather kill myself than have to access them again' (woman, fifties).

⁶ An example of a negative sentiment is: ***'passed from pillar to post, counselling ended with no follow up'*** (woman, twenties) and ***'I was given a session for one to one therapy. The therapist was not compatible with me, she gave me more issues. Did not help me, made me more anxious'*** (woman, fifties). An example of a mixed sentiment is: ***'Support is good but short term and medium - long term follow up even just a call to check life is still balanced is missing. The strategies given were good and have been implemented but it feels like you are on a conveyor belt and that when you reach the end you fall off the cliff with or without the knowledge that you have a parachute'*** (woman, age unknown). An example of a positive sentiment is: ***'Their mental health [was] assessed. Identified their needs. Allocated CPN/ support worker. Plan of care formulated and implemented'*** (woman, forties). Please also note that these figures include individuals who were both successful and unsuccessful in accessing services but exclude individuals who accessed services that are not provided or commissioned by the NHS, and services provided to anyone under the age of 18 (i.e., provided by schools, provided by CAMHS).

While there was also some positive feedback collected, negative experiences were generally reflected across different groups, with many participants conveying disappointment regarding the (lack of) care and support they have received, or in some cases, were yet to receive. The defects, however, were not always attributed necessarily to the NHS or to NHFT itself but rather to the wider system/government, with participants and respondents acknowledging the difficult position that the NHS finds itself in. Some of those system challenges are touched upon in various sections in this report.

Across all of the key themes identified, participants noted that their care was inconsistent for a variety of reasons. The reasons included inconsistencies in staffing, with staff often being off sick for extended periods with no cover staff assigned or contact, inconsistencies within service users' records (i.e., their records differing from real-life experience and/or containing incorrect personal details), and inconsistencies in care due to long waiting times between referrals. It appeared to resemble somewhat of a postcode lottery, with the quality of care that service users received being somewhat determined by their locality and the service(s) they were deemed eligible to receive.

In general, there was a desire for services to work closely together in a more integrated fashion – ***'improving the way both health and social care work together when it comes to a person's health and wellbeing' (man, sixties)*** – providing holistic care, only referring service users to appropriate services for their needs and ensuring consistency in care throughout every stage of an individual's receipt of service(s).

Although disappointment was expressed, for the most part participants were understanding of the difficult situation that the Trust finds itself in, in terms of system challenges. They acknowledged the pressures, staffing difficulties, and funding constraints faced by services, with many expressing similar views to ***'I don't blame my doctor or any NHS worker for the way they treat me, it's the system' (man, fifties)***. Many also understood that ***'there isn't an infinite budget for everything/everyone!' (woman, fifties)***, opting instead to suggest that if services are to be improved then ***'more funding from the government'*** is required because ***'the staff work very hard, but the demand is very high' (woman, forties)***. Hence, to remedy the issues reported throughout, respondents frequently told us that ***'like everything else more funding is needed' (woman, fifties)***, as only with increased funding was it felt that the recruitment of more professionals, the development of inclusive and accessible services (e.g., having services that go out to schools or visit people in their homes), and reduction of waiting times could be achieved.

Furthermore, some participants suggested solutions to this, including commissioning Voluntary, Community and Social Enterprise (VCSE) organisations to provide services wherever possible, reducing the amount of money spent on service evaluations and studies that **'cost a fortune'** and instead **'spend it on the people' (woman, sixties)** and **'investing in services to improve them – spend more money in the short term for long-term benefit' (anonymous respondent)**.

As the subsequent discussion will demonstrate, positive feedback tended to centre around receipt of appropriate, relevant, and timely care; smooth referral processes (e.g., from inpatient to outpatient care or from CAMHS to adult services); understanding and caring staff; and the usefulness of being taught sustainable coping mechanisms.

Public Awareness

The first question our research sought to explore was, 'What is people's awareness of the availability of community mental health services? Where would they go if they have mental health concerns?'. The first survey question was 'If you, a friend or a relative had a concern about mental health, what would you do?'. The results (see Figure 2) indicate that the general public would contact primary care first and foremost; over 70% of respondents told us that they would contact their GP if they had concerns about their own or a loved one's mental health.

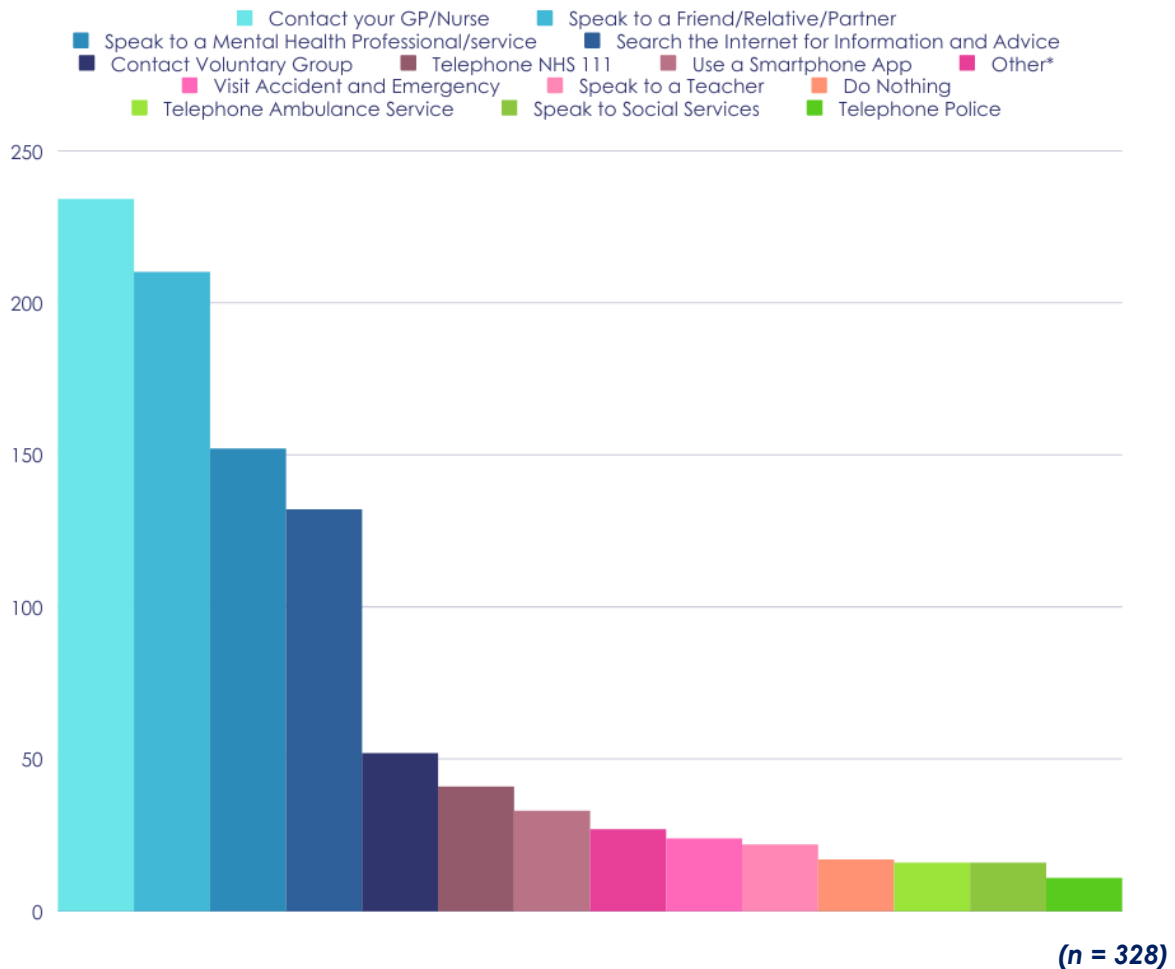


Figure 2: A graph illustrating the responses to the survey question 'If you, a friend or a relative had a concern about mental health, what would you do?'. Please note, this only illustrates responses to the survey.

Key Feedback Themes

Access

Access was one of the most significant themes, with feedback spanning long waiting lists, primary care functioning as a barrier to services, referrals between services, and the difficulties faced when trying to regain access to services post-discharge. As noted in the previous section, we are aware of and appreciate the resourcing, system-level, and post-pandemic related issues that influence service delivery; however, now is the time to find creative solutions to these problems.

Of the 328 survey respondents, 41% [134 of 328] had successfully accessed services, 36% [118 of 328] had not tried to access services⁷, and 23% [75 of 328] had tried to access services but were not successful⁸.

Responses to our initial survey also indicated that half of people who answered the question, 'is it easy or hard to access specialist mental health support?' found them to be either very easy or easy to access [61 of 120]⁹. Focus group participants suggested the opposite, with 55% [12 of 22] telling us they had found accessing services to be **'a very difficult and fraught process**, particularly when **'getting people to actually pass the right messages on to the right departments' (woman, sixties)** (see Figure 3 for full data).

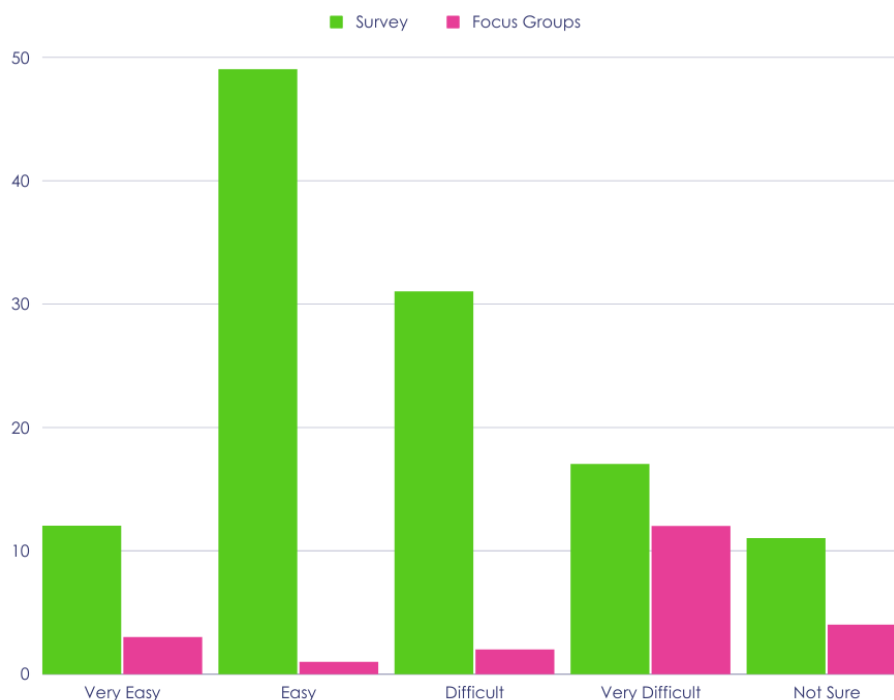


Figure 2: Graph illustrating the answers to the questions 'is it easy or hard to access the specialist mental health support services?' (focus groups) and 'please rate how easy it was to access the service' (survey respondents).

⁷ Please note that as these participants had not tried to access the services, they were routed out of the rest of the survey and asked to provide demographic information.

⁸ These participants, who tried to access services but were unsuccessful, were subsequently asked to tell us about their experience of trying to access services before being routed out to the demographic information.

⁹ This equates to less than a fifth of survey participants (19%).

Similarly, we were told, **'we get told there's all these services, all this help, all this consideration, all this thoughtfulness, but actually getting it is near impossible' (woman, sixties).**

Those who found the process difficult or very difficult found it so due to the **'astronomical waiting lists'** and times associated **(woman, late teens)**, unsuccessful interactions with services (e.g., not hearing back from them until their conditions had significantly deteriorated), and issues with their referrals, among other factors. Those who reported being unsure noted experiencing differing ease of access with different services. For instance, it being easier to access online support than to access support from a real person. Or it being easy to access diagnostic services for Personality Disorders, but not for medication. And hospital and aftercare teams being **'excellent' (woman, thirties)** but not so for specific assessment teams (e.g., for sectioning), due to 'staff capacity'. This is not to say, however, that all participants had positive experiences of hospital and/or inpatient care, as we received some concerning feedback regarding the levels of care received while individuals were hospitalised.

In terms of locations/specific services, Improving Access to Psychological Therapies (IAPT), Insight IAPT, Trent PTS, MIND, Portland Pathways, Let's Talk Wellbeing, Vitamins, and Bryon House (Newark) among others, were noted as services that were either very easy or easy to access, particularly following self-referrals¹⁰. Similarly, Cognitive Behavioural Therapy (CBT) was reported as being relatively easy to access via various providers. Secondary, specialist services, such as Local Mental Health Teams and Local Community Mental Health Services, were reported as being very difficult to access, unless an individual was in the care of the Postnatal Team, had very recently been hospitalised, were close to being hospitalised and/or were at crisis point. In this instance, positive feedback was noted, with individuals feeling fortunate and grateful for the care they had received as both inpatients and outpatients.

¹⁰ Although some of these services are no longer commissioned by the Trust, feedback was collected from service users who had accessed services between 2020 and 2023, hence their inclusion. It is also important to note that the survey attracted responses from respondents who had accessed services wider than the Specialist SMI Services remit that was evaluated through the interviews and FGs. This is not to say, however, that individuals under Specialist Services had not also accessed CBT, Talking Therapies and so forth, as many reported being referred to these services before the severity of their conditions were acknowledged, recognised, or confirmed via diagnosis.

For example,

'I've been extremely, extremely lucky, from day 1, you know, Cruse, Highbury Vale, The Recovery College, after discharge with my CPN. I feel - I just feel very lucky... When I was sectioned it kind of came at the right time, you know, the help that I got in there was just next to none, and it's like, they've been like that since I've come out of hospital, and they've gradually carried me through to where I am here. My CPN brought me up here [The Recovery College] and introduced me and took me round and it's just, I can't believe the experience. I can't find any fault, and I've just been extremely lucky and cared for otherwise I wouldn't be here. I must have been one of the lucky ones' (woman, sixties).

On the contrary, we were told that services including the Beeston Mental Health Clinic, The Rushcliffe Mental Health Team, the City Mental Health Team(s) and Local Mental Health Teams in Broxtowe and Hucknall were hard to access and subsequently access consistent support¹¹. In some cases, services like Local Mental Health Teams were reported as requiring not only a referral but also ***'a letter of introduction/ recommendation'***¹² to justify an individual's referral and explain why it was felt they needed ***'more support than [GP's and Talking Therapies] could offer' (woman, twenties)***, while others simply rejected referrals based on individuals ***'being too complex' (woman, fifties)***. Multiple respondents told us that they were ***'too complex for one service but not complicated enough for another' (woman, forties)***. For example, ***'I was told by IAPT and Let's Talk Wellbeing that my issues are too complex and told by local mental health team I'm not ill enough for them to help me' (woman, thirties)***. As a result, they were left without any support.

Long Waiting Times

For many respondents, waiting times and the need for earlier intervention were noted as serious problems. For example, of the survey

¹² For reference, the full quote regarding this experience is ***'I was initially rejected from the local mental health team in favour of recommending the GP to just change my medication level. After the initial rejection, a talking therapy service that also rejected me (for needing more support than they could offer) but had to write a 'letter of recommendation' (explaining why I need this care) alongside my second referral to the community mental health team'.***

respondents who told us how specialist mental health services could be improved, a reduction in waiting times represented just over 26% of the total responses [(n=111) 29 out of 111]. This was indicative of people receiving reactive care (i.e., services reacting to mental health crisis and/or addressing the problem/condition after it has already occurred and possibly deteriorated) rather than proactive care (providing support before a problem worsens or before an individual reaches crisis point).

Due to long waiting times, many respondents reported that their mental health deteriorated while they waited, leading them to become desperate for support - **'14 weeks waiting time to get back assessed at Marlow House, I doubt I'll make it that long, I'm desperate, it's crazy.'** (woman, forties). Similarly, some respondents reported that **'there is little support early on, before you get to crisis point,'** because **'it takes months to get to speak to someone after an initial assessment, even when the assessment identifies a risk.'** (anonymous respondent), and **'it is almost like you have to reach crisis point to receive any services'** (woman, twenties).

