

Mental health survey results 2022/23

Responses collected May 2022 to March 2023

Published: November 2023

Contents

| Executive Summary | 2 |
|---------------------------------------|----|
| Introduction | 9 |
| Section 1 – 2022/23 survey | 11 |
| Survey questions | 11 |
| Other data collected | 54 |
| Section 2 – comparison to 2017 survey | 58 |
| Tick-box questions | 58 |
| Key messages from 2017 | 64 |
| 'I statements' co-produced in 2017 | 65 |
| Demographics | 66 |
| Acknowledgements | 68 |
| Appendix | 68 |
| Copy of survey questions 2022/23 | 69 |
| Glossary of abbreviations | 76 |

Executive summary

Healthwatch Tameside is the independent consumer champion for health and social care in Tameside. We listen to local people and gather information about their experiences of using health and social care services.

Healthwatch Tameside is informed by our connections to local people and our expertise is grounded in their experience. We are the only body looking solely at people's experience across all health and social care in Tameside.

As a statutory watchdog, our role is to ensure that local decision makers put the experiences of people at the heart of their care, so that those who buy (commissioners) and provide services (NHS Trusts, GPs, the voluntary sector, and independent providers) can benefit from what Tameside people tell us.

What is this survey about?

In 2017, we carried out an extensive project around mental health. The report can be read at <u>https://www.healthwatchtameside.co.uk/report/2017-11-</u> 08/mental-health-report-2017.

The Living Well project started not long after the report was published, and the Minds Matter service was later launched.

Our intention was always to repeat the survey at a later date, to compare what effect the new services would have on the feedback received about mental health care. COVID-19 unfortunately delayed this project.

We launched the survey in May 2022, and it remained open until March 2023. The questions are the same as in 2017 (for direct comparison of responses), with a few additional questions based on the feedback received previously about the format of the survey.

We know from last time that people experiencing mental health issues (whether diagnosed or not) may find it difficult to engage with a survey.

We have provided the opportunity for as many people as possible to have a chance to take part, if they want to. The survey has been available for completion:

- Online
- On paper
- Over the phone
- At community groups
- In the community

The number of completed surveys in total was 198, using the following completion methods:

| Online | 145 |
|----------------|-----|
| On paper | 39 |
| QR code | 8 |
| Over the phone | 6 |

Key messages from the 2022/23 survey responses

The feedback has shown that people who seek support for their mental health have a mixed experience. There are some comments which give cause for concern, highlighting areas where improvements could be made. These can be grouped into the following key messages:

- Access to care access to care can be difficult for people who do not use the internet, or who do not like to use the phone when they are feeling unwell. When English is not a person's first language, that can be an added barrier.
- Care care is not always available when it is needed, especially in a crisis. There are long waiting lists for both diagnosis and treatment. Appointments are not always flexible for people who work or have family commitments. Services can be difficult to contact.
- 3. Care provided care that is provided is not always a positive experience. There can be frequent changes of staff, meaning stories have to be told again, which can be traumatic. Care may not be personalised, and reasonable adjustments are not always made when needed. People told us they can feel judged, and don't feel they are being listened to. Understanding of the complexities of their overall health (physical and mental) are not always understood by staff. When staff leave, or retire, patients can be left to struggle whilst waiting for their care to be rearranged.

- 4. **Carers** carers told us they do not always feel supported. They are not always given enough information to support their family member well, or told who they can talk to if they have questions.
- 5. **Communication** communication could be improved. Phone calls are not always returned, or messages passed on. People do not always know who they can contact if their mental health worsens.
- Discharge discharge from a service can be too early for some people. They told us that a higher number of therapy sessions would have prevented their mental health from worsening, leading to a crisis after the sessions stopped.
- 7. Information being provided with good information and explanations helps people to learn how to cope for themselves and take control of their mental health. This does not always happen. This includes being kept informed about what is happening and how long they will have to wait to be seen, and the availability of community groups and other support.
- 8. **Medication** medication works well for some people, but not for everyone. People told us they have been left taking medication which makes them feel worse, and are unable to get a medication review to look at alternative medication. Other people said they thought medication would help them, but it was not offered.
- 9. **Waiting lists** when people are on a waiting list, they told us this can result in additional mental health issues, and no-one checks to see whether their mental health has got better or worse.
- 10. Working together services do not always work together, whether this be teams within the same organisation, or different organisations who all provide care for a person.

The information in this report tells us that there is not enough help available for the number of people requiring support. People do not always want to talk to their families or rely on them for support. Support needs to be provided before a person reaches crisis.

Conclusion

The key messages from the 2017 report are shown on page 64. We have also included the 'I statements' which were co-produced in the community in 2017. These are still relevant today.

Although additional services were launched after the 2017 report, the responses to the 2022 survey are very similar. There is a mixture of positive and negative responses (although still more negative than positive), with the same themes appearing in both surveys.

It is interesting to note that the key messages for the 2022 report were written before looking back at the 2017 report, to avoid any bias. They are very similar.

So, have the new services not improved people's experiences in the way that was expected? Or is it that the demand for care has increased so much that mental health services are unable to keep up with the needs of the local population? Has Covid-19 affected the way the planned changes to services have been implemented? Or are there other factors to be considered?

This report will be published on our website and presented at various meetings attended by both providers and commissioners of mental health services in the coming months. We look forward to discussing the findings of the report, and how the feedback can be used to inform future improvements to mental health services.

The survey has been completed by a sample of people, and Healthwatch Tameside understands the responses may not be representative of all mental health service users. However, based on what we have been told, improvements to the care available would be helpful to many people.

Recommendations

 Access to care - our findings showed that access to care is not always straightforward, and people can wait a long time, be referred between services, or have care stopped mid-treatment. It can also be difficult to access emergency care when it is needed.

Healthwatch Tameside recommend that care is provided in the right place, with the right service, at the right time and asks that this includes giving consideration to where is the best place to support someone aged 16 – 18, or under 25 with special educational needs. Would children's or adult services be more suitable? Healthwatch Tameside will follow up with providers in 6 months.

2. **Communication** - our findings showed that communication is not always as good as it could be.

Healthwatch Tameside recommend that communication is improved (in all forms mentioned in this report), including the provision of information. Staff should actively listen to people and take them seriously, without judging.

The way people feel they have been treated has a big impact on whether they consider the experience to be positive or negative. Healthwatch Tameside will ask providers to describe how they have improved the provision of information in 6 months

Statements from providers/commissioners

Healthwatch Tameside shared the report with the following commissioners and providers for comments and a response to the recommendations outlined in this report.

- NHS Greater Manchester Integrated Care [Tameside]
- Pennine Care
- Big Life Group

Healthwatch Tameside received 1 response from the Big Life Group which is outlined below:

Big Life Group

My name is Heather Etheridge. I am Director at The Big Life Group, a voluntary sector organisation that delivers mental health services in Tameside.

The findings of this Healthwatch report are things we have heard over the last 12 months, whilst delivering services here. As a Mental Health system, there are a number of things we have done to improve some of the issues raised by people, but there is a still a long way to go.

Care

Access to care was discussed a lot in the report, and we are currently working on a system where there are multiple ways you can be connected to support; but if the place you are first connected to isn't the right place for you, we will find the right place for you. The workforce will have the permission to work with you and get you to the right place, so there is no wrong door, and you won't have to repeat your story to get what you need.

This sounds simple in practice, but the way services are commissioned and processes, can sometimes prevent this from happening. There is also a need for the whole workforce to be trained in person-centred and trauma-informed approaches, to apply those approaches in conversations with the people they support, so that every experience is a positive one.

Communication and Information

Communication does need to be improved across the system – communication with the person wanting to access support, the person who referred them, and their carer if they have one. The clinical mental health work force is extremely stretched across the country right now, but we have to find a way as a system to keep people informed, updated, and aware of their choices. With limited resources in therapy for example, people could be accessing other offers of support, and we need to ensure the whole workforce has the information to get people connected to other forms of support whilst they wait.

