## healthwetch

## What did people tell us about adult mental health services during the pandemic?

April 2021 - March 2022

### Introduction

In 2019, NHS England published the Long Term Plan, which laid out the ambitions for health and care for the following 10 years. Mental health was a major focus of the Long Term Plan, with pledges to put greater focus on it, and give it an increasing proportion of the NHS budget. The need for this is clear: the NHS reported that at the end of February, 1.5 million people were in contact with NHS mental health services!

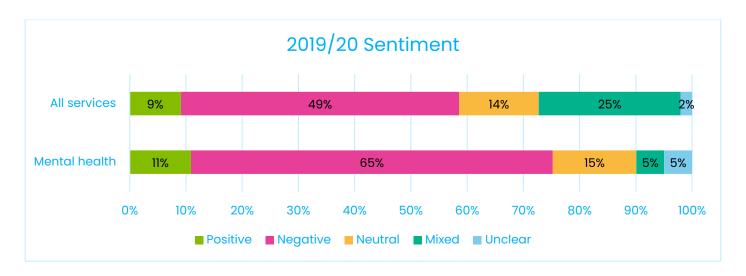
During the development of the Long Term Plan in 2019, Healthwatch England engaged over 40,000 people across England to find out what people wanted from the next ten years of the NHS. Mental health was one of the principal topics people told us about, with experiences being largely negative.

In a survey of over 5,000 people with certain long term conditions, 52% of those who had experience of NHS mental services described the experience as negative, with only 23% positive. That negative figure is higher than other services: with only people with autism had more negative experiences of the NHS. Reasons for this include long waiting times for diagnosis, assessments, referrals and treatment, and a lack of available support in the meantime. People also felt GPs were ill-equipped to provide mental health support, and people felt they could not access the right treatment or could not do so for as long as they wanted.

With the Long Term Plan due to be updated following the Covid-19 pandemic, we have taken a look again at what our data now tells us about mental health. This report focusses on adult mental health, with a separate one focusing on children and young people's mental health.

Before the pandemic, most of the feedback we received on mental health was negative. This continues to be the case in 2021/22. In 2019/20, we heard from 759 people about their experiences of mental health services. 65% of these experiences were negative, whilst only 11% were positive. This was much more negative than our overall data for all services.

In 2021/22, we heard from far more people about their experiences of mental health services, with 1,451 people telling us about their experiences. 58% of people told us their experiences was negative, compared to 14% positive. Whilst the negative figure has come down, it is still higher than for all services. Additionally, for all services the positive figure has increased a large amount, whilst for mental health the increase in positive experiences lags far behind, only increasing by 3% compared to 15% for all services.





#### Key findings from this research

- GPs vary in how well-equipped to deal with mental health issues they are, and people can struggle to get their GP to refer them for specialist mental health support.
- Waiting times are long at all stages of the mental health system.
- Crisis services are over-subscribed and therefore often inaccessible.
- Assessments can feel perfunctory and often do not lead to the outcome people want.
- Inpatient treatment is an unpleasant experience, whilst community treatment is patchy and at times unhelpful.
- Services communicate poorly both with patients and with other services.
- Treatment often ends too early, before people feel they are ready, and without adequate follow-up support.

## Methodology

#### Where is our data from?

The analysis in this report has been conducted drawing upon data from two sources.

- Local Healthwatch feedback and signposting data between April 2021 and March 2022, we heard from over 50,000 people via our CRM. These data come from local Healthwatch hearing individual stories and signposting people to services. In 2021/22, 1443 people shared their experiences of mental health services with us. This briefing is based on a dip sample of 581 adults who shared their experiences. Our briefing on children and young people is based on a dip sample of 129 young people and their families.
- Local Healthwatch reports local Healthwatch conduct individual research projects throughout the year, engaging with specific groups about their experiences of services. 28 local Healthwatch reports on people's experiences of adult mental health services between April 2021 and March 2022 were reviewed, as well as one Healthwatch England report

#### This briefing is informed by:

The experiences of **581 people**, shared with 51 local Healthwatch across England, between April 2021 and March 2022.

28 research reports from local Healthwatch, and one Healthwatch England report. These reports represent the views of 4,054 people.



#### How did we reach our conclusions?

We conducted a thematic analysis on our feedback and signposting data, reading through each individual story and categorising it based on overall sentiment, services involved, and overarching themes. We were able to calculate how much of the feedback was negative, positive, or neutral, and indicate common issues people experienced, based on this coding. We also included supporting figures from local Healthwatch research. Quotes are anonymised and used to illustrate wider themes.