The sentiment among service users was, therefore, **'if we actually got the help when we needed when we needed it, then it could have prevented a lot of things happening as a consequence'** (woman, sixties). Similarly, **'the biggest issue is the waiting time from crisis point to effective treatment. Mental health is not always something you can "put on hold" and wait for'** (woman, sixties). This is problematic not only because long waiting times were reported to worsen service users' mental health conditions but also because, once an individual accessed services, the focus was often on crisis management rather than the prevention of further deterioration or maintaining their wellbeing. Consequently, this places more demand on services and prolongs what is often a difficult period in the service users' lives.

We were also told that delays in accessing treatment place pressure on VCSE services, as assisting service users in crisis prevents them from providing the more holistic planned care. For example,

'Improving Lives, they've been a life saver for myself. However, most of our time was spent sorting out issues with [the] mental health team and medication, so their service - what they were supposed to actually come to me and provide - we didn't actually get to do any of that work because their time was took up sorting

out issues which they shouldn't be needing to be' (anonymous participant).

Not only does this stand out due to the number of responses citing waiting times, but also because, even in cases where service users were satisfied with the care received, waiting times were mentioned as an area for improvement – **'I think they are doing good, but it was difficult having to wait three months to start – I'd like this to be faster' (woman, forties)**. Hence, it is clear that there is not only a need for shorter waiting times, but there is also a call for earlier intervention, alongside proactive rather than reactive support. Proactive care identifies the condition(s) and issue(s) early on, implements support and coping strategies, focuses on keeping them well and prevents further deterioration to crisis point.

Primary Care = A Barrier to Access

Not only were long waiting lists and waiting times reported as being barriers to access, but Primary Care itself, particularly experiences with General Practitioners (GPs), also posed challenges for service users. 71% [259 of 367] of the people we spoke to or were surveyed noted that they had spoken to their GP when trying to access mental health services. Many respondents expressed positive feedback regarding their GP, including **'he was brilliant' (woman, fifties)** and **'if I hadn't seen him, I don't know if my experience would have been the same' (woman, forties)**. However, 28% [72 of 259] of those who had consulted their GPs noted difficulties. They mentioned that their GP's lacked knowledge and compassion, which often resulted in GPs reluctance to refer patients to specialist services, preferring instead to prescribe medication.

'GP declined a referral despite ongoing mental health difficulties (3 years of suspected PTSD), and I was advised to try more medication' (woman, twenties).

'I felt the GP's empathy, compassion, and support in relation to mental health was limited, which was an invalidating experience when I had taken a difficult first step to seeking support' (woman, twenties).

This was particularly noticeable among respondents with more complex cases or conditions (e.g., bipolar disorder and PTSD), neurodevelopmental conditions

(e.g., Autism and ADHD) and/or individuals with multiple diagnoses. They told us that they visited their GP and were given antidepressants for prolonged periods before finally being referred to more specialist services for assessments, diagnoses and specialist or community-based support.

'My GP gave me antidepressants for seven years before I was referred on to a psychiatrist' (man, forties).

'Periods of depression were managed by my GP and then I was okay, but she did not really recognise or join up all the dots about bipolar' (woman, fifties).

Where patients reported negative views around Primary Care, feedback generally suggested that Primary Care Practitioners often lacked knowledge and/or understanding of both mental illnesses themselves, and the support services that are available to the patient, locally or otherwise. This has multiple consequences, including delays in service users accessing diagnoses and subsequently receiving treatment. It also contributes to further deterioration in their condition. In some cases, it leads service users to reach a crisis point before accessing adequate or appropriate support that is relevant to their condition.

For instance:

'When I was seeing my GP and telling them I was really suicidal and feeling like I was going to end it all, he put me on antidepressants. And I've done that lots of times to a point where I was saying I'm physically ill, because I did not know what depression was. I didn't know what to feel, and it took seven years before they referred me to a psychiatrist and when the psychiatrist saw me, they immediately diagnosed me with bipolar disorder, so I was on the wrong medication for seven years.

Being diagnosed and referred to a psychiatrist saved my life because if it wasn't for the diagnosis and the right medication, I think I'd tried to top myself a few times and having that diagnosis and knowing that its bipolar and being put on a mood stabiliser

and knowing that I'm feeling like this because of this, has made a huge difference and I think if it wasn't for that it would have been a very different story' (man, forties).

To address this issue, respondents recommended that GPs and primary care professionals be trained to identify the signs of more complex and severe conditions, such as bipolar disorder, schizophrenia, PTSD, ADHD, autism, and eating disorders. It was also noted that GPs need to increase their awareness of the variety of services available to support their patients because, at present, it is felt that GPs and primary care professionals do not have the knowledge to make appropriate diagnoses or referrals for further support.

'Let's start from the beginning. If you don't feel very well, you go to the GP, the GP needs to be trained to identify the illness [in this case bipolar] and then the rest should flow' (man, forties).

The latter could be as simple as incorporating resources like nottshelpyourself.org.uk, ASKLiON and SelfHelpUK's "Find a Group" function, when signposting and/or referring patients¹³. These resources provide central points where service users and professionals can source information about the support services and peer support groups available in Nottingham and Nottinghamshire. Not only do they provide means of identifying what services are available but could also be used to empower individuals to take more control over choosing the right support to meet their holistic needs. These websites could be used during consultations with patients to direct them to relevant information or services.

Alternatively, if broadening the knowledge of GPs is not possible, respondents recommended that GP Practices hire specific, specialised staff members (either a GP or nurse) to work with patients experiencing mental health problems, for instance, First Contact Mental Health Practitioners and/or Mental Health Nurses. Alternatively, and/or where appropriate, Social Prescribing Link Workers¹⁴ could also be involved early on in a patient's mental health pathway

¹³ These resources can be found at the following links – [SelfHelpUK Directory](#), [NottsHelpYourself](#), and [ASKLiON](#).

¹⁴ Social Prescribing Link Workers, also known as Social Prescribers, work in GP practices to ensure that the wider needs of patients are addressed. Namely to ensure that an individual receives holistic care, focusing on what matters to them. It is an approach that connects people to activities, groups, and services in their community to meet the practical, social, and emotional needs that affect their health and wellbeing.

to make patients aware of the range of services and support groups available to them.

Issues with Referrals between Services

In addition to increasing professionals' awareness of the support services available, we were also told that the process of being referred between services was difficult. In some cases, it took a **'long, long, long time' (woman, twenties)** to get to the right service. As our Case Study (Appendix C) highlights, participants not only experience delays in accessing the relevant services following their assessments and diagnoses but also while being transferred from one service to another. In some cases, this left service users feeling **'abandoned and betrayed' (man, late teens)** as they waited often with little, if any, support. They reported feeling left to their own devices, whether it be to research their condition following a diagnosis and prior to receiving treatment, to find support from additional organisations, or to generally cope with managing their condition while trying to live their day-to-day lives:

***'I've been referred to the Long-Term Adult Mental Health Team, but I haven't heard from them for about six months, and I haven't received any support for nearly a year. I'm basically left without any support because I need more specialist support, and the services are unable to offer that. Because of this lack of support my mental health declined to a point where I had to drop out of college for a year. Since going back, I've had to rely on my tutors in place of professionals to keep me afloat...'* (man, late teens).**

***'They had a referral to the service from their GP and had an initial assessment which deemed them high-level need but not an emergency as they weren't suicidal. After that, they were told that they should have their first session in 6-8 weeks, but there was no further contact from the service even 4 months later. My friend didn't follow up and frankly shouldn't have to, especially considering the state of their mental health'* (non-binary participant, twenties).**

We were also told that participants spent a significant amount of time chasing up their referrals, in some cases requiring support from their GP. In other cases, respondents found out that the referrals they had been promised had never

been made or had **'gone missing' (woman, forties)** after many months of waiting.

***'Fortunately, I've got a really fantastic GP who's been really, really good and spent a lot of time chasing up referrals...'* (woman, thirties)**

***'I had to chase my referral after six months, but the person I spoke to was really apologetic, horrified even. It turned out that my referral had been lost due to IT error, something to do with the way they'd been transferred over'* (man, twenties).**

***'She said she would refer me onto Step 4 / The Trauma Centre for EMDR. She said we should hear back within a couple of weeks.... 10½ weeks later, I gave up waiting and rang them myself. They said they had no record of an appointment or referral taking place'* (woman, fifties).**

It is important to highlight, however, that despite its flaws, we were told that secondary care remains the gateway to all other services and support. This is because it enables service users to access additional support, whether this be in the form of VCSE organisations or those provided by NHFT.

***'the thing with secondary care is it opens doors, I mean, I've got a psychiatrist that's not very good at all, but it opens doors because I couldn't come here [Improving Lives] if I wasn't in secondary care, you know'* (woman, age unknown)**

This signifies the importance of both timely referrals and knowledgeable staff, as only with such can service users access the right services at the right times. Therefore, it is all the more important that referral processes be reviewed, improved, and streamlined to stop NHFT from **'passing people from pillar to post'** (woman, twenties) and from one service to another.

As part of this, participants noted that it would be useful to receive communication regarding their place on a waiting list and an approximation

of their expected waiting time. This could take the form of an online waiting list management system, similar to the one implemented by The Transgender Centre for Health and the Gender Identity Clinic¹⁵. Such a system would assist with transparency and communication between service user(s) and the system, as well as managing the expectations of those waiting to access services. Alternatively, it could involve pooling resources and using administrative staff to make initial contact, providing details of the waiting times along with signposting to other organisations that may be able to offer support in the interim. Not only would this help manage clinical priority, but it would also reassure service users that they haven't been forgotten.

(In)Consistency in Care

Another recurring theme regarded the consistency, or in most cases, the lack thereof, in the care received. Participants acknowledged that this inconsistency could occur for various reasons, including IT issues, complex referral processes, the complexities of job sharing, staff sickness (both long and short term), staff turnover, and poor or failures in communication, among others.

***'I haven't had any mental health support for 3 months now. My psychologist has been off sick all this time, and there is nobody else to see. This is causing me great difficulties with my mental health.'* (woman, forties)**

***'I was under the Postnatal Team for the first year and then passed over to the community sort of like Psychiatric Team and I was under them for about six months or so, and then passed back on to my GP so over the last five or six years I've sort of been backwards and forwards between different teams...'* (woman, thirties)**

***'When my care coordinator left last August, after my appointment with the psychiatrist had been cancelled, there was no contact for 6 weeks. Nobody checked how I was even though I was on a weekly care plan.'* (woman, forties)**

¹⁵ Please see the waiting list page on their website, [here](#). Here they publish their recent waiting list figures.

“I think it's important to have some sort of consistency in seeing the same sort of person... I didn't have that, every time I'd go to clinic and see a different face’ (woman, thirties)

We were also told that the longer service users lived with their conditions, the less support they felt they received, and even though their need for support varied, their need to feel supported remained the same. For example, despite being diagnosed with bipolar for 18 years and remaining under the care of a psychiatrist, one participant told us that their daughter felt confused and as if she had been left without **‘any help or support’** since the period following her diagnosis:

‘When [name] first had her first episode 18 years ago, the crisis team came in, and were fantastic, came to see her every day. Now it's 18 years later, they just leave us to it basically. We've got a good family support and that's all we rely on now.’ (woman, sixties).

Similarly, we were told that support offered by Local Mental Health Team's (LMHT) Crisis Teams is consistent during periods of crisis, but it becomes inconsistent or even non-existent once a period of crisis is over. Hence, it appears that the care received can be described as **‘either all or nothing’**, and for some, it feels like **‘they're either hounding you and putting you through assessments or nothing’ (woman, forties)**. This reinforces the presence of gaps within treatment plans and service provision, and thus highlights the need for care that supports the maintenance of service users' mental health, in addition to improving mental health.

Discharge

‘... you know that when you're ready to fly you go, but they tend to throw you out your nest before you're ready ...’ (woman, sixties)

The need for consistency in care also extends to discharge. Some participants told us that they were discharged too early and sometimes in a rush, even before they felt they were ready. This was partly as a result of only being eligible to access services for a limited period of time (e.g., three months). As a

consequence, many ended up being re-referred to services shortly after their discharge due to deterioration. For example:

'The obsession with trying to fit serious, long term or life-long issues into an 8 Week Course is detrimental to everyone involved. Service users can't get the help they need, and service providers can't do a good job and eventually quit' (anonymous participant).

Similarly,

'you can only access the services for a certain time, and they stop after that, so as soon as you feel a little bit better, they kind of think, yeah, let's push you on, which is a good idea in some circumstances, but for myself I could do with some more help again, and it's virtually impossible to get it' (woman, sixties).

'I was informed that in the future I would no longer be able to continue in the service as they had to get people off the books. I am devastated by this. After many, many, many, many years of being passed from pillar to post and having to start from the beginning all over again each time, I have finally found a service and a psychologist that I am able to engage with and do some good work with. Getting rid of me is completely pointless as my GP will have to refer me straight back into mental health services and I will be on a long waiting list again, no doubt will be passed from pillar to post again. I can't tell you how damaging this is to me and only makes my mental health problems worse' (woman, forties).

As illustrated above, participants also noted that the thought of being discharged often caused them undue stress, anxiety, and concern, particularly in cases where they felt the support had made substantial differences to their health, wellbeing, and overall mental health:

'it almost feels like a tightrope that at the moment, you have got all the padded cushions underneath and obviously when The Recovery College finishes, are all of those cushions going to be stripped away? I mean yes you still have the tools like you said, but in reality, it's not having that reminder that actually yes you can put

it into place... it is more difficult when you are doing it on your own' (woman, twenties).

A proposed solution to this was to:

'remove the constant pressure on psychiatrists [and staff more generally] to discharge patients with enduring mental health problems and instead, have a latent caseload where they are not automatically seen every 6 months but instead can be seen if when they request it to prevent relapse' (woman, forties).

A further proposed solution was for services like The Recovery College and Turning Point to offer **'refresher sessions'**, peer support sessions and coffee mornings (woman, sixties), which participants could attend every three months or so to further develop their knowledge and tools. We were also told that more VCSE organisations should be commissioned and/or signposted towards because they are good at offering additional support where required and/or available. This support sometimes comes in the form of online support, peer support, and/or referrals to other relevant services. For example, we were told that Improving Lives would allow service users to continue attending group sessions once they had been discharged from their individualised support, where possible, rather than simply discharging them:

'... in the lockdown I had a lot of help, and then they gradually took it all away, and I can't now get back into that. Improving Lives has been great and I can still come along to what goes on, but I can't have their support because I was with them for over 18 months, so I need to go to a different provider, but I know the people here, it's beginning again... it takes you back, way back again, and I feel I've gone back to the beginning if not worse, because you have the help, and then it's gone, and you need more, it's support for the rest of your life, not as intense maybe as at the beginning, but towards the end, you know that when you're ready to fly you go, but they tend to throw you out of your nest before you're ready' (woman, sixties).

Some of this may be happening already and where this is the case, a greater awareness needs to be highlighted about the additional support available,

(i.e., increased publicity and visibility of the support services, how to access them, and who is eligible for them).

We were also told that it's useful when organisations have conversations with service users regarding their discharge, what it means for them and any concerns they may have. This may involve signposting them to other services and/or means of support rather than leaving them feeling alone and abandoned (see

Appendix C – Case Study as an example). As noted in discussions of holistic, person-centred care, this may be where longer-term treatment and recovery plans prove useful, as they provide service users with structure and goals to work toward while they are not receiving regular support.

For those who require more structured, regular support, especially for individuals who repeatedly return to services post-discharge, we were told that a **'handholding'** or **'buddy'** service would be useful. This is because:

'the service that [groups like Improving Lives] provide is good, but it is a shame that it is so limited and that it is not a hand holding service which I think many of us in this group probably could do with' (woman, sixties).

The aim of a service like this would be to provide structured support for service users following their discharge, assist them to maintain their mental health, attend appointments, groups or support sessions with them, advocate for them, and generally support them with the day-to-day tasks they find difficult. It was felt that consistent, means-tested support like this is currently lacking, particularly in relation to their lives outside of medical settings, appointments, or support groups.