Language is also important - words like discharge can be triggering for people, and we have been discussing language as part of a quality review. Could other terms be used, such as 'next steps plan'. A clear next steps plan can also prevent mental health from worsening, as people know they can still access a form of support when needed.

Medication is a problem, and a shared care model is currently being looked at by colleagues at Greater Manchester level, to improve the experiences of people accessing medication.

Working Together

There has been lots of work done on services working together. There is now an official Living Well Partnership in Tameside, working on bringing all organisations and services together, to deliver one seamless Mental Health system in Tameside. This partnership includes The Big Life Group, Pennine Care, Tameside Council, The Anthony Seddon Fund, Tameside Oldham & Glossop (TOG) Mind, Change Grow Live (CGL) and Infinity Initiatives.

These organisations and services are now working together in a place-based neighbourhood model. Whilst we have achieved partnership working, we now need to focus on creating impact for the people of Tameside through this partnership. Our focus needs to be on services ensuring care and support is accessible to meet the needs of people, to equip them with information, communicate effectively with people, and ensure that people only have to tell their story once in order to get the support they need.

There is also a further step we plan to take in the next 12 months, to align Living Well (as described above) to work alongside Primary Care Networks and Community Mental Health Teams.

We welcome people to get involved with the work we are doing to make improvements across all services in Tameside. If this is something you are interested in, please feel free to get in touch.

Heather Etheridge, Director at The Big Life Group.

Introduction

Adult mental health was one of the three main areas that the public asked us to look at over the course of this year. For this project, we wanted to understand the experiences of using (or trying to use) mental health services in Tameside. Are there any barriers that prevent people from seeking help and support when they experience mental health difficulties?

We aimed to understand if there have been any changes to the experience of mental health provision as a result of the previous project that we ran in 2017.

Methodology

The number of responses has produced a variety of opinions and experiences. We look at all of these, both positive and negative, and where suggestions for improvements have been made, these are also included in the report.

Where possible we have used the actual words that people have used in their responses. Where a number of people have said something similar, we have summarised these together to avoid repetition.

The survey is in-depth and asks a number of questions. Not everyone completed all the questions. The number of responses for each question is shown.

This report has two sections:

Section 1 – 2022/23 survey (called 2022 survey in the report)

Section 2 - comparison to 2017 survey

Section 1

In section 1 we look at the responses to each of the 2022 survey questions. There is a mix of tick-box questions and a chance for people to tell us about their experiences in their own words.

Most people have not said in their free write responses to different questions which of the organisations or support groups they are talking about in that question. Question 6 responses list all the different organisations a person has been involved with. To avoid misleading anyone with only a few specific comments about any one organisation, we have not included organisation names in the other questions in section 1. Where we have a comment about a specific service, this has already been shared anonymously with the relevant service as part of our monthly reporting.

We have also included information collected outside of the survey.

Section 2

In section 2 we compare the results of the 2022 survey with the 2017 survey.

Glossary

There are a number of instances where abbreviations have been used for the name of organisations, services, and medical conditions. These are described within the report, but for ease, there is a complete list in the appendix at the end of the report.

Section 1

Survey questions

In this report, we look at each of the questions and the responses received in order. Some of the free write responses also answer later questions; these comments have been included with the most relevant question, to avoid repetition.

Question 1 – this question asks about the person completing the survey – 'I am completing this survey as:'

196 people completed this question, with some people experiencing mental health challenges themselves, as well as being a carer, family member, etc.



'Other' includes:

- Friends/neighbours of people with mental health challenges
- Parents of adults/children with mental health challenges
- Partners of people with mental health challenges
- Professionals completing on behalf of a service user
- Relatives of someone who committed suicide

Question 2 - Here is a list of examples of mental health conditions - we know there are others too. Please tick all those which apply to you.

Which mental health conditions apply to you? Anxiety 160 Depression 144 Panic attacks 81 PTSD 51 Mental health condition Personality disorder 29 OCD 25 Other 23 Psychosis 17 Agoraphobia 17 Dependency issues 16 Eating disorder 15 Bi-polar 11 Dementia 9 Schizophrenia 5 0 50 100 150 200 Number of people

194 people answered this question, many having more than one condition.

Other conditions mentioned include:

- Anger issues
- Bereavement
- Complex Post Traumatic Stress Disorder (CPTSD)
- Dysmorphia
- Emotionally Based School Avoidance (EBSA)
- Isolation
- Mental health affecting eating
- Multiple conditions, struggling to get diagnosis
- Paranoia
- Premenstrual dysphoric disorder (PMDD)
- Rather not say
- Self-harming
- Stress
- Suicidal
- Vertigo

Question 3 - Neurological conditions which can affect, or be affected by, your mental health could include the following. Please tick any that apply to you.

64 people provided information in response to this question. Some people ticked more than one of the choices.



Some people described more than one condition in 'Other', including:

- Brain tumour
- Dyslexia
- Dyspraxia
- Encephalitis
- Epilepsy
- Fibromyalgia
- Foetal Alcohol Syndrome Disorder
- Functional neurological disorder
- Herpes
- Lost eye in accident
- Multiple sclerosis (MS)
- Myalgic encephalomyelitis (ME)
- Neuro damage post-surgery
- Persistent Postural-Perceptual Dizziness (triple PD)
- Sensory processing disorder

Question 4 - Have you received care for your mental health in the past 12 months?

180 people answered this question.



The second part of the question says 'Please tell us more, and also whether you have a diagnosis'.

123 people provided additional information in the free write box. Many people talked about what they needed care for, but did not confirm whether they had a diagnosis, or not.

People who said they had received a diagnosis:



Some people told us about the support they received.



Some people provided information about waiting for support.

Others told us about support they felt would be helpful, but could not access. Some had received support previously, but it was no longer available to them.



We will now look at the comments provided in response to this question, grouped into themes. Our findings show:

Many of the comments repeated information about the condition(s) they had been diagnosed with. This has been covered in questions 2 and 3 and will not be included here. The remaining comments were mainly negative.

The question asked about receiving care in the last 12 months. Comments were also received from people who had not accessed care in this period, with many including the reasons why not.

Positive comments:

- People told us how they have been learning how to cope.
- Non-medical therapeutic help such as art therapy and music is appreciated.
- Regular appointments with CPN, psychiatrist, community mental health team, etc. are helpful.

Negative comments:

- Cannot get a referral:
 - School won't refer child for counselling.
- Discharged:
 - After counselling stopped, mental health worsened.
 - Discharged after autism diagnosis, with no care for mental health provided.
 - Discharged without support in place, leading to a crisis.
 - Son discharged by CAMHS before diagnosis, so no treatment or help being provided.

Depends on your definition of 'care'... I've been under the mental health service but would not say I've been 'cared for'

My family member has been under mental health services for decades. We had been raising for years that we thought they were Autistic. This kept getting dismissed. They have numerous mental health difficulties. A lot of them caused by harm from services treating them as though they weren't Autistic. Which has created significant trauma. latrogenic harm! They were finally diagnosed Autistic and we thought we would finally get the right treatment. Now we're told Autism isn't a mental health condition and discharged from all services. This is absolutely appalling! We know Autism isn't a mental health condition, but all the other things are! Saying to us Autism is the primary diagnosis and then leaving them! Suicide is the biggest killer for Autistic people. 9 times more likely to die by suicide than the average person and this is why!

Family member

- Had to pay for private care:
 - No response to referral after several months waiting, so accessed care via work or privately.
 - Too long to wait for NHS care when mental health worsened. 'My counsellor is very good, but it cost a lot'.

Private counsellor is great but the financial stress of trying to pay for it sort of cancels the benefit sometimes.

- Unhappy with diagnosis made by NHS
 psychiatrist, and lack of knowledge of other staff, so patient arranged private diagnosis and care with psychiatrist who understood symptoms.
- Unhappy with response from staff at NHS appointment and arranged private counselling.

