Waiting for Wellness

An investigation into people’s experiences and the accessibility of mental health services in Lancashire

healthwatch
Lancashire

Contents

Abbreviations

GP	General Practitioner
CBT	Cognitive Behavioural Therapy
CAMHS	Child and Adolescent Mental Health Services
ASD	Autism Spectrum Disorder
NSPCC	National Society for the Prevention of Cruelty to Children
MHA	Mental Health Act
HTT	Home Treatment Team
LSCFT	Lancashire and South Cumbria Foundation Trust
IRS	Initial Response Service
AMHP	Approved Mental Health Professional
LCC	Lancashire County Council
PICU	Psychiatric Intensive Care Unit

Executive Summary

The aim of this project was to explore the experiences of people who are receiving or on a waiting list to receive mental health support. Questions explored how long people had to wait to receive support, any barriers they had experienced and what support they would consider in the future. The project also gathered feedback from people who had not accessed mental health support to explore their reason for this, whether they would know where to go for support and what support they would consider in the future if required.

156 respondents

Feedback gathered from 156 people revealed key themes. Support received included GP support, secondary NHS care including Talking Therapies and support from third sector/charitable organisations. Satisfaction rates for NHS care were mixed ranging from very satisfied to very dissatisfied. In contrast, the majority of respondents who received third sector/charitable support were satisfied.

Feedback revealed that the main barrier to accessing NHS mental health support was the long waiting lists, leaving people feeling let down and unsure when they would receive support. Despite waiting lists being lengthy, more than half of respondents were not signposted to additional support whilst on a waiting list. Respondents did not know what mental health support was available to them locally.

Third sector/charitable organisations received a substantial amount of positive feedback; mainly regarding respondents having an opportunity to socialise with other people, being able to talk about their experiences, taking part in activities and receiving advice.

It was also found that female respondents were more likely to access NHS support, whereas males were more likely to access third sector/charitable organisations. Despite these differences, the most preferred form of support was support groups and face to face support for all genders. From our data, it showed that males aged between 55-64 and females aged between 25-34 were the most prevalent in accessing mental health support. It was also revealed that of those that shared that they do not have a support network (friends and/or family), 78% shared that their mental health had got worse over the past 12 months.

Feedback from 7 respondents highlighted a lack of appropriate support for those with a dual diagnosis of mental health and autism. Challenges included professional staff not acknowledging an autism diagnosis, as well as people not accessing support because the service did not meet their needs and/or not being able to afford the cost/contribution for the service.

For those who had not accessed mental health support, 46% shared that they would not know where to go for support if they needed it in the future. A further 18% shared that they do not feel able to ask for support.

These findings indicate a need for better education, advertisement and signposting of local mental health support.

The most common form of support respondents (those who had received support and those who had not) would consider in the future was support groups and face to face support.

These findings have demonstrated areas of good practice as well as areas for improvement and consideration. This has helped to inform a series of recommendations.

Introduction

About Healthwatch Lancashire

Healthwatch was established in April 2013 as part of the implementation of the Health and Social Care Act 2012. Healthwatch uses people's feedback to better understand the challenges facing the NHS and other care providers and we make sure people's experiences improve health and care for everyone – locally and nationally. We can also help people receive information and advice they need to make the right decisions for them and to get the support they deserve.

Introduction

Healthwatch Lancashire heard an increased amount of feedback, including Mark's story (see Appendix 1) about mental health during 2022/23. Particularly, the long waiting lists people are experiencing when accessing mental health support.

It was important that this feedback was considered and in response, a project was designed and conducted to explore people's experiences of mental health in Lancashire. There was a particular focus on the waiting times of those accessing mental health support and whether people were aware of other support in the community whilst on a waiting list.

Another aim of the project was to gather feedback from people who have not accessed support for their mental health; to investigate their reasons for this and whether they would know how to access support should they need it in the future.

Analysis of feedback has informed recommendations for the attention of the NHS and other relevant stakeholders. The aim is for mental health support to become more readily available for Lancashire residents as well as improving local knowledge about what mental health support is on offer.

Acknowledgements

Healthwatch Lancashire would like to thank all the people who took part in this project by sharing their views and experiences.

Methodology

Engagement ran from 3 April 2023 to 30 July 2023. Qualitative and quantitative data was captured through an online survey and case studies. Feedback was received from 156 people; 146 completed the online survey, 8 took part in a focus group and 9 shared their experiences in detail through a case study (7 people completed the survey and a follow-up case study).

In addition to the feedback received from members of the public before the project start date, a full literature review was completed to inform the engagement plan and survey questions. The review revealed that many people are having to wait longer than 12 weeks for mental health support and many are resorting to emergency services or a crisis line to receive mental health support[1].

To ensure a wide range of demographics and communities were included in the research, engagement was conducted through pop-up events in town centres, as well as targeted engagement through community groups such as employability groups, mental health support groups and carers groups. This also ensured that those considered seldom heard were also included in the project. During engagement, Healthwatch Lancashire staff completed the survey with respondents and inputted this onto the online platform. Staff also had signposting information to mental health support on hand to provide to anyone who requested it.

Case studies were collected and to protect confidentiality and anonymity, all names have been changed and identifiable information has been removed.

The survey explored the views and experiences of both those who have accessed mental health support in the past 12 months, as well as those who have not. The aim of the research was to explore the experiences of those receiving mental health support in Lancashire, how long they had to wait for support, any barriers they experienced and what support they would consider if available to them. For those who had not received support, respondents were

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[1] Royal College of Psychiatrists. (2022), *Hidden waits force more than three quarters of mental health patients to seek help from emergency services*. Available at https://shorturl.at/pvAKP > (Accessed: 17/07/2023)

asked their reasoning for this, whether they would know where to go for support and what support they would consider in the future if they felt they needed it.

Disclaimer: some quotes and case studies refer to the term ‘Mindsmatter’. During the time period of this project, Lancashire and South Cumbria Foundation Trust (LSCFT) changed the name of Mindsmatter to ‘Talking Therapies’ as part of a national rebranding exercise. In this report, when respondents use the term Mindsmatter, this is the same as the Talking Therapies service.

Demographics

Age	**Number of respondents**
0-15	3
16-17	11
18-24	12
25-34	20
35-44	23
45-54	20
55-64	22
65-74	15
75+	3

Gender

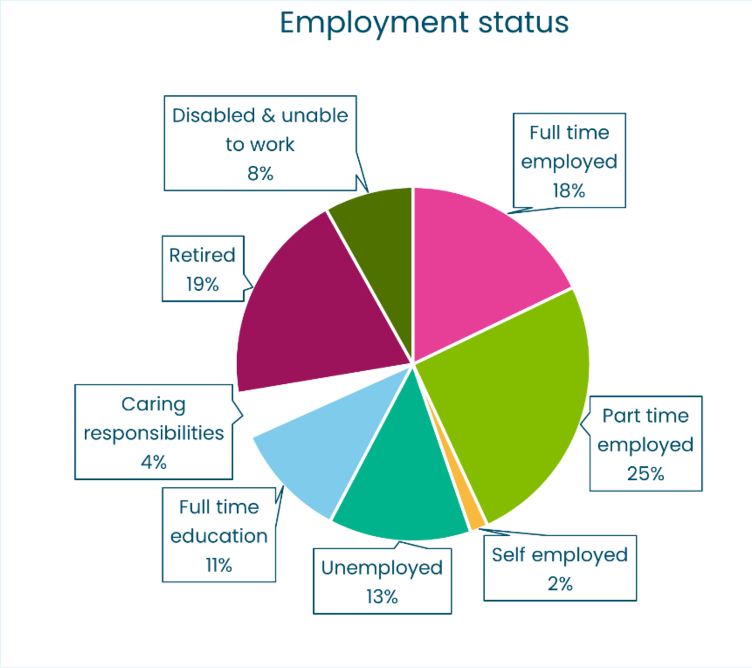
48 male

76 female

1 non-binary

1 self-described as genderfluid

Ethnicity	**Number of respondents**
White	
British	95
Irish	7
Other	6
Asian or Asian British	
Pakistani	9
Bangladeshi	3
Indian	2
Other	1
Black or Black British	
Caribbean	1
Other	1
Mixed/Multiple	
White and Asian	3



Demographics cont.

19% (23) shared that they do not have a support network (friends and/or family). Of this, **78%** shared that their mental health had got worse over the past 12 months. **61%** had accessed mental health support.

10% (13) were neurodivergent. Of this, **46%** shared that their mental health had got worse over the past 12 months. **69%** had accessed mental health support.

10% (13) of respondents were part of the LGBTQIA+ community. Of this, **62%** shared that their mental health had got worse over the past 12 months. **54%** had accessed mental health support.

30% (37) of respondents had a disability. Of this, **66%** shared that their mental health had got worse over the past 12 months. **60%** had accessed mental health support.

27% (34) of respondents had a long-term condition. Of this, **62%** shared that their mental health had got worse over the past 12 months. **62%** had accessed mental health support.

15% (18) of respondents had caring responsibilities. Of this, **67%** shared that their mental health had got worse over the past 12 months. **61%** had accessed mental health support.

Findings

Responses have been analysed by those who have received mental health support in the last 12 months and those who have not. Demographics have also been analysed to identify whether there any themes within specific demographic groups.

Those who have accessed mental health support.

47% (70) of respondents shared that they had accessed mental health support in the past 12 months. 72.5% of these respondents shared that their mental health had got worse in the last 12 months. Support accessed from respondents included NHS, private and third sector support. Barriers and successes have been analysed as well as what form of support respondents would consider accessing in the future.

Have you been diagnosed with a mental health condition in the last 12 months?
51% (36) Yes
37% (26) No
11% (8) Prefer not to say

Support accessed

GP

The most common type of support received from respondents was support from a GP, with 19 (27%) respondents receiving GP support for their mental health. 47% of respondents who received mental health support from their GP had been diagnosed with a mental health condition in the last 12 months. 52% of respondents received this support through a phone call.

> *"I get a lot from walking groups but not a lot from my GP".*
>
> *"They declined me for any further support all they can offer me is another round of CBT or medication which won't work".*
>
> *"The GP are terrible with signposting to agencies. I took the first initial step for help and support, and I was told there was nothing they could do. I don't want to go back home and search support when it's their job to help me".*

For 10/19 respondents, their GP was the only form of mental health support they had received (other respondents had received other support in conjunction with support from their GP). Of those respondents who had only received support from their GP, 50% of respondents had been diagnosed with a mental health condition in the past 12 months, with 50% not receiving a diagnosis.

Satisfaction ranged from very satisfied to very dissatisfied. Feedback was mixed ranging from the GP being "very helpful" to the GP making respondents feel "dismissed and not listened to properly". 4/9 respondents were still on a waiting list for support from their GP at the time they completed the online survey. All respondents who answered the question (7) shared that they had not been signposted to any additional support whilst waiting for support from their GP.

> "It took two years to get a diagnosis and I was up and down with symptoms".

Female aged 17

> "I was really struggling as I had been in a bad relationship and it became hard for me to cope. I looked up support services in my area, but it was very confusing. My mum ended up taking me to the doctors, the doctor was not great with me and it was very hard to communicate what I needed from him. I felt he didn't know much about mental health and didn't really listen to me. The doctor eventually gave me a leaflet for Mindsmatter and put the referral in for me as I was confused what to do."

Support from third sector/charitable organisations

Closely, 16 (23%) people shared that they had received support from third sector and/or charitable organisations including victim support, group therapy and local walking groups. The way in which this support was delivered varied much more than GP support with most people receiving support either through phone call, face to face group support, and face to face support at a centre. Online video calls, online chats, texting services and face to face at home support was also mentioned.

