2020 Community mental health survey
Statistical release

NHS Patient Survey Programme

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Independent data analysis
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Summary of findings

According to NHS England and NHS Improvement, mental health problems represent the biggest single cause of disability in the UK, with one in four adults experiencing at least one diagnosable mental health condition in any given year. Mental health service reform aims to improve community-based care in an effort to minimise the strain on acute and inpatient services, while helping people to have more control over their care at home. The NHS Long Term Plan and the NHS Mental Health Implementation Plan 2019/20 – 2023/24 set out new integrated care models for primary and community mental health care. Plans for community mental health services incorporate access to psychological therapies, personalised and trauma informed care, help with physical health care and medicines management.

There have been reports of mental health services facing huge pressures for a number of years. More recently, the Royal College of Psychiatrists (RCP) predicts alarming increases in demand for mental health services, especially crisis care services, as a result of the COVID-19 pandemic. A survey of 250 of the most senior leaders in the English NHS has shown that 72% of leaders expect a 20% increase in demand, against a 10%-30% reduction in capacity, in the coming months.

The 2020 community mental health survey received feedback from 17,601 people who received treatment for a mental health condition between 1 September 2019 and 30 November 2019. The national COVID-19 lockdown began during our fieldwork period, on 23 March 2020. In depth analysis suggests that the survey findings have been affected by this and so the 2020 results are presented in isolation, rather than comparing against data from previous surveys.

This report shows that people are consistently reporting poor experiences of NHS community mental health services, with few positive results. For example, poor experiences were reported for support and wellbeing, crisis care and accessing care. We have also found disparity in the experiences of different groups of people, especially among respondents with different diagnoses.

Positive results

There are few results where the majority of people reported good experiences of mental health care. However, ‘organising care’ is an area where people were found to be more positive.

Most people (97%) who have been told who is in charge of organising their care and services said they knew how to contact this person if they had a concern. In addition, 91% said the person that organised their care did so ‘very well’ (58%) or ‘quite well’ (33%).
Another area where people were found to be more positive is ‘respect and
dignity’. The majority of people (73%) reported that they were ‘always’ treated
with dignity and respect, while a further 19% said they were ‘sometimes’ treated
with dignity and respect.

**Key areas for improvement**

**Support and wellbeing**

Results for support and wellbeing questions (for example, questions about
support with physical health needs and support finding financial advice) show
that many respondents reported negative experiences. Research shows that
drivers for good mental health include financial stability, employment and
maintaining good social interaction.7,8,9

Almost two in five people (36%) had not had support with their physical health
needs. Almost half of people (43%) did not receive help or advice in finding
support with financial advice or benefits. Similarly, 43% did not get help or advice
in finding support for keeping or finding paid or voluntary work, but would have
liked this help.

Over a third of people (37%) did not receive support in joining a group or taking
part in an activity, but would have liked this.

**Crisis care**

Over a quarter of people (28%) indicated that they would not know who to
contact, out of office hours in the NHS, if they had a crisis. Of those who did try to
contact this person or team, almost a fifth (17%) either did not get the help they
needed or could not contact them (2%). Just over half (53%) reported that they
‘definitely’ received the help they needed.

**Accessing care**

Forty-four per cent of respondents who have received NHS therapies in the last
12 months felt they waited too long to receive them. In addition, almost a quarter
of all respondents (24%) felt they had not seen services often enough to meet
their needs, while around six in 10 (59%) said they were ‘definitely’ given enough
time to discuss their needs and treatment.

**Involvement**

Around half of all respondents (53%) who had agreed with someone what care
they will receive were ‘definitely’ involved as much as they wanted to be in the
planning of their care, while just over half (52%) of those who have been
receiving medicines in the last 12 months were ‘definitely’ involved in making
decisions about their medicines as much as they wanted to be. In addition, half
(50%) of respondents who had received NHS therapies in the last 12 months
were ‘definitely’ involved as much as they wanted to be in deciding which therapies to use.

**Communication**

Although there were some positive results with regard to organisation of care, people were not as positive about communication in this area. For instance, over a quarter of respondents (28%) indicated that they had not been told who is in charge of organising their care. Similarly, almost a quarter of people (24%) who had been receiving medicines in the last 12 months for their mental health needs had no discussion about the possible side effects. In addition, two out of five people (41%) had not had the purpose of their medicines discussed with them fully.

**How experience varies for different groups of people**

Analysis has found a disparity in the experiences of people with different diagnoses. People with more challenging and severe non-psychotic disorders, as well as those with complicated cognitive impairment and dementia disorders consistently reported worse than average experiences. When compared with the better than average experiences of people with psychotic disorders, especially those experiencing a ‘first episode of psychosis’, the difference is stark. For instance, people receiving treatment for non-psychotic chaotic and challenging disorders reported worse than average experiences across most aspects of care covered by our survey – for example crisis care (care), communication, involvement, and being treated with dignity and respect.

People receiving treatment for a first episode of psychosis reported better than average experiences in almost all themes, including crisis care (access), organisation of care, and support and wellbeing.