It is important to note that this report has been based only on experiences of people who have interacted with the health system because of their mental health. In other words, it does not cover people who are struggling with their mental health but have not sought support for it from health and care services. We know from our daily work of reviewing what the Healthwatch network is hearing, that during the pandemic this became a particularly large cohort of people. It is worth bearing that in mind when reading this report. For all the patient experiences analysed here, there are many more people having negative experiences with mental health, but not interacting with mental health services. This does not mean, however, that these people are not putting pressure on the healthcare system. They may be putting burden on physical health services because their mental health needs are not clear. For example, people may make repeat visits to the GP or A&E for physical concerns, when it is their underlying mental health issues that need addressing.

# Common issues across our feedback

#### **GPs and referrals**

We heard a lot about GPs, much of it negative. Many issues reflect what we hear from everyone regarding GPs. Throughout the pandemic, we consistently found 60 – 70% of the experiences of GPs shared with us were negative. The principal issues are the same as those raised by people in our mental health data: long waiting times, difficulty speaking with a GP face to face, and issues getting a referral for specialised treatment.

However, we also received feedback specifically about GPs and mental health. A consistent theme is that many GPs are not equipped to deal with mental health issues. We heard from several people who found a mental health appointment with a GP unsatisfactory. Some found their GP to be unempathetic with their struggles, and to seemingly lack knowledge of mental health conditions.

Patient told his GP he has an eating disorder 4 months ago...he is not happy with his GP surgery and the fact they don't recognise him saying he has an eating disorder. – Healthwatch Warwickshire

The biggest complaint about GPs though was the difficulty of getting a referral for either further assessment or specialist treatment. We heard from numerous people who said their GP promised a referral to another service, but nothing ever came of it. Even those who did successfully get referrals often reported having to wait a long time to get one, and on occasions having to repeatedly chase their GP in order to get it.

Finally, some people told us they did not feel the referral they got was appropriate. Often this was because people felt their condition needed serious mental health support, but their GP only referred them to talking therapies, or even local community support groups.

GP gave them a number for a support group and when she phoned they only dealt with rambling and gardening which is not what she wants...son has mental health problems and they are being let down all of the time. GP has supposed to have written to CMHT and son is getting more and more anxious. – Healthwatch Birmingham

Although we heard about a lot of negative experiences, others have told us that they have found their GP knowledgeable, empathetic and supportive.

The GP supported the patient through years of very severe depression, which included daily suicidal thoughts and "writing her will". – Healthwatch Sheffield

The variation in experiences with GPs suggests that how likely you are to get help and support depends largely on who your GP is.

#### **Waiting times**

Waiting times are not just an issue with GPs, but at every stage of the mental health system. Once someone has managed to see their GP, they often then face a further wait to get a formal assessment, and therefore diagnosis, which is generally necessary for any support to begin. The time it takes to get any form of support was something we heard a lot about.

Honestly the worst service I have ever experienced...I call every week to ask for an update on when I might get some treatment or something, to which I'm told 'we will have a meeting and let you know'. 8 months on still nothing. – Healthwatch Birmingham

We heard from people who experienced months of waiting at various points of the system. This leaves them in limbo, waiting for their support to start, whilst trying to self-manage their mental health. Several people told us that for people with serious mental health issues, waiting for treatment is not just an inconvenience, it's dangerous.

I have been on a waiting list to see complex psychology for 2 years for suicidal ideation due to attachment disorder. How can the wait possibly be this long for something so serious that could kill me. Every 3 months the psychiatrist checks in & tells me he will chase the appointment and get his secretary to update me. I never hear anything back. He told me it would be 8 months initially. – Healthwatch Birmingham

Waiting times are compounded by the fact people do not always get referred to the correct service. We heard from people who waited to access a service, to then be told that another service would actually be more suitable. They then must join the queue for that service. This makes people, sometimes vulnerable individuals, wait longer than necessary.

#### **Assessments**

A mental health assessment is a conversation between a person experiencing mental health issues and a mental health professional. The purpose of assessments is to talk about the person's condition to establish their needs, and therefore recommend a suitable next step of support or treatment. We heard largely negative experiences of assessments. Several people told us that their assessment had felt perfunctory and that the assessor did not really listen to them.