81%

were satisfied.

80% of respondents receiving this support, had self-referred. Feedback received from respondents was mainly positive with 81% of respondents sharing that they were satisfied or very satisfied with the service. Only 1 respondent shared that they were dissatisfied with the service; they did not provide any further comment but they did share that they had been on the waiting list for 7-9 months.

Positive comments were received about the advice provided by third sector organisations as well as signposting to further support.

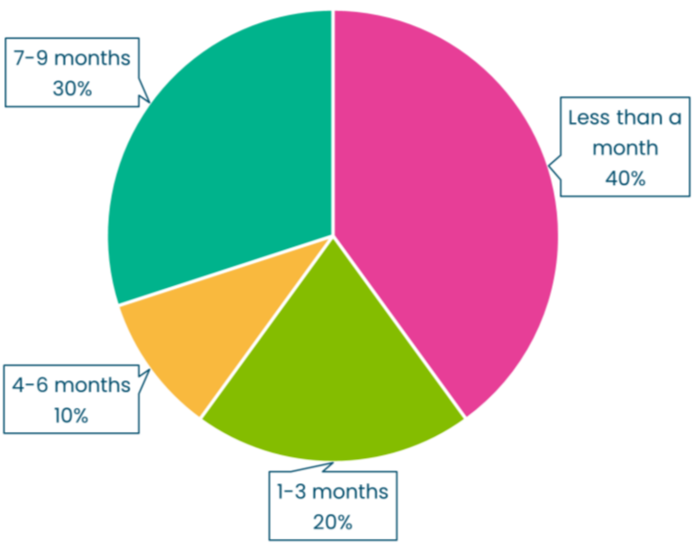
"If it wasn't for the [employability] group and my volunteering I wouldn't leave the house some days".

"I have been signposted to lots of different groups in the area by people who attend the groups and by the people who run them"

Waiting times for third sector/charitable support was varied, ranging from less than a month to up to 9 months.

"They helped me find myself again".

How quickly did you receive an assessment or gain support?



Below shows some of the support received by respondents

Gardening clubs
Employability group
Heartbeat group
Walking groups
Lancashire women
PUKAR centre
Domestic abuse support
Peer talking groups

Overall, support received from third sector/charitable organisations was mainly positive due to the chance to socialise, the quality of support received and signposting to other services. In comparison to support received by GPs, feedback about third sector/charitable support was more positive.

> *Trust House was amazing and helped a lot. [They] recommended seeing a doctor about medication and [they] talked through my experiences with me. Mindsmatter would not diagnose me with a mental health condition and [they] terminated my counselling during my time with them”.*

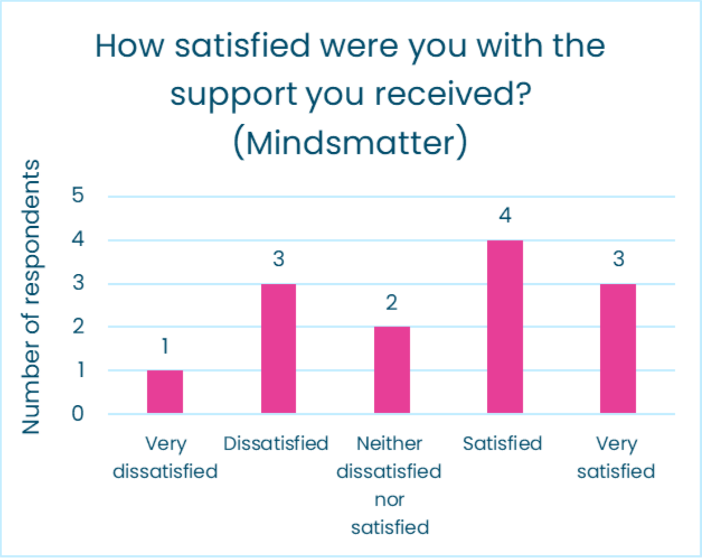
NHS secondary care support

Of those who had received mental health support, 33% (23) of respondents shared that they had received secondary care NHS support.

Talking Therapies

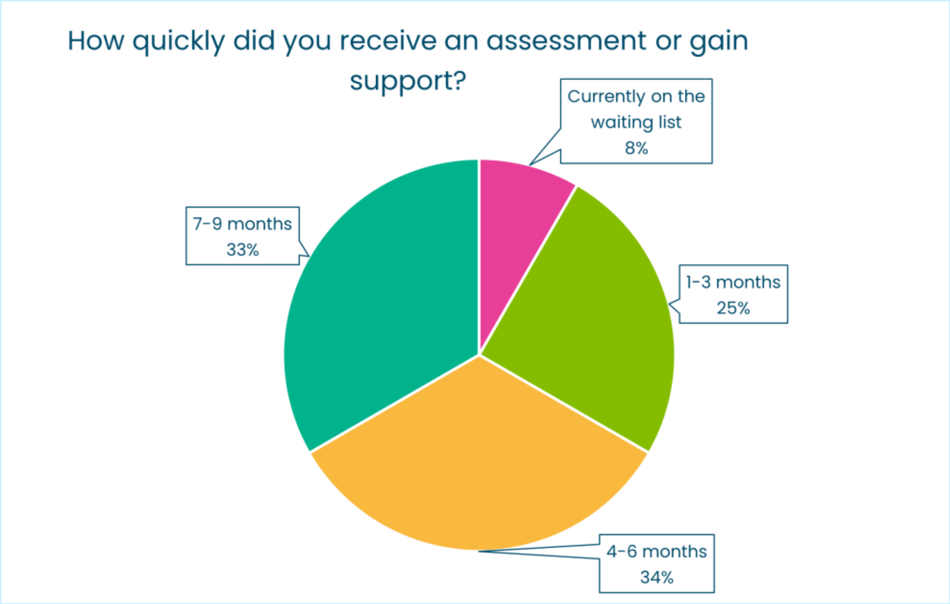
Talking Therapies, an NHS service provided by Lancashire and South Cumbria NHS Foundation Trust, was the most commonly mentioned NHS secondary support service, mentioned by 13 (19%) people.

Of these 13 people, 6 had been diagnosed with a mental health condition, 6 had not and 1 chose not to answer. Only 2/13 people shared that their mental health had got better over the past 12 months, with the remaining 11 sharing that it had got worse. 92% of



respondents accessing Talking Therapies had received this service through a phone call, with 62% self-referring to the service.

> *"I was on the waiting list for Mindsmatter, and I was told there was a 7-9 month wait for this service. I rang them and they told me I had been taken off the wait list as they didn't know I still needed support. I went back to my GP and they just told me I had to wait again. You are supposed to 'nip it in the bud' but you do and [there is] still no support."*



Feedback about Talking Therapies was mixed. No respondents had received support from Talking Therapies in less than a month, however, no one had been waiting longer than 9 months.

Female aged 70 years

"My problems go back 55 years. I am currently having CBT; it is helping and it was only a short time I had to wait.

I was told by the person who did the initial assessment of me on the phone that I could benefit from a therapy that involved eye movement as I am sure my problems are related to my childhood. But this has still not been offered to me.

It is annoying to be told by the team that it will be helpful but then to find out it is not available in my area. I am receiving CBT but it is only scratching the surface. I am still left with my problems with no way to treat them and get sorted out once and for all.

My CBT therapist is already discussing the end of my sessions and I am worried what is going to happen when my sessions end.

I have an eating disorder, I am an alcoholic and I have had mental health problems for around 55 years. Why can't I access the treatment that might help. I am still left with feelings of suicide and low self-worth with seemingly no end to them."

Rachel’s story

Rachel, who is currently at college, shared her experience of dealing with poor mental health from a young age, due to various safeguarding concerns. Rachel received support from her school and Childline but felt let down by the Safeguarding Team, Child and Adolescent Mental Health Services (CAMHS), Social Services and Police. Her story describes referrals to CAMHS in high school where she was then discharged, leaving Rachel feeling like she did not receive appropriate support. It wasn’t until Rachel started college, that she was able to seek support from a counsellor who supported her to self-refer to CAMHS. Rachel is now waiting to receive support from CAMHS but is apprehensive due to approaching the age of 18 shortly and she is unsure about what support she will be able to access in the future.

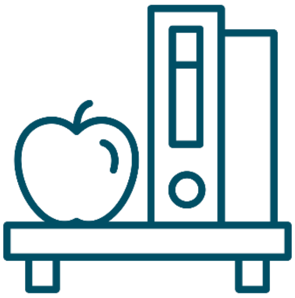
Below is an extract of Rachel’s story:

> “My behaviour got worse and my mental health got worse. I was misbehaving in school and had the mindset of...no one is listening to me...I’m never going to do well in school, no one even cares about me...I had bad anxiety...I skipped classes and I got myself into trouble a lot”

Rachel was eventually referred to CAMHS.

> “I got put with CAMHS...I told them most things and they tried to refer me to the higher part of CAMHS but due to be being in year 11, they were also going to refer me to CBT. But they said its pointless starting CBT when you’re leaving school now, and you’ve got your GCSE’s. I didn’t get put through the higher part of CAMHS because I struggle to communicate, my favourite teacher used to sit with me in most sessions, because I physically couldn’t verbalise. She was basically my advocate. Because I struggled to communicate how I was feeling and I’d literally become mute, they said that I need to talk...my parents had to know [but] they don’t believe in mental health, and are so against me trying to receive help for my mental health...CAMHS wrote me off, and I got left again.”

> “I felt helpless... like I cant be helped and that everyone will just give up on me. “My mental health deteriorated really badly, it was the worst it had ever been. I stopped telling anyone what was going on in my life”



Rachel has shared that her new college *“have been so supportive”* but that her college only offers *“six weeks of counselling...after the summer holidays I have to get put back on the waiting list”.*

> “I have been speaking to Childline so much especially recently because I feel like I have no one else to talk to, or someone who will actually listen to me. I was speaking to them for probably a month...but every single day”

Rachel has now completed a CAMHS self-referral and added:

> “I am currently waiting on them, but I am quite literally against a clock because I’ll be 18 next year”.