Analysis also found differences in the experiences of people in different age groups, with those in the 18 to 35 age group reporting worse than average experiences across 11 of 14 themes, and those aged 66 and older reporting better than average experiences across the same 11 themes. In addition, those who had been in contact with NHS mental health services for less than a year and people who identified as heterosexual reported better than average experiences across many areas of care.
Introduction

In England, one in four adults experiences at least one diagnosable mental health condition in any given year, with NHS England stating that mental health problems represent the biggest single cause of disability in the UK. The National Institute for Health and Care Excellence (NICE) notes that the most prevalent mental health conditions are depression, generalised anxiety disorder, panic disorder, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and social phobia/social anxiety disorder.10

People experience mental health conditions differently. Some people receive support from mental health services, while others are able to self-manage their condition.11 Some may have a one-off episode of a mental health issue, resulting in short-term contact with mental health services. Others may experience multiple or long-term conditions, varying in severity throughout their lives, which may involve ongoing or intermittent contact with mental health care providers. Those who have been in contact with mental health services for more than a year are more likely to have severe and enduring mental health problems.

Community mental health teams (CMHTs) provide support to people, in a community setting, who have complex or serious presentations of mental health conditions.12 A CMHT can include psychiatrists, psychologists, community psychiatric nurses, social workers and occupational therapists. Care and treatment can often be delivered in a person’s home, though some specialist care may involve visits to clinics based in mental health centres or hospitals.

The government has set out its ambitions for mental health service reform over a number of years. Publications including the Next Steps on the Five Year Forward View (2017), the NHS Long Term Plan (2019), the NHS Mental Health Implementation Plan 2019/20 – 2023/24 (2019) and the Green paper ‘Prevention is better than cure’ (2019) specifically highlight the importance of community-based mental health care in these plans.13,14

There have been reports of mental health services facing significant pressure for a number of years and recent national policy has sought to address the issues. However, the coronavirus (COVID-19) pandemic, which has presented the NHS with unprecedented challenges, has placed additional pressures on community mental health services. Services have adapted at pace, with many face-to-face treatments adopting virtual methods and others being temporarily cancelled.15

Determinants of poor mental health, such as unemployment, financial instability and a lack of social interaction, have been exacerbated for many people as a result of the UK-wide COVID-19 lockdown and subsequent restrictions, including further regional lockdowns.16 The Royal College of Psychiatrists has noted that fear of contracting the virus, along with other more practical issues, such as childcare or shielding, deterred people from attending their usual appointments.
This has resulted in a rise in the number of people seeking crisis care. This new, unexpected and unplanned for demand from people needing support due to the wider impacts of the pandemic, and the demand from those who would have been referred to services even if the pandemic had not happened, has resulted in experts warning of severe and imminent strain on mental health services.
The community mental health survey

The community mental health survey has been conducted almost every year since 2004 to collect information about the experiences of those using NHS community mental health services. In 2020, 55 providers of NHS mental health services in England participated in the survey.\(^a\) This includes combined mental health and social care trusts, foundation trusts and community healthcare social enterprises that provide mental health services.

Those aged 18 and over were eligible to take part if they were receiving specialist care or treatment for a mental health condition between 1 September 2019 and 30 November 2019. Fieldwork took place between February 2020 and June 2020. It should be noted that on 23 March 2020, in response to the COVID-19 pandemic, the UK government announced a lockdown in England. This occurred during the fieldwork period for this survey. We received responses from 17,601 people, a response rate of 26%.\(^b\) Of these responses, 10,671 were received before lockdown and 6,930 were received during lockdown.

The survey collected basic demographic information from everyone who took part, and this anonymised data is available in the ‘About you’ section in the Open data published on CQC’s website. The basic demographic characteristics of respondents in 2020 were similar to previous survey iterations for age, gender and ethnicity.

Where possible, the questions remain unchanged over time to monitor change in the experiences of people who use services. However, questions are amended, added or removed to reflect changes in policy or survey best practice. We also seek guidance from an external advisory group to make sure the questions remain relevant.\(^c\)

This survey is part of the NHS Patient Survey Programme, which covers a range of services including adult inpatient, children’s inpatient and day-cases, urgent and emergency care, and maternity services. To find out more about the NHS Patient Survey Programme and to see the results from previous surveys, see the links in the further information section (appendix F).

\(^a\) Cumbria Partnership NHS Foundation Trust (RNN) and North Cumbria University Hospitals NHS Trust (RNL) merged from 1 October 2019 to become North Cumbria Integrated Care NHS Foundation Trust (RNN). This has affected two other trusts, as the newly merged trust does not provide community mental health services. Service users located in the north of the area were transferred to Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (RX4) and service users in the south were transferred to Lancashire Care NHS Foundation Trust (RW5).

\(^b\) We report the ‘adjusted’ response rate. The adjusted base is calculated by subtracting the number of questionnaires returned as undeliverable, or if someone had died, from the total number of questionnaires sent out. The adjusted response rate is then calculated by dividing the number of returned useable questionnaires by the adjusted base.