A need for improved Crisis Care

While waiting to access services, and/or following discharge from services, some respondents noted contacting Crisis Care (e.g., Crisis Lines), being referred to Crisis Services after attending A&E or contacting emergency services. Feedback around Crisis Care itself was mixed. On the one hand, we were told that **'the crisis team were excellent' (woman, thirties)** and **'really easy to access' (woman, thirties)**, responding quickly to referrals or following their first contact. On the other hand, we were told that support can be **'rubbish' (woman, late teens)** because **'if you ring the crisis number, you get asked "what do you want us to do about it?"' (woman, fifties)**. One participant shared the following concerning experience with us:

'I once rang them, and I was told to just to put a bit of radio on in the background, and I thought, "right is that the only advice you could give me, put the radio on in the background because it will get me through the night?" And that is in your moment of need

when you are at your lowest because obviously, you not just going to ring the crisis line just for the fun of it are you? I don't think I'd ever use them again' (woman, thirties).

From feedback, crisis care itself is not consistent and varies dependent upon whether you contact your LMHT or the Crisis Line. It appears to be somewhat of a postcode lottery and/or luck of the draw who you get through to and who you are subsequently reliant on to provide care.

Participants told us that Crisis Care could be improved in the following ways:

- Provide clear communication regarding who to contact (e.g., LMHT or Crisis Line(s)) in different scenarios.
- Introduce Crisis Cafes or safe places to access support and encouragement, ***'like a space to go to when you can try to become creative or do something' (man, thirties)***, rather than remaining isolated at home. If these services already exist in some form (e.g., crisis sanctuaries) then there a need for greater awareness of these services, including how and where to access them.
- Ensure that all staff are trained to communicate with people in crisis and are able to provide adequate advice and/or suggestions of coping strategies; ***'if you call the nurse line, then they are quite professional and really helpful. If you get through to the talking service, I found that they offer just random advice...'*** (woman, twenties). This would ensure that everyone calling crisis lines receives appropriate support for their needs, rather than some feeling further triggered by the lack of suitable care that was sometimes received.
- Provide more out-of-hours support and crisis care that offers more than ***'basic answers, like "have a bath/cup of tea/ go on a walk"'*** (woman, late teens).

It was also suggested that:

' ... there needs to be something to fill the gap between GP - Crisis Team - someone who can come out when someone says they're in crisis to reassess - is this indeed a crisis that needs to be referred to crisis team or could/can this person be managed by another service/person/self for now? This would take pressure off the crisis team, leaving them available for when really needed, so people don't end up in A&E or in an ambulance because no other help is

available. This would take pressure off the ambulance staff and A&E' (woman, thirties).

Again, some bridging services like this may already exist, in which case, it will be a matter of raising awareness about them.

It is also important to note that many participants felt that they only reached crisis point as a result of the lack of support they received elsewhere. This further reinforces the importance of remedying these system difficulties and challenges. If services worked together effectively, in a more integrated fashion to ensure that service users receive timely support, then people would be less likely to reach crisis point.

Staff knowledge and understanding

Similarly, to the points raised earlier regarding primary care professionals' knowledge and understanding of mental health conditions, service users reported that it would be beneficial if staff were trained and upskilled to increase their knowledge, awareness, and understanding of both the nature and variety of mental health conditions, and the range of mental health-related services that exist. Respondents recommended this as a key area for improvement – mental health awareness that spans across all professionals, working within Primary Care context, which is the first gateway for most people. For instance, ensure that **'receptionists are trained in how to deal with people with mental health conditions, after all that's all they speak to' (woman, fifties)**. Furthermore, improve knowledge and understanding of neurodivergences throughout the system because the current **'understanding of neurodivergences [is] appalling' (woman, thirties)**, and thus the needs of individuals with ADHD or those on the autistic spectrum are often neglected through a lack of understanding.

'Many specialist services just refer autistic individuals on to learning disability teams because they do not understand autism (which is very obvious if they are referring people on to learning disability services when autism IS NOT a learning disability). My friend went on to end his own life. It was 100% avoidable; the mental health services let him down. The crisis team line told us that if he stepped in front of a train, he would be the police's problem. Not very helpful at all' (woman, twenties, survey respondent).

Respondents noted that this would not only increase their satisfaction with the support they receive but it would also increase their individual knowledge and understanding of their own condition(s), as well as providing them with much-needed information in terms of where to turn for additional support if required.

Increased knowledge, awareness and understanding among staff at every level, in every service, may also decrease the number of referrals to inappropriate services. Gaining a greater understanding of different symptoms, in addition to knowledge around what services offer, may prevent service users from being referred to the wrong services, where their needs are considered **'too complex' (woman, fifties)**, or entirely inappropriate, as outlined above in broader discussions of the theme 'access'. The relationship between access, referrals, staff knowledge and understanding shows that referral processes cannot be streamlined in isolation as the process itself is impacted by additional factors.

Staff relationships with service users and communication skills

Not only were we told that staff sometimes do not understand an individual's condition or symptoms, but we were also told that it often feels like staff are not interested in building and maintaining rapport with service users, nor in developing an understanding of how an individual's condition impacts their day-to-day life. Respondents felt that staff do not always listen to service users, nor acknowledge their individual experiences. For instance, we were told **'every now and then you meet absolute gems who listen, but 9 times out of 10 that doesn't happen' (woman, twenties)**. Similarly, **'I felt like they didn't listen to a lot of stuff, like I'd have a really good conversation with them and really clearly agreed on an action and then I would get a summary letter and it would be completely the opposite' (woman, thirties)**. Thus, clinicians failing to actively listen had negative consequences for service users.

This theme also links to points made regarding (in)consistency in care, service user involvement, and holistic, person-centred care. For example, service users noted a lack of meaningful relationships with their assigned staff member(s). They also mentioned that staff members sometimes failed to actively listen and properly engage with their notes, which contributed to them feeling as though

they were not **'treated as a human being' (man, thirties)**, indicating a need for compassion and care. Service users reported a lack of compassion and that it felt like the practitioners were **'not interested'** in what they **'had to say' (woman, sixties)**. For instance:

'...the system seems so much more clinical and lacking compassion now, so long as you aren't hurting yourself or others you are left to your own devices' (man, thirties).

'Staff seem depersonalised from their job - why are they in a caring environment if they're not going to make bonds with people? It feels like a lot of people have a plastic smile. Overall, everyone is very dismissive' (anonymous participant, late teens).

We were also told that communication skills demonstrated by staff require improvement, with essential information sometimes not being communicated from staff member to service user; for example, service users' medication being changed without information regarding the change, the new medication, or possible side effects being communicated to them - **'my medication was changed without being told so I didn't understand what was happening to my mind' (man, thirties).**

Although some feedback was negative, we also heard about occasions where staff spent time to build relationships and actively listen to their service users, using what they heard to design treatment plans that worked for them as individuals. As a result, service users reported positive experiences.

'I do enjoy the contact with my CPN - he helps me put my last fortnight into perspective. The medication keeps me out of possible return to hospital. They really make me want to impress them, so I am incentivised to do well' (man, thirties).

The common denominators present in positive experiences were personalising conversations with service users, actively listening, maintaining regular and consistent contact, and taking **'time to explain things to those who don't really understand and are reluctant to ask questions like they do at Mental Health Services for Older People (MHSOP)' (man, seventies)**. We were told that certain

services do this well, including: MHSOP, Turning Point, Improving Lives, Nottingham Sexual Health and IAPT. The following quote provides an example of what service users would like their relationships with staff to look like:

'There was a light and day difference between recent experience with IAPT and the support I am getting at CMHT. My therapist at IAPT listened to me, cared about me, took what I said on board and remembered it, involved me and that really showed how different my interactions with the CMHT were. IAPT was a more positive experience because she really listened to me, she kind of developed an appreciation of what I was like and what my life was like, she didn't rush to judgements or tell me to do silly things that I haven't got a hope of doing, she remembered things I'd said and used them to kind of build a picture of me that she could use to make sense of other things I said and help me have insights. She didn't get hemmed in by a diagnostic label, and I wasn't just a problem; I was a person, and she was there to do her best to help me' (woman, thirties).

Improved communication within, and from, the system

An essential component of the themes above was a need for improved communication within the system, within services (e.g., between staff members and departments), between services, and between the system and the service users. It was noted that communication and information sharing, both within and between services, as well as from service-to-service user, were **'appalling' (woman, thirties)**. This included limited communication regarding waiting times or in between appointments, issues with responses following referrals (e.g., failing to acknowledge that a referral had been received), and services failing to ensure that communication methods were accessible for service users with different needs (i.e., those with physical and learning disabilities).

'My adult son has been under psychiatric care for a decade. He remains on strong meds for bipolar disorder but has a brief chat with a psychiatrist on average about every 9 months. Appointment letters are sent out, cancelled, not re-arranged without us contacting them. He is currently waiting again, having been told in July that his November appointment was cancelled. He has contacted Notts Healthcare and was told a letter would be sent out but no news yet, a month later' (man, thirties).

'More consistency and more communication - I've had on multiple occasions where there has been 6 months between appointments with no communication as to why or when I'd next get seen' (woman, twenties).

We also heard that service users struggled with poor communication and information sharing from staff member to staff member and from service to service. Failures in communicating service users' information meant that they had to repeatedly share their stories and experiences, something they found to be distressing. For example:

'In our case, we had informed mental health services on many numerous occasions that we did not want to be repeatedly contacted about the same situation that we had spent hours explaining to many people it was absolutely ridiculous - we had reassurances that this had been entered onto the system, but it obviously had not been' (woman, sixties).

'... you want to go and be listened to and have them understand you and have them know from the off what is going on, you do not have to tell the same things to different people, and that is one thing that you do end up doing between all the counselling, all the doctor's appointments, new doctor or a new counsellor... You are explaining the whole thing over and over again' (woman, twenties).

In order to prevent this, one participant told us that she had put together a timeline to hand to staff whenever she was asked to share her story:

'... I have got to the point now where I have made a timeline and all the information is there, and when I go and see a new person, I just pass it over and say, "Can you just read that first?" because they are not updated, they have not read anything...' (woman, twenties).

Although consistency in staffing would be the best possible solution to this issue, as it would allow service users to develop personalised, meaningful relationships with their assigned CPNs, psychiatrists, and healthcare professionals, we understand that this may not always be possible for a variety of reasons, including staff sickness and staff turnover. We therefore recommend that service users' information is centrally stored and shared between services and staff members, person-centred care plans co-produced early on with the service user and kept current with changes and timelines. These could be similar in structure and content to the 'person centred passports' proposed by Healthwatch North Yorkshire and agreed to by North Yorkshire and York Mental Health Alliance (2023: 62).

This document should function as a place where all information regarding the service user's condition can be stored, including 'what helps or hinders their health appointments', factors contributing to their condition, how their condition impacts their day-to-day life, and the nature of their support network (Healthwatch North Yorkshire & North Yorkshire and York Leadership Alliance, 2023: 62)¹⁶. Family members should be consulted when appropriate, as should their healthcare professionals.

This information should be available digitally on their file, and service users should also be given the option to carry a hard copy (e.g., to bring to appointments and share with providers). This will facilitate smoother appointments and provide staff members with insights into service users' circumstances and conditions ahead of their initial encounters, thereby improving communication within the system, between staff members, and between staff members and service users. It will also help staff develop positive relationships with their service users from the outset.

Holistic, person-centred care

Despite an N&N ICS 'Strategic Pillar' involving the implementation of 'an approach that focuses on the individual (physical and mental health)', respondents told us that their care and support is often not holistic or person-

¹⁶ These may already exist in the form of "Care Plans" or "Wellness Recovery Action Plans" ([WRAP, 2023](#)), however, from the feedback received it appears that they are not used consistently in practice (i.e., they are not read and/or engaged with by staff ahead of appointments, or they are not co-produced at the outset of a patients treatment as they should be).

centred (NICE, 2011; N&N ICS, 2019: 22). Instead, it is based around set questions, treatments, and often uncommunicated treatment plans over which they have little to no control. Several participants told us that it felt like services revolved around **'tick-box'** exercises, constituting **'a tick-box culture'**, where professionals were more interested in having participants complete surveys and set questions than in getting to know them as individuals, understanding how their condition affects their day-to-day life, and identifying potential sources of assistance. For example:

'When I get to see my psychiatrist, I get about five minutes to speak and then he has a list of prepared questions – "Are you sleeping? Are you eating? Are you doing household tasks? Are you going to kill somebody? Are you going to kill yourself?" and every single time I go, he asks me these questions, and most of my consultation, which is about 15 minutes is spent on answering these stupid questions' (woman, age unknown).

By not getting to know service users or understanding how their conditions impact their day-to-day lives, we were told that the care provided is often not appropriate to the service users' lives, abilities or needs. For instance, one participant had a substantial disability and is a wheelchair user, which they felt was not taken into consideration. They told us, ***'they would always tell me to do things that I couldn't do with my disability', e.g., "you should go and bake a cake, go and take a walk" and there was never any appreciation of my limitations' (anonymous).*** We were told by a female participant, who is married to a woman, that ***'at every single appointment, my psychiatrist gets my partner's pronouns wrong (e.g., "is he supportive?"). There's no consideration that that's an option. I understand that it's natural to assume that I'm in a relationship with a man, and I don't mind people making that mistake, but I've been with the consultant for a long time, and he should know that by now' (woman, thirties).***

Similarly, another participant told us that her mother had passed away, which was part of the reason for seeking support. However, when they met with their psychiatric nurse, he had not read any of their notes. They explained, ***'so I came into the meeting expecting him to know stuff about me, but then when I started explaining my mum's ill health he said 'oh, is she okay now?' and he had not read any of it. So, I would recommend that they actually read the notes before having a meeting would be helpful' (woman, twenties).*** Meanwhile, another participant mentioned that CBT did not work for them; however, there

was no consideration of this, nor of their holistic needs, so it felt like **'a sticking plaster on a gaping wound'** (woman, forties).

Participants would prefer to receive **'more personalised'** (woman, twenties), holistic, person-centred care and treatment that is proportionate to their condition and personal needs. They emphasised that services should move away from a **'one-size-fits-all approach'** (man, age unknown), instead treating **'patients as individuals, not textbooks'** (woman, forties) and treating **'the person, not the diagnosis'** (woman, twenties). This is because those who do not fit into predefined categories or checklists often do not receive adequate help.

As a possible solution, one respondent suggested that it would be useful to receive a one-on-one assessment at the beginning of their treatment to identify their needs and **'understand the bigger picture'** (woman, fifties), rather than just focusing on their diagnosis or symptoms. Without an understanding of how a condition or conditions affect an individual, how can they be effectively treated to live independently with it? Longer-term service users (who reported repeatedly returning to services post-discharge) suggested that incorporating longer-term planning into their treatment would be useful. This approach would not only allow them to keep track of their recovery journey but also to explore **'why things keep getting bad'** (woman, fifties). It would also prevent them from **'losing hope of ever getting better'** (woman, fifties) and reduce their need for frequent returns to services. To achieve this, providers need to ensure that professionals, irrespective of their specific job role, are up to date with service users' notes.

This is not only about designing care plans based on an individual's needs but about considering the varying needs and conditions of service users, in addition to wider determinants of health, when planning, designing, and delivering services. It involves ensuring equitable access so that services are accessible to a diverse range of service users to ensure that nobody is excluded. This includes making appointments, group sessions or consultations accessible to all, including those of working age (i.e., by offering appointments outside of work hours) and parents (i.e., by ensuring that appointments/sessions do not clash with school drop-off times).

This could also involve offering sessions or education courses (e.g., similar to those offered by The Recovery College and Turning Point) online where

appropriate. This must not be seen as a solution for all service users, however, as not all service users will have access to, nor an understanding of, the technology required for such. Hence, it is essential that services are offered via a variety of means, at a variety of times.

'... for me to get out of bed to come here, that's why I needed an afternoon course because with mental health and anxiety and probably all the medication that you're on, it's hard enough to function, you know, never mind get out of bed' (woman, sixties).