The initial assessment was ok? The practitioner wasn't very open and didn't fill me with huge confidence, it just seemed like a few tick box questions. – Healthwatch Buckinghamshire

Many people told us that their assessment did not lead to the outcome they wanted. We heard cases of people who feel they are quite mentally unwell but were assessed as not in need of support.

On his last psychiatric assessment, even though he reported hearing voices, seeing things and suffering with delusional parasitosis, he was told that he is not ill enough to be supported by the mental health team. – Healthwatch Gloucestershire

Other people said they were offered support, but not the type they need. Finally, we heard dissatisfaction that the assessment process can consist of multiple assessments and referrals, rather than one assessment that diagnoses the necessary support.

You self-refer, then get assessed, then get referred, then wait some more, then get assessed again. – Healthwatch Bedford Borough

#### **Treatment and support**

Whilst many people struggle to get treatment and support, we also heard from plenty of people who did. Broadly, these experiences can be split into two categories: hospital treatment and community treatment.

#### Hospital treatment and support

We heard from people who had recent experience of mental health inpatient care. Generally, this appears to be a negative experience. A theme running through all these experiences is a lack of consideration for the needs and rights of mental health patients. Feedback frequently mentions lack of communication with patients about their treatment, especially around changes to medication.

Several people also told us about unnecessary use of physical restraint, and patients being left in their rooms unattended for long periods of time.

Her experiences include being held unnecessarily in physically secure positions, given injections against her will, kept heavily sedated for prolonged periods, having no OT or physical therapy to help with issues, left alone in rooms with no communication for several days and feeling what she described as continually threatened with possible sectioning and the removal of her children. – Healthwatch Bristol

There are also indications that inpatient care is not well coordinated with other services. We heard multiple cases of follow-up care not being in place upon discharge, and hospital stays therefore becoming a repeat occurrence for some people. Overall, running through all the feedback on hospital-based treatment and support is a sense that it is an unpleasant experience.

A lawless environment not conducive to healing...no regard for patient human rights or the mental health laws at large. – Healthwatch Birmingham

Finally, we heard a number of negative experiences of discharge from hospital. We heard from multiple people who had been discharged from hospital to their GP, crisis team, or CMHT, seemingly without much information being passed on. We even heard of cases where the person's GP did not seem to know the discharge to their care had happened. Additionally, as discussed, GPs are generally quite inaccessible currently for everyone. This can leave people fending for themselves soon after what may have been quite a serious mental health incident.

Extremely concerned about the lack of care and after care of my son's partner after she tried to end her life 3 days ago in front of her children. She has been sent home from hospital without any help and was told to ask family or friends. – Healthwatch Torbay

#### Community treatment and support

Most of our feedback concerns people out of hospital, rather than inpatients. As noted, a major issue is how long it takes to get this type of support and treatment. However, once people do get it there are a range of experiences, again, unfortunately, mostly negative.

Community Mental Health Teams (CMHT) are central to helping people manage their mental health and access the services and support they need. However, people told us they are inaccessible, with face-to-face appointments unavailable, and even phone contact difficult.

On multiple occasions both my husband and GP would try to call the manager of the [location] CMHT to speak directly with him but he wouldn't return calls and often even the main contact number for the CMHT would go unanswered. – Healthwatch Cornwall

That person's experience is not unique. Lots of people told us that they struggle to speak to their CMHT. Even when people can speak to them ad access support, often we heard that the support given was not what the person wanted and not helpful.

Son is under CMHT. He is getting no support apart from seeing an Occupational Therapist who is no help.

– Healthwatch Birmingham

This sense that not enough consideration is given to the appropriate treatment for people is reflected in a number of the experiences shared with us. For example, we heard about people being offered CBT, when they feel they need counselling, or being told therapy was the only option available to them. Overall, there is a strong sense in our data that people do not feel listened to by mental health professionals. Generally, people seem to experience treatment as something that happens to them, rather than something in which they are an active participant.

I then saw a psychiatrist who point blank didn't listen to me, spoke over me (so much) and said a few buzzwords for effect. – Healthwatch Buckinghamshire

The inaccessibility and ineffectiveness of support in the community has a serious knock on effect. As a report by <u>Healthwatch Richmond</u> notes, it means that people are more likely to be unable to get help until their situation escalates to crisis point.

Many people experience problems with accessing care because of the thresholds for referral into services. This means that people approaching a crisis are unable to get help to avoid it escalating. An inevitable result of this is that more people will experience a crisis and that more of the people who do access care will have higher levels of need. – Healthwatch Richmond.