\(^c\) For this survey iteration, members included representatives from CQC, NHS England/Improvement, NHS mental health trusts and people who use mental health services.
The importance of collecting data on the experiences of people who use services

According to research, positive experience of using healthcare services has many benefits for both people who use services and providers. This is as true for those using mental health services as those accessing other types of NHS care. For people who use services, good experiences are linked to better health outcomes. For providers, good experience for people can lead to lower costs of care and good organisational reputation. It is therefore important that people who use services and families are given an opportunity to feed into the system that has been set up to protect and care for them.

The 2012 NHS Patient Experience Framework outlines a number of elements that are important to people’s experiences of NHS services. These include:

- emotional support
- respect for patient-centred values, preferences and expressed needs, such as cultural issues and shared decision-making
- welcoming the involvement of friends and family
- access to care, with attention given to waiting times.

The NHS Constitution, updated in 2015, commits the NHS to support people in giving feedback about their experiences and to use this in service improvement. People’s experiences provide key information about the quality of services across England. This information is used to encourage both national and local improvements among providers and commissioners of services. In addition, the Health and Social Care Act 2012 states that those who commission services must promote and facilitate the involvement of people who use services, and their carers, in decisions about their care and treatment.

The NHS outcomes framework (Domain 4) and the Department of Health and Social Care’s NHS Mandate for 2018/19 also recognise the importance of patient experience in relation to a high quality of service. The latter, in particular, places a high degree of importance on good care, by including a goal for NHS England to ensure that the NHS meets the needs of each individual with a service where people’s experience of their care is seen as a core component of overall quality.

\[\text{d} \quad \text{The ‘NHS Mandate 2018/2019’ has recently been superseded by ‘The Government's 2020-2021 mandate to NHS England and NHS Improvement’. The latest mandate focuses heavily on the NHS response to the COVID pandemic, rather than the importance of service user experience that has been central in previous mandates.}\]
Mental health policy

This section discusses some of the broader policy and contextual issues relevant to community mental health care in England.

Mental health service reform has been the central theme of all government mental health policy over the last decade, with community services highlighted as playing an important role in reform that aimed to reduce pressure on inpatient services. More recently, in 2019, the NHS Long Term Plan set out the key priorities for the NHS over a period of 10 years. The plan discusses:

- a redesign of core services by 2023/24
- increases in funding for both primary and community mental health services
- improving access to services, especially for those who need specialist help in a crisis.

The plan also discusses prevention and the need to tackle health inequalities, urging the NHS to encourage behaviour change in the general population. This resulted in the green paper, Prevention is better than cure. The paper advises the NHS and local authorities to put prevention at the centre of everything they provide, addressing the root causes of ill-health. Specifically, the paper highlights the value of community mental health care services in offering early support at home and helping people to live healthy and independent lives for longer.

More recently, the onset of the COVID-19 pandemic has presented huge challenges for the NHS, including mental health services. However, it also resulted in NHS staff responding swiftly to the crisis, implementing new tools and ways of working at pace, such as a mental health hotline that was implemented within a week and virtual appointments. This has resulted in calls from the Secretary of State for Health and Social Care, Matt Hancock, for grassroots service reform. In a speech about the future of health care, he reflected on the successful changes that were made to every day processes by those working in the NHS, which were made quickly and in pressurised circumstances. As a result, he encouraged the removal of bureaucracy, silos and top-down reform plans. Instead, he favoured innovative and collaborative working that provides workers with processes and tools that are useful and fit for purpose.

In terms of the high-level impact that COVID-19 has had on mental health services, the NHS Confederation has raised concerns about staff burn out and capacity issues, as well as stating that the additional £2.3 billion of funding, announced in 2019 as part of the NHS Long Term Plan implementation, is no longer enough. There has been unexpected spending needed to deliver services, such as adaptations to space where face-to-face care and treatment is delivered, as well as the creation of digital platforms that allow people to access care from their home.
In addition, providers of services have reported that, following a significant decline in the number of referrals to treatment during lockdown, numbers are now exceeding pre-COVID-19 levels, with people presenting with more significant needs. The NHS Confederation conducted a survey of 250 of the most senior leaders in the English NHS. Their findings showed that 72% of leaders expected an increase in demand for NHS mental health services of more than 20%, against a 10%-30% reduction in capacity.

**Care and treatment**

As set out in the NHS Objectives for 2019-2020, one of the overall aims of the NHS is the delivery of the safest, highest quality of health and care possible through continuously reviewing and improving services.

In 2019, the National Institute for Health and Care Excellence (NICE) updated its quality standard on service user experience in NHS adult mental health services. The quality standard highlights the importance of ensuring that high-quality mental health support can be accessed in a timely and effective manner. Specifically, the updated statements concentrate on:

- ensuring people who use mental health services are treated with dignity, respect and sensitivity, to encourage them to use services (NICE quality statement 1)
- supporting people to be active in decisions about their care and treatment (NICE quality statement 2)
- timely access to mental health services, including crisis care, which should be available 24 hours a day, seven days a week (NICE quality statement 5)
- ensuring the involvement of individuals in agreeing their care plan, and identifying the support needed to help them live an independent life and achieve their goals (NICE quality statement 6).