Other support

10 respondents mentioned other support received from the NHS. 4 of these respondents shared that they had accessed the 'crisis line'/emergency mental health support. Three out of four respondents who accessed the crisis line were not signposted to additional support. Poor feedback was received about the crisis line:

> *"No, they were not helpful and told me they would ring me back and they didn't. I had to ring them back and they were very rude with me."*
>
> *"I did not receive any support from this service they treated me horrendously. They did not support me at all and left me to support myself due to being a recovering alcoholic."*

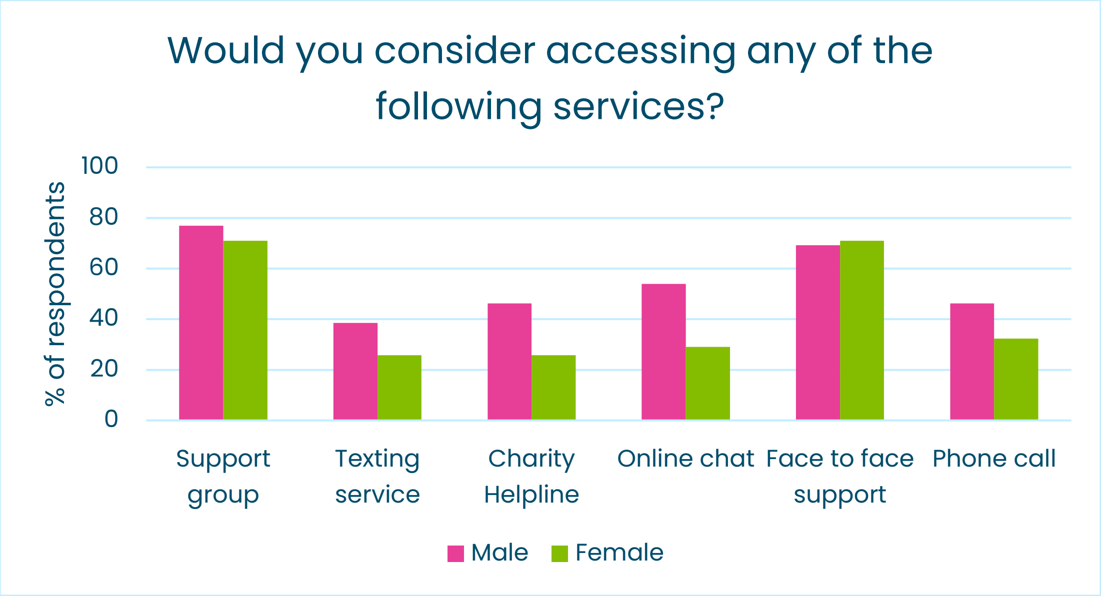
Demographic analysis

Gender

Of those who accessed mental health support, 56% were female and 30% were male. 1 respondent was non-binary and 1 self-described their gender as genderfluid.

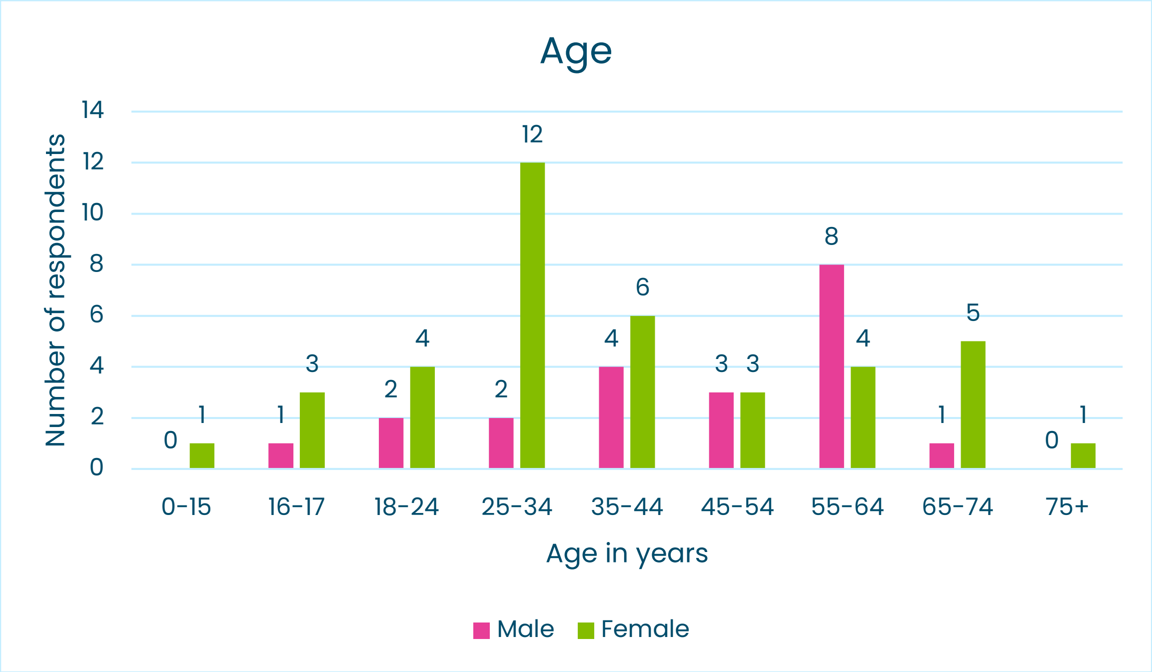
According to our findings, female respondents who accessed mental health support were more likely to access NHS support (62%) than charity and/or community support (26%). However, males were more likely to access charity and/or community support (52%) than NHS support (43%).

Respondents were asked what form of mental health support they would consider. Below displays the findings and differences between genders. Support groups and face to face support were the most preferred forms of support for both genders. However, texting services, charity helplines, online chats and phone calls were preferred more by males than females.



Age

Of those who had accessed mental health support, the range of ages were different between males and females. Males between 55-64 and females between 25-34 were the most prevalent in accessing mental health support.



“I’ve received multiple [forms of mental health support]. The college teacher is good [but] the doctors were bad. They told me to hold a crystal and my issues would be solved “

“Every mental health service I have accessed, has let me and people I know down. Resulting into a worse decline in mental health and people less likely to open up and talk”

Youth Zone focus group

A focus group was held at a Youth Zone with 8 participants aged between 14 and 18. Mental health was discussed and the lack of support and awareness for mental health was the main issue raised.

Young people shared that waiting times for mental health support are long. Often, young people reach 18 and they're too old for their initial referral to the CAMHS team and then have to start again at the end of another waiting list for Adult mental health services. Members of the group shared that during this time, young people are not given access to any alternative services to help during their waiting time; they feel that they were just *"left to it".*

Concerns were raised about the lack of mental health support in schools, and around the confidentiality and boundaries around the support that there currently is. Some young people wanted the ability to discuss issues without it being relayed to their parents and they didn't know of anywhere they could do that.

A few young people said that some interventions from CAMHS had made their situation worse and felt that they were not listened to about this. There was also some concern about a lack of awareness by GPs around mental health issues in young people and how to support them. They felt that young people today are experiencing a number of mental health issues that have previously not been as common, and that training of General Practitioners has not kept up with those changes and how to best engage with those young people.

Autism

Feedback from 7 respondents who identified as neurodivergent (with some providing further detail of an autism diagnosis) left feedback about the mental health service not meeting their needs, with comments suggesting that professionals do not take their autism diagnosis into account when providing mental health support. Feedback has highlighted a lack of appropriate care for those with a dual diagnosis of mental health and autism.

Of those who had not received mental health support, 2 respondents shared that the service did not meet their needs and a further 2 shared that they could not afford the cost/contribution to the cost of the service.

> “I got support but not to the level I would have hoped and [I] sometimes felt dismissed and not listened to properly”

> “I waited 4 years for an autism diagnosis. It was awful and I can’t ever get help for what I need”

Mike’s story

My child Mike suffers from autism and has only recently been given a dual diagnosis that explains some of the issues that he is suffering. He lives with autism and suffers from multiple personality disorder and paranoia.

The main problems that we face are that we are going in circles with referrals, discharges and re-referrals when we see that his behaviour and actions place himself and others in danger. The support we get is very reactive and only comes into play when things are at their worst.

I feel that there is no continuity of care for people struggling with their mental health. There is no connection between social care and mental health and the two-go hand in hand. Mike has been sectioned several times and twice highlighted as needing a specialist unit due to a lack of continuity and failings of [facility A] who on both occasions of him being there, changed agreed treatment plans. He has not received the help that he requires.

> He recently spent a year under Section 3 awaiting a specialist place but set plans were changed by [facility A] so special funding has been wasted along with other resources and a year of Mike’s life. He struggles every day and remains both vulnerable and a risk.

(See Appendix 2 for full case study)

Themes

Waiting times

Analysis revealed that the main barrier to accessing NHS mental health support was long waiting lists. This left many respondents feeling let down and unsure of when they would receive mental health support.

Male aged 40-50

"The Mindsmatter process started. It must have been three months before I got a triage appointment. I shared that I did not want CBT so I got put on talking therapies which was a slightly longer waiting list. I was told it would be around six months as I was not a priority. I understood this as it was a precious resource and people needed it.

Months and months went by and I was left on my own and I was thinking "its going to come." Mindsmatter then sent me a letter asking me if I wanted to stay on their waiting list. It was really impersonal and I felt so insulted because I had been waiting for months. I then got another letter saying that I had been discharged."

(See Appendix 3 for full case study)

"I was left for thirteen months with no support because of the failings from different organisations regarding my mental health and ASD diagnosis"

Alex’s story

The below story is told from a mother about her son, Alex, who has a diagnosis of bipolar disorder and has been sectioned three times within the last 8 months.

Alex moved from Manchester to Lancashire to be with his parents as his mental health was deteriorating and he was struggling to receive the appropriate level of mental health support. Alex showed violent and challenging behaviour, often involving the police, due to his mental health and wanted to go into hospital for treatment but was repeatedly told that there were no beds.

Alex was repeatedly turned away from mental health services and his parents were told to contact the police and vice versa; leaving them desperate for support.

> “It was beyond cruel to witness someone with a known health condition and under the care of NHS mental health services, deteriorate so badly and be denied access to appropriate treatment, when he had requested support.”

After being turned away by multiple services, Alex finally received a mental health assessment. Hospitalisation was recommended but there were still no beds available and so his parents continued to care for him.

> “Throughout the week Alex requested access to hospital – he said he didn’t mind going to a police cell he just wanted to feel safe.”

A doctor then reviewed Alex and suggested a new medication. Luckily his mother had noticed that this was a medication that Alex should never be prescribed and that it should have been clearly identified in his notes.

Alex received new medication and this resulted in aggressive behaviour. The police were called and finally Alex was admitted to hospital. The next day Alex was informed that he had a bed in a hospital in Stevenage – a 368 mile round trip away from home.

Alex’s mother has since said:

> “We spent a period of six days witnessing Alex’s health deteriorate whilst requesting support from professional services which failed to address his needs - it was beyond cruel. We managed his illness and behaviours in our home setting for five days with barely any support. We have had the most terrible time, with mental health services telling us they couldn’t come out because there was a risk to their staff and police refusing to come because they said it was a mental health problem. Now, due to bed capacity in the North West he has been taken away from us and we are unable to visit him.
>
> Since his admission in this private and no doubt costly unit his health has deteriorated further and he has been held in a seclusion unit since last Thursday.
>
> This is about the health of a lovely young man who unfortunately has a diagnosis of bipolar disorder and became unwell. I am an expert in my son and his care needs. It would be useful to see how services work with carers going forward. All my family feel this could have been completely avoided if Alex had been able to access appropriate and relevant mental health care in a timely manner.”

The full case study can be found in Appendix 4.

Successes

53% of respondents who have accessed mental health support in the past 12 months were satisfied with the support they received.

Female aged 17

I received a phone call a month later from Mindsmatter saying they could help me and give me some counselling sessions. They could only offer me a phone call appointment as this was all they had available at the time. I was only waiting for 2 months to be seen but my referral had been put through as urgent.

The sessions from Mindsmatter were very good and helpful. I now have private counselling as the NHS and charity sessions ran out, but I don't mind paying as it helps support me. Before accessing Mindsmatter, I had never heard of them before, the leaflet the doctor gave me was very good and had a lot of different websites and phone lines to ring if I need them. I have had a very good experience of mental health services, but I think this is in regard to my circumstances."

(See Appendix 5 for full case study)

37% (13) of respondents who accessed NHS mental health services were satisfied with the support they received. In contrast, 81% (17) of respondents who received mental health support from third sector organisations were satisfied with the support they received. 50% (4) of those who accessed private services were satisfied.

Most positive feedback received about NHS mental health support was around the service being "helpful". No further detail was received.

More detailed positive feedback was received about third sector support. Positive feedback was given about socialising with people with similar experiences, being able to talk about their experiences, advice given and taking part in activities.