We heard a lot about the strain this is putting on crisis services. Crisis services are an essential part of community mental health. This is especially the case when waiting times are so long for services, meaning there are a lot of people with mental health needs waiting a long time before they can access support. Crisis services need to be there for people, to support them if their situation deteriorates before they can get support from other services. Unfortunately, the overwhelming feedback on crisis services is that they are inaccessible. Crisis services seem to be oversubscribed, and therefore unable to support the number of people who need to access them.

Partner advised that client tried to contact Crisis Team several (25) times, they have spoken to her recently but no action was taken and they are not getting any support. – Healthwatch Gloucestershire

This person is not alone, we heard from numerous people that they had tried to contact crisis

services and not been able to, or been promised contact from crisis services that never came. Likely as a result of being over capacity, we also head from people who had been able to access crisis services and found the support lacking. Several people who had accessed crisis services told us that they had not been offered any meaningful support following the interaction.

We did also hear positive comments about crisis services. Some people told us that they had managed to access crisis support, and that it had been quick, reactive and supportive, and helped to either deescalate their situation or find them support elsewhere.

I called the Crisis Team and they could hear how agitated my husband was while I was on the phone. They said they were coming straight away and they did. – Healthwatch Sunderland

It seems likely that this dichotomy of experiences represents the result of service rationing. Because they are over-subscribed, crisis services must pick and choose who they can help and how much, prioritising those most in need, which can leave quite vulnerable people without help. However, for those they prioritise, crisis services may still offer a good service.

#### Communication from and between services

We heard lots of complaints about poor communication within the adult mental health system. People told us that services and practitioners do not communicate with patients. This often leaves patients in the dark, not understanding what decisions are being made about their care and support, and why. Because of this, patients are left feeling anxious, or feeling that the burden falls on them or their friends and relatives to find out what is happening.

I completely understand why my relative cannot receive the test at the moment but am at a loss to understand why there has been a complete failure to communicate this accurately. This failure in adequate communication has led to a deferred treatment for relative for another condition and has tied up staff in numerous unnecessary calls. – Healthwatch York

The lack of coordination between services also leads to people being 'bounced' between services. We heard from multiple people who told us that their experience of the mental health system is being sent from service to service, without feeling like anyone is ever really taking charge of your care. Combine this with the lack of communication with patients, and it makes the system feel impossible to understand and navigate.

Feels that there was not enough communication between different organisations and lots of 'passing the buck' with who was responsible and not enough follow up after each episode so he could get proper care. Likened it to a computer game where you have to unlock one piece of the puzzle to get to another, and people giving advice on what to do but when you tried to do what they suggested, meeting resistance and signposting elsewhere. – Healthwatch Northumberland

#### Limits on treatment and support

Finally, we heard from people who received treatment support but found it too limited. In some cases, this is because people have been only given time-limited support, such as a few weeks of therapy or a set number of sessions. People told us this support ends, even though they did not feel mentally well.

This is her second course of 6 weekly teams calls...The course ends today and she does not feel she made much progress and has not been told if she can get any more help. – Healthwatch Bristol

This is underlined by a report from <u>Healthwatch Wigan and Leigh</u> on discharge from mental health services. They found that people feel they are discharged too early and in a poorly planned manner, with little follow-up support post-discharge.

This can make services a revolving door. We heard from people about how they end up using services repeatedly, because they are discharged before they are ready to manage without that service, and without the necessary support in place. This is particularly stark when people get discharged from hospital, and then end up back there again a short time later, which is clearly bad for both patient and hospital.

She...sits around at the hospital for hours waiting to speak to somebody from the MH team for them to say there is nothing that they can do and send her home. Walks from A&E back to the pharmacy, gets more medications, goes home and takes another overdose. – Healthwatch Blackpool

## Health inequalities

#### People with autism and learning disabilities

We heard about how people with autism and learning disabilities find services often inaccessible. For example, services that are only contactable via phone exclude people who cannot, or do not want to, use the phone, which often includes those with autism and learning disabilities.

As well as access, mental health services themselves are not well designed for people with autism and learning disabilities. There is a lack of understanding in services about how autism and learning disabilities interact with mental health. This leads to issues specific to this group not being identified, and treatment therefore being less effective.

This lack of personalisation can get people in a vicious cycle. They find it hard to engage with services, their condition worsens, and therefore when they do engage there's a higher chance of a negative experience.