However, as a result of the COVID-19 pandemic, mental health services are expected to face additional demand that could put at risk the realisation of both NHS objectives and NICE quality standards. Although the number of people accessing mental health services dropped during lockdown, the NHS Confederation is expecting services to see three drivers of additional demand in the coming months.

- demand from people who would have been referred to services had the pandemic not struck

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* The most recent NHS Objectives for 2020-2021 are heavily focused on responding to the pandemic. However, the objectives discussed in the text above were relevant during both the sampling and fieldwork periods.
• existing service users needing more support due to a deterioration in their mental health during the pandemic
• new demand driven by people needing support due to the wider impacts of the pandemic, such as self-isolation, increases in substance abuse and domestic violence.

The report also highlights concerns about the inequalities in accessing mental health services and recovery rates of Black and ethnic minority communities, noting that these inequalities have been exacerbated as a result of the pandemic.

Crisis and acute care

Building on pledges set out in both the Five Year Forward View Implementation Plan and the NHS Long Term Plan to improve both the access to and timeliness of mental health crisis care\(^1\), the NHS Medical Director has carried out a clinically-led review of existing NHS access standards.\(^{37}\) Following this review, new waiting time standards are now being field-tested in pilot trusts around the country.\(^{38}\) One new standard specifically relates to mental health crisis and requires an expert assessment to be carried out within hours for emergency referrals (although the standard does not provide a target for the exact number of hours) and within 24 hours for urgent referrals in community mental health crisis services.

However, changes to the normal patterns of access and flow of people using services, as a result of the pandemic, will add pressure to pilots. The Royal College of Psychiatrists (RCP) has predicted a large increase in the number of people accessing urgent and emergency mental health services in the coming months. Many psychiatrists believe that people are only accessing care when they reach crisis point. This is also true in other acute (non-mental) health services across the NHS, following concerns that people have been avoiding or postponing treatment due to social-distancing measures, school closures and the fear of attending hospital and risking contracting the virus.\(^{39}\). A survey conducted by the RCP found that 45% of psychiatrists had seen a fall in their most routine appointments following the COVID-19 lockdown. At the same time, 43% of psychiatrists had seen an increase in urgent and emergency cases following the COVID-19 lockdown. This raises concerns about an overburden on mental health crisis care services and what the RCP describe as a ‘tsunami’ of mental illness, in the near future.

\(^{1}\) The NHS will provide a single point of access, ensuring that anyone experiencing mental health crisis can access 24/7 age-appropriate mental health community support through NHS 111. For adults and older adults, the NHS Long Term Plan outlined a commitment to ensure that a 24/7 community-based mental health crisis response is available across England by 2020/21, with intensive home treatment available as an alternative to an acute inpatient admission.
Early intervention

People who experience early intervention in mental illness generally recover faster and have better long-term outcomes, as well as a reduced risk of relapse and suicide. In 2016, the Mental Health Taskforce introduced a national access and waiting time standard for Early Intervention in Psychosis (EIP) services. This standard expects 50% of people with a first episode of psychosis to start treatment with a NICE-recommended package of care within two weeks of referral. This figure will increase to 60% by the end of 2020/21. The EIP standard is still a priority as discussed in the NHS Long Term Plan and the NHS Mental Health Implementation Plan 2019/20 – 2023/24.

Building on this, new waiting time standards for mental health services are currently being trialled following a clinically-led review by the NHS Medical Director. The review suggested a new four-week waiting time for adult and older adult community mental health teams.

Physical health interventions

Research has shown there is a connection between poor mental health and poor physical health. This is reiterated by the World Health Organization (WHO), which estimates that people with severe mental illness die 10 to 25 years earlier than those who do not have a severe mental illness. In response to this, the NHS Long Term Plan commits to provide physical health checks to 280,000 people with severe mental illness by 2020/21 and 390,000 people by 2023/24.

NHS England set a standard for 2019/20 that required that 60% of people on a GP severe mental illness register should have a comprehensive physical health check in any setting at least once a year. At the end of 2019/20, 36% of people on a GP severe mental illness register were given a physical health check. However, it should be noted that 30 of the 191 clinical commissioning groups (CCGs) did not submit data during this period.

Equality between physical and mental health services

The Royal College of Nursing suggest there are many complex reasons for the mortality gap between those with and without severe mental illness, including poor physical health and life choices; discrimination and stigma; poor life chances; the use of long-term medication; and the way in which mental health services are structured. This highlights the importance of valuing mental health and physical health equally.

Parity of esteem strives for equal priority for both mental and physical health. It has been on the government agenda since 2011, with the publication of the No Health Without Mental Health report. This was then enshrined into law in 2012 through the Health and Social Care Act 2012.
Since then, the Five Year Forward View for Mental Health has reinforced the government’s commitment to this issue by recommending that the Department for Health and Social Care carry out a review of the Health and Social Care Act 2012 to identify disparities in provision for both mental and physical health. The NHS Long Term Plan continues this commitment with additional funding to improve access to talking therapies and crisis care, the introduction of new waiting time targets, and a focus on encouraging people to join or re-join the workforce.