'I had some difficulties accessing sessions and courses due to my commitments with childcare, so it would be good to have a balance with the same courses being offered in both morning and afternoon slots, not like it is now with specific ones being run in the afternoon and specific ones in the morning' (woman, thirties)¹⁷.

Based on feedback regarding service user involvement, (the lack of) holistic, person-centred care, and staff relationships with service users, it is clear that there is a need for individualised care plans. These care plans could come in many forms and should not only be written but frequently revisited, reviewed, and actively engaged with by all individuals involved in a service user's care.

Another central component of what respondents deemed holistic and person-centred treatment is receiving education and information around their condition(s), which they feel is currently lacking. Service users have requested the commissioning of more services that provide education about individuals' conditions. They also requested the provision of leaflets and guidance on other available services and resources, for instance:

'a simple thing like when you're given that diagnosis, just to have a pamphlet with information, benefits, everything in it, so people don't go away scared and google something and get all mixed up' (man, forties).

¹⁷ By this, the participant was referring to their desire for the Trust, and particularly The Recovery College, to offer the same courses at multiple or different time slots, in different terms, giving people an option to attend, irrespective of caring or working responsibilities.

They noted that this would be beneficial not only because it would allow them to understand their conditions and access relevant support, but also because it could prevent people from **'turning to other sources'** (e.g., the internet and alternative therapies) which **'can be very dangerous, because there are experimental treatments that are licensed in different countries, but not licensed here'** (woman, thirties).

Some also suggested employing culturally competent individuals who have similar lived experiences and/or people who had experienced mental health issues as healthcare professionals, serving in roles as **'experts by experience'** (woman, forties) and/or in peer support roles. They believe that this also might help in designing and delivering care that is person-centred by default (i.e., **'You need people that suffer from mental health to advise you, to be in these teams'** (man, sixties)). This approach was something that service users of The Recovery College praised, with similar sentiments as the following:

'Coming to The Recovery College was like something else, it's not someone who's perfect and telling what all the rules... they're human, they're real, and when they share their experiences which they do, and you know, when one of them said, oh, I've been sectioned three times, I was so shocked, to think that they were sharing their, you know, life, but I felt it really helped me because it didn't make me feel I was, you know, what's happened to me? Is just, you know, it's a thing that can happen to anyone' (woman, sixties).

'All the staff have been amazing, enthusiastic, supportive. By having experienced mental health problems themselves and sharing their stories and struggles, they made the experience so much deeper and better. I cannot thank all the staff enough. Please let this service continue. If I had been hospitalised it would have cost a lot more money to get me to this point' (woman, age unknown).

Involve friends and family

Some participants expressed a need for family, friends, and carers to be consulted and recognised where possible. We were told that, at present, they are often sidelined despite being integral to the recovery of their loved ones, whether this be due to their understanding of their loved one's condition(s) and symptoms, or the care they provide. We were also told that it's difficult for

carers or family members to contact professionals if/when their loved ones are in crisis, particularly when it comes to discussing the medication required. For example:

'... my daughter has Bipolar... When she goes into an episode, she will not take her medication, she needs to up her medication, getting her medication is horrendous. Getting the higher dose that she needs to bring her down off the ceiling is impossible because she is an adult, so they won't speak to me. I look after her, so it's really, really hard. Every time she goes into an episode, we have a fight on our hands...' (woman, sixties).

This subsequently delays service users' access to required medication, prolonging their periods of crisis. On the other hand, we were told that when family members and carers are involved, the care of their loved ones markedly improves. For example:

'As a carer for my husband, I have found that this psychiatrist is excellent and I can contact his secretary and speak on behalf of [name] and say could you get medication ready, could you do this... I found that if there's an issue with my husband, if I ring the psychiatrist's secretary, she will put a note on and let the psychiatrist know and that way they can call back.' (woman, forties).

Similarly, we were told it would be useful if:

'family members and loved ones [of service users] could be given free mental health first aid training, hearing voices/psychosis training, depression, and anxiety training, etc., so they are better equipped to care for their loved ones at home and to protect their own mental health too. This again would take pressure off the NHS staff and help loved ones immensely' (woman, thirties).

In turn, this not only helps the system in caring for those with severe mental health conditions but also supports families, as numerous respondents told us that they, as family members, did not feel adequately supported.

The involvement of family, friends and carers could take various forms. It could involve liaising with agreed family members regarding medication and/or care. It could also encompass asking family members to provide **'a written statement'** regarding **'their concerns about what they have seen, heard or experienced with'** the service user **(woman, fifties)**. It was noted that this might make things a lot quicker and highlight areas **'to target or investigate further'** **(woman, fifties)**.

The importance of their involvement is further reinforced by the number of people (64% [210 of 328]) (see Figure 2), who indicated that their first port of call for mental health support was their family and/or friends. This is significant as it shows the importance of support networks in the support and recovery of those experiencing and/or living with a severe mental illness.

Service user involvement

Respondents said that there was room for improvement when it came to service user involvement within their care. While half of our interview participants [8 of 16] told us that they felt involved or very involved in their care, focus group participants and survey respondents indicated that service user involvement was a key area for improvement. For example:

'In a lot of my appointments, I felt like I could have had a cardboard cut-out sitting there of me and it would have been exactly the same. For example, I would say that I'm really struggling with suicidal thoughts every day and I'm worried I'm going to hurt myself and they'd sort of nod and go "hmm", write something down and then just carry on like I never said anything. They were dismissive and it was like they didn't really see me as a person. I felt more like I was just a problem or a number on a list' **(woman, thirties)**.

Those who indicated that they felt involved or very involved told us that through active participation in the treatment process, they were able to co-create **'the right level of support'**, which meant having regular support yet support that did not eat **'into [their] life and activities'** **(man, thirties)**. On the other hand, those who reported that service user involvement was an area for improvement told us that they were given limited choices or opportunities to influence their care. For example, **"I did get to make some choices, but it was mainly just like here's the options we've already picked, you can pick A or B.**

There was a very limited amount of choice[s] given' (woman, thirties) and 'I never got to speak to anyone so I never got asked what I thought would be helpful. It felt like a one-sided power imbalance, like, we've decided what you need, and we are the experts, so you do what we say' (woman, twenties).

Participants reported that they felt that if they were to advocate for themselves or their family member, or if they were to act in a way that was not aligned with being ***'the perfect compliant patient'***, their concerns or preferences would be disregarded, used against them, or seen as ***'more evidence of [their] disorder[s]'*** (woman, thirties). They were concerned that such actions might even be used as grounds for discharge from services.

'I feel like I can't argue because they feel like I have BPD. There's no way to ask for help without it being turned back on you. If you don't ask for help, they ask why, and if you do, then they say you don't need help or don't meet the criteria' (woman, forties).

Participants raised similar feedback regarding complaints processes and procedures, including concerns about ***'badly handled'*** complaints. Some respondents reported that if they were to complain, they feared it would be used against them, consequently impacting their treatment, and/or that the individual they made a complaint about would be made aware of it. One respondent shared an experience of making a complaint about their consultant and requesting to change after what they felt to be a judgemental encounter, ***'only to get a phone call back from the consultant himself who challenged [them] as to why [they] wanted to change'*** (woman, forties).

Similarly, we were told, ***'I was asked to give feedback by the Trust through a message, so I did but then deleted it. It went straight to the care coordinator, even though I thought it was confidential. I was then asked to discuss what I was dissatisfied about. It needs to be clear who the feedback goes to and that it is not confidential'*** (woman, forties). Not only this, but there should also be feedback routes that remain confidential, allowing service users to be fully transparent and honest regarding their experiences without fear of retribution or concern that it may impact their future care.

Stigma and discrimination

We received mixed feedback regarding stigma and discrimination. Some participants felt that services **'have improved massively'** in recent years due to the declining stigma surrounding mental health.

'When my dad was alive, mental health wasn't recognised, especially in men. It was just "man up." There was a stigma behind it all. But now, whether it be women, men, children, whatever, they can all turn around and say, "I need help" ... there's no stigma attached to it anymore' (man, thirties).

This sentiment was particularly notable in feedback regarding VCSE organisations, where service users mentioned feeling wholly accepted and understood, irrespective of their gender identity, sexuality, experiences, or diagnoses.

Contrary to this, some respondents highlighted the presence of stigma in both primary and secondary care, which subsequently affected care related to certain disorders. Although very few participants told us that they felt they had been discriminated against because of their protected characteristics, we were told that protected characteristics were **'sometimes taken into consideration and sometimes not'** (woman, forties).

Race is a particular area to highlight - **'race played a big role in the care and treatment received or not received'** (anonymous participant). We were told that services, and consequently resources, treated service users as a monolith with a very **'one-size-fits-all'** approach, disregarding people's racial, ethnic, and cultural backgrounds. For example:

'My son was mixed race, so I found that there wasn't anything... everything was generic' (woman, age unknown).

One participant mentioned that this is like when Black people are diagnosed with mental health conditions due to their race, **'no matter what you suffered from'** nor what symptoms they were experiencing (man, fifties).

The second area of concern is religion, as some individuals who expressed their spiritual beliefs told us that these beliefs were deemed to be further evidence

of their condition rather than accepted as their beliefs¹⁸. On the contrary, another participant told us that their **'therapist was mindful of [their] Islamic and Middle Eastern background and took this into consideration. This was positive experience' (woman, thirties)**, which indicates that experiences of discrimination varied depending on the member of staff.

Other discriminatory remarks were reported. For instance, weight was a factor, with one participant telling us that **'there was no discussion at all about food or lifestyle, but she clearly took one look at me being so fat and told me I should eat healthier. She also told me that [details regarding a previous incident of self-harm] was me being an attention-seeker.'** (woman, fifties). Another issue was self-harm, with some participants receiving remarks from staff regarding their histories of self-harm. One participant told us that they had self-harmed in childhood, and once in adulthood, however, their 'so-called' history of self-harm had been used as evidence of their personality disorder diagnosis. Despite the fact that they had developed healthier coping mechanisms in recent years, the participant felt that the professionals repeatedly brought up self-harm. They also told us that **'the psychiatrist implied that I have lied about how much I have self-harmed previously... it feels like they're latching on to something I did in childhood and using it against me'** (woman, thirties), despite this not being an accurate reflection of her current mental health or coping strategies.

In terms of stigma, service users reported feeling as though they were **'looked down upon'** and labelled as **'burdens' (man, fifties)** or **'drains on the system' (woman, forties)**. They often encountered hostility from staff and were made to feel like problems, rather than individuals deserving of help, compassion, or support. For example, one participant reported repeatedly being asked questions like **'why should we help you?'** and **'what do you want?'**. They also mentioned being told **'you're not going to be discussed ... it's not worth the Doctor's time reviewing you'** (woman, fifties), when reaching out to services in desperation.

Stereotypes

Similarly, other participants told us that they felt professionals tended to (mis)diagnose individuals based on stereotypes, and consequently, they didn't

¹⁸ This is not to say that these individuals may not be unwell, but rather that they believed that their spirituality was deemed to be evidence of illness, rather than accepted as their spiritual belief.

feel taken seriously, especially if they were employed, owned their homes, maintained relationships and/or had children, among other factors. For example:

'They don't take me seriously because I can hold down a job. A lot of people they work with aren't in that situation. I have issues that go back to childhood, and I've learned to mask things as a coping strategy. Just because I can hold down a job and I have my own house doesn't mean I don't struggle' (woman, forties).

'... if you generally look alright, they don't think... if you look clean and you don't smell, etc., etc., or you've got clean clothes on, they tend to judge you more on that, and it took me a very long time to get any help' (woman, sixties).

Returning to an earlier point regarding (in)equitable access, numerous participants told us that if they were employed (either part or full-time), this affected their treatment. This influence extended not only in relation to their ability to access appointments or treatment, but also to their diagnoses. For example, one participant told us that her:

'First care coordinator was a nice lady but would ring with 10 minutes' notice to say she is coming down with a colleague from the crisis team. I work full-time, so can't just stop everything. I couldn't let them in which resulted in an assessment that afternoon' (woman, forties).

She also told us that this felt like a punishment to her and demonstrated a lack of understanding about her situation and condition. It was assumed that she could not work due to her condition, thereby reinforcing the presence of stereotypes in staff understandings and the provided treatment.

The same applied to stereotypes surrounding certain diagnoses and condition - ***'the stereotypical and traditional assumption of Personality Disorder is what they make their treatment plans upon. This approach is not helpful and quite often destructive' (woman, thirties).*** As a result, respondents requested that ***'services look at people as a whole rather than just a diagnosis' (woman,***

thirties), which was also discussed in the theme of holistic and person-centred care.

There was an impression that the age of staff played a role in their knowledge, understanding, and compassion as well as their use (or not) of stereotypes:

'Attitudes towards certain mental health issues really need updating. In general, I have found a lot of younger and middle-aged nurses/professionals have a very different attitude to certain diagnoses. The more experienced older members of staff who quite often hold senior roles have a very traditional approach and attitude which often means that people with challenging diagnoses, such as personality disorders receive less care and consideration than others with different diagnosis' (woman, thirties).

"At Turning Point, everyone's protected characteristics were very much taken into consideration" (woman, forties).

"People's intersectionality was definitely considered. They are aware that everybody's got different things and they know what protected characteristics are and Equalities Act and they were very conscious of making sure all of those things were adhered to" (woman, forties).

Medication

Some service users felt that specific services were ill-equipped to administer prescriptions and/or medication in either a timely manner or to ensure that the correct medication was prescribed and provided to service users. For example, multiple people mentioned that ***'Byron House, Newark is an excellent service but waste time writing prescriptions by hand. A printer is needed!' (respondent, sixties)*** and again, ***'provide the clinicians at Byron House with prescription printers... they have been "coming" for years and writing prescriptions by hand wastes precious time!' (man, seventies).***

Furthermore, some service users had concerns regarding the general prescribing of medication, including being prescribed unrequired medication,

by Community Psychiatric Nurses (CPN's). They were concerned about the negative consequences this can have on service users and their families.

'... I was assigned a CPN prescribing meds, he was prescribing anti-psychotic medication, mood stabilisers but he wasn't qualified as a psychiatrist. He completely messed up my medication, messed up my health for a year until I was referred back to a psychiatrist who was then able to fix everything... the CPN completely ruined everything. So, prescribing nurses should not be able to prescribe new medication for bipolar patients. It should come from a psychiatrist. I think if they are prescribing continuous medication, then it's fine, but they can't experiment with new medication. I think they're not qualified to do that, and they shouldn't be trying' (man, forties).

'I have an issue with CPN prescribing full stop. I think it should be a psychiatrist. Why are they passing the buck to a CPN? They are not medically qualified. If they are qualified and they've been there for 10 years or something, fair enough, if you've just become a prescribing nurse for a year. The one that we had for my husband, she was terrible, she threw so much different medication at him, new medication, not knowing the outcome and it really messed him up. So, I think if they are going to prescribe, they should have a lot of experience, a lot of training and not just be given the authority to prescribe medication willy-nilly' (woman, age unknown).

What works? Examples of best practice

Not all of the feedback we received was negative. Some services received nothing but praise, and as such, these pockets of good practice must be acknowledged and celebrated. They provide insight into how the entire system could be improved to better meet the needs of those it serves.

There were certain things that, when done well, really made the difference to service users' experiences of using services. These included:

- VCSE organisations offering timely, holistic, person-centred support that includes providing service users with education regarding their conditions in safe, comfortable, welcoming environments. These environments were often led by culturally competent staff who were patient, caring, understanding, and had lived experience.
- Educating people regarding their condition and providing them with helpful, sustainable coping strategies.
- Providing comfortable settings for accessing peer support.
- Ensuring clear, timely communication.
- Smooth referral processes with clearly communicated waiting times and support offered in the interim.
- Ensuring that service users were involved in their care and allowed to make decisions regarding which treatment options or care plans suited them.

MHSOP at Byron House in Newark received several commendations, with feedback stating the service is **'Superb!' (man, seventies)** for a variety of reasons, including:

'telephone calls will be answered by one of three people that we know, so it is accessible and approachable... They are really responsive - if I rang MHSOP in the morning, somebody would ring back by the afternoon... Everything about Byron House is very calm and is taken step by step steadily. They are good at shared decision making' (man, seventies).