The enquirer told us that mental health services aren't suitable for people with ASD in crisis. Their son ends up at A & E because they can't go to the Psychiatric Decisions Unit because they self-harm and the Home Treatment Team (HTT) won't accept him again as he has struggled to engage with them in the past. ...Their son's bad experiences of A & E include him leaving before he was assessed and then police picking him up and taking him to the Place of Safety under a Section 136. This all had a negative impact on their son, especially because they have ASD and no reasonable adjustments were made. – Healthwatch Sheffield

#### **LGBTQ+ people**

Our evidence shows that LGBTQ+ people tend to be poorly served by the mental health system. We heard that practitioners often lack knowledge and specialised support is lacking, especially for transgender people. A <u>Healthwatch Yorkshire</u> survey of more 200 LGBTQ+ people found that

mental health services needed to train staff better on LGBTQ+ specific mental health issues, and work to improve the visibility and promotion of LGBTQ+ mental health needs generally.

What I would like is just representation. What would be really lovely, would be to go into the GP's clinic and just see one poster or a leaflet or just something that says LGBT stuff or something to show that just maybe these people understand what you're talking about. – Healthwatch North Yorkshire

Similarly, <u>Healthwatch Worcestershire</u> conducted a survey of 186 LGBT+ people and found that 44% said they did not think mental health services showed an understanding of LGBTQ+ people. Meanwhile, Healthwatch Kent undertook research specifically on the transgender community, which reflects what we heard directly. <u>Healthwatch Kent</u> found that transgender people felt their GP had not listened to them or understood them and that there is a need for improved understanding amongst professionals of the specific mental health issues and needs of transgender people.

An A&E doctor had pulled up my old medical record after I had been told that the records would be combined, and the Doctor had called me by my deadname (forget or use another name repeatedly). At the time, I needed support due to my mental health and being referred to by my dead name, which I had advised them not to do, exacerbated the situation. – Healthwatch Kent

Several other Healthwatch have conducted similar research, and the lack of appropriate and accessible treatment and support for transgender people is an issue that appears repeatedly.

#### People with language barriers and/or hearing difficulties

We heard that mental health services can be inaccessible for people who have language barriers or hearing difficulties. One person told us how sign language users are forced to communicate in a way that causes misunderstandings, which is particularly problematic when discussing a complicated topic such as mental health. Another person told us how the access they get to a British Sign Language (BSL) interpreter is not enough.

Her son is 35 years old. He was born deaf and developed numerous other serious health conditions over the years...He only has access to a BSL interpreter for 2 hours per day which is not enough for the psychological and physical therapies he needs. – Healthwatch Torbay

This same person pointed out the shortage of specialist clinicians skilled in working with Deaf people with mental health issues. There are only 3 facilities in the whole of England, which in this case meant travelling over 200 hundred miles to be able to access appropriate treatment.

We also heard about problems with language interpreters. In mental health it is vital to be able to accurately communicate feelings and experiences, so interpreters are particularly important. However, they are hard to access. One person raised a specific issue with interpreters joining virtually, and this being unsuitable for people with mental health issues. We know from our broader work on accessible communications that it is vital for services to record what works and what doesn't for each individual patient and avoid making assumptions.

An interpreter had been booked for the session, but was linked via a laptop, which totally confused my mother and made her confused and upset. – Healthwatch Sunderland

<u>Healthwatch Oxfordshire</u> also noted in a report that the presence of an interpreter impacts the nature of an appointment or session.

In a mental health appointment, patients often will talk for long periods of time and doing this and being listened to is part of the support really. When there is an interpreter there, they need the pace to be slower and might need the person to stop mid-flow so they can interpret what they have just said. So, I think the function of the appointment ends up being much more practical and information-focused than therapeutic in its own right. – Healthwatch Oxfordshire

This is why support or treatment being delivered directly in the patient's language is preferable, though obviously not always possible.

#### Race and ethnicity

Healthwatch research indicates mental health services are not well adapted to people from different racial and ethnic backgrounds. Experiences of mental health differ across communities, and therefore so do needs, but we heard that services do not reflect this. For example, Healthwatch Lancashire noted that treatment and outcomes for Black Caribbean people were worse than the wider community, which stems from how services have historically perceived people from these communities. This has created a vicious cycle, with those people now distrusting those services. To counteract this, mental health services need 'greatly increased cultural competency'. For example, a previous Healthwatch England report identified the need for healthcare staff to be more aware of the stigmas around mental health in some cultures.