Finding and keeping work

Stable employment is an important factor in maintaining good mental health. As well as providing financial security and important social networks, research has found that for people with severe mental illness, work can provide social support, independence and improved wellbeing.\(^{49}\)

Recent mental health policy recognises the importance of helping people with severe mental illness to find and keep work. In response, NHS England pledged to double access to Individual Placement and Support (IPS) by 2020/21.\(^ {50}\) IPS is a vocational rehabilitation intervention for people with severe mental health difficulties.\(^ {51}\) In addition, the NHS Long Term Plan discusses new integrated models of community mental health care. These new models of care include employment support and improved digital support services to fit around work.

However, the COVID-19 lockdown and forced closure of workplaces has brought economic uncertainty to many people. As well as the stresses associated with financial insecurity and the loss of vital social networks, unemployment can result in a fall in standards of living, the stigma of being unemployed and being in receipt of social welfare.\(^ {52}\) These all have an immediate and negative impact on mental health. The Mental Health Foundation conducted a survey looking at the mental health effects of the pandemic. The study found that socio-economically disadvantaged groups were more likely to experience anxiety, panic, hopelessness, loneliness and to not cope well with the stresses of the pandemic. Furthermore, 24% of unemployed people reported having suicidal thoughts, which is almost double that of the population as a whole.

Staffing

In the Five Year Forward View, there is a clear emphasis on reducing the demand for acute services and the need for inpatient beds, by strengthening community health services and providing care outside of hospital settings. This shift will require an expanded workforce and training for the existing workforce in key areas, such as crisis care and mental health liaison. In 2017, Stepping forward to 2020/21: The mental health workforce plan for England stated that the NHS would be establishing 21,000 new posts to meet the commitments set out in the Five Year Forward View.\(^ {53}\)
NHS Digital workforce statistics for the period of January 2017 to May 2020 showed an increase of 1,915 community mental health nurses, but a reduction of 202 mental health nurses in other settings. In addition, there had been an increase of 569 doctors in psychiatry services.

In 2019, The Kings Fund reported that, to meet the commitment set out in the NHS Long Term Plan, which plans to provide mental health services to an additional two million people by 2023/24, there would need to be 27,460 new posts in addition to the 21,000 identified in the workforce plan. They also added that NHS board papers described how staff shortages result in missed staff breaks, the inability to attend training or provide supervision, and increases in the workload for substantive staff. This in turn affects staff morale, sickness and turnover.

As discussed earlier in this section, there are expectations that, as a result of the pandemic, demand for mental health services will rise substantially in the coming months. The NHS Confederation describes concerns of senior leaders who are reporting poor staff wellbeing due to increased workloads and adapting to unprecedented working situations. They state there are major staff shortages in key areas of mental health provision, risking high levels of burn out and attrition rates.

**Funding**

Historically, mental health services have suffered from underfunding. In 2015/16, the Mental Health Investment Standard (MHIS) was introduced, replacing Parity of Esteem (PoE), to encourage CCGs to increase investment in mental health services in line with their overall increase in allocation each year. Ninety-six per cent of CCGs met this standard in 2019/20, with 92% of CCGs meeting the target in 2018/2019. The NHS Mental Health Dashboard also shows that mental health spend accounted for 14% of local health spend in 2019/20, an increase of one percentage point since 2015/16. However, a report from NHS Providers raises issues around transparency and governance of funding flows, stating that funding for mental health does not always reach the frontline services that need it most.

In 2018, as part of the NHS Long Term Plan, the Department of Health and Social Care announced that NHS funding would increase by 3.4% in real terms, each year for five years. This will increase funding by £20.5 billion over the five-year period, with mental health services for adults and older people with severe mental illness expected to receive £1 billion of this funding.

**Prevention**

In 2017, the government created the Prevention Concordat for Better Mental Health. The concordat encourages cross-sector action to address and reduce

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9 May 2020 is the latest data set available at the time of writing.
mental ill-health, through the implementation of evidence-based planning and commissioning. As part of this, Public Health England developed a set of key resources, including guidance and tool kits, which are aimed at helping stakeholders to promote better mental health.

In 2019, the Department for Health and Social Care published the green paper, *Prevention is better than cure*. This set out the government’s vision for the future of mental health care, planning to adopt a prevention first approach to mental health problems in order to reduce the burden on acute and inpatient services. The paper acknowledged the need for better integration between hospital-based and community-based mental health services, as well as the need to recruit and retain more community-based staff. The paper also highlighted the importance of technology in this vision. It acknowledged that technology and data collection needed to improve to enable staff to be more effective in their roles. Improved technology would also allow for a more strategic and targeted approach to providing services that are focused on preventing mental health issues from arising.
Results from the survey

The national lockdown in response to COVID-19 began on 23 March 2020, partway through the fieldwork period of this survey (February to June 2020). The lockdown brought about changes to delivery methods of community mental health services. For instance, many face-to-face services were delivered using virtual means, while some services were temporarily closed. It is evident from our analysis that the way in which services changed varied between trusts, with some trusts reporting that services saw significant changes, while others saw little change.