- Late diagnosis:
 - Diagnosed with Autism as an adult – issues throughout life with bullying and being told they are not good enough.
- Made a complaint about lack of care.
- Out of area care inpatient bed required urgently, and after 2 days a place was offered nearly 200 miles away. Family had to drive patient there, and large costs to family for visiting over several weeks. Mental health of family affected by the experience.

I found myself in a horrible place and had to pull myself out of it using help from a private company. The government/NHS funded services are much too stretched at the moment and, unfortunately, I believe this will get worse in the coming months due to the cost-of-living crisis.

- Person with mental health condition refusing to access support:
 Son not attending charity support and won't do online support.
- Receiving care, but not enough:
 - Had a group session but they don't help.
 - Have regular appointments but sometimes can't manage and need additional support.
 - Received some support, but not for all issues.
 - Struggling with past experiences.
 - Take medication but still struggle daily.
- Unable to access care:
 - No contact since Covid.
 - Previously diagnosed, but unable to access support recently.
 - Psychiatrist left post, and patients left to struggle without any contact since.
 - Referrals made, people assessed, but still waiting for support:
 - Resulting in additional mental health issues.
 - Still waiting for the right treatment and medication.
 - Tried to get bereavement counselling without success.
 - Unable to get an appointment.
 - Waiting for years.
 - Wants a face-to-face GP appointment.

Elderly mother has a chronic recurring serious depression which debilitates and has hospitalised her for 3 months at least 4 times in the past 10 years. She is drug resistant and only recovers through other treatment, which is no longer offered to her (too old?). Due to a lack of continuity of care (her care coordinator has retired and her psychiatrist has been changed) our pleas for help were ignored. There is no time for weeks of observation and increased drug dosages as she does not improve and rapidly declines into psychotic depression.

Family member

We are told later in the survey that some people do not think there is anything wrong with their mental health, so have not asked for help. Families and friends feel limited in what they can offer without professional support.

Question 5 - Have you used any of the following services for your mental health in the past 12 months?

Have you used any of the following services for your mental health in the past 12 months? GP 126 1 to 1 counselling 44 A & E 35 Community support group 29 Type of service Other 26 Psychiatrist 23 111 15 CPN (Community Psychiatric Nurse) 12 Group therapy 9 Mental health ward 8 999 7 Walk-in Centre 7 100 20 60 80 120 140 0 40 Number of people

163 people told us which services they had used.

'Other' includes:

- CAMHS
- Carers
- College
- Community/neighbourhood mental health team
- Counselling arranged by employer
- Early intervention team
- EMDR therapy
- Healthy Minds
- Hospital
- Mental health helpline
- Mental health practitioner/nurse
- NHS website
- Parent
- People explaining why they haven't used services
- Play therapy for NVR (non-violent resistance) parenting
- Private psychotherapy
- Psychologist
- Research papers
- Spiritual director
- The Samaritans

Question 6 - Please tell us the name(s) of the organisations and/or groups you have used. If there is more than one, do they work together?

129 people answered this question, although only 9 people answered the second part. These 9 people said that organisations do not work together.

The following graphs show which organisations people said they used. However, not all the services were mentioned in the responses to this question. For example, only two people mentioned their psychiatrist in this question, but in question 5, 23 people ticked the box to say they had seen a psychiatrist in the last 12 months.



There are also services which have only been mentioned once:

- Hattersley Hub
- Jigsaw Housing
- Manchester Rape Crisis
- Probation service
- Psychologist at allergy clinic
- School
- Silver Cloud



There are also organisations which have only been mentioned once:

- 42nd Street
- Action Together
- Barnardo's
- Beacon Counselling
- Christians against Poverty
- Magical Memories
- NVR parenting
- Positive Steps
- Research papers
- The Samaritans

The remaining responses said:

- 5 people had not used services.
- 5 people had accessed support arranged by their employer.
- 7 people had accessed private care they arranged themselves.

The second part of the question asked whether services worked together.

Only 9 people responded, and they all stated that services did not work together.

The comments included:

- Being passed from one service to another, as they don't work together.
- Different teams within the same organisation do not pass on relevant information.
- Gave consent for services to work together with family, but this doesn't always happen.
- NHS provider and private provider did not communicate.
- Professionals appear to work separately (supported housing organisation helped to co-ordinate GP, psychiatrist, and CPN).
- The family did not feel care was co-ordinated.

I am telling my story over and over again and when telling the services what's happening, they just fill in their tick sheet and do not listen to me. Why don't they share information with services so all know my case?

Service user

It would be BRILLIANT if they DID all work together.

Question 7 - Have you been prescribed medication for your mental health?

178 people answered this question.



Question 8 - Do you take your mental health medication?

162 people answered this question.

Out of the 48 people who answered 'No', 31 people also answered 'No' to Question 7 (they had not been prescribed medication to take). The second graph excludes these responses.



72 people included information in the free text box.

The prescribed medications mentioned included:

- 11 Sertraline
- 4 Fluoxetine
- 3 unspecified antidepressant
- 2 each for Citalopram, Mirtazapine, Pregabalin, propranolol/beta blockers, Quetiapine
- 1 each for Amitriptyline, Diazepam, Escitalopram, Promazine, Venlafaxine

Here are some of the comments about taking medication:

- Always take medication:
 - I take diazepam when my anxiety is particularly bad and I can't cope.
 - I take this daily without fail. It really helps me.
 - It is likely that I will need to stay on this medicine long term.
 - My husband takes medication for his Alzheimer's to slow disease down.

• Sometimes take medication:

- He was only prescribed for 2 months but didn't take regularly.
- $\circ~$ I do forget to take my medication as my memory not great.
- I do take it most days but occasionally get tired of taking tablets and take days off.
- I suffer from 'brain fog' and sometimes forget to take medication on time.
- It makes me drowsy. Also, it can affect my sex drive so I don't want to take it.
- Makes me feel numb and tired all the time.

Most of the time I do, but because my medication is never reviewed (as it should be) nor my diagnosis, I often question if it's even effective.

Service user

I have to take my medication because if I don't, I will be back to wanting to take my own life.

Here are some of the comments about not taking medication:

- Not happy taking medication:
 - As a vegan and someone who does not feel comfortable with chemical interventions, I have managed my mental health myself.
 - Doctor unsure if they will affect my epilepsy medication.
 - I don't want medication.
 - I don't find pharmaceuticals work for me. I take herbal alternatives that suit me better and don't have side effects that impact on my symptoms.
 - I was prescribed but felt it may be responsible for dramatic hair loss. GP has not prescribed an alternative.
- Medication has not been prescribed:
 - I asked about medication for Dementia, but doctor has not prescribed. We have been referred to Admiral Nurse service.
 - Not currently prescribed any medication.

No one has diagnosed my grandson's problem therefore he cannot be treated.

Family member

- Stopped taking medication because:
 - There were side effects:
 - It didn't suit me excessive tiredness, escalated depressive moods.
 - It made me ill and triggered a cardiac arrest. Kept vomiting, felt dizzy, loss of bowel control.
 - Made me feel worse.
 - Prescription stopped:
 - Following recent hospitalisation, I was taken off it and haven't had to take it since.
 - GP stopped prescription and alternative not provided.
 - I could not get GP appointment to arrange to continue medication.

Question 9 - Are you able to get appointments for your mental health when you need them?

163 people answered this question.



98 people provided comments in the free write box. 19 of these people had answered 'Yes' to this question, 39 people answered 'No', 34 people answered 'Sometimes' and 6 people did not select an option, but provided a comment.

We have summarised the comments below, set out in themes.

Positive comments:

- GP appointments:
 - Doctor is very good.
 - GP provides regular check-ups.
 - GP is supportive.
- Mental health care:
 - A counsellor has helped me for the last few years. I know I can contact her if I'm in need of help.

My doctor understands my mental health and is a great help. She explains things to me so I know how to look after myself.

- Initially had to wait quite a while for CBT but once I was allocated a therapist we agreed when would be a suitable time to meet.
- Can always speak to mental health team.
- If needed I can approach my HR department to ask for further help, but so far, I haven't needed any since my sessions ended.
- Have regular appointment with CPN/counsellor.