Furthermore, individuals who accessed VCSE sector organisations (such as The Bipolar Lift, Framework, Nottinghamshire Sexual Violence Support Services, Improving Lives and Turning Point) found that these organisations tended to

provide more holistic, person-centred care, focusing on the person as a whole rather than solely on their diagnosis. These organisations were local and provided support in various formats. The Recovery College and Turning Point primarily focused on providing peer-based, educational support, informing students about their diagnoses, and teaching them coping strategies and techniques that they could implement in their daily lives to promote self-management and recovery. We were told that being taught how and why the brain functions in certain ways is particularly valuable (i.e., being taught the historic and evolutionary backgrounds of anxiety, and the root of fight or flight responses). Participants appreciated that this content was often made **'fun' (woman, thirties)**. They also valued that it was grounded in lived experience and appreciated the social aspect of their courses. Learning materials were accessible and understandable, such as presentations, videos, and handbooks. Participants noted that this set these services apart from other approaches to support such as CBT or Talking Therapy:

'I was very surprised because I'm so used to talking counselling that just doesn't work for me. I thought it'd be like a group session where we'd have to stand up and say 'I'm [name], I have a depression' but it wasn't at all. I turned up every week because I wanted the help, and it was willingly offered. It was much more helpful than I thought it would be and it exceeded my expectations. The materials are very easy to read and comprehensive, particularly the Crisis Survival Workbook. They use visual aids, audio aids and video aids to ensure that there's something everyone can understand/follow' (man, twenties).

"The Recovery College has been a lifesaver for me. I was so ill when I first started last September ...I was so frightened and anxious and couldn't function in any way. I was closing down and on the verge of being hospitalised. Anxiety, depression, in a very dark place. Stuck. Week by week I learnt new things about the way the brain functions, behaviours, trauma reactions. It has helped me so much and given me the strength and tools to survive. It is an invaluable service that helps people understand and find themselves again. After coming here, gradually the colour started to come back into my life" (woman, sixties).

As a result of this, service users felt they were **'given the knowledge and skills to help [them] to deal with those impulsive moments, where [they're] more likely to be at risk' (man, twenties)**.

Organisations like The Bipolar Lift and Improving Lives work closely with people living with mental health conditions with the aim of improving their overall wellbeing. They provide emotional and practical assistance as well as meaningful, organised social activities for service users to develop skills, confidence, and combat isolation. Both organisations also assist with paperwork (e.g., bills, applications, self-referrals), offer individualised support related to benefits and employment and in some cases, accompany them to services/appointments, amongst other areas. The value of organisations like The Bipolar Lift is clear, with respondents telling us that it gives them an opportunity to **'talk to people and give things a go. They organise trips out for us and it's so nice to go, feel yourself and have people understand you. It's a very good bonding experience because nothing can be said here that the people here don't understand or appreciate'** (man, thirties).

Additionally:

'If you really want to change the system, have a look at this place here, Improving Lives, that should give you an indication, because it's helped me. I was locked in my house watching Bargain Hunt, all day, 24 hours a day... I came to Improving Lives and look where they've put me ... I'm in [theatre groups] now, I've not long played [a leading role] you know, and there was a time where I wouldn't come, and I wouldn't be in room with just you or talk to you. And you need to see these small charities and see how they handle people that suffer from mental health, and you need to learn from them...' (man, fifties).

VCSE organisations were also praised for their support beyond agreed time frames. This is because instead of discharging patients and service users who do not feel "ready", they hold consultations to ascertain their individual needs. This allows them to provide additional support, if/when required, often in the form of peer support groups. It also serves as an opportunity to signpost service users to other service providers who can offer help and support:

"Nottinghamshire Sexual Violence Support Services have been absolutely fantastic. And even the fact that they told me that there is over a 2 year wait for the therapy, has not affected me because they've put something else in place... They've also followed it through with emails of contact numbers for more support. This wasn't the same with LMHT" (woman, fifties).

The services mentioned here were particularly praised for being the most responsive, both in terms of communication and the services they offer (e.g., unlike lengthy wait times often exceeding three months, these services provided support promptly when needed). VCSE organisations, in particular, were applauded for their clear and rapid communication. They informed service users of waiting lists soon after referral and provided interim support where feasible. Being left to deal with diagnoses, self-referral processes or symptoms alone can cause service users to feel forgotten about, dejected and demotivated to seek additional support. Despite being under resourced and, in some cases, receiving minimal funding, VCSE sector organisations provided support that **'was so different to anything'** service users reported **'experiencing previously' (woman, forties)**.

It was clear from participants' accounts that the value of these services should not be understated. Many wished that NHFT could provide education and knowledge regarding their individual condition, particularly following receipt of a diagnosis. Due to this, a key recommendation of this report is for the Trust to continue commissioning and funding a variety of VCSE organisations wherever possible. HWNN understands that those currently commissioned are Improving Lives, Framework, MIND, Double Impact, First Steps, Nottingham Recovery Network, Change, Grow, Live and Turning Point.

Conclusion

This report presents the findings of HWNN's mixed methods research project regarding Specialist and Community Mental Health Services commissioned or provided by NHFT in Nottingham and Nottinghamshire. We heard from 367 individuals who had accessed or tried to access services in the past two years, all of whom shared their experiences with us and offered suggestions regarding what could improve their experiences going forward. Many of our suggested improvements align with the NICE Guidelines (2011) and the N&N New Integrated Mental Health and Social Care Strategy (2019), as outlined in the literature review.

To conclude, the discussion returns to the key questions outlined at the outset of this report:

- *What is people's awareness of the availability of community mental health services? And where would they go if they have mental health concerns?*
- *What are people's experiences of the barriers to accessing mental health services?*
- *What are people's experiences of Community Mental Health Services and how can their experiences be improved?*

Overall, the survey highlighted wide variations in service users' experiences of accessing Specialist Mental Health Services, with some experiences highly positive and others highly challenging. 71% of survey respondents [234 of 328] told us that their first point of contact would be their GP, closely followed by speaking to a friend or family member [(64%) 210 of 328], speaking to a mental health professional or service [(46%) 152 of 328] and searching the internet for information and advice [(40%) 132 of 328]. Although it is positive that over 70% of survey respondents told us that they would consider contacting a GP or Nurse if they themselves or somebody close to them experienced mental health concerns, in some cases respondents found obtaining an appointment with, and/or a referral from, their GP challenging for reasons explored in 'Primary Care = A Barrier to Access'.

It appears that Primary Care services often serve as a barrier to accessing secondary mental health services, with GPs having limited knowledge regarding both conditions and services, influencing individuals' ability to access referrals. Primary care practitioners sometimes serve as gatekeepers of

secondary care, and without sufficient knowledge of a wide range of mental health conditions, they can prevent those who need it from accessing appropriate support and/or diagnoses in a timely manner. Although feedback regarding primary care does not directly reflect on the services provided and/or commissioned by NHFT, it remains valuable and arguably crucial if services are to be improved. This is due to the knock-on effects that this barrier has on service users' ability to access, or to not access, the care and services NHFT does provide. To this end, we recommend that NHFT work closely with the Integrated Care Board (the ICB), the ICS and Primary Care providers, to reduce the knowledge gaps and increase the efficacy of Primary Care's involvement, as detailed in recommendation one.

Many respondents wanted more information about the Community Mental Health Services and VCSE organisations available to them, whether this be provided by their GP, nurse, or psychiatrist. For many, this meant searching the internet or using resources (e.g., leaflets) available in waiting rooms to find support services they could access without having to wait for prolonged periods. In some cases, this meant that service users were aware of Community Mental Health Services and specialist treatment options (e.g., EMDR or Step 4 Trauma Therapy) but faced difficulties when trying to access a referral to such.

Those who were aware of, or had accessed, Specialist and Community Mental Health Services told us that the pathway is not easy, with complicated referral processes, lost referrals, and long waiting times among the most common issues reported. We also found that despite the ethos of NHFT's transformation programme being 'no wrong door', many people approach or are referred to the wrong 'doors'. This caused a number of respondents to feel lost, preventing them from receiving the help or support required in a satisfactory time frame and sometimes causing their mental health to further deteriorate.

Although some service users expressed disappointment, for the most part they were understanding of the difficult situation the Trust, and more generally the NHS, finds itself in. They acknowledged the national, system level pressures, staffing difficulties, and funding constraints faced by services, with many expressing similar views to **'I don't blame my doctor or any NHS worker for the way they treat me, it's the system' (man, fifties)**. Many also understood that **'there isn't an infinite budget for everything/everyone!' (woman, fifties)**, opting instead to suggest that if services are to be improved then **'more funding from the government'** is required because **'the staff work very hard, but the demand is very high' (woman, forties)** and **'staff are great, but there are not enough of them...The problem is lack of resources rather than the staff themselves, as they**

were always excellent.’ (woman, fifties). To remedy the issues reported, respondents frequently told us that they think **‘like everything else more funding is needed’ (woman, fifties)** and **‘the only way forward is more money, more time, more focus and more empathy’ (male, fifties),** as only with increased funding was it felt that the recruitment and retention of more professionals, the development of inclusive and accessible services, and reduction of waiting times could be achieved.

For some participants, Specialist and/or Community Mental Health Services were **‘life-changing’**, providing them with **‘a sense of hope’** and allowing them to feel like **‘there is light at the end of the tunnel’ (woman, forties).** Others, however, felt that they were **‘here despite mental health services, not because of them’ (woman, forties)** due to inconsistencies in their care, their lack of involvement, and receiving care that focused on their diagnosis, rather than their holistic needs and/or the broader context of their lives. Due to this, service users felt like **‘nobody joins the dots’ (woman, forties),** whether that be in looking at the wider determinants that influence an individual’s mental health, looking at their physical and mental health in combination, or in failing to communicate with other staff members or services involved in an individual’s care.

We heard that Secondary, Specialist Mental Health Services, such as Community Mental Health Teams, acted as the door to community organisations within the VCSE sector. These community organisations received praise due to their holistic, person-centred approaches and their ability to meet the needs of service users by providing timely, frequent, face-to-face care, despite the demand on their services and the constraints that these organisations generally face. Respondents told us that their experiences could be improved through further commissioning of VCSE organisations, as explained in ‘What works? Examples of best practice’.

Recommendations

These recommendations are made with the knowledge that they will require commitment in both time and investment. In the long run, however, we anticipate that if implemented, they will free up resources to support service users referred to and accessing services. It is also important to note that these recommendations are not one-size-fits-all because each service user will have different needs based on their diagnoses and experiences, again reinforcing the importance of service user involvement throughout every stage of their care. What we are recommending, however, could improve the situation for patients and service users, past, present, and future.

1. Prioritise early intervention with the dual aim of reducing waiting times and providing clear guidance on how long waiting lists are, to ensure that service users are given information on how to 'wait well'.

The link between waiting times and the need for earlier intervention was noted as a serious problem by many respondents. Once people are referred to community mental health services, they report being left for long periods without any communication regarding when they might access care and support. Many respondents reported that their mental health deteriorated while they waited, leading them to become desperate for support. This was particularly concerning because it meant that once they accessed services, they received reactive care rather than proactive care.

We therefore recommend that the Trust and wider partners look into addressing the issue of waiting times, not only in terms of reducing the time for assessments, diagnosis and treatment, but also in communicating better on waiting times to service users and supporting them while they wait. This could include providing guidance around how to wait well (i.e., providing material on coping mechanisms that may be useful)¹⁹ and signposting service users to services that they could access in the interim. We recognise that the availability of funding would influence what is offered, so perhaps there needs to be a wider review into how mental health services are structured and funded to enable speedier responses and timely support.

¹⁹ See this [web page](#) and [leaflet](#) from Derbyshire Healthcare NHS Foundation Trust as an example.

2. Examine and improve the way in which patients are identified to receive care from Primary Care Mental Health Practitioners, especially for those with long term mental health needs.

There was a clear message from respondents, especially those surveyed, that Primary Care is the first point of contact for seeking support for mental health needs. Feedback indicated that there is a gap both in terms of knowledge and understanding surrounding the range of mental health conditions, and the availability of appropriate services, including referral routes, to support service users. The Trust should work collaboratively with wider partners, ICB Place Based Partnerships (PBPs), Primary Care Networks (PCNs) and Primary Care practitioners, to highlight this point, and to enhance the Primary Care offer. This should assist in triaging patients more effectively, reducing referrals to incorrect service(s) and ensuring the receipt of timely support from appropriate service(s).

3. Streamline referral process and ensure that services are accessible to all.

A key focus here is the reduction of lost and/or missed referrals. An essential component of this is ensuring that technology works but also remains consistent across services. This should assist in preventing the number of lost referrals from files corrupting and/or not being transferred over in a format that is incompatible with the service required. There is a need to improve technological solutions available to support and centralise the storage of service users' notes.

4. Implement centralised, co-produced, 'person-centred care plans' to support consistency in care and ensure all service users receive holistic, person-centred support.

As far as possible, there should be consistency in the clinician(s) involved in an individual's care. It is even more important to ensure the existence of a centralised document, such as 'person-centred care plans' with timeline and key information to inform a service user's treatment and support from the outset. This could be similar to the 'simple personalised care and support plan' that Social Prescribing Link Workers produce with their service users, focusing on 'what matters to them?' (NHS England, 2023).

5. Invest in more services to holistically support service users, such as those offered by The Recovery College and Voluntary, Community, and Social Enterprise (VCSE) organisations.

As well as implementing 'person-centred care plans', NHFT should ensure that all support provided is holistic. This means that, in addition to getting to know a person beyond their condition, individuals should be signposted and/or referred to services that address their holistic needs. Throughout this project, VCSE organisations were praised for offering timely, holistic, person-centred support, which includes providing service users with education regarding their conditions in safe, comfortable, welcoming environments. These environments are often led by culturally competent staff, who are patient, caring, understanding, and have lived experience. It is therefore recommended that the Trust learn lessons from the voluntary sector and considers investing in more VCSE organisations to holistically support service users, whether this be while service users are on waiting lists or as a means of complementing their structured treatment plans.²⁰

6. Ensure that service users are given information regarding their condition(s), particularly following their initial formal diagnosis.

This involves providing service users with more information following a diagnosis, when individuals are issued with new medication, and regarding the support services available to them. For instance, ensure that professionals take time to discuss an individual's diagnosis and/or any prescribed medication(s) with them to ensure that they understand what it means for them and how it may impact their day-to-day life.

Information leaflets and resources produced by charities can be used, such as Bipolar UK, MIND, Mental Health UK, and the Charlie Waller Trust. Furthermore, ensure that organisations like The Recovery College provide a wide variety of courses that cover a range of existing mental health conditions, perhaps drawing on resources provided by other Recovery Colleges across the UK. Similarly, signpost all service users to appropriate services, charities, and VCSE organisations wherever possible or applicable; existing resources like ASKLiON – Nottingham City Directory and Self-Help UK²¹ could be adopted to identify relevant groups and organisations.

²⁰ This recommendation also applies to the ICB, due to their responsibility for commissioning services that adequately serve Nottingham and Nottinghamshire citizens.

²¹ These resources can be found at the following links – [SelfHelpUK Directory](#), [NottsHelpYourself](#), and [ASKLiON](#).

7. Review the current crisis provision with the dual aim of improving services and increasing the public's awareness of crisis services.

Due to the mixed feedback we received regarding crisis services, it is essential that NHFT reviews the crisis provision across the City and County to identify what works, where there are issues, what those issues are, any solutions to remedy these, and any further training opportunities for staff.

It also became clear that the public's awareness of the current crisis provision is limited. NHFT should improve the public's awareness of their crisis provision (e.g., crisis sanctuaries), who is eligible, where services are located (if accessible in person) and how to access them. This should include clear communication for patients on who/where to contact (e.g., LMHT, Crisis Lines, Emergency Services) in different scenarios.

8. Ensure that any further service evaluations engage with a sample that is representative of service users and the local population.