Respondents accessing NHS mental health services experience care that is ongoing and many of the questions in our questionnaire ask for feedback on their experience “in the last 12 months”. Therefore, it is likely that some reported experiences are based on the revised service that people received during the pandemic and lockdown.

Following in-depth analysis, the 2020 results are not considered comparable with results from previous years. We found statistically significant differences in the results received during the later stages of fieldwork (that is, during lockdown) when compared with an equivalent period in previous surveys. These differences could be attributed to differences in the way services were delivered post-lockdown, or they could be affected by people’s perceptions of the NHS at a time when there was great national support for frontline NHS workers. Therefore, we are unable to present long-term trend data as we have in previous surveys. For more information about the investigations carried out, as well as p-charts that show trends over time where available, see appendix I: COVID-19.

This section presents key results for the 2020 community mental health survey, under the following themes:

1. Care and treatment
2. Health and social care workers
3. Organising care
4. Planning care
5. Reviewing care
6. Crisis care
7. Medicines
8. NHS therapies
9. Feedback
10. Support and wellbeing
11. Overall

h. Responses to questions such as “don't know/can't remember” are not shown and excluded from percentage calculations. The wording for these responses is designed for when a respondent cannot remember or does not have an opinion.
Within the results, we have included subgroup analysis that compares the experiences of different groups of people. Using a set of themes based on the National Patient Experience Framework, the analysis models the mean scores of subgroups of people using community mental health services according to differing characteristics. These characteristics are:

- age
- gender
- religion
- sexual orientation
- ethnicity
- Care Programme Approach status
- diagnosis (care cluster codes)
- length of contact
- long-term conditions
- ‘proxy response’ (whether the questionnaire was completed entirely by or with the support of someone other than the person who used the services).

Overall, this analysis found that people aged 18 to 50 reported worse than average experiences in 11 of the 14 areas of care covered by the survey, while those in the older age categories (aged 66 and over) reported better than average experiences for the same 11 areas. Disparities were also found when considering the experiences of people assigned to different care cluster codes. People in the non-psychotic care cluster categories and those assigned to cognitive impairment and dementia care clusters, with both challenging and severe disorders, typically reported worse than average experiences in multiple areas of care explored in this survey. In contrast, people assigned to psychotic care clusters codes typically reported better than average experiences, particularly people experiencing a first episode of psychosis who reported better than average experiences in 13 of the 14 areas of care explored by this survey.

See appendix G: Subgroup analysis for more information and charts. A full summary of results can be found in the Subgroup analysis summary: how experience varies for different groups of respondents section.

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i. The sum of question scores divided by the number of questions in the composite.

\(^{1}\) Care cluster codes were created by clinicians to help manage their caseloads. There are 21 codes in total. People are assigned to different care cluster codes based on the level of need and risk that they have, as well as their diagnosis. Care cluster codes also help people to establish what type of treatment is available to them.
1. Care and treatment

Ensuring people have access to a high standard of mental health care is central in all relevant national policy and wider discourse. The NHS Long Term Plan, the most recent significant policy that affects mental health services, commits to ring-fencing funding for mental health services to allow for service expansion. The plan highlights that one of the main outcomes of this funding would be faster access to community and crisis mental health care.

NICE quality statement 5: Access to services emphasises the importance of making sure people have access to high-quality mental health services when they need it. Furthermore, the national access and waiting time standard for Early Intervention in Psychosis (EIP) services requires at least 50% of people with a first episode of psychosis starting treatment with a NICE recommended package of care within two weeks of referral.

As previously discussed, experts, such as the Royal College of Psychiatrists, expect demand for NHS mental health services to significantly rise over the coming months as a direct result of the pandemic. Our results show that a quarter of people (24%) already accessing services did not feel that they saw services enough for their needs; and less than half (43%) felt they ‘definitely’ saw services enough for their needs.
Q3. In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs?

Answered by all. Respondents who stated that they didn't know have been excluded. Total number of respondents: 16,738.

There was wide variation in response to this question across different groups of people. The general disparities in experiences of those belonging to different age groups and care cluster codes, as discussed above, were also evident for this question. In addition, people who are on a new Care Plan Approach (CPA) reported better than average experiences, as did those who have been in contact with services for less than a year and those who identify as heterosexual.

2: Health and social care workers

Research shows that positive interactions between people using a service and mental health staff can positively impact overall outcomes. Therefore, relationships that allow for both parties to communicate equally and with respect are important.

**NICE quality statement 3: Involvement** to improve services reinforces this by highlighting the importance of involving people who use services in making decisions about their care and treatment, as well as encouraging service providers to promote self-management.
Questions in this section consider whether staff provided people who use services with the opportunity and time to discuss their individual circumstances, as well as recognise the impact their mental health has on other areas of their life. When asked if they were given enough time to discuss their needs and treatment, 59% responded ‘yes, definitely’. Thirteen per cent of all respondents reported that they were not given enough time to discuss their needs and treatment.

Q4: Were you given enough time to discuss your needs and treatment?