Negative comments:

- Discharge:
 - Discharged as soon as diagnosed Autistic.
 - Discharged early when symptoms had worsened. Didn't want to know about suicidal thoughts.
- GP appointments:
 - Face-to face:
 - Depends on level of appointment asked for... and who with. They need to be face-to-face. They seem reluctant to do face-toface appointments.

I could get a telephone appointment, but this is not what I need. I don't want the doctor to be prescribing other medication without seeing me and I can't get a face-to-face appointment with him.

- Not easy getting to see my GP.
- Phone calls:
 - Always fobbed off. People promise to call back, they never do.
 - Have a lot of problems sleeping so can't get up at 8am to ring GP surgery for an appointment.
 - I do not want to discuss over the phone with the receptionists.
 - I struggle to get appointments I don't like talking on the phone.
 - It is difficult to speak to the same GP twice and I do not want to keep discussing traumatic events.
- Waiting time:
 - I cannot get an appointment on the day if I'm having an extreme episode and when I call for routine {appointment} they are all gone.
 - Last week (in September) I booked a face-to-face GP appointment and the first one I could get is October 31st - have to wait over a month.
- Long wait for mental health care appointment:
 - Assessed in August 2022, given appointment for February 2023, even though had to present at A&E for overdose.
 - Been waiting months for a counsellor.
 - Received quick appointment to discuss issues, referred to correct team on a waiting list. No-one can tell me how long the wait will be.
 - When my daughter was first referred, we were told approx. 10 weeks for a first appointment. It took 17 weeks!

My former therapist retired. When he left, I wasn't picked back up or passed on to another person. I phoned them and they had closed my case file. I wasn't aware of this until I phoned to chase who I would be passed onto. I have been waiting over a year to be accepted again and back in therapy. Nobody wants to help me and just never receive any responses back.

Service user

- Mental health care:
 - Access to care:
 - Anything beyond my GP seems impossible.
 - Referred to counselling but there was no flexibility with appointments; I work full time and am a single parent.
 - The number of sessions of therapy is not enough.
 - Unable to access the care I need.

More flexibility and support for individual needs. I am trying to work to keep a roof over my head but services don't work around my circumstances. Everyone isn't available 9 – 5 when trying to book appointments.

Service user

- Lack of response:
 - Referred for therapy but no response received.
 - Very challenging to speak to professional in this sector.
- Private care:
 - Had to arrange care via work as NHS waiting list too long.
 - The wait was too long and I was really worried about my mental health so I went private.
- Other support
 - There isn't any support for dementia.
 - Using some of the hotlines, they do get busy so you don't always get through.

Had to fight, beg, make numerous phone calls to eventually receive CBT for anxiety.

Service user

Suggestions:

- Autism training for staff they don't understand the Autistic experience and invalidate my reality because of lack of training.
- For some people I feel telephone support would be beneficial.
- There's not enough help available for the amount of people suffering.

Question 10 - What would help you if you have not been able to make an appointment?

123 people answered this question.

A number of people explained what they would do, rather than what would help them. They said:



Some of the responses provide feedback which is also included within other questions. We are not repeating the information here.

14 people said they did not know what would help them. 7 people said nothing would be helpful.

Within the responses, people talked about wanting to be taken seriously, and to feel that people cared about them.

- Offer of someone to talk to whilst waiting
- Regular check-ins to see whether mental health has improved or deteriorated whilst waiting for appointment. This could be by phone or video call.
- To be put in contact with a counselling service.
- Walk-in clinic.

Information. I feel that knowledge is power. I like to read and having readily available information that will help me manage my symptoms can help.

Service user

- offered.
- for appointment.
- Anxiety kicks in and I don't want to leave the house.

Service user

Here is a summary of the responses explaining what would be helpful if an appointment is not available.

- Communication:
 - Open and honest conversations.
 - Return any phone calls made to a service.
 - To be kept informed about referral and waiting time.
- Easier accessibility to services:
 - Being able to speak to someone straight away, rather than being passed on for an observation.
 - I would be happier if I could just go into my GP surgery and make an appointment.
 - Knowing an appointment will be made available in a few days would be helpful.
 - To re-arrange appointments cancelled by service provider quickly.
- Information and advice:
 - Provide information about community groups and drop-in sessions.
 - To help manage symptoms.
- Medication a prescribing service other than the GP to be made available.
- Support:
 - From employer.
 - Interim or short-term NHS support to be

Question 11 - Do you feel listened to and respected by the people who provide mental health care for you, or the person you care for?

161 people answered this question.



75 people provided comments in the free write box. 17 of these people had answered 'Yes' to this question, 26 people answered 'No', 28 people answered 'Sometimes' and 4 people did not select an option, but provided a comment.

Some of the comments described what was good or could be improved about care provided. These will be included later in the report with the responses to questions 16 and 17.

We have summarised the feedback about listening and respect into themes.

Positive comments:

- Staff are described as:
 - o Compassionate
 - o Courteous
 - o Helpful
 - o Kind
 - o Listen to me
 - o Respectful
 - o Sympathetic
 - Understanding

These comments related to both the person receiving care and/or their carer.

Negative comments:

- Carers:
 - o I don't think that our needs were taken into account.
 - No-one to talk to about concerns.
- Listening:
 - I end up taking my husband to confirm things I say and then GP listens to him.
 - Not everyone listens to me.
- Service user feelings:
 - Don't feel listened to or supported, feel brushed off.
 - I have suffered with depression and anxiety for the last few years of my life, and I have only started receiving help now. I had previously reached out for help yet never got anywhere with it, I always felt ignored and neglected.

Nobody really cares. First off, I'm a man, why would they care? Genuinely anytime I've called a place because I'm not okay and want someone to talk to, everyone says it's wasting "valuable time".

Service user

- I feel like because you state mental health, practices don't take it seriously and just fob you off.
- GPs surgeries are the worst. Talk down to me.
- Staff are described as:
 - I have found the professionals at and to ultimately be dishonest, uncaring, disinterested, aggressive and mocking.
 - Staff have been rude, dismissive, and evasive.
 - They do NOT care. Nor listen. Disrespected constantly. No compassion.
 - Consultant was very negative and insensitive at the point of diagnosis and said we were left to get on with things on our own (dementia).
 - Some counsellors excellent, others less so (lacking some empathy).
 - One junior doctor was actually respectful and listened. Others were unhelpful and appeared generally disinterested.

If doctors had taken the time to listen when I previously reached out for help it would've saved me a lot of struggling and could have prevented my mental health from deteriorating

Question 12 - Do you get enough information to understand about care provided for you or the person you care for?

156 people answered this question.



50 people provided comments in the free write box. 6 of these people had answered 'Yes' to this question, 26 people answered 'No', 13 people answered 'Sometimes' and 5 people did not select an option, but provided a comment.

Positive comments:

- Community groups provide information.
- Good at sending out information.
- I have had information from my GP and the Dementia team.
- Look online.
- My doctor explains things.
- The online course is very good.

Negative comments:

- Family/carers:
 - After dementia diagnosis you are given a pack but then it is left up to you.
 - Family given limited information.
 - Family not provided with information about support techniques to help child.
 - Sent YouTube videos that are patronising and not helpful.

- Service user:
 - Been referred but still waiting for some support. This is not good as you
 just don't know when you're going to be offered help.
 - I feel that in mental health services in general, communication is not good.
 - I had to find out information through work.
 - o I wouldn't say I'd had much information about my mental health.
 - \circ It has been very variable.
 - $\circ~$ l've had no information that helped me.
 - Not always told about waiting list and treatment available.

I would like to know more about what will happen in the future. Because I live alone, I do feel a bit vulnerable now.

Service user with mild dementia diagnosis

General comments:

- I forget a lot because of brain injury.
- I have done my own research.
- I have learning difficulties.
- I have not asked for any information. My mum helps me with things and has organised my assessment.
- I would like to see more information for LGBTQ+ people.
- I'm not online so it is difficult.


Question 13 - Do your family or friends know how you are feeling?

165 people answered this question.