> *"I have been coming to this community kitchen and employability group for two years now which has been a really good support network for me. If I didn't have this or my volunteering at the charity shop…I would never go out at all"*

Awareness of local services

58%

were not signposted to additional support.

Feedback has revealed that a large majority of respondents did not know what local support was available that they could access. Respondents were asked if they had been signposted to any additional support whilst on a waiting list for their mental health. Of 52 respondents who answered the question, 58% shared that they had not been signposted.

However, of these respondents who had not been signposted, 72% said that they would consider using a support group. It should be considered to signpost people who are on a waiting list to local support, so that they can receive support for their mental health whilst waiting for NHS mental health support.

Asian or Asian British: Pakistani Male aged 65-74

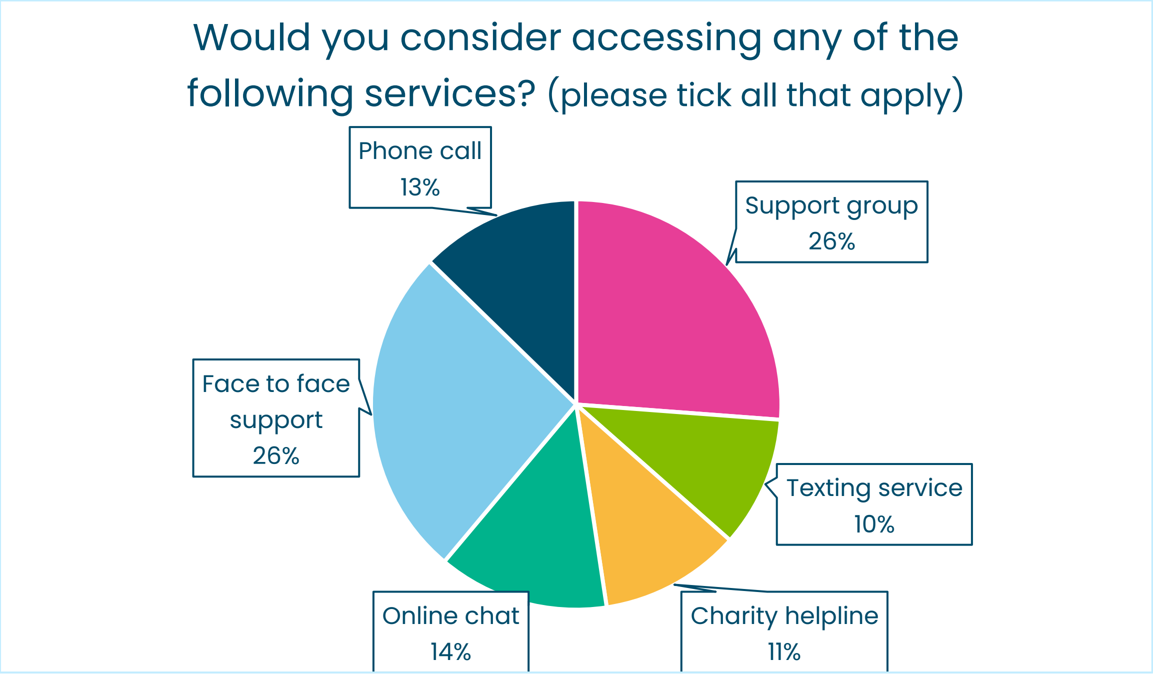
My wife has had issues for the last 25 years. There was a lady who would come and take her out for coffee and spend time with her. They gave her medication and when she became better, they discharged her.

She had a relapse and it was very difficult to get her back into the system. We had to go to hospital to be assessed and they said it would take a long time to get something in place. Eventually she was assessed and given medication, but the doses weren't right and it was very difficult for her.

It would be better if there was more support for people within my community. Even now, we don't fully understand mental health and people don't want to get any treatment. I try to explain it to the community but they don't understand.

> The younger generation seems to be more aware of the issues that people face. We need more support on how to access the mental health team and who we need to speak to.
>
> I have had to retire from my job to care for her which has caused some strain on my own health. I have tried to get help for her but her understanding of English is so poor we struggle with talking to professionals as I try to translate but she still doesn't understand. We need people to come and talk to us to help us understand things better but there aren't many people to help us.

The below chart displays what support people who have previously accessed mental health services would consider in the future. Accessing support through a support group and/or face to face was the most common form of support that respondents would consider in the future. Texting services and charity helplines were the least considered options.



Those who have not accessed mental health support.

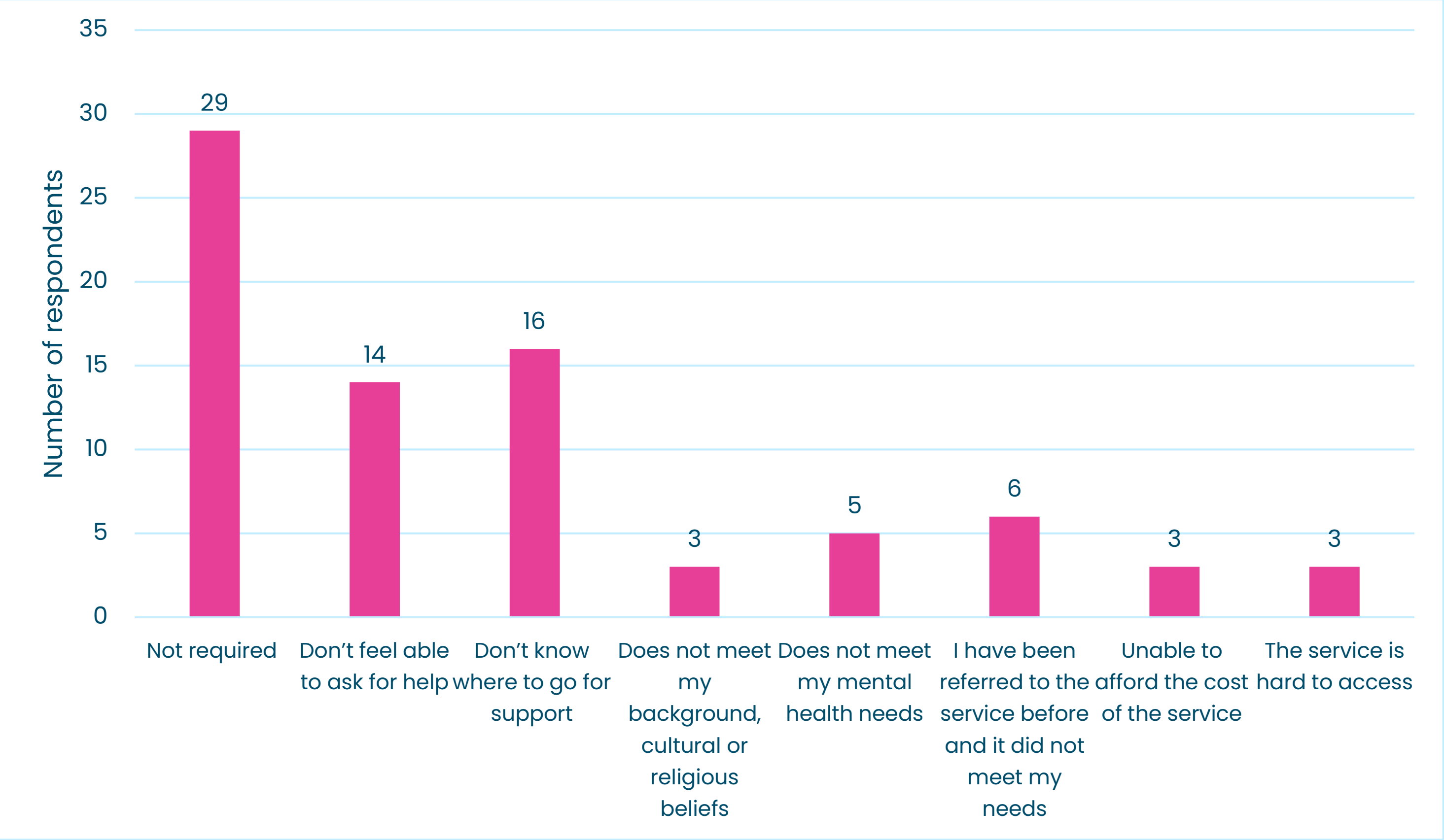
76 (51%) respondents shared that they have not accessed mental health support in the past 12 months. Despite this, 49% of these respondents shared their mental health had got worse over the past 12 months. In addition, 10 respondents have received a mental health diagnosis in the past 12 months but not received support.

46% of respondents would not know where to go if they needed support for their mental health. The 36 respondents who did know where to go shared that they would go to:

GP	15
Third sector organisation	8
Talking Therapies	6
Friends/family	4
Support group	3

Other sources mentioned included: online information (2), teacher (2), youth worker (1), occupational health (1), benevolent fund (1), mosque (1), gym (1).

Respondents were asked why they have not accessed support and the following reasons were given.



Although a large proportion shared that they did not access mental health support because they did not feel they required it, there were respondents who have not accessed support as a result of barriers in access. 21% (16) of respondents shared that they did not know where to go for mental health support. This reveals a need for better advertisement and signposting of the available options in accessing mental health support in Lancashire.

18% (14) of respondents shared that they do not feel able to ask for support, with one respondent sharing that they feel “embarrassed”. 8 of these respondents shared that they have a disability and/or long-term condition. There were no large differences between age and gender of these 14 respondents.

Similarly to those who had accessed mental health support, the most common form of support respondents would consider in the future was support groups (59%) and face to face support (59%).

Conclusion

The aim of this project was to explore the experiences of people who are receiving mental health support, including how long they have had to wait for support. Feedback from those who have not accessed mental health support was also collected including respondents' reasons for this and whether they would know where to go if they needed support in the future.

Feedback was received about NHS mental health services, as well and third sector/charitable organisations. Feedback was mixed for NHS services and the main barriers to this support were long waiting times. Despite waiting lists being lengthy, more than half of respondents were not signposted to additional support to access whilst on a waiting list.

Positive feedback was received about third sector/charitable organisations, mainly due to giving respondents the opportunity to socialise, talk about their experiences, take part in activities and the advice given.

From our sample, female respondents were more likely to access NHS support, with males more likely to access third sector/charitable organisations. Our sample also showed that males between 55-64 and females between 25-34 were the most prevalent in accessing mental health support. Data also revealed a need for more joint up care for those with a dual diagnosis of mental health and autism.

Support groups and face to face support were the most favoured form of support, as well as the most considered for people who had not received mental health support in the last 12 months.

Findings have revealed that there is a clear need for better signposting information about available local support in the community for mental health, as well as raising awareness of mental health to help reduce stigma specifically for those within the Pakistani community, those with disabilities and/or long-term conditions and young people.

Recommendations

Below displays Healthwatch Lancashire's recommendations based off the findings of this project, along with provider responses from Lancashire and South Cumbria Integrated Care Board and Lancashire and South Cumbria NHS Foundation Trust

Response from Lancashire and South Cumbria Integrated Care Board

"We were grateful to be given the opportunity to consider this report which focused on feedback about NHS mental health services, as well and third sector/charitable organisations. We note that feedback was mixed for NHS services and the main barriers to this support were long waiting times. Notably, we learned from this that more than half of respondents were not signposted to additional support to access whilst on a waiting list.

A finding that concurs with our insight and understanding was that female respondents were more likely to access NHS support, with males more likely to access third sector/charitable organisations, and that support groups and face to face support were the most favoured form of support, as well as the most considered for people who had not received mental health support in the last 12 months.