Even when services attempt to adapt, it may be done an insensitive manner by conflating people of different backgrounds.

My mother is originally from Bangladesh and although she has been under this service for some time now, they came with an assessment which would be suitable for people with Indian origins. I informed the nurse that this was inappropriate. – Healthwatch Sunderland

There is also a lack of information and advice on how and where to access mental health support, according to reports from several Healthwatch. Despite high levels of need, awareness of services remains low, with lack of culturally and linguistically appropriate information and advice likely to be part of this problem.

#### People with other issues that affect their mental health

Finally, there is a group of people we heard about, which is those whose mental health is intertwined with other issues. Often these people can have quite negative experiences of the mental health system, because it is not good at dealing with complicated situations.

For example, we heard about issues faced by people who struggle with substance misuse. This is common amongst people with mental health issues, known as dual diagnosis, but the system does not handle it well. We heard from several people about the trap people get caught in between mental health and substance abuse services.

Psychiatric Liasion and Community Health Teams (CMHT) are pathetic when it comes to Dual Diagnosis patients. They hide behind their local policies and procedures which leaves those suffering from a mix of addiction and mental health issues are most often denied access to the mental health services where

current guidance says addiction and mental health cases should be tackled together. They don't talk to someone who is currently using. – Healthwatch Cornwall

Many mental health services will not engage with someone whilst they are actively abusing alcohol and/or other substances. However, alcohol and substance misuse are often a result of poor mental health, so trying to tackle it before getting mental health support is very difficult. Furthermore, many alcohol and substance abuse services will themselves not take someone with mental health issues unless they are already receiving treatment for them. This can leave people unable to get support for either of their issues.

Another group we heard about was people experiencing homelessness. Like substance abuse, homelessness and mental health are very closely tied. However, people experiencing homelessness are not well supported by the mental health system. Like everyone, they struggle to access mental health support, however it can be particularly complicated navigating the system without a fixed abode. For example, services may ask for proof of address and identification.

When they do interact with the system, they may also encounter stigma and judgement from staff, as well as a lack of understanding of specific issues related to being homeless.

In the past they've put me down and talked through me, literally sit there and they're just looking through me. – Healthwatch Blackpool

Finally, information providing and outreach to people experiencing homelessness around mental health can be poor. A report from <u>Healthwatch Sandwell</u> found that they were not really aware of the services available to them for their mental health and how to access them. This is particularly problematic given how intrinsically tied mental health and homelessness are, with it being very hard to tackle one without the other.

# What do our findings say about the LTP's vision for mental health?

What is striking about these findings, are how closely they match what Healthwatch England found when conducting a similar analysis for the Long Term Plan's original publication in 2019. The issues are almost the same, and experiences remain largely negative. This is despite the pledges made in the Long Term Plan.

In 2019 the Long Term Plan pledged to transform mental health care, so that more people can access treatment, including talking therapies, crisis care and non-medical alternatives to A&E and hospital admission. To achieve this, it stated that mental health would receive a growing share of the NHS budget. Our data seems to suggest that this investment is not yet seeing results in terms of tackling the issues identified in 2019 or making experiences of the mental health system more positive.

However, there is a caveat to this, which is that the Covid-19 pandemic makes it difficult to truly judge the impact of the Long Term Plan to date. The pandemic negatively impacted the mental health of large numbers of people, so it is possible that the investment the Long Term Plan made in mental health has simply been eaten up by greater demand, and therefore we do not see an improvement in how people experience the system. It is possible that the investment is what stopped our data from becoming more negative during the pandemic. Unfortunately, it is not possible to discern whether this is the case or not.

What we can say, is that the issues identified in 2019 remain prevalent in 2022, and therefore the vision of the Long Term Plan is still very much required. There is still a great need to improve both the breadth and speed of access for services across the mental health system and increase the spread of mental health expertise across the wider health system. With the Covid-19 pandemic likely to be storing up mental health problems in future for large numbers of people, the Long Term Plan's pledge for increased focus on, and resources for, mental health remains absolutely necessary.

Healthwatch England National Customer Service Centre Citygate Gallowgate Newcastle upon Tyne NEI 4PA

www.healthwatch.co.uk t: 03000 683 000 e: enquiries@healthwatch.co.uk

@HealthwatchE

f Facebook.com/HealthwatchE

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