59 people provided comments in the free write box. 21 of these people had answered 'Yes' to this question, 13 people answered 'No', and 25 people answered 'Sometimes'.

Some of the comments were repeated in the responses to Question 14, and are not included here.

When people talk to their family/friends:

- All my family know and my work colleagues.
- Her family are looking after her. Grandchildren do care and make sure that she is alright.
- I only tell certain people about my mental health. I don't wish to share with everyone.
- My husband is really supportive, my children and friends are also there.
- They know about my conditions but don't really understand how I feel.
- We have family carers that know the issues.
- With my family I keep myself open. They know what to look out for.

When people don't talk, and why:

- I am still learning to open up and be honest.
- I try not to let them know as they have their own issues to deal with.
- Keep things to myself.
- My relative is very guarded about what happened to him and doesn't discuss it.
- Says family broken by social services, who have placed children with the mother of service user.
- With end stage dementia it is difficult for the person to express how they are feeling.

Other comments:

• They are as frustrated as me - both my adult sons are struggling too.

Question 14 - Not everyone has family or friends who can provide support. If you do, what support do they provide? Are they able to provide the support you would like? Are you happy for them to support you?

116 people answered this question.

Some of the comments have been included here from Question 13, to avoid repeating information from the same person.

Family and friends mentioned as providing support included:

- Brothers and sisters
- Children
- Church
- Family
- Friends
- Grandchildren
- Husband/wife, partner
- Parents
- Trusted people
- Voluntary groups
- Work colleagues

Few people specifically answered the last two questions. Of those who did, not all families and friends were able to provide the support people needed. Where support could be provided, people were generally happy to receive it.





'Support' includes:

- Emotional support.
- Where people say they are helped by someone else but have not explained how.
- Where the word 'support' has been mentioned.

'Other' includes:

- Distracting me from what is in my head.
- Helping me to express my thoughts.

Some people received limited support, with reasons given including:

- Family and friends not available all the time as they are at work.
- Family and friends not available at night when person alone.
- Family and friends not knowing how to help, other than be there to listen.
- Family and friends not understanding enough about mental health, and/or Autism, etc.
- Family and friends not understanding what would be most helpful.
- Professional support needed.

Many people told us why they did not receive support from family or friends. Here is a summary of the reasons support was unavailable:



'Other' includes:

- Carers need time to look after themselves.
- Difficult when 16-year-old is expected to access online adult services, even with a learning disability.
- Need to be careful who you share your feelings with.
- Prefer to talk to a psychiatrist when feeling suicidal, so as not to worry friends and family.
- Prefer to talk to people outside family and friends.

How can I be happy about discussing my darkest feelings with people I love or care about? It's a massive ask? A burden for most, maybe because of how it is most commonly perceived in society?

Service user

Question 15 - Do you have any other illnesses or conditions which affect, or are affected by, your mental health? Please say what, and how they are affected.

101 people provided feedback about other illnesses and conditions. Of these people, 23 people answered 'No' or 'N/A'. 1 person answered 'Yes' with no additional comment.



Here is a summary of the conditions mentioned more than once.

Conditions mentioned once included: - Anaphylaxis, eye condition, foetal alcohol syndrome, hair loss, immune thrombocytopaenia, long Covid, neuropathy, phobias, tuberous sclerosis complex, and unsteady on feet.

People described how these physical conditions affected their mental health, or how their mental health affected their physical conditions. Here is a summary.



Other ways people were affected which were only mentioned once included:

- Brain fog
- Eating disorder
- Feeling poorly
- Frustration
- Lack of independence
- Lack of motivation to exercise
- Shout at people

Question 16 - What is good about your mental health care?

121 people provided a comment.

To summarise the positive comments:



Positive comments

We will look at the comments describing what was good about care/support in the order listed in the chart above. They included:

Staff:

- Words used to describe staff include:
 - o Experienced
 - o Friendly
 - o Kind
 - o Supportive
 - o Understand

Fabulous therapist. Learnt strategies to help me to manage my emotions and responses.

Service user

feels.

Mental health survey results 2022/23

Care provided (NHS):

- Accessible.
- Follow up was provided.
- I can get help when I need it.
- Local.
- Not being seen as attention-seeking by the therapist.
- Person-centred.
- The group at the hospital was very helpful but my wife will not go there now.
- The well-being and mindfulness sessions are good for me.
- There seems to be more support now but still room for improvement.
- Weekly sessions with the same counsellor.

Was listened to:

- Don't feel alone.
- Feel comfortable talking to the worker.
- Kind listening coach.
- Opening up to someone.
- People listen to me. I am able to make my own choices.
- Someone is always there for us to speak to.
- The therapist really listens to my partner. •

Medication:

- I take meds every night.
- My doctor prescribes me on time and wants me to get well.
- The medication I take is under constant review.

Community/peer support:

- I couldn't manage without their support.
- I recently went and might go back. It did help a bit.
- The network of people who know how it

Attending peer support group really helps to keep mental health stable.

Service user

It's personal to me and I feel I can tell the worker anything and not feel like they are judging me.

Service user

My partner has been 11 times to see a counsellor, and is so lucky. He said the 1-1 sessions are helping greatly with his PTSD.

Partner of service user

Advice/information:

- What was good? Advice and a person to talk to.
- Explained everything well to me.
- Helpful information.

Online care/helplines:

- My mental health has been helped by support.
- My way of "releasing" is to self-harm, but they have talked me down before.

My online supporter encourages me to keep going and the course helps you to overcome the problem yourself.

Other positive comments:

Personal strengths:

- I allow myself to have days doing nothing.
- I have learnt to recognise when my mental health is poor and when I need to rest.
- I have taken control of my own mental health. I try to be mindful of the things I do have and that I'm grateful for.
- I think I am a strong person.
- It has enabled me to self-manage with the help of medication. Also, I have good insight into my mental health.
- Opening up to someone, not bottling things in.

It gave me clarity of thought, how to deal with situations better, how to cope when I could feel myself spiralling.

Service user

Service user

9 people said they are responsible for their own mental health.

Not everyone had anything good to say. The comments from these people were generally brief, including single words such as 'Nothing'.



Question 17 - What changes could make your mental health care work better for you?

125 responded to this question. Some of the people who did not complete this question did include comments within earlier question responses which are included here.

We have summarised the suggested changes into themes:



6 people said nothing needed improvement, and 8 people didn't know what to suggest.

What could be improved?

We will now look at each of the suggested improvement themes in more detail, in the order listed in the above graph. Many of the comments are repeated by different people.

Support/care provided:

- Be more responsive.
- Better support.
- Greater consistency of staff and continuity of care.
- Longer GP appointments to be available where required.
- More face-to-face appointments.
- More flexibility of appointments for people who work.
- Not waiting for a crisis before providing support.
- Provide a promised service without waiting for a complaint to be made.
- Provide follow-up care and regular check-ups.
- Provide non-judgemental counselling with the right specialist.
- Provide the right diagnosis/service with the right professional.
- Support for young people, in the right service for them.
- The number of counselling sessions to match the need of the person receiving counselling.
- To be able to seek help when needed.
- Prevent discharge from service because of lack of engagement.

The repetition of what my problems are makes me feel worse. A lot of appointment time is wasted going over past history when they should just read the notes beforehand.

Service user

visit A & E for support.

Being able to get support at 16

when nobody wants to know.

Suicidal and self-harms. Have to

Parent

Easier access to care:

- Being able to contact GP or mental health service.
- Easier access to appointments (GP and mental health services).
- Easier emergency access to mental health care.
- More direct approach to care rather than triaging and moving from list to list.

Poor service which is not fit for purpose - too many delays and steps in place for people who have significant anxiety.

Service user

- Out of hours contact.
- Provide a choice of accessibility options. Not everyone has access to, or is able to use, the internet. Other people may find it difficult to talk on the telephone. English may not be the first language of the person asking for help.
- Reminder/support to attend appointments when feeling unwell.
- Schools to refer for counselling.