We also note that the findings have shown that there is a clear need for better signposting information about available local support in the community for mental health, as well as raising awareness of mental health to help reduce stigma specifically for those within the Pakistani community, those with disabilities and/or long-term conditions and young people.

We are actively considering these findings, and have shared them with our mental health services commissioning team and with our communication team to see how we can respond to these findings. We will be sharing the insight from the report in our public involvement and engagement advisory committee and will bring this to the attention of our quality committee. These committees investigate engagement and provide assurance to the Board on matters of public and patient engagement, and the quality of services.

We were particularly struck by the lived experience stories and we would be keen to include either a particular story or a composite of these stories in our lived experience programme. These stories are heard by the Integrated Care Board and the Quality Committee."

Theme	Recommendation	Responsibility	Provider response	Timescale
Signposting	1. Utilise Primary Care Networks to ensure that there is standardised information about pathways to mental health support in Lancashire is available to all individuals.	Lancashire and South Cumbria Integrated Care Board		
	2. Ensure all front-line staff are trained in mental health pathways and how to signpost appropriately.	Lancashire and South Cumbria Integrated Care Board		
Waiting times	3. Ensure all crisis line call handlers have up to date information on live waiting times and communicate this clearly.	Lancashire and South Cumbria NHS Foundation Trust	The Trust has developed and Initial Response Service (IRS) and this will be fully rolled out across the whole Trust by end of September 2023. The service has live call and referral information whereby calls are answered within 20 seconds, urgent referrals are triaged within 1 hour and routine referrals are triaged within 5 working days. Face to face assessments take place within 4 hours. Call Handlers are able to provide a person with timescales for their triage or assessment at the point of call. The IRS teams are also able to book people directly into appointment	End Sept 2023 for IRS launch, ongoing re monitoring data

			slots for Home Based Treatment Team and Community Mental Health Teams. As this service develops we will continue to monitor and refine these timescales.	
	4. Undertake an audit of patient records to explore the information provided to people on waiting times for support and the actual time of intervention and use intelligence to improve process. If this information is not recorded, we recommend that it is recorded.	Lancashire and South Cumbria NHS Foundation Trust	This will be discussed at the audit committee by the Associate Chief Nurse. The Trust has an Unallocated Cases (under Community Mental Health Team CMHT) Procedure, this highlights the standards expected when a referral is accepted by the CMHT but an appropriate lead professional is unable to be allocated and therefore will be subject to a triage process. Red rated Service Users (SU) should be prioritised for allocation, if it is not possible to allocate, this should be escalated to the service manager. Amber rated SUs should be reviewed by the MDT to determine initial clinical need and risk mitigation. Frequency of contact should be agreed dependent on clinical need and risk. Green rated Sus, staff will then establish what input from a mental health perspective is needed and also ensure that the care provider is aware of how contact can be	

			made with LSCFT in a crisis situation or when the SU presentation deteriorates. The receiving CMHT is responsible for ensuring that the SU is contacted if appropriate. All unallocated SUs should have a care plan complete, each contact should be documented in the SUs electronic care record, where there are signs of deterioration appropriate actions should be taken for referral for crisis intervention, where appropriate. The Community Mental Health Transformation programme has a patient flow work stream to improve access to care providers within primary care and community settings. This aims to ensure that waits for community and in-patient services reduce as the enhance provision within primary care is developed and embedded. Trust audit to commence in Q3 (October 2023)	Phase 1 starts 16th October 2023 Phase 2 February 2024
Awareness raising	5. Produce and promote a document which clearly describes which services LSCFT offer in particular their helpline services. For	Lancashire and South Cumbria NHS Foundation Trust	The Trust has recently developed their website to ensure that all urgent care services and telephone numbers are prominently highlighted; this will be updated as the IRS is full rolled out. The IRS, who act	Ongoing

	example, a flow chart which asks individuals a set of questions and directs them to the most appropriate service for their needs.		as a single point of access, also signpost to other services within and external to the Trust.	
	6. Create a campaign online and through posters/leaflets to raise awareness of social prescribers and health and wellbeing coaches. The focus of this should be on prevention and education about non-clinical services to support wellbeing in a holistic way.	Lancashire and South Cumbria Integrated Care Board		
	7. Create a campaign online and through posters/leaflets to provide reliable information about mental health to the Pakistani community, with an aim to reduce stigma and increase education and awareness of local support. Utilise the ICB engagement team to connect with local	Lancashire and South Cumbria Integrated Care Board		

	mosques and community groups			
	8. Raise awareness of the Recovery College and the services it provides to promote prevention and support for health and wellbeing.	Lancashire and South Cumbria Integrated Care Board Lancashire and South Cumbria NHS Foundation Trust Healthwatch Lancashire	The Recovery College has recently changed its name and is now called Community Roots. This service is promoted across the organisation and people are signposted appropriately by their clinical teams, the curriculum and coo-production events are highlighted across partner organisations, community groups and across social media platforms. The Community Roots internet site has recently been improved to support greater participation Additionally, the Community Roots offer is being promoted within inpatient services, particularly through the Peer Facilitators and Recovery Support Workers. The Community Mental Health Transformation Programme will also ensure that Community Roots are promoted as part of the overall integrated community mental health offer.	April 2024
	9. Share the findings of this report to Healthwatch Together partners to identify trends or themes across the Lancashire and South Cumbria footprint.	Healthwatch Lancashire		

	10. Raise awareness of people’s rights to accessing mental health services including the quality of service they should expect and how to challenge when services fall below this including NHS complaints advocacy and PALS.	Lancashire and South Cumbria Integrated Care Board Lancashire and South Cumbria NHS Foundation Trust	The LSCft Complaints and PALS service is advertised to patients, families and carers via a number of routes. These include: - Posters in our in-patient and out-patient settings (see Appendix 6) - Information cards (see Appendix 7) - Proforma – enabling service users to make us aware of concerns, make suggestions, or give compliments see Appendix 8) – which are forwarded to the department from clinical areas - Website – links as follows: Complaints: https://www.lscft.nhs.uk/complaints Patient Advice and Liaison Service (PALS): https://www.lscft.nhs.uk/pals Our Complaints leaflet is currently being updated (proof copy attached) Additionally, a large number of our Patient Information Leaflets also have the PALS details on the back (copy of example leaflet attached)	Autumn 2023 December 2023

			Furthermore, drop in sessions from the PALS team are planned to start December 2023.	
Carers	11. Ensure staff involve the views of family/carers where the individual is not capable of communicating independently, lacks mental capacity to make specific decisions at the time they need to be made, or the individual gives consent for them to be consulted. This must be clearly recorded in the patient records.	Lancashire and South Cumbria NHS Foundation Trust	As we transition from CPA to DIALOG+, all mental health clinical staff are receiving a comprehensive training programme. This includes a co-developed session on coproducing care plans with service users and their carers which includes: - Ensuring, where service users consent to involvement, that carers are involved as full partners in every appropriate aspect of the person's care and treatment - Exploring complexities arising from service user not consenting to the sharing of information and the fact that this does not prevent staff from receiving information from carers, relatives or friends is promoted. The Trust electronic Patient Record (RiO) now has an assessment section dedicated to carers, as part of the initial assessment the staff will confirm with the SU that the carer information is correct, and update if needed. If the SU is a new patient, we would ask if they have a carer or indeed are a carer. We would ensure consent from the SU for their carer to be involved in their care and	Dialog + roll out across Trust on going

			treatment this should be noted in the consent to share section on RiO. All notes from the carer (any feedback given, notes taken etc.) is written up in the daily entries section, RiO is currently being refreshed and plans are being developed for a carers notes section.	
Young people	12. Produce campaigns aimed at young people addressing the concerns raised in this report including • Reduce stigma of mental health • Raise awareness of different forms of mental health support • Information about when the NHS have a duty to inform parent/carers about a young person's mental health • The pathway from CAMHS to adult mental health services	Lancashire and South Cumbria Integrated Care Board		

Autism	13. Ensure that there is a strong communication pathway between autism and mental health teams within the NHS for more joined up care	Lancashire and South Cumbria NHS Foundation Trust	The Trust has established a Learning Disability and Autism in Mental Health Group which is taking forward the Green Light Toolkit Standards and other relevant initiatives to improve care for people with a Learning Disability and Autistic People within MH Services. Members of the Specialist Autism Team sit on this group. There is an annual work plan which includes the development of a new Joint Autism and Mental Health Interface Policy.	January 2024
	14. Provide neurodiversity training to all staff working within mental health to increase knowledge of how to support individuals with a dual diagnosis aiming to reduce/remove barriers to accessing mental health services and people falling between the two services.	Lancashire and South Cumbria NHS Foundation Trust.	The Oliver McGowan Mandatory Training on Learning Disability and Autism is being rolled out nationally LSCft went live with the e-learning component of this training in July 2023 and are currently 62% compliant trust wide. Work is ongoing with the ICB to develop the face to face element of the training at a system level.	

Next steps

Healthwatch Lancashire will present these findings to Lancashire and South Cumbria Foundation Trust (who delivers mental health support, including Talking Therapies) for their comment and work closely with them to monitor improvements made.

The report will also be sent to Lancashire County Council and Healthwatch England for their information.

Healthwatch Lancashire aim to expand on the findings of this project by investigating mental health and access to mental health support for young people. This report will be sent to NSPCC and Healthwatch Lancashire hope to work with them to produce campaigns for young people. The aim of this it to reduce stigma, raise awareness and increase education around mental health.

References

[1] Royal College of Psychiatrists. (2022), *Hidden waits force more than three quarters of mental health patients to seek help from emergency services.* Available at https://shorturl.at/pvAKP > (Accessed: 17/07/2023)

Appendices

Appendix 1: Case study collected prior to this project commenced, which describes the experience of a man (told by his parent) diagnosed with treatment resistant schizophrenia and his experience of attending A&E for his mental health and then being moved to inappropriate hospital wards.

Mark is our son, he is 38 years old, and suffers from treatment resistant schizophrenia, characterised by episodes of psychosis and loss of mental capacity. Every time he relapses there is always the risk that he may not recover sufficiently to ever leave hospital so any severe episode of psychosis could be potentially life-changing. As a consequence, it is vitally important to ensure that if Mark's mental health is poor he is kept safe, and also protected from any unnecessary stress, in order to reduce the likelihood of catastrophic relapse.

Mark was admitted to a secure mental health ward in Blackburn in November and was detained under Section 3 of the Mental Health Act. Acutely unwell in his mental health, and suffering from Strep A infection, he then developed a severe respiratory infection in early December.

DAY 1

With oxygen levels dropping below 90% staff on the mental health ward followed the established procedure and AMBULANCE NUMBER ONE was sent for, to take Mark 200 yards across the hospital car park to A&E. Mark then sat on a chair from 11 o'clock at night until 8.30 the following morning, without being seen; exhausted and distraught he ABSCONDED, running out of A&E with his two mental health nurse minders following in his wake. Lacking full mental capacity, and suffering from pneumonia, Mark was at significant risk in this situation. He does not know Blackburn, and if he had left the hospital grounds he would have been totally lost. It was bitterly cold, and Mark had no coat on. Fortunately, he made his own way back to the mental health ward.

DAY 2

Further monitoring revealed his oxygen levels had dropped still further, and it was clear he was extremely ill and in need of medical care. A SECOND AMBULANCE was sent for, however in spite of very persuasive efforts by the paramedics Mark refused to go with them so they left.