There is a need to look at the demographic profile of service users and compare it with those who were participants in this review. For instance, we heard predominantly from White women so consider, is there any inherent bias which means that minority ethnic communities may not use the services you commission? Are there cultural barriers to receiving this help which need to be explored and overcome? Similarly, are there gender specific, age specific, or language barriers to understanding and/or accessing services? This gives rise to some consideration as to why certain communities or demographics may not engage with specialist mental health services. The Trust needs to review and mitigate this disparity for any future commissioning and service evaluations.

Acknowledgements

Thank you to everyone who has engaged with HWNN throughout this project. With notable thanks to Improving Lives Nottingham, The Bipolar Lift CIC, The Recovery College, and Turning Point Nottingham for promoting this project, linking us to your service users and allowing us to host focus groups and interviews. Thank you to all the other organisations and individuals not listed above who shared our survey, promoted the project, or helped us gather feedback.

We would also like to thank Notts Healthcare NHS Foundation Trust, especially Louise Randle (project lead) and her team for all the support and counsel throughout this project.

Most importantly thank you to the people who shared their feedback and experiences with us via our survey, focus groups, interviews, or case studies. Your voices should now help to inform and shape the mental health services provided across Nottingham and Nottinghamshire.

Appendix A – Demographics

Please note that the total for each question may vary as not every participant answered every demographic question, the percentages may not always total 100% due to rounding, and the number marked “(n =)” represents the sample size for each question. The “(n =)” figures remain the same throughout Appendix B – Demographic Graphs. ‘Not Known’ refers to unclear responses and the number of individuals who did not answer the question.

In which area do you live?

	Number	Percentage
Nottingham City	116	31.60%
Bassetlaw	50	13.62%
Ashfield	45	12.26%
Rushcliffe	40	10.9%
Broxtowe	32	8.72%
Gedling	31	8.45%
Newark & Sherwood	26	7.08%
Outside of Nottinghamshire	15	4.09%
Mansfield	11	3.00%
Not Known (i.e., Answer Unclear or Undisclosed)	1	0.27%

(n = 367)

Gender

	Number	Percentage
Woman	258	70.3%
Man	93	25.34%
Prefer Not To Say	6	1.63%
Prefer To Self-Describe	4	1.09%
Non-Binary	4	1.09%
Not Known (i.e., Answer Unclear Or Undisclosed)	2	0.54%

(n = 367)

Self-Descriptions

Trans masculine

Genderfluid

Is your gender identity the same as recorded at birth?

	Number	Percentage
Yes	341	92.92%
No	13	3.54%
Prefer Not To Say	8	2.18%
Not Known (i.e., Answer Unclear or Undisclosed)	5	1.36%

(n = 367)

Age

	Number	Percentage
<18	9	2.45%
18-24	35	9.54%
25-49	140	38.15%
50-64	93	25.34%
65-79	56	15.26%
80+	7	1.91%
Prefer Not To Say	4	1.09%
Not Known (i.e., Answer Unclear or Undisclosed)	23	6.27%

(n = 367)

If aged 16+, what is your sexual orientation?

	Number	Percentage
Heterosexual/Straight	224	61.04%
Not Known (i.e., Answer Unclear Or Undisclosed)	86	23.43%
Bisexual	16	4.36%
Prefer Not To Say	10	2.72%
Asexual	8	2.18%
Lesbian/Gay Woman	7	1.91%
Pansexual	6	1.63%
Gay Man	5	1.36%
Prefer To Self-Describe	5	1.36%

(n = 367)

Self-Descriptions

Queer/Unlabelled

Are you a carer?

	Number	Percentage
No	277	75.48%
Yes	70	19.07%
Not Known (i.e., Answer Unclear or Undisclosed)	20	5.45%

(n = 367)

Are you cared for by anyone? (paid or unpaid)

	Number	Percentage
No	295	80.38%
Yes	60	16.35%
Not Known (i.e., Answer Unclear or Undisclosed)	12	3.27%

(n = 367)

Do you work?

	Number	Percentage
Full time	113	30.79%
Part time	80	21.8%
Retired	70	19.07%
Unable to work	48	13.08%
Student	26	7.08%
Not Employed	26	7.08%
Prefer Not To Say	2	0.54%
Not Known (i.e., Answer Unclear or Undisclosed)	2	0.54%

(n = 367)

Which of these statements best describes you? (Please note Christian includes all Catholic, C of E, Methodist etc).

	Number	Percentage
Christian denominations) (all	138	37.6%
No Religion / Atheist	150	40.87%
Other	34	9.26%
Prefer Not To Say	19	5.18%
Muslim	10	2.72%
Buddhist	4	1.09%
Not Known (i.e., Answer Unclear or Undisclosed)	4	1.09%
Hindu	3	0.82%
Jewish	3	0.82%
Sikh	2	0.54%

(n = 367)

Examples of "Other"

Humanist	Pantheist	Spiritual Other	Muslim-
Agnostic	Pagan	Jehovah's	Christian
Jewish Secular	Eclectic	Witness	Christian &
Buddhist, Hindu &	Pagan		Jewish
Pagan	Pantheist	Spiritualist	
		Hellenic Pagan	

What is your ethnic group?

	Number	Percentage
White	302	82.29%
Mixed/Multiple Ethnic	21	5.72%
Black	10	2.72%
Not Known (i.e., Answer Unclear or Undisclosed)	10	2.72%
Prefer Not To Say	8	2.18%
Other	6	1.63%
Asian	5	1.36%
South Asian	3	0.82%
Arab	2	0.54%
Gypsy / Traveller	0	0.00%

(n = 367)

Examples of "Other"

White Latin American
 White South American
 Northern Europe

What is your main preferred language?

	Number	Percentage
English	351	95.64%
Not Known (i.e., Answer Unclear or Undisclosed)	9	2.45%
Other – Arabic	3	0.82%
Other – Spanish	1	0.27%
Other - Hungarian	1	0.27%
Other - Polish	1	0.27%
Other - German	1	0.27%

(n = 367)

How would you describe your nationality?

	Number	Percentage
British (inc. UK, White British, Black British)	282	76.84%
English	30	8.17%
Dual British (inc. Dual Brazilian & British, Britain & New Zealand, Mixed Asian & British, Italian and South African among others)	9	2.45%
Not Known (i.e., Answer Unclear or Undisclosed)	33	8.99%
German	3	0.82%
Indian	2	0.54%
Scottish	2	0.54%
Dual English (i.e., Indian English)	1	0.27%
Welsh	1	0.27%
European	1	0.27%
South African	1	0.27%
Hungarian	1	0.27%
Kuwaiti Bedouin	1	0.27%
Syrian	1	0.27%

(n = 367)

Are you pregnant or do you have any children under the age of 5?

	Number	Percentage
No	340	92.64%
Yes	18	4.90%
Not Known (i.e., Answer Unclear or Undisclosed)	7	1.91%
Prefer Not To Say	2	0.54%

(n = 367)

Would you be identified as any of the following?

	Number	Percentage
Asylum Seeker / Refugee	5	1.36%
Homeless	1	0.27%
Sex Worker	0	0.0%
None of the Above	361	98.37%

(n = 367)

Do you live with any of the following? (Please tick all that apply)

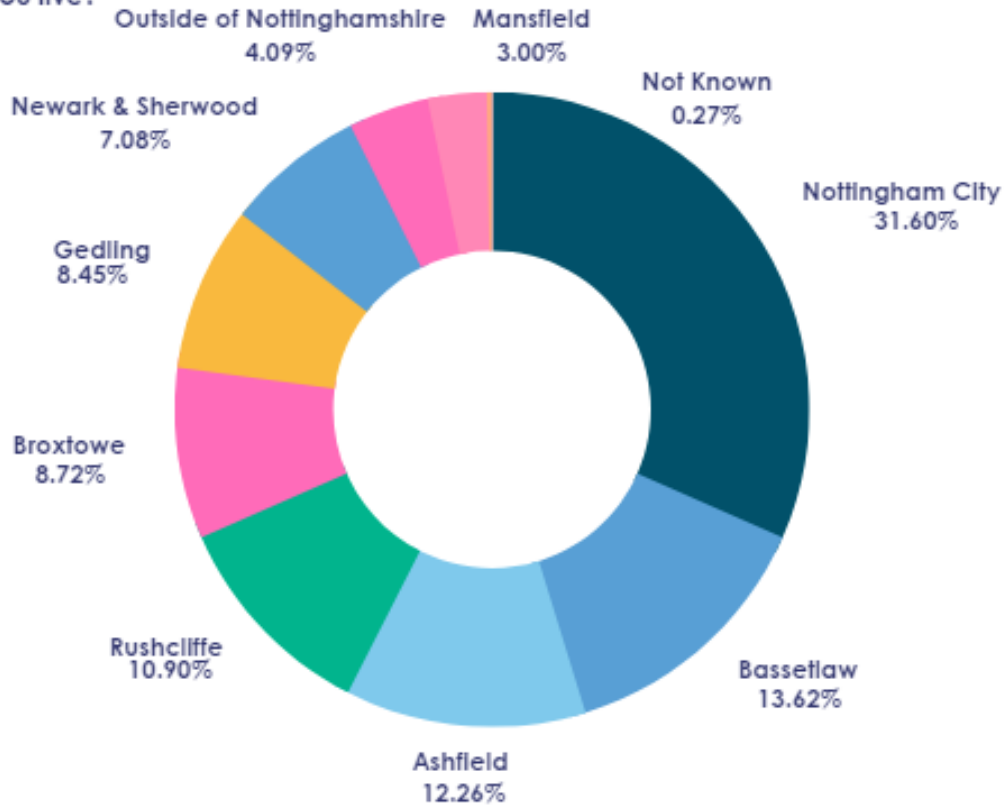
	Number	Percentage
Mental Health Concern	173	37.45%
A Long-Term Health Condition	139	30.09%
Physical Impairment	52	11.26%
Hearing Impairment	32	6.93%
Learning Disability	28	6.06%
Social/Behavioural Problems	24	5.19%
Visual Impairment	14	3.03%

(n = 352)

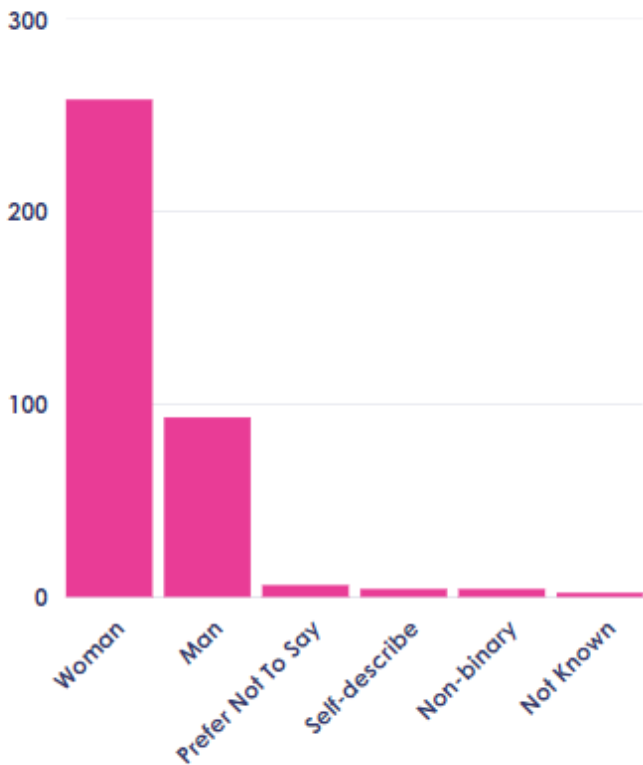
As a multiple-choice question, 352 people ticked 462 boxes, with 15 participants preferring not to answer. These 15 respondents have been excluded from the sample size stated above.

Appendix B – Demographic Graphs

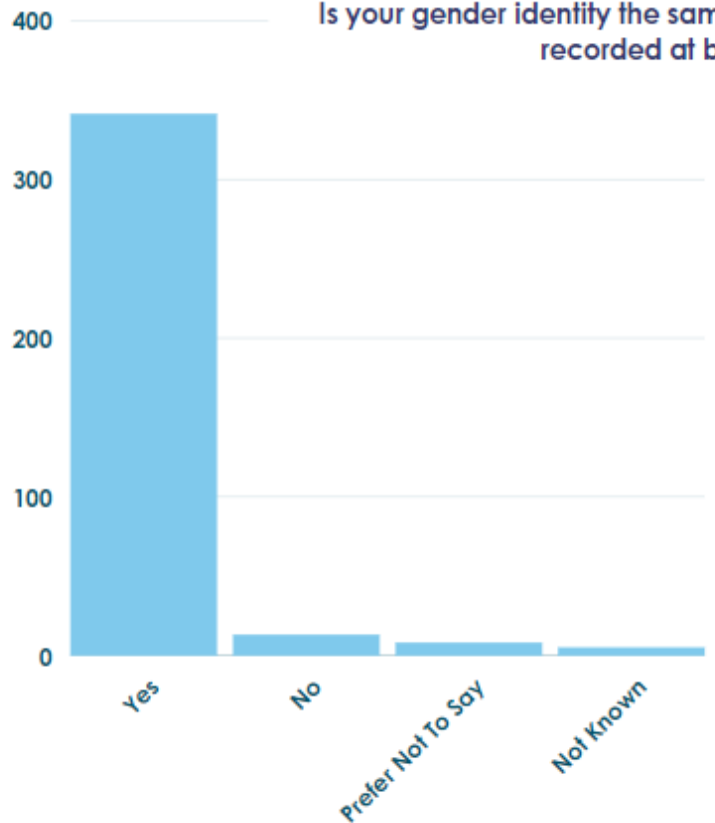
In which area do you live?