Staff interactions:

- Increase awareness of what 'mental health' is.
- Less interrogation.
- More understanding generally.
- More understanding of complex conditions (physical and mental).
- Need effective communication skills.
- Not being judged and not put into the wrong boxes.
- To be treated with respect and listened to.
- To spot the signs earlier and to take people more seriously when they reach out for help.

Reduce waiting lists:

- Access to different groups and therapies that you don't have to wait a long time for.
- Provide counselling when it's required and not having to wait for months to do it.
- There are long waits for assessment for every mental health service.

Therapist support available sooner would have helped me address my issues much sooner, but the service is in high demand

Service user

Meet individual needs:

- Be more customised and personal.
- Consider what physical conditions are affecting mental health. Is support being provided for these conditions?
- Consider whether a 16 18-year-old is ready for adult services before making any changes.
- Find something that works for my partner.
- Is care being provided by the right person, or could a change of support worker be considered?
- Listen to what the person receiving the care wants, rather than offering standard option.
- Look at a person holistically.
- Make it easier for people with Autism to communicate via email instead of phone call.
- Provide support through play/creative counselling/therapy rather than just talking, especially for young people with a special educational need.
- Would the person receiving care benefit from having a regular support worker?

Letters contain 'threats' and intimidation of discharge if they don't follow the rules to the T. Or forget them or get emotional. This isn't support. This is making people who need support fear services and professionals, which makes people more vulnerable as they can't then be safeguarded.

Carer

Additional resources:

- A 'drop in drop out' would help, so you didn't have to keep referring us to the services.
- Having appointments in a therapeutic space rather than a clinical setting.
- Having more mental health nurses.
- I wish Safe Haven was still open.
- More emphasis on prevention.

A & E is NOT the place for mental health sufferers to go. It is a hugely traumatic experience. There needs to be a separate emergency area.

Service user

Once a personal diagnosis has been achieved, tailor to suit my needs rather than all expected to sing from the same hymn sheet.

Service user

• More therapists to work in doctor's surgeries.

Communication:

- Information sessions for parents on how to support an anxious teen.
- More communication generally.
- More transparency.
- Provide more information.
- Provide updates.
- Receive a return call when I leave a message for professionals.
- Sometimes messages don't get passed on.

Medication:

- Provide medication when it will be helpful.
- Review medication regularly.

Training:

- Better understanding of dementia patients.
- Encourage more conversations about Autism.
- Provide Autism training to all staff.
- Provide more mental health training for staff.

Get a diagnosis:

- Get the person diagnosed by the right professional.
- Too long waiting for a diagnosis.

More social/peer support:

- More accessible support groups.
- To meet more people for coffee and a chat, then that will help each other.

Other:

- Complete overhaul of system.
- Different working practices.
- Improved assistance from work.

Working together:

• Services to work together.

The system is not built to be approached by people struggling with their mental health issues.

Service user

Service user

I will feel happy if I get my diagnosis. It might help a lot of things fall into place. I hope it will lead to me getting help to find a job.

Service user

Working with my family more and ensuring they contact them when I've given consent.

Mental health survey results 2022/23

• Services to work with families and carers.

Question 18 - Do you have any other comments about your mental health care? Healthwatch Tameside wants to understand what works for you, and what makes you feel worse.

Many of the comments provided in responses to this question summarise what people had said in previous questions, particularly question 17. We will not repeat those comments here, but will include any additional comments or suggestions.

Suggestions:

- Improve knowledge about mental health care:
 - Increase understanding of less wellknown conditions.
 - Information:
 - For LGBTQ+ and BPoC community.
 - Generally.
 - To help parents.
 - Mental health and wellbeing should be more heavily included on the school curriculum.
 - Open days.
 - Visits to schools and more support in schools.
 - Ways to access care.
- Increase services for eating disorders.
- Make reasonable adjustments to help service users who need them.
- Make sure appointments are accessible by public transport.
- Remove the 'taboo' of mental health, and the shame people feel.
- Take anxiety more seriously.

The mental health nurse is not advertised anywhere so patients are unsure how to access and therefore avoid altogether.

Service user

As a parent, hearing a child of any age tell you they want to die is the worst thing. I would have liked to have known how to handle it in a better way.

Parent

Reach out please to more of the Asian and south Asian community. Our community shun and hide away from it (it's the elders who don't understand mental health) and it affects so many people.

Service user

A few people commented about the mental health system in general:

- Can only get care if your mental health is bad enough for you to be on a psychiatric ward.
- Feel let down after working hard and paying into the system all their lives.
- Feel let down by the provider I work for do not look after our own staff well enough.
- Need better social care funding, to support people with mental health conditions.
- Service not fit for purpose.
- Services are flawed.

It's been so bad trying to access basic support. I asked for a personal health budget but was told I can't have one because I don't use NHS services enough (because they won't provide me with a service). It's appalling and to be told by numerous staff that they "understand I've been let down repeatedly" and it's "not good enough" only for nothing to change is soul destroying.

Service user

A few people commented about this survey. These included comments about:

- How completing the survey made them feel worse.
- Seems pointless as nothing will change.

- The survey being long.
- Unhappy with wording of questions.

The second part of the question asks about what works for people, and what makes them feel worse. The following is a summary of the responses:

What works for people:

- Adoptive parents received support from organisation which supported child's mental health and rebuilt family relationships.
- Being able to get help when it is needed.
- Being able to talk about mental health and not be judged.
- Being alone.
- Helplines.
- Peer support and community groups.
- People want to feel:
 - o Acknowledged,
 - o Believed,
 - o Listened to,
 - o Safe,
 - \circ Understood,
 - \circ Valued,
 - o Welcome.
- Regular check-ups and a care plan that is followed.
- Staying in bed.
- Talking to people.

What makes people feel worse:

- Behaviours by staff such as:
 - Judging a person without understanding the circumstances.
 - Unhelpful comments and advice.
 - Victims of past violence (leaving physical scars) not being believed when later asking for help with

Being told by the helpline that I need to "try harder" when I say I'm not coping isn't helpful.

Service user

Peer support has been a lifesaver. Knowing I can go somewhere even when I'm in a state and people won't judge me is priceless.

Service user

mental health. Staff assume scars are self-inflicted harm which "feels like being victimised twice over".

- Being alone.
- Lack of communication.
- Lack of support:
 - Being sent home from A & E without care.
 - Form filling for help, such as benefits or the blue badge, adds to the stress of caring.
 - Leaving families trying to cope, often affecting their own mental health.

When people are crying out for help, take note. If a person at crisis does reach out, they are actually desperate.

Service user

- \circ $\,$ Long waiting lists for diagnosis and care.
- $_{\odot}$ Sitting in A & E waiting for tick boxes to be completed.
- $\circ~$ When in a crisis and feeling suicidal.
- Medication (or lack of), and missing medication reviews.
- Stressful environments.
- Worry about dying.
- Worry about needing treatment (other than medication) from a mental health professional.

Other data collected

Focus group

In November 2022, we met a group of six service users at the Whittaker Unit (Pennine Care). Many topics were discussed. We have summarised anything relating to mental health care here. The other topics were included in our anonymous monthly reporting, and shared with the relevant provider.

The topics have been grouped into themes:

Change to female single-gender wards and being located in Stockport – concerns about:

- Have to see a different specialist.
- Too far for people to visit.
- What happens when discharged? Who provides the follow-up?

Community support groups:

- Partner has mental health conditions and goes to Anthony Seddon Fund and TOG Mind.
- People like to be listened to. "My faith really helps me. I get a lot of support for my mental health and other conditions from the church and the church community."

Emergency care:

 Has vascular dementia and went to A & E with the condition. After 19 hours, had still not been seen, and couldn't stand the environment any longer, so left (noise, bright lights).

Mental health care:

- During Covid there was no contact not on the phone, by video or in person.
- Hates phone consultations, just can't cope with them.
- I've found that support for people over 65 is very different. I support my daughter who is in her 30's and we can't seem to be able to get anything to help her.