Answered by all.
Respondents who stated that they didn’t know / couldn’t remember have been excluded.
Total number of respondents: 16,738

As discussed earlier, overall subgroup analysis found disparities in the experiences of people based on age and the care cluster code they were assigned to. This is also evident with regard to people feeling they were given enough time to discuss their needs and treatment.

People were also asked if those they saw understood how their mental health needs affected other areas of their lives. Just over half of people (53%) reported that the those they saw had ‘definitely’ understood how their mental health affected other areas of their lives, while 14% responded ‘no’.

The Five Year Forward View for Mental Health considers what a person’s experience of mental health services should look like. It states that each person should be able to see the same mental health team or professional, allowing for relationships to be built on familiarity and trust. Meeting with people who are
unfamiliar or unaware of a person’s treatment history can result in people having to repeat their history multiple times, leading to frustration and poor overall experience.

People using the service were asked if those they saw appeared to be aware of their treatment history. Just over half of all respondents (52%) said staff were ‘completely’ aware of their treatment history, while another 35% felt they were ‘to some extent’. The remaining 13% of respondents did not feel the person or people they saw appeared to be aware of their treatment history.

### 3: Organising care

For people to feel fully supported and receive successful treatment, it is important that people know who is in charge of their care. The Royal College of Psychiatrists states that a care coordinator should get to know the person they are working with, discuss care plans with them and make sure the care plan is very clear about how the person will be helped.

NICE quality statement 4: Contacts for ongoing care advises that people who use community mental health services are supported by staff from the same multidisciplinary team. This is also followed by the current Care Programme Approach (CPA), by requiring a multidisciplinary package of care in which the assigned care coordinator maintains contacts with the person receiving care, building a good relationship. Continuous care from the same team will support a relationship of familiarity with the person receiving care. This in turn will encourage people to more effectively manage their mental health and the impact it has on other areas of their life.

To understand people’s relationship with those providing care, they were asked if they have been told who is in charge of organising their care and services. Over a quarter of people (28%) had not been told who this person is, and the remaining 72% stated they had been told.

Supplementary questions were asked of respondents who knew who was organising their care (and where this was not their GP).

Ninety-seven per cent responded ‘yes’, when asked if they knew how to contact the person in charge of their care. Most respondents (91%) felt this person organised the care and services either ‘very well’ (58%) or ‘quite well’ (33%).
Q10: How well does this person organise the care and services you need?

Answered by those who have been told who is in charge of organising their care and services, and the person in charge is not a GP.
Total number of respondents: 7,833.

When considering the results for different people for the theme ‘organisation of care’, there is a clear disparity in experiences based on the type of treatment the person receives. Those reporting better than average experiences were receiving treatment for psychotic conditions. People reporting worse than average experiences were all receiving treatment for cognitive impairment and dementia.

People aged 66 and over reported better than average experiences, as did people who were on a new CPA, those who have been in contact with services for less than a year. Younger people, aged between 18 and 35, reported worse than average experiences.

4: Planning care

NICE, alongside partner organisations, has created an action plan that aims to make shared decision-making central to all routine care, across all healthcare services. NICE quality statement 6: Joint care planning highlights that, by jointly agreeing a care plan, people using mental health services can identify how
support can help them to live an independent life, achieving their goals and desired outcomes.

Guidance produced by the Department of Health and Social Care for the CPA emphasises that actively involving people in the creation of their own care plan ensures care and support are tailored to an individual’s specific needs, thereby improving recovery. 68

When asked if they had agreed with someone from NHS mental health services what care they would receive, less than half of all respondents (42%) stated ‘yes, definitely’. A fifth of all people responded ‘no’.

Q11. Have you agreed with someone from NHS mental health services what care you will receive?

Answered by all. Total number of respondents: 16,969.

People who had agreed with someone from NHS mental health services what care they would receive were also asked if they were involved as much as they wanted to be in agreeing what care they would receive. Just over half responded ‘yes, definitely’, while 8% said they were not, but wanted to be.
Q12. Were you involved as much as you wanted to be in agreeing what care you will receive?

Answered by those who have agreed with someone from NHS mental health services what care they will receive. Respondents who stated that they didn't know / couldn't remember or did not want to be involved have been excluded. Total number of respondents: 12,794.

Subgroup experiences were analysed for the theme of involvement in care using a composite of ‘Were you involved as much as you wanted to be in agreeing what care you will receive?’ and ‘Did you feel that decisions were made together by you and the person you saw during this discussion?’. In line with findings in previous themes, there were disparities in the experiences of people based on age group and the care cluster code they were assigned to. In addition, people who identify as heterosexual reported better than average experiences, as did those who have been in contact with NHS mental health services for less than a year.

Respondents were also asked if the agreement on what care they will receive took into account their needs in other areas of their life. Less than half (47%) responded ‘yes, definitely’, with one in 10 (12%) stating that their agreed care does not consider their needs in other areas of their life. The remaining 41% said the agreement took their needs in other areas of their life into account to ‘some extent’.

When analysing subgroups for the theme of respect for person-centred values, we used a composite indicator, combining ‘Did the person or people you saw
understand how your mental health needs affect other areas of your life?’ and ‘Does this agreement on what care you will receive take into account your needs in other areas of your life?’ Analysis found that, similarly to earlier themes, there are inconsistencies in the experiences of people belonging to different age groups and those assigned to different care cluster codes.