Later that day Mark's oxygen levels were lower still, and giving serious cause for concern, so a THIRD AMBULANCE was sent for, and at this point staff asked the family to help persuade Mark to attend A&E. Mark eventually agreed to go into the ambulance, and I asked for a copy of his MENTAL HEALTH RISK ASSESSMENT, so it could be given to the medical staff in the main hospital. However, when I offered to give the risk assessment to the medical staff in A&E they gave it back to us, saying 'they didn't need it'. There was no piped oxygen in the cubicle, so bottles of oxygen were brought, and Mark was given oxygen.

Blood tests had been ordered on the mental health ward; A&E sent Mark for an X-ray, and we were told he had pneumonia. He would need to be admitted to a medical ward.

DAY 3

Still in A&E, waiting for a bed.

DAYS 4, 5 and 6

Mark was sent to the medical assessment unit (AMU), and this was followed by a transfer to a bed on the Respiratory ward, when one became available.

THE RESPIRATORY WARD

Lacking the mental capacity to make sensible decisions regarding his treatment, Mark refused to have a catheter fitted. Once again, family were sent for in order to help persuade him.

Mark was quite poorly, and while he was on oxygen he was effectively tied to the bed, which was in a ward with other patients. At all times while he was in the medical side of the hospital Mark had two mental health nurses with him.

The problems began when Mark's oxygen was disconnected. Mark immediately ABSCONDED FROM THE WARD, once again leaving his mental health minders trailing behind him. Mark went to the shop, where he bought a bottle of cough medicine, and promptly drank half of it.

After he had returned to the ward (which he did under his own steam, so once again it was fortunate he did not go further and get lost in Blackburn), Mark asked if he could shave, and so one of the medical nurses gave him a RAZOR. Mark went to the bathroom, so could not be followed by the female mental health nurses, and while there he self-harmed. Blood everywhere.

Later on Mark went to the bathroom again, and self-harmed a second time. Blood everywhere; again. Altogether there were three serious incidents in just one day.

Mark is a big man, and can be aggressive when mentally unwell. On this occasion the only person who was harmed was Mark himself, but in the context of a busy ward with other seriously ill and bed-bound patients alongside, there was the potential for harm to others.

DAY 7

A week since he had left it to go to A&E Mark was deemed sufficiently fit medically to return to his bed in the mental health ward (which had been empty throughout his stay in the medical ward).

It had been hoped that Mark would be well enough in his mental health to be allowed Section 17 leave to spend Christmas Day with his parents. However, his journey through A&E, the AMU and the Respiratory Ward took its toll on his mental health, which (unsurprisingly) deteriorated considerably in the days following his return to the mental health ward. Mark spent Xmas Day in hospital instead of with his family, and it is likely that his mental health admission will be considerably longer than it would otherwise have been.

In 2021 Mark made a similar journey from the mental health ward in Chorley Hospital to the Respiratory Ward in Preston Royal Infirmary, also with pneumonia. On that occasion he spent 7 hours in an ambulance queue outside the hospital, and then two days in A&E before being found a bed. (Note: Chorley Hospital has an A&E Department and ,also a Respiratory Department, but Mark was taken to A&E in Preston in an ambulance because that is the established procedure). On that occasion Mark occupied the medical bed in Preston and also the mental health bed in Chorley for two weeks, and throughout his stay in the medical ward TWO mental health nurses had to be with him 24/7. Surely not the best use of hard-pressed resources.

It is important to say that at all times, the staff working with Mark, both mental health and medical nurses and doctors, were professional and caring. Everyone did their best within the constraints of the established procedures. It seemed to us that it was the system/s that need to change. There were times when Mark was at risk of serious harm.

It is worth considering that the way Mark was managed was cost-intensive, and alternative strategies would not only be better for the patient but also more cost-effective as well.

1. I was told by one of the paramedics that patients on the mental health wards ‘used to be able to go straight to a medical ward, but they stopped that three years ago’. The journey through A&E for a person who is already an in-patient on a mental health ward is ridiculous, and needs to be changed.

2. If mental health nurses can walk across the car-park to sit with a patient in A&E, then I am sure medical nurses/doctors could walk to the mental health ward to examine a patient. The several days Mark spent in A&E would have been better spent in the safety of a secure mental health ward, with bottles of oxygen sent there if needed instead of being brought to a cubicle in A&E, while he waited for a medical bed.

3. Ways need to be found so that a mental health patient does not occupy two beds at the same time, a mental health bed and a medical bed. Although the two Trusts are completely separate, it is not acceptable for one Trust to waste the resources of the other, even if they are not paying for the waste themselves.

4. A mentally ill patient who has a record of aggressive behaviour towards others should not be allocated a bed in a crowded ward. If there is a history of absconding, they need to be kept in a secure area. The only way this can be achieved is by allocating a single room with a lockable door.

5. Mark is lucky; he has a loving and supporting family. Many mental health patients are not so fortunate, and have no-one to advocate for them. It is important that systems are in place to ensure all mental health patients have access to medical care in a safe and secure environment.
6. Medical staff need to be aware that mental health risk assessments are written for a reason.

Appendix 2: Case study told from a parent of a young man with a dual diagnosis of mental health and autism. Their experiences involve a lack of continuity of care, poor communication between services and a lack of understanding of diagnosis.

My child Mike suffers from autism and has only recently been given a dual diagnosis that explains some of the issues that they are suffering. He lives with autism and suffers from multiple personality disorder and paranoia. The main problems that we face are that we are going in circles with referrals discharges and re-referrals when we see that his behaviour and actions place himself and others in danger. The support we get is very reactive and only comes into play when things are at their worst.

It all began aged 16 when we noticed a decline in Mike’s wellness, and it was confirmed when he tried to harm himself. We first made contact with our GP, and we worked with CAMHS in the first instance. They saw him once and said that it was “boyish behaviour” and discharged him. Mike was then sectioned and sent to facility A but was discharged after 28 days. We were told that there would be support in place when he re-entered the community and that he would be looked after. We were told about the support which would be given and we were happy that it would help. None of this was actually put into place and the Community Mental health team refused to get involved.

Eventually we needed to go to Accident and Emergency, where Mike was kept for 7 days. We knew he was going to be sectioned but we spent a long time waiting for a mental health bed to become available. He then got sent to a new mental health facility and we could see a big improvement in his condition in terms of how he was responding to medication and the care he was being given. In the next 12 months he was sent to three different mental health facilities and when he was discharged there was no plan in place.

The social worker was not informed about the [discharge] plan and the social worker asked [the facility] why we were not consulted and their response was “we are not obliged to do so as it is a private facility.” Eventually we were able to get Mike back into his own flat but it was not right for him to be there and he did struggle. He would smash things when he was frustrated. We had a meeting eventually to discuss the support and to raise our concerns, where we were informed that there was a need for Mike to receive some extra support but that they weren’t able to provide anything due to a lack of available funding. The ironic thing is we eventually received some autism funding and he was given an assessment to see what was needed and a specialist unit was to be found.

He was sectioned again and sent to the facility A where I was not happy with his treatment. They eventually nominated him a bed at a fifth facility for 12 months. Towards the end of the section the doctor said “you may as well go now” so he went back to his flat without a discharge plan.

He started to show a decline again. The Community mental health team became involved and said that he would need assessing due to his living conditions. The flat was very messy, and he struggled to keep it clean. It was made worse when he trashed the place when frustrated. They set up a treatment plan to support him and he was discharged from this within two days. We did not get a reason as to why this was the case. During this time, he refused to let his social worker or anyone into his premises. This went on for a while and we saw another decline in his wellbeing.

I rang the community mental health team to get some support and they said that I would need to go back to my GP. This is again us going around in a circle. I phoned the GP…eventually the out of hours team came at 11pm at night to see what they could do to help. They arranged for a psychiatrist to come out at 2am to see him and he was sectioned straight away but there was no bed available and we needed to wait for one. He was sectioned again for the next 12 months. He was moved several times due to his behaviour.

It was apparent that nobody had taken the time to consider the autism in his treatment.

He was then sent to a sixth mental health facility and they were brilliant and actually had a conversation with me about my concerns for Mike's wellbeing. It was here that it was highlighted again that he was a danger to himself and others and that he needed to be sent to a specialist unit. After an assault on a member of staff they needed to move him. I told staff that "I don't want him going to the Facility A." He was then sent to Facility A which I was not happy about. I know that while he was in the Facility A he was left a lot to his own devices and that the staff and social worker at the time did not understand his needs. They only said that Mike chose not to engage with them. One consultant who had not looked at his history disputed the fact that he had been given an autism diagnosis. He said that they didn't know he had a formal diagnosis for autism, despite it being discovered several years ago.

Mike is receiving support from the autism team and they are doing what they can to support him. There is also a care worker who visits two times a week. He is now with his 4th social worker who is taking their time with him to help him make some decisions and he is ok but still needs lots more support than he receives.

I feel that there is no continuity of care for people struggling with their mental health. There is no connection between social care and mental health and the two-go hand in hand. Mike has been sectioned several times and twice highlighted as needing a specialist unit due to a lack of continuity and failings of Facility A who on both occasions of him being there, changed agreed treatment plans. He has not received the help that he requires. He recently spent a year under Section 3 awaiting a specialist place but set plans were changed by facility A so special funding has been wasted along with other resources and a year of mikes life. He struggles every day and remains both vulnerable and a risk.

Appendix 3: Case study of Male aged between 40-50 who experienced long NHS waiting lists so sought out third sector support.

It started about five years ago when my son was born, I certainly got very depressed. I felt like I was borderline in some kind of psychosis it was the worst mental health that I have ever had. I did reach out for support I self-referred to Mindsmatter at the time. I phoned the mental health crisis line and told them that I felt like I was losing my mind and that I felt like I seriously needed hospitalising. Their response was “nobody is working at the moment. We will try and get someone to phone you but it might not be until after the weekend”. No one ever phoned back. I was waiting for a call and that callback never ever happened. I was just totally abandoned by them.

The minds matter process started. It must have been three months before I got a triage appointment. I went there and the guy who saw me was genuinely interested. He was very empathic, listened to me and I felt like he understood the situation.

I shared that I did not want CBT so I got put on talking therapies which was slightly longer waiting lists. I was told it would be around six months as I was not a priority. I understood this as it was a precious resource and people needed it. Months and months went by and I was left on my own and I was thinking “it’s going to come.”

Mindsmatter then sent me a letter asking me if I wanted to stay on their waiting list. It was really impersonal and I felt so insulted because I had been waiting for months. I then got another letter saying that I had been discharged.

You have to take personal responsibility at some point and I did then reach out to a number of peer support groups. It was just that space to open up and be around other people who are opening up.

These peer support groups helped, especially the men's only groups. I think a lot of mental health problems come from isolation and that lack of community and purpose. These groups give you a lot of that. It was really positive and I have to say that was really the start of pulling myself out of all of this. The men's group really validated me which helped me to approach a domestic violence charity for support.

I then approached Cedar House, a charity in Preston for those on low-income. I told them I was on a Mindsmatter waiting list and they said that Mindsmatter refer people to them so when people reach the end of the Mindsmatter waiting lost they get put on Cedar House's waiting list. They said I had done the right thing going to them directly and I had to wait a couple of months. I had a lot of sessions and it was supremely helpful.

I have relied on the voluntary sector throughout all of this. That is where the support is. There was no signposting from Mindsmatter given at all. Support is not a 'one size fits all' and there are all sorts out groups out there.

I think social prescribing is the place where people should go. They provide a signposting role but people don't know signposting services exist to give people their options. Social prescribers will do that bit of handholding and help you get past the barriers that people face is accessing support.