- Not had an assessment in last 3 years – pathway has changed? Now attends group at Whittaker Unit which is great.
- Son has schizophrenia fantastic service.
- Staff are good but services overstretched.
- Staff treat you with compassion and are welcoming to the group.
- Transport costs are becoming a barrier to attending groups, appointments, and daycare services.

The talk about going out after the lockdowns made me feel so anxious. I didn't want to go anywhere. I didn't want to go back to the groups that I went to before the lockdowns. It has been really stressful trying to make myself leave the house.

Service user

Physical health:

- Pain following surgery affected mental health badly. After a few years previously of improving mental health (starting with an inpatient stay and then regular psychiatrist appointments), I was right back having to start again. Drugs can only go so far. Support from family and friends helped.
- Partner's planned heart surgery cancelled at short notice, and 3 months later still not re-arranged, even though GP sent them to A & E by ambulance. The worry is affecting the mental health of both the patient and their partner.

Services people use and/or are aware of:

- Admiral nurses
- Anthony Seddon Fund
- Church groups
- GP
- Healthy Minds
- Home intervention team
- Infinity Initiatives
- Mile of Smiles
- Minds Matter
- Pennine Care helpline
- TOG Mind

Outreach

In November 2022 we attended an event at Tameside College. Comments received about mental health included:

- Person said that she had been in the care of CAMHS. She and her mother attended an appointment with a psychiatrist who said to her mum, "This is the last session with CAMHS", and that her daughter would be transferred to the adult team. The psychiatrist said, "Good Luck with that".
- Person said that she too had had her last session with the CAMHS service. A similar thing was said to her and her mum. They were told that the psychiatrist didn't know if the adult service would be able to find anyone to treat her.

Healthwatch England maternal mental health survey

A survey was carried out nationally in November and December 2022 by Healthwatch England. There were 7 responses from people living in Tameside, and the following feedback was provided about mental health in relation to maternity.

Experienced mental health difficulties for the first time:

- I was given information about organisations to contact for more mental health support.
- Staff seemed to have very little training and not enough time to offer the support needed when I experienced post-natal depression and anxiety.

Experienced an episode of a mental health problem that I had previously recovered from:

- Covid lonely and isolating time because of the fear of the unknown during pregnancy. Attending appointments, giving birth, staying in hospital – all alone. This was absolutely horrendous and terrifying, and absolutely what resulted in my severe post-natal anxiety and depression.
- I was referred to a mental health support service.
- I wasn't offered a referral or any information about organisations.
- It is only later down the line (baby aged 6 months) that my mental health has suffered and at this point, there is no support.
- My symptoms got worse whilst waiting for treatment.

Experienced mental health difficulties in addition to my current mental health problem(s):

• I was given information about organisations to contact for more mental health support.

The final questions in the survey ask about the post-natal check-up. Within the Tameside responses, all respondents said that either not enough time was spent asking about mum's mental health, or that it wasn't mentioned at all. The national findings can be found at https://www.healthwatch.co.uk/news/2023-03-14/six-week-postnatal-checks-are-failing-many-new-mothers

CQC reports about mental health nationally 2021/22

The Care Quality Commission (CQC) publish reports each year about the state of care in a particular sector. Here are the links to the latest reports which include mental health:

https://www.cqc.org.uk/publications/surveys/community-mental-healthsurvey

https://www.cqc.org.uk/publications/monitoring-mental-health-act

https://www.cqc.org.uk/publication/surveys/maternity-survey-2022



Comparison to 2017 report

In this section we are looking at how the responses to the surveys in 2017 and 2022 compare. The link to the 2017 report is <u>https://www.healthwatchtameside.co.uk/report/2017-11-08/mental-health-report-2017</u>

The number of responses to each survey is different. We are therefore using percentages, rather than actual numbers, to make the comparison clearer. We have shown the number of people completing each question on the graphs.

Tick-box questions

Here is a list of examples of mental health conditions - we know there are others too. Please tick all those which apply to you.



The percentage of people with Anxiety and PTSD are higher in 2022, compared to the responses in 2017. All other conditions are lower or the same. Could this be due to the impact of Covid-19, the increased cost-of-living, or some other factor(s)? In the findings of the 2022 report, people told us that delays to receiving diagnosis and treatment were having a negative effect on their mental health.

Neurological conditions which can affect, or be affected by, your mental health could include the following. Please tick any that apply to you.

This question was not specifically asked in 2017, although most of the conditions were included in the previous question. We do not know how many people completing the survey in 2017 had a learning disability.



We have shown actual numbers on this graph.

In 2017 there were few comments in the responses relating to these conditions. The increased numbers in 2022 provides greater meaning to the feedback given about diagnosis and care provided.



Have you received care for your mental health in the past 12 months?

On page 59, we saw that a higher percentage of people had anxiety or PTSD in 2022, yet this graph shows that a lower percentage of people have received care for their mental health conditions in 2022 than in 2017.

Have you used any of the following services for your mental health in the past 12 months?



Use of A & E and 111 are higher in the 2022 responses, compared to 2017 responses, whilst use of all other services is lower. Referring to the previous question about care received in the last 12 months, people told us that not receiving mental health care when it is needed means they have to seek emergency help via A & E or 111.



Have you been prescribed medication for your mental health?

A lower percentage of people are receiving medication in 2022 than in 2017. The reason for this is not clear.





Of the people who do receive medication, a lower percentage of people in 2022 are taking it regularly. In the responses, we were told about people who chose to stop taking the medication because it didn't seem to be working, or they didn't like the side-effects, and they were unable to arrange a medication review.

Are you able to get appointments for your mental health when you need them?



A much lower percentage of people in 2022 are able to arrange an appointment for their mental health when it is needed, compared to 2017.

Do you feel listened to and respected by the people who provide mental health care for you, or the person you care for?



A much lower percentage of people in 2022 are happy with the way they feel after contact with service providers, than in 2017. There is a definite move from 'Yes' to 'No' for whether people feel listened to and respected.

Do you get enough information to understand about care provided for you or the person you care for?



The percentage of people who say they were provided with enough information has reduced in 2022, compared with 2017. This could be linked to the reduction in the percentage of people receiving care when they need it.

Do your family or friends know how you are feeling?



This final graph shows an increase in the number of people receiving support from friends and family in 2022. Again, this could be linked to the reduced percentage of people receiving care when it is needed.

Key messages from 2017

In the executive summary at the beginning of this report, we have listed the key messages from the responses to the 2022 survey.

The **key messages** in the 2017 report read:

- 1. Any person receiving mental health care is to be respected as a human being, who has feelings, with everyone cared for in a personalised way.
- Getting the access to services right is critical. This includes the length of waiting times to start treatment, or for follow-up appointments. Appropriate support is needed at a time of crisis. The process to accessing care is complicated, with too many barriers.
- 3. Effective communication in all areas can make the difference between a positive and a negative experience.
- 4. People want to feel supported. They want to be listened to and understood. They want to receive the right care at the right time, in the right place, and with the right service. They want employers to be understanding.
- 5. The health and wellbeing of carers needs to be considered alongside the treatment provided for service users.
- 6. Peer support is very important, and is often found at community and charity support groups.
- 7. When people are struggling with their mental health, they often do not want to burden their families, and suffer alone. If families understand mental health better, people may be more likely to discuss how they are feeling with those they are close to.
- 8. When anyone is being treated for both physical and mental health conditions, they are treated separately, and the impact on each other is not always considered treat the person as a whole.
- 9. When a person is a multi-service user, all the agencies involved need to work together, whilst respecting confidentiality.
- 10. The way a member of staff interacts with service users is remembered. For example, do they always smile, even when they are busy?

'I statements' co-produced in 2017

- I expect caring, compassionate support, delivered by competent, understanding staff, who realise that I need to trust them if they are going to help me.
- I want to get the right type of help when things start to be a problem, at the right time, in the right place, and without having to wait until things get worse.
- I should be listened to, given time to tell my story, and feel like what I say matters.
- I have a voice to control the planning and delivery of my care and support.
- I want to feel safe in hospital.
- I have the information to keep me up to date about my care and to stay healthy.
- My family is supported, which helps me to cope. I want them to understand the issues so that we can support each other.
- I want my situation to be treated sensitively, and I should be respected and not feel judged.
- I want my physical and mental health to be treated together.
- I want to feel that services are shaped around my needs, and not the other way around, especially if I need to see different people and services.