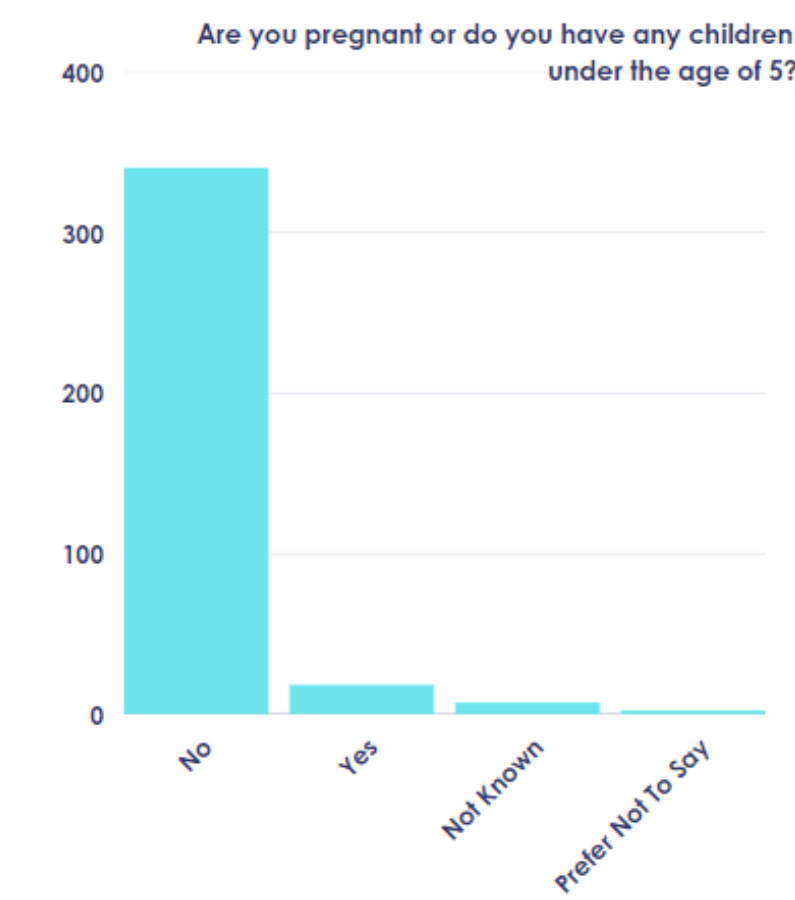
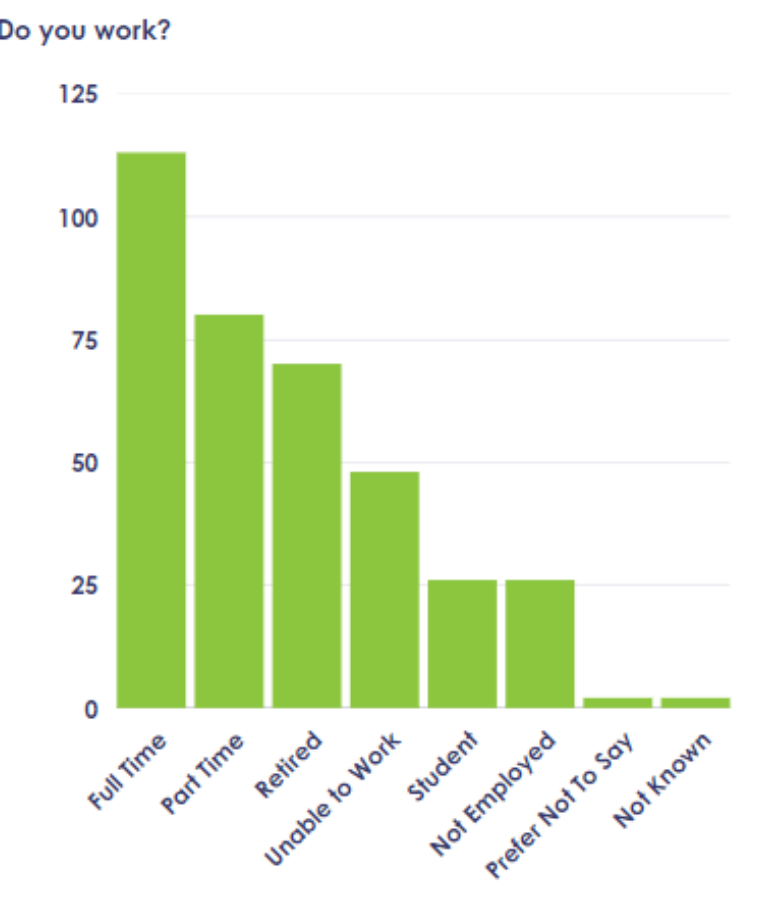
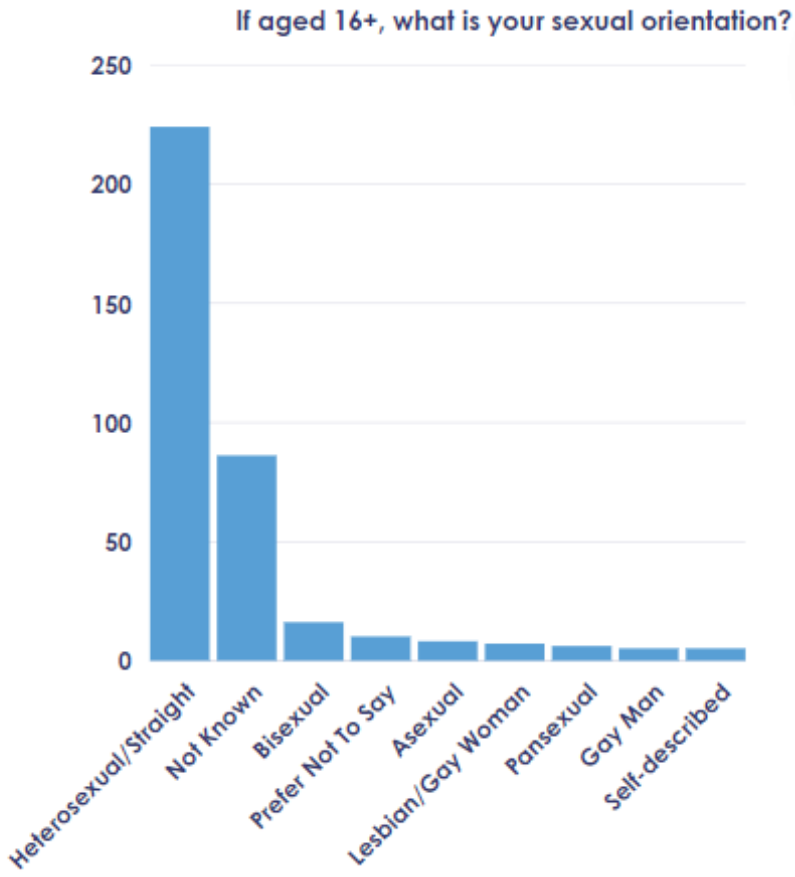
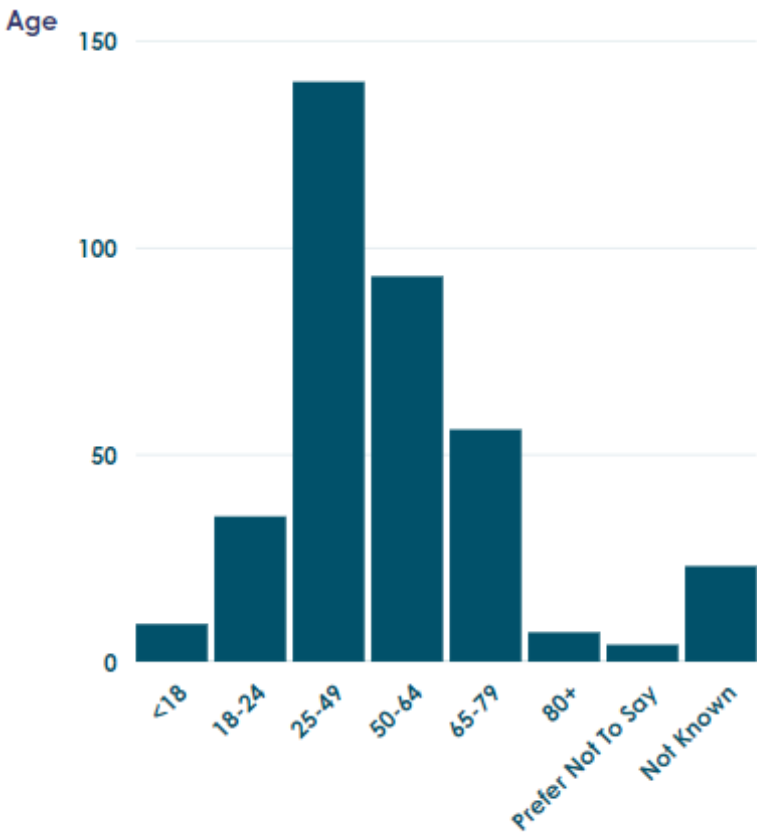


Gender

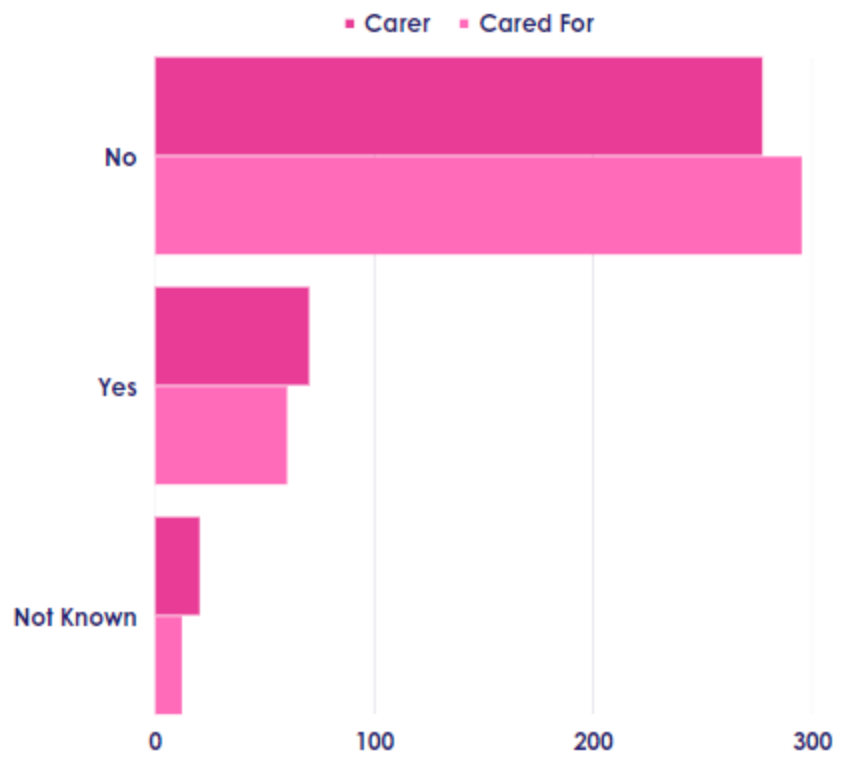


Is your gender identity the same as recorded at birth?



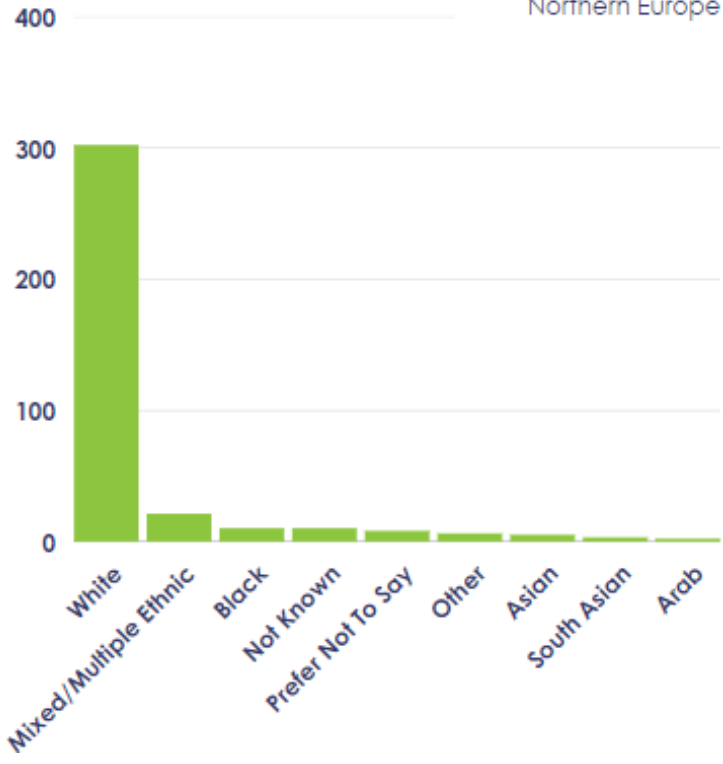


Are you a carer? Are you cared for by anyone?

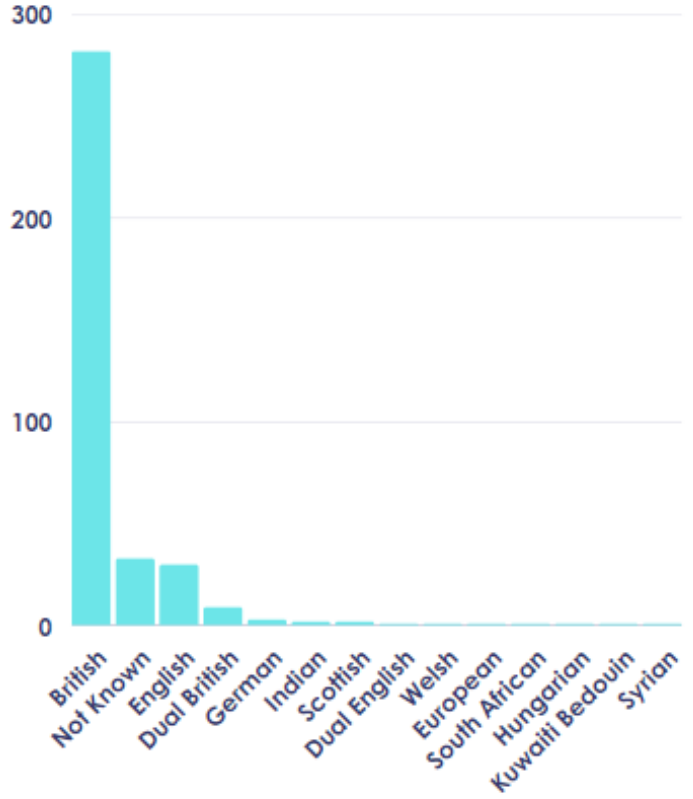


What is your ethnic group?

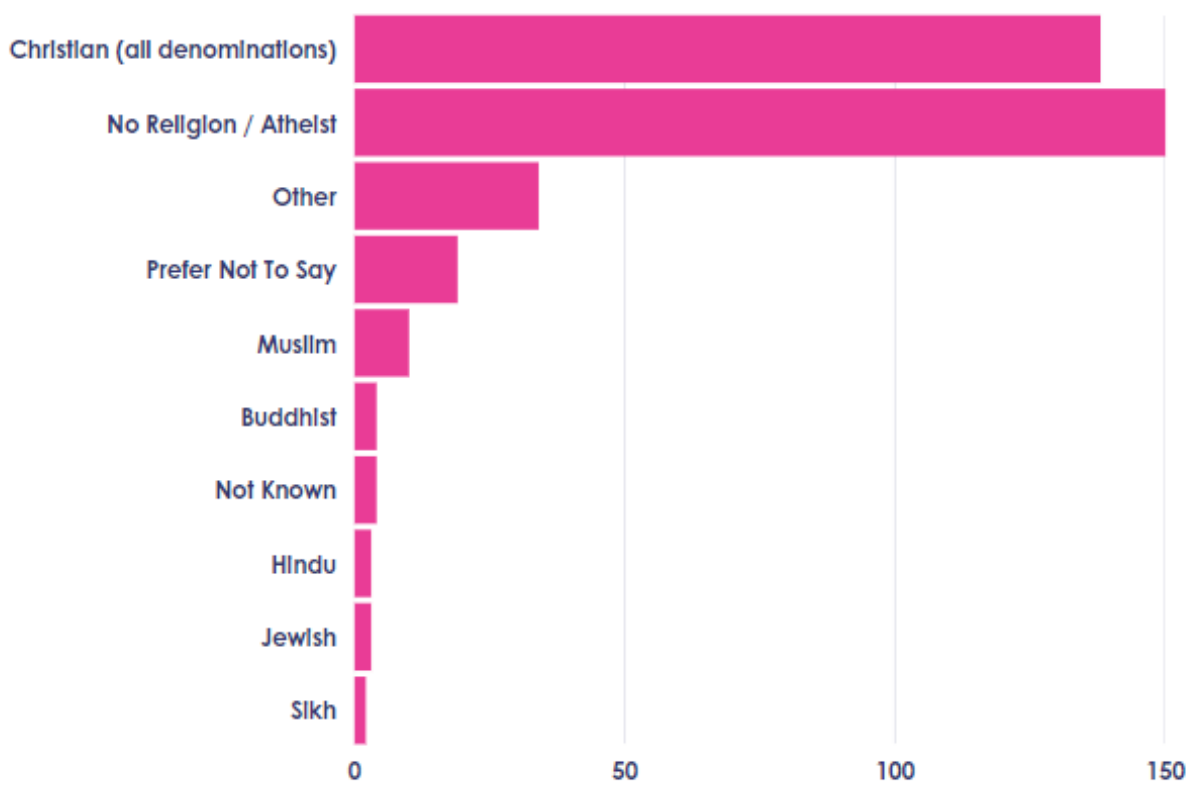
Examples of "Other"
 White Latin American
 White South American
 Northern Europe



How would you describe your nationality?