Appendix 4: Case study told from a mother about her son who is diagnosed with bipolar disorder and experienced a lack of appropriate care due to long waiting lists.

Alex had previously had two psychotic episodes when he was 18 and 19 and was diagnosed with bipolar disorder.

In November 2022 he was detained under section 2 & subsequently 3 of the Mental Health Act (MHA) at Trafford Hospital. He returned to our family home in January 2023 but was subsequently sectioned again in February whilst visiting friends in Manchester and was placed under section 2 of MHA again and admitted to Salford Hospital. During this time, we were informed by medical staff at Salford Hospital that the drug Haloperidol was adversely affecting his heart function and that he must never be prescribed this again. They assured us that this would be clearly identified in all his notes.

What happened in Manchester:

In May I received a phone call from Cheadle Heath Police station to say that Alex had been arrested. I notified the officer that Alex had a diagnosis of bipolar disorder and that his behaviour may be an indication of his ill health. I also informed them that if he had been kept in overnight he would not have had his medication.

When Alex is well he is not normally unruly or disruptive so I presumed he was unwell and contacted both the Manchester Crisis Helpline (MCH) and the Trafford Home Treatment Team (HTT). The MCH informed us that they cannot offer support to those registered with Manchester services and suggested taking Alex to A&E or speaking with him directly.

I also contacted the Trafford HTT, they informed me that they were unable to support anyone in the community unless they were registered with their service. They suggested I contact both Manchester & Lancashire crisis teams and request from LSCFT that Alex's care was transferred back to Manchester so they could support him.

I called the Kendal HTT and LSCFT Initial Response Service (IRS) but both said they couldn't deal with anyone out of area. I asked if they could transfer his care back to Manchester, but they said not.

Alex had been released from a police cell and his girlfriend had told us that he was not well and that she did not feel safe. We were receiving texts from Alex asking us to collect him. He sent me messages saying, "I'll sleep better if mum and dad are here" and "I want to come home now, do you think that will be possible?"

What happened in Lancashire:

We arrived back to our family home in Lancashire in May and Alex asked if he could see someone from the mental health service as he felt unwell and thought his meds needed reviewing. I had left a voicemail on the mental health Community Team leaders' mobile phone over the weekend and was able to talk to her directly. She told me that she had had to cancel all her meetings that afternoon to deal with Alex's case as a priority but that she couldn't send anyone out from her service if there was a risk of violence and explained that she was undertaking a risk assessment and trying to arrange a transfer of care to the HTT.

Eventually the HTT phoned to say that they would be visiting and attending with a policeman. I said we desperately needed support as we could see that Alex's health was deteriorating (he at this point had become urinary incontinent which was highly distressing for him). We explained that we felt he needed urgently reviewing by a doctor and that we needed support as it was difficult to manage and contain his behaviour when his mood was so elevated.

Alex requested to go into hospital – I discussed this with the team and they said getting a bed was almost impossible and the easiest way to go up the priorities list for beds was to call the police. We were advised not to go to A&E as this could put Alex in a greater sense of distress and we would not be able to access a bed any quicker.

Later that day we were contacted by an Approved Mental Health Practitioner (AMHP) to inform us that Alex would be assessed under the MHA at 10.30pm that evening. At 11pm I awoke Alex and gave him his medication then we all went to bed.
At 11.15pm we received a knock on the door (2 doctors and the AMHP that had got lost!) Doctors said they couldn't assess him if he had just had medication and they left.

The next day we received a phone call from LCC AMHP to say that they couldn't action a MHA assessment because they believed it was not the responsibility of LCC as Alex's address was in Manchester and having read through his case file he was unsure of his safety. Alex and I decided that we would pack up a picnic and go to A&E that evening as the situation had become untenable for us all, but most especially for Alex. We ate tea and were getting ready to leave when we were informed by AMHP that a MHA would be undertaken that evening.

Alex was assessed by two Doctors who visited us and initially suggested that he could be treated in the community. We stated that we did not think this was a viable option and that we wouldn't be able to keep him safe. It was heartbreaking. This was re-considered and ultimately hospitalisation was recommended. However, there were no beds and so Alex remained in our care in a highly agitated and psychotic state. He was wandering off and doing strange things whilst his urinary incontinence had got worse. It was beyond cruel to witness someone with a known health condition and under the care of NHS mental health services, deteriorate so badly and be denied access to appropriate treatment, when he had requested support.

Throughout the week Alex requested access to hospital – he said he didn't mind going to a police cell he just wanted to feel safe. In desperation I called the police and asked if they could help me. They politely said no as he was in a place of safety and nobody was in danger – so we were referred back to the mental health services. I was asked not to keep contacting IRS as they were just duplicating my efforts to contact the HTT. The Kendal HTT manager informed me that they were urgently trying to find a bed but there were some discussions going on about who would pay for it and where Alex was actually based. She said she was pushing very hard to sort out a bed and would deal with the politics later, for which I had great respect.

The doctor was suggesting to introduce Haloperidol. I was beside myself, it should have been all over his notes that he could not and should not be given this drug due to its impact on his heart. It was only due to my intervention that the HT team checked and 'somewhere' in a bundle from Manchester' this vital medical information was found.

The HTT arrived on Friday evening with a new prescription for Alex. We explained that Alex would be leaving our home now he had his medication and would attempt to travel to a football game, in his very unwell and distressed state and that we wouldn't be able to stop him. They suggested we phoned the police if he left as he was vulnerable and that we should also call the police if he became aggressive in any way. Five minutes later I called the police, Alex was thumping and kicking my husband as he had challenged him about leaving. This is the first time I have ever seen my son violent, and I was concerned. Police arrived but eventually we were left at home (again) with a very unwell young man. It was explained that our telephone could be 'tagged' meaning any 999 silent calls would be treated as an emergency.

Alex awoke at around 6am and was trying to take his new and quite complicated regime of medication. He became aggressive with me and I was scared so I dialled 999. He had taken the wrong amount of medication so I wanted to know if it was OK if he continued on the regime. I phoned the HTT (in Barrow) who said they didn't have access to all the records but 'it should be fine' I requested clarification that it would be fine and having spoken to colleagues she said that was fine. Approximately 30 minutes later I was called with an apology to say that the Police Station had had a number of 999 calls that morning and someone would be with us soon. I was asked how Alex was and mentioned that he had calmed down a little, but I was reassured that we were finally going to get some help. Approximately 20 minutes later I was called again by the same officer who told me that her sergeant had reviewed the log and that as I had said Alex was calmer the police would not be attending as it was a mental health concern. I don't know how I found the energy to do this but I then found the contact for LCC Adult Mental Health Social Services.

Finally with a warrant 1 police officer, 3 paramedics, 1 Doctor and an AMHP arrived at 10.15pm we awoke Alex from his sleep and he went compliantly in the ambulance to Blackburn Hospital. This is all he had wanted since he returned home. We were assured he would have a bed at some point soon.

At around 8am we received a telephone call from Alex asking us to visit him as soon as possible as the staff had told him he would be going to Stevenage that day. We spoke to an AMHP at great length explaining this was not in Alex's best interest to be deprived of his friends and family in this way. Stevenage is a 368-mile round trip from our home. The AMHP said that it had to be out of area because the medical recommendation was for a PICU bed. The AMHP said she would look into it but did not get back to us. We were just told it was someone in LSCFT.

Since his admission in this private and no doubt costly unit his health has deteriorated further and he has been held in a seclusion unit since last Thursday.

All my family feel this could have been completely avoided if Alex had been able to access appropriate and relevant mental health care in a timely manner.

In summary, we spent a period of six days witnessing Alex’s health deteriorate whilst requesting support from professional services which failed to address his needs - it was beyond cruel. We managed his illness and behaviours in our home setting for five days with barely any support. We have had the most terrible time, with mental health services telling us they couldn’t come out because there was a risk to their staff and police refusing to come because they said it was a mental health problem. Now, due to bed capacity in the Northwest he has been taken away from us and we are unable to visit him.

This is about the health of a lovely young man who unfortunately has a diagnosis of bipolar disorder and became unwell. I am an expert in my son and his care needs. It would be useful to see how services work with carers going forward.

Appendix 5: Case study of 17-year-old female with positive experience of mental health support

I was really struggling, I had been in a really bad relationship, and it had become very hard for me to cope. I had looked up support services in my area, but it was very confusing and I was scared as I didn't think I was bad enough for counselling.

My mum ended up taking me to the doctors, the doctor was not great with me, and it was very hard to communicate what I needed with him. I felt he didn't know much about mental health and didn't really listen to me. The doctor eventually gave me a leaflet for minds matter and said you can self-refer or I can refer you. The doctor then put the referral in for me as I was confused as to what to do.

I received a phone call a month later from minds matter saying they could help me and give me some counselling sessions. They could only offer me a phone call appointment as this was all they had available at the time. I was only waiting for 2 months to be seen but my referral had been put through as urgent. The sessions from minds matter were very good and helpful.

The victim support team also referred me to trust house for pre-trial therapy who were incredible with me, very supportive and offered face to face sessions with no long wait list. The service was great, and I felt it really supported me and my mental health. I was advised that medication would be helpful so I contacted my doctor and I received medication for anxiety and depression.

I was very worried when I first approached the GP as I didn't know what was going to happen, I had received some support from college. My college have a wellbeing section where you can access help and support which is good.

I now have private counselling as the NHS and charity sessions ran out but I don't mind paying as it helps support me. I find face to face support so much more beneficial that over a phone call. I have regular check ups with the nurse to monitor my medication and she is lovely and always checks how I am and if I'm receiving the right support.

Before accessing minds matter, I had never heard of them before, the leaflet the doctor gave me was very good and it had a lot of different websites and phone lines to ring if I need them. I have had a very good experience of mental health services.

Appendix 6: Example of a Lancashire and South Cumbria Foundation Trust PALS poster

"PALS were so understanding. I finally felt like someone understood my situation."
Aiza

PALS stands for
Patient Advice and Liaison Service.

This is a free and confidential service for service users, families, carers and friends.

You can contact PALS if you:

- Are worried about aspects of care you, your friend or your loved one has received and you're not sure what to do, where to go, or who to speak to;
- Need greater clarity about something relating to your care;
- Want to tell us about the experience you've had with our service - good or bad;
- Need information about the NHS or other services;
- Have suggestions on how we can improve our services.

0800 234 6088

www.lscft.nhs.uk/PALS

How does PALS work?

When you contact PALS, a member of the PALS team will listen to you and discuss the best way to take your concerns forward. This will usually involve contacting people — be it doctors, nurses, managers or other support organisations — on your behalf to get the answers to your questions or to give your feedback. We will always keep you up to date with progress.

We aim to resolve your issues as soon as we can, or within 3 working days. However, if they cannot be addressed within 3 working days and need investigating in line with our Complaints Policy, then PALS will refer your concerns to the complaints team.

Who are PALS?

The PALS team acts independently and confidentially when dealing with concerns on your behalf. None of the information you share with the PALS team will be entered into patient records.

If you are raising a query on someone's behalf, we will need consent from the individual.

PALS works closely with other services e.g. clinical services, advocacy and voluntary sector, to ensure we can respond effectively to your issues.

Contacting PALS

As well as being available on the telephone, drop in clinics will be in place across the Trust on a regular basis and will be advertised in clinical areas and on our website.

Contact information

By post to:
Patient Advice and Liaison Service,
Lancashire & South Cumbria
NHS Foundation Trust,
Sceptre Point,
Bamber Bridge,
Preston PR5 6AW

Free-phone: 0800 234 6088
Landline: 01772 676028
Email: pals@lancashirecare.nhs.uk
Web: www.lscft.nhs.uk/PALS

We are available Monday to Friday, from 9am to 5pm. If there is no one available to take your call or it is outside of these hours, you can leave a confidential message on our answer machine and you will be contacted as soon as possible.