The key messages in 2017 are very similar to those from the 2022 survey.

The 'I statements' are still relevant in 2023, based on what people told us in their survey responses.

Demographics 2022 survey







147 people described themselves as White British



Acknowledgements

Thank you to everyone who has supported Healthwatch Tameside in our work. This includes the people who completed our surveys, the individuals and organisations who promoted them, and the places in the community we have been able to chat to people.

We also thank our volunteers for the support they provide.

Appendices

Copy of survey



MENTAL HEALTH SURVEY 2022

At Healthwatch Tameside, we work on behalf of the community to make sure health and care services are working as best they can for you, influenced by what you tell us.

This survey gives you a chance to feed back about mental health services you have used (or tried to use) recently. Carers can also tell us about their experiences.

We will share the anonymised findings with local health and care partners. The information will be used, alongside other feedback, to plan future services for the local population.

Please spend a short time completing this survey, to help us influence the health services provided locally. Thank you for your time.

If you would like help filling in the survey, or would like to complete it over the phone, please give us a call on **0161 667 2526**.

If you would prefer to complete the survey online it can be found at: www.healthwatchtameside.co.uk/share-your-views

If you get to the end of this mental health survey and still have feedback to share about other services, we have a general health and care experiences survey online at www.healthwatchtameside.co.uk/share-your-views.

We can post out paper copies, or complete the survey over the phone. Please give us a call on **0161 667 2526.**

I am completing this survey as:

Someone with recent experience of mental health challenges

Carer (please give feedback about the experiences of the person you care for, and you as a carer)

Other

Here is a list of examples of mental health conditions – we know there are others too. Please tick all those which apply to you.

| Agoraphobia Anxiety Bi-polar Dementia Dependency issues | Depression Eating diso CD Panic attac Personality | ks | Psychosis PTSD Schizophrenia Other | |
|--|---|---------------|---|--|
| Neurological conditions which include the following. Please tid | | r | , your mental health could | |
| ADHD Autism spectrum | □ Brain injury □ Learning di | sability | Other | |
| If you have ticked 'Other' to eit | her of the above | lists, please | name the condition(s) here: | |
| | | | | |
| Have you received care for your mental health in the past 12 months? Yes No Please tell us more, and also whether you have a diagnosis. | | | | |
| Have you used any of the following services for your mental health in the past 12 months? | | | | |
| GP GP | | Psychiat | rist | |
| Walk-in Centre | | 1 to 1 cou | • | |
| A & E | | Group th | , , | |
| 111 999 | | | mmunity Psychiatric Nurse) health ward | |
| Community support group | 1 | Other | ieutun wara | |

Please tell us the name(s) of the organisations and/or groups you have used. If there is more than one, do they work together?

| Have you been prescribed medication for your mental health? |
|---|
| Do you take your mental health medication? |
| Please tell us more |
| |
| Are you able to get appointments for your mental health when you need them? |
| Yes No Sometimes |
| Please tell us more |
| |

What would help you if you have not been able to make an appointment?

Do you feel listened to and respected by the people who provide mental health care for you, or the person you care for?

| Yes | | No | |
|---------------------------------------|-------|----------------|---|
| Please tell us mor | re | | |
| | | | |
| Do you get enoug person you care f | | formation to | understand about care provided for you or the |
| Yes | | No | Sometimes |
| Please tell us mor | re | | |
| | | | |
| Do your family or | frien | ds know how | v you are feeling? |
| Yes | | No | Sometimes |
| Please tell us mor | re | | |
| | | | |
| Not everyone has | fam | ily or friends | who can provide support. If you do, what support do |

Not everyone has family or friends who can provide support. If you do, what support do they provide? Are they able to provide the support you would like? Are you happy for them to support you? Do you have any other illnesses or conditions which affect, or are affected by, your mental health? Please say what, and how they are affected.

What is good about your mental health care?

What changes could make your mental health care work better for you?

Do you have any other comments about your mental health care? Healthwatch Tameside wants to understand what works for you, and what makes you feel worse.

Some questions about you - Equalities Monitoring Statement

Healthwatch Tameside has a legal duty to work with and provide services equally to the different communities in Tameside. It will help us to know that we are doing this if you answer the questions on this page. We will treat your answers in strictest confidence.

These questions are all optional so you can leave any of them blank if you prefer not to answer.

Gender

| Male | Eemale | | | |
|---|----------------------------|------------------------|--|--|
| Is your gender identity | the same as the sex you we | ere assigned at birth? | | |
| Yes | No No | | | |
| Sexual Orientation | | | | |
| 🔲 Heterosexual (straig | ght) 🔲 Gay | Lesbian | | |
| Bisexual | Other | Prefer not to answer | | |
| Age group | | | | |
| Under 16 | | | | |
| 16-25 | 26-35 | 36-50 | | |
| 51-64 | 65-74 | 75+ | | |
| Which town doyou liv | vein? | | | |
| Ashton-under-Lyne | Dukinfield | Stalybridge | | |
| Audenshaw | Hyde/Hattersley | Glossop | | |
| Denton | Longdendale/Mottr | | | |
| Droylsden | Mossley | Outside Tameside | | |
| | | Where? | | |
| Are you a disabled p | erson? | | | |
| Yes | No No | | | |
| Are you a carer (unpaid family member or friend)? | | | | |
| Yes | | | | |
| | No6 | | | |

Ethnicity

| White British | Black British | Asian British |
|---------------------|---------------|---------------|
| White Irish | Caribbean | Indian |
| Other White | African | Pakistani |
| | Other Black | Bangladeshi |
| | | Chinese |
| | | Other Asian |
| Any other ethnicity | | |

| Religion / Beli | ۶f | |
|-----------------|----|--|
|-----------------|----|--|

Thank you for taking the time to tell us what you think. If you would like a paper copy of any of the reports we produce, please give us a call.

This survey is anonymous, but if you would like to be added to our mailing list, so you can stay up-to-date with our news and our work, please provide your details overleaf (which can be detached from the survey) or get in touch by:

Telephone - 0161 667 2526

Email - info@healthwatchtameside.co.uk

If you would like more information about Healthwatch Tameside please have a look at:

Website - www.healthwatchtameside.co.uk

Twitter - @HealthwatchTame

Facebook-Facebook.com/HealthwatchTameside

If you want to receive further information and surveys from us in the future, please fill in your details over the page. This section will be detached from your survey responses so that we can analyse your survey responses anonymously.

Glossary

| A & E | Accident and Emergency |
|---------------|---|
| ADHD | Attention Deficit Hyperactivity Disorder |
| BPoC | Black and People of Colour |
| CAMHS | Child and Adolescent Mental Health Services |
| CBT | Cognitive Behavioural Therapy |
| CGL | Change Grow Live |
| COPD | Chronic Obstructive Pulmonary Disease |
| CPN | Community Psychiatric Nurse |
| CPTSD | Complex Post Traumatic Stress Disorder |
| CQC | Care Quality Commission |
| EBSA | Emotionally Based School Avoidance |
| EMDR | Eye Movement Desensitisation and Reprocessing |
| GP | General Practitioner |
| HR | Human Resources |
| IBS | Irritable Bowel Syndrome |
| LGBTQ+ | Lesbian, gay, bisexual, transgender, queer/questioning & more |
| ME | Myalgic Encephalomyelitis |
| NHS | National Health Service |
| NVR parenting | Non-violent resistance parenting |
| OCD | Obsessive Compulsive Disorder |
| PMDD | Premenstrual dysphoric disorder |
| PTSD | Post Traumatic Stress Disorder |
| TOG Mind | Tameside Oldham and Glossop Mind |
| Triple PD | Persistent Postural-Perceptual Dizziness |



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