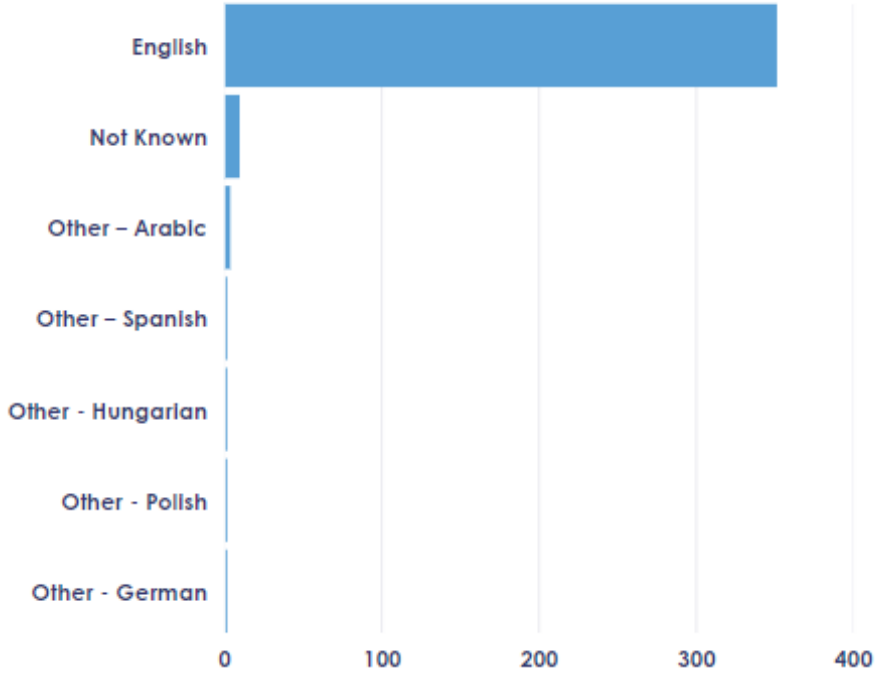


Which of these statements best describes you? (Please note Christian includes all Catholic, C of E, Methodist etc).

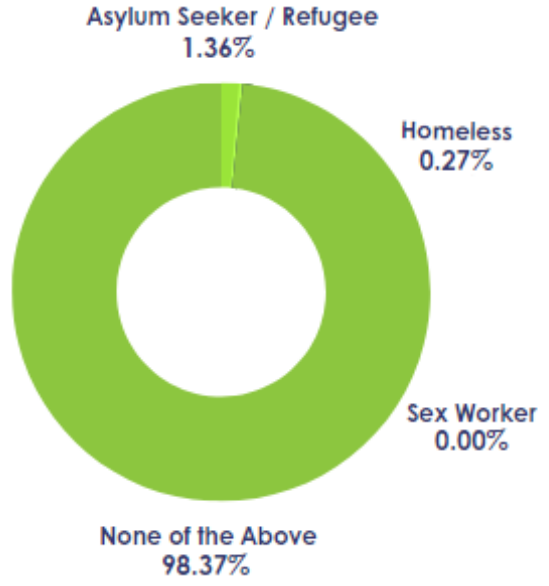


- Examples of "Other"**
- Humanist
 - Agnostic
 - Jewish Secular
 - Buddhist, Hindu & Pagan
 - Pantheist
 - Pagan
 - Eclectic Pagan
 - Pantheist
 - Spiritual Other
 - Jehovah's Witness
 - Muslim-Christian
 - Christian & Jewish
 - Spiritualist
 - Hellenic Pagan

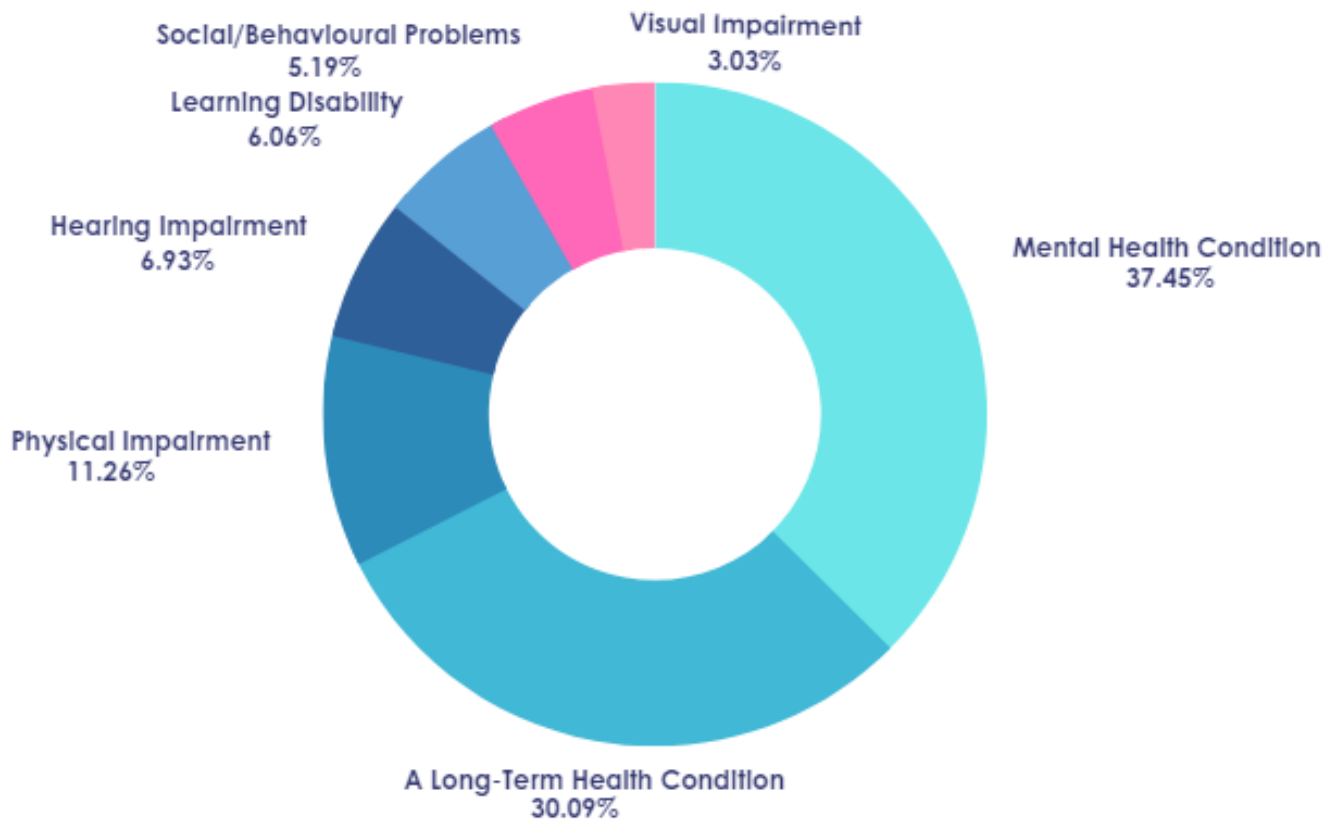
What is your main preferred language?



Would you be identified as any of the following?



Do you live with any of the following? (Please tick all that apply).



Appendix C – Case Study

18 Years Old and Sitting in Limbo between CAMHS & Adult Specialist Mental Illness Services

August 2023

'I started experiencing mental health problems, including anxiety and panic attacks, when I was around 12/13 years old. They were triggered by a traumatic year in my life, and to this day, I deal with the significant trauma that this caused. In the few years after, I spent a lot of time in and out of CAMHS therapy trying to cope with the trauma. Some of the counsellors were good and some of them weren't. One of them had no contact with me for about 6 weeks; she didn't tell me why, she didn't tell me whether she was going to come back, and I didn't know if I was going to get any other help. I was just left on my own to deal with my health, the trauma, intrusive memories, flashbacks and separation from my identity and experiences. I had no therapy or medication, so it was really difficult. I felt abandoned and betrayed and I went through crisis a couple of times.

Once I turned 16, I was able to get a referral to Community CAMHS, but after they referred me, I wasn't offered any support until I reached the top of the waiting list. When I finally accessed the community services, they were more professional and better suited to my needs, but they weren't able to offer as much support as I would have liked because there were only a few months left until I aged out of the system. I liked my most recent therapist; they were very good and helped me to prepare for the transition between Children's and Adult Mental Health Services because they knew how badly I'd been affected by my previous counsellors' periods of no contact, but as soon as I turned 18, they stopped because "they were not allowed to help anymore", so I was left without any support. As part of the transfer, I've been referred to, and self-referred myself to, CBT and Talking Therapy but they've all referred me onto somewhere else because I need more than they can offer. I've also been referred to the Long-Term Adult Mental Health Team, but I haven't heard from them for about six months, and I haven't received any support for nearly a year. I'm basically left without any support because I need more specialist support, and the services are unable to offer that.

Because of this lack of support my mental health declined to a point where I had to drop out of college for a year. Since going back, I've had to rely on my tutors in place of professionals to keep me afloat. They're supporting me to keep me in college because they know if they don't, I'll drop out again, so they are supporting me to prevent this.

I've been constantly trying to manage my own life whilst almost begging for help with it. I feel like I've done more of the work than the people who are actually paid to do it.'

Appendix D – Survey Questions

Q1: If you, a friend or a relative had a concern about mental health, what would you do? *(Please tick all that apply).*

- *Contact your GP/Nurse*
- *Speak to a friend/relative or partner*
- *Speak to a mental health professional/service*
- *Search the internet for information and advice*
- *Contact Voluntary Group*
- *Telephone NHS 111*
- *Use a smartphone application*
- *Visit Accident and Emergency*
- *Other **
- *Speak to a teacher*
- *Telephone ambulance service*
- *Speak to Social Services*

*Q2: If other, please tell us more.

Q3: Have you, or someone you know, accessed/tried to access specialist mental health services in the last two years in Nottingham or Nottinghamshire? *(NB: These are usually the services you are referred to after seeing a GP, Crisis Team, or Community Mental Health Professional).*

- *Yes, I/they successfully accessed services*
- *Yes, I/they tried to access services but were not successful*
- *No*

Q4: If you/they tried to access specialist mental health services but were not successful, please describe what happened? What difficulties / challenges did you encounter?

Q5: If you/they accessed specialist mental health services, please rate how easy it was to access the service?

- *Very easy*
- *Easy*
- *Not sure*
- *Difficult*
- *Very difficult*

Q6: Please tell us more about the rating you have given.

Q7: Did you/they get the support needed?

- *Yes*
- *No*

Q8: Please tell us more about the answer you have given.

Q9: How could specialist mental health services be improved?

Appendix E – Interview Questions

Q1: When did you first access specialist mental health services? (month and year).

Q2: What is the name of the service / place where you were receiving treatment or support?

Q3: How was the treatment or support provided? Was it face to face, by email, online, in group sessions, at drop ins, or in another way?

Q4: Can you tell me what happened from when you first decided to ask for support, up until when you received the support needed?

Q5: What difference, if any, did the support services make to you?

Q6: Can you please rate to what extent did you feel you were listened to? with the scale being '1. they didn't understand me at all' and '5. they understood everything / completely understood me.'

Q7: Can you please rate to what extent you understood what was being talked about? with the scale being '1. Did not understand anything' and '5. Understood everything.'

Q8: Can you please rate to what extent you felt involved in your care? with the scale being '1. Not involved and '5. Very involved.'

Q9: Note for the interviewer - Before asking Q11 - Q12, please explain to the participant that we are now going to ask them questions about a range of legally "protected characteristics" because we want to understand if people have experienced discrimination, or been treated differently, as a result of their protected characteristics. The nine protected characteristics are: disability, gender reassignment, age, religion or belief, pregnancy and maternity, race, sex, sexual orientation, and marriage and civil partnership. Please note which protected characteristic(s), if any, the participant notes. Note for the interviewer - By "discriminated against" we are referring to being treated differently or less favourably than others, as a result of your protected characteristic(s). If you have a protected characteristic, did you feel it was properly taken into consideration by the support service?

Q10: Did you feel you were discriminated against/treated differently because of your protected characteristic or characteristics? By "discriminated against" we are referring to being treated differently or less favourably than others, as a result of your protected characteristic(s). Note for the interviewer - this is an optional question to be asked if required (i.e., If the person has not shared information above).

Q11: If yes, in what way do you feel you were discriminated against? Note for the interviewer - this is an optional question to be asked if required (i.e., if the person has not shared information above).

Q12: How could your experience of the mental health services have been improved?

Q13: Is there anything else you would like to tell us about your experience of using mental health services?

Appendix F – Focus Group Questions

Q1: Who did you first contact when you had concerns about your mental health?

Q2: Is it easy or hard to access specialist mental health support services? Please tell us about your experience.

Q3: What is working well for you with the care and treatment you are receiving?

Q4: What difference, if any, did the support services make to you?

Q5: What is not working so well for you with the care and treatment you are receiving?

Q6: How could the support services be improved?

Q7: Is there anything else you would like to tell us about your experience of specialist mental health services?

References

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Response from Nottinghamshire Healthcare Foundation Trust

The report is welcomed by Nottinghamshire Healthcare Foundation Trust and will be shared broadly across the Mental Health Services Care Group. The recommendations from the Healthwatch *Specialist Mental Health Services* report will be considered by clinical and operational colleagues collaboratively with other organisations across the care system who deliver mental health and well-being services. The report's recognition of the requirements to individualise care to achieve best patient outcomes is noted and appreciated. The alignment and integration of suggested actions to pre-existing transformation plans and intentions, will be critical to their implementation.

1. Ensure that Primary Care Practitioners are well-equipped to recognise serious mental illness and know where and how to refer patients to appropriate services.

Nottinghamshire Healthcare Foundation Trust (NHFT) are committed to the delivery of secondary care services and clinical expertise closer to home. In practice, this means the development of real working relationships between primary care and secondary care at both a place and neighbourhood (or PCN) level so that local people receive the care they need, when they need it.

We refer to these teams as integrated neighbourhood (or place-based) teams who work together on a daily basis to understand and meet the presenting needs of local people. The System's Mental Health Partnership Board will be critical to providing the collective leadership in order for these teams to become a service provision reality for patients. NHFT are committed to deliver this way of working which includes practical support, access to local mental health clinical experts and training for integrated mental health teams.

2. Streamline referral process and ensure that services are accessible to all.

NHFT are committed to continually improving our access to services for patients and referring professionals. Critical success factors and priorities include a user-friendly digital referral system, access to timely local multi-disciplinary conversations for the most complex patients, access to support during periods of waiting and dynamic capacity and demand management to ensure clinical resource is well managed.

We are also aware that the term "mental service services" can mean many different things to different people and that sometimes a patient's needs can

be best met by a partner organisation or by a member of NHFT working with another professional. As part of the community mental health transformation programme we are introducing a telephone triage system which means that every patient referred into local services will have the opportunity to speak to a mental health professional to discuss their needs at their first point of contact. We will talk to patients regularly to ensure that their experience meets these expectations.

3. Implement centralised, co-produced, 'person-centred passports' to support consistency in care and ensure all service users receive holistic, person-centred support.

Collaborative clinical accountability for a patient's care of the place-based teams is part of NHFT's strategy to improve continuity of care for patients which is evidenced to deliver better outcomes for patients. NHFT recognised the importance of helping patients to tell their story once and well and will work with partners to investigate different ways of doing this safely.

4. Invest in more services to holistically support service users, such as those offered by The Recovery College and Voluntary, Community, and Social Enterprise (VCSE) organisations.

NHFT are committed to working with local partner mental health, well-being and support service organisations to ensure patients experience an individualised and complete mental health offer. The offer needs to be different for different communities to respond to changing needs, and local organisations offer a unique opportunity to understand and care for local people more effectively.

VCSE organisations are critical partners to the delivery of services as well as ensuring that local people are understood. It is so important that partnerships between clinical health services and VCSE organisations at a place and neighbourhood level are nurtured to release the potential benefits for patients. It is equally important that such organisations are also a critical part of the strategic partnership arrangements.

5. Ensure that service users are given information regarding their condition(s), particularly following their initial formal diagnosis.

NHFT are committed to transparent and honest communication with its patients and their families. People have varying preferences for how this works best for them but it is recognised that a consistent suite of information

for diagnoses would be of benefit to those patients who are unwell. The specific recommendations and references are noted and gratefully received.

In addition, a useful piece of work for system partners would be to work with patients to think about how best to describe a non-medical condition that whilst not requiring a clinical diagnosis, still requires needs to be understood, explained and met by a service within the system partnership.