Alternative Support

In addition to PALS we've made it easier for everyone to access our services or support. There are two other services you may need. They are:

OUR NEW CRISIS LINE:
It is available **24/7 on 0800 953 0110.** It is staffed by trained mental health professionals who are able to provide assessment and referrals to appropriate services – ring it if you need to access services or for advice about someone who needs treatment/support.

OUR MENTAL HEALTH AND WELLBEING HELPLINE
Can be contacted on **0800 915 4640** or by texting **'Hello'** to **07860 022846.**

It is staffed by volunteers and those with lived experience. It offers emotional support for anyone who wants to chat about mental health or are lonely.

We are LSCft

@WeAreLSCFT @WeAreLSCFT @WeAreLSCFT

Appendix 6: Example of a Lancashire and South Cumbria Foundation Trust PALS information card

we are your

PALS | Patient Advice & Liaison Service

NHS
Lancashire & South Cumbria
NHS Foundation Trust

"I'm worried about speaking to anyone about my problem. Not sure what I'd have done without PALS."
Oscar

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@WeAreLSCFT @WeAreLSCFT @WeAreLSCFT

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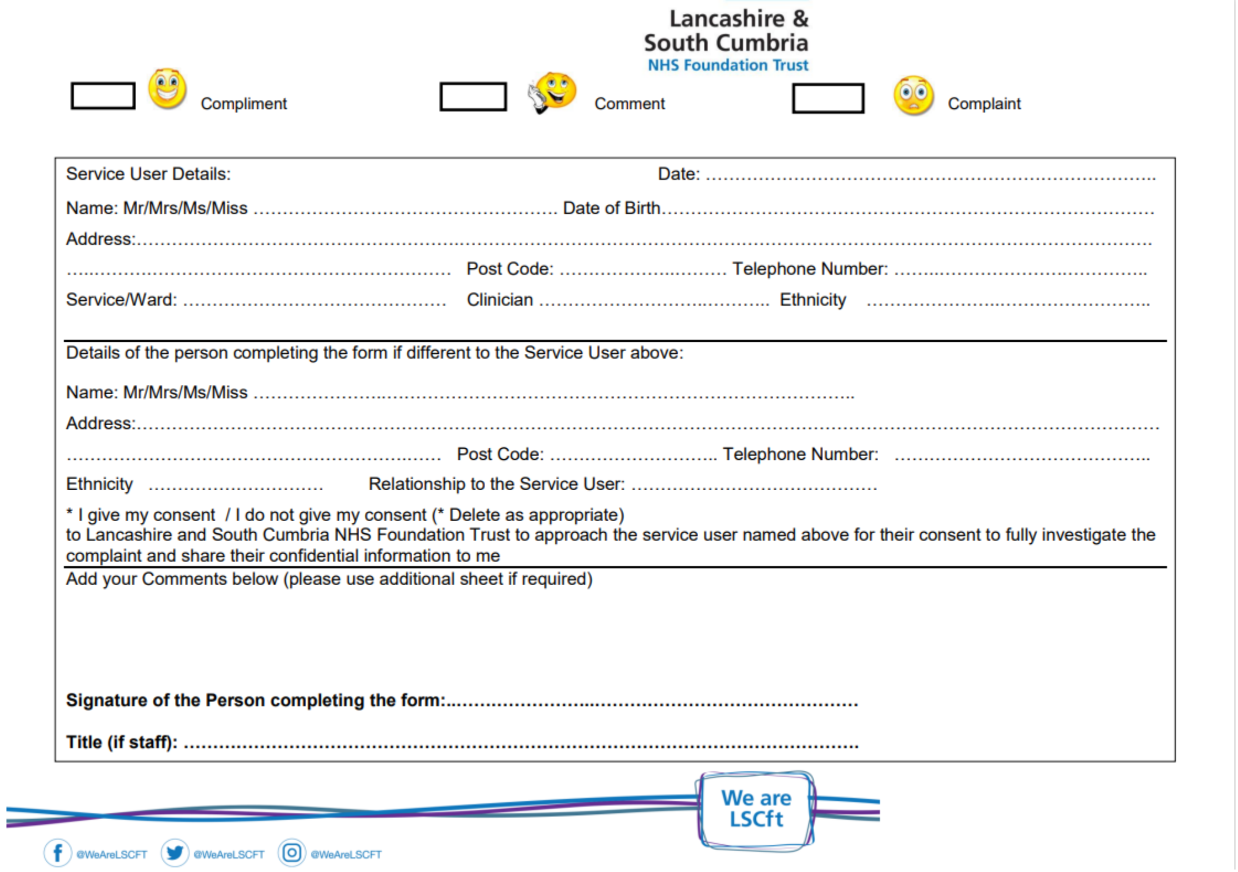
We are LSCft

@WeAreLSCFT @WeAreLSCFT @WeAreLSCFT

Appendix 6: Lancashire and South Cumbria Foundation Trust patient proforma



Lancashire &
South Cumbria
NHS Foundation Trust

☐ Compliment ☐ Comment ☐ Complaint

Service User Details: Date: ……………………………………………………………

Name: Mr/Mrs/Ms/Miss ………………………………………… Date of Birth……………………………………………………………

Address:………

……………………………………………… Post Code: ……………………… Telephone Number: …………………………………

Service/Ward: …………………………………… Clinician ……………………………… Ethnicity ………………………………………

Details of the person completing the form if different to the Service User above:

Name: Mr/Mrs/Ms/Miss …………………………………………………………………………………

Address:………

……………………………………………… Post Code: ……………………… Telephone Number: …………………………………

Ethnicity ……………………… Relationship to the Service User: …………………………………

* I give my consent / I do not give my consent (* Delete as appropriate)
to Lancashire and South Cumbria NHS Foundation Trust to approach the service user named above for their consent to fully investigate the complaint and share their confidential information to me

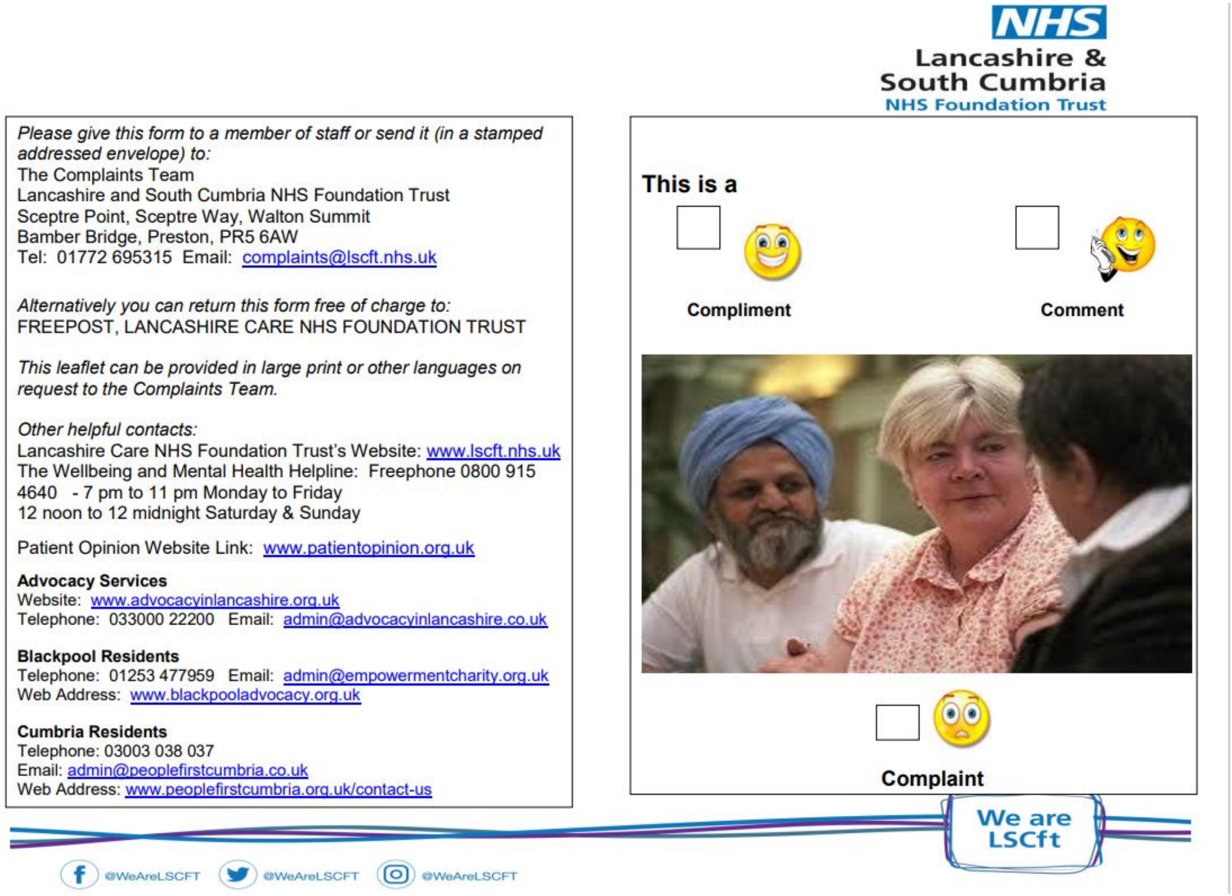
Add your Comments below (please use additional sheet if required)

Signature of the Person completing the form:……………………………………………………………

Title (if staff): ……………………………………………………………………………………………

We are LSCft

@WeAreLSCFT @WeAreLSCFT @WeAreLSCFT



NHS
Lancashire &
South Cumbria
NHS Foundation Trust

Please give this form to a member of staff or send it (in a stamped addressed envelope) to:
The Complaints Team
Lancashire and South Cumbria NHS Foundation Trust
Sceptre Point, Sceptre Way, Walton Summit
Bamber Bridge, Preston, PR5 6AW
Tel: 01772 695315 Email: complaints@lscft.nhs.uk

Alternatively you can return this form free of charge to:
FREEPOST, LANCASHIRE CARE NHS FOUNDATION TRUST

This leaflet can be provided in large print or other languages on request to the Complaints Team.

Other helpful contacts:
Lancashire Care NHS Foundation Trust's Website: www.lscft.nhs.uk
The Wellbeing and Mental Health Helpline: Freephone 0800 915 4640 - 7 pm to 11 pm Monday to Friday
12 noon to 12 midnight Saturday & Sunday

Patient Opinion Website Link: www.patientopinion.org.uk

Advocacy Services
Website: www.advocacyinlancashire.org.uk
Telephone: 033000 22200 Email: admin@advocacyinlancashire.co.uk

Blackpool Residents
Telephone: 01253 477959 Email: admin@empowermentcharity.org.uk
Web Address: www.blackpooladvocacy.org.uk

Cumbria Residents
Telephone: 03003 038 037
Email: admin@peoplefirstcumbria.co.uk
Web Address: www.peoplefirstcumbria.org.uk/contact-us

This is a

☐ **Compliment** ☐ **Comment**

☐ **Complaint**

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healthwatch
Lancashire

Healthwatch Lancashire
Leyland House
Lancashire Business Park
Centurion Way
PR26 6TY

www.healthwatchlancashire.co.uk
t: 01524 239100
e: info@healthwatchlancashire.co.uk
@HW_Lancashire
Facebook.com/HealthwatchLancs