5: Reviewing care

A collaborative approach to planning care as discussed above, also extends to reviewing care. According to NHS advice, care plans should have an initial review within a few months of set up and annually after that.69 Mind, the mental health charity, states that care plans should be reviewed regularly to:

- monitor progress and make changes should a person’s needs change
- consider how the care plan is meeting specific needs and allowing an individual to achieve personal outcomes
- keep the plan up-to-date
- determine which services may be needed in future.70

To establish if care plans are reviewed annually, respondents who had been in contact with NHS mental health services for more than 12 months were asked if they had had a specific meeting with someone to discuss how their care was working during this time. A quarter of people (25%) responded ‘no’, with the remaining 75% stating that they had met with someone.

In addition, those who stated that they had met with NHS mental health services to discuss how their care was working in the last 12 months, were also asked if they felt that decisions were made together with the person they saw during the discussion. Sixty per cent of people responded ‘yes, definitely’, while 8% of people responded ‘no’. 
Q15: Did you feel that decisions were made together by you and the person you saw during this discussion?

Answered by those who had been in contact with mental health services for one or more years, and had a specific meeting with someone from NHS mental health services in the last 12 months to discuss how their care is working. Respondents who stated that they didn’t know / couldn’t remember or did not want to be involved in making decisions have been excluded.

Total number of respondents: 9,361.

6: Crisis care

A mental health crisis can be defined as an emergency that poses an immediate threat to a person’s emotional or physical wellbeing. Some people experience mental health crises as part of their ongoing mental health conditions, while others may experience crises as infrequent or one-off occurrences.

There are four key areas organisations should focus on when working collaboratively to provide care and treatment during a mental health crisis. The Crisis Care Concordat, a national agreement between different services and
agencies involved in delivering care and support to people in crisis, identifies these key areas as being:

- access to support before a person reaches crisis point
- urgent and emergency access to crisis care
- the quality of care and treatment when a person is in crisis
- recovery and staying well.

Crisis care has also been identified as an area for improvement in a number of recent national policies. Most significantly, the Five Year Forward View for Mental Health said that people experiencing a crisis should have access to a high standard of care 24 hours a day, seven days a week, as they would if they needed emergency physical care. The plan also urges NHS England to make steps toward the provision of a 24 hours a day, seven days a week community-based mental health crisis service across England. The aim of this would be to reduce inpatient admissions and provide intensive home treatments where possible.

People were asked if they would know who to contact within the NHS, out of hours, if they had a crisis. More than a quarter (28%) of respondents indicated that they would not.

When comparing the experiences of accessing crisis care for different groups of people, analysis shows that people aged 80 and over reported worse than average experiences. This is the only occurrence of this group reporting worse than average experiences, across all 14 themes analysed.

As is evident in other themes, those accessing care for cognitive impairment and dementia conditions reported worse than average experiences, while those reporting better than average experiences were receiving care for psychotic conditions.

Those who indicated that they would know who to contact within the NHS, out of office hours, if they had a crisis, were asked if in the last 12 months they had received the help they needed when they tried to contact this person or team. Almost a fifth of respondents did not get the help they needed (17%) or could not contact this person or team (2%). Just over half of respondents (53%) ‘definitely’ received the help they needed.
Q17: In the last 12 months, did you get the help you needed when you tried contacting this person or team?

Answered by those who knew who to contact out of office hours within the NHS if they had a crisis. Respondents who stated that they couldn’t remember or had not tried to make contact in the last 12 months have been excluded. Total number of respondents: 7,415.

With regard to accessing crisis care, the experiences of different groups of people using the service reflected those in other care themes, with experiences of people in different age groups and those assigned to care cluster codes 8 (Non-psychotic chaotic and challenging disorders) and 10 (First episode of psychosis) differing significantly.

7: Medicines

Adherence to treatment is often low for people with mental ill-health. Reasons for this are multifaceted but can include an individual’s perception of illness and medicines, intolerable side effects, and some demographic characteristics such as homelessness.
Research has found that people who do not use medicines regularly are more likely to use multiple health services, leading to higher costs of treatment.\textsuperscript{74,75} As well as lengthy hospitalisation, suicide rates for people with bipolar disorder increase when medicines are not routinely taken, as do relapse rates for people with schizophrenia.\textsuperscript{76}

To help professionals understand an individual’s motivations for taking or not taking medicines, as well as to increase overall compliance, guidance produced by NICE recommends that people using the service are included in discussions about prescribed medicines.

Respondents who had received medicines in the past 12 months for mental health needs were asked if they were involved as much as they wanted to be in decisions about which medicines they would receive. Just over half (52\%) indicated that they were ‘definitely’ involved to the extent they wanted to be, while around one in 10 people (12\%) responded ‘no, but I wanted to be’. Respondents were also asked if the purpose of their medicines had ever been discussed with them. Fifty-nine per cent of people responded ‘yes, definitely’, while 8\% said their purpose had not been discussed at all.

When asked if the possible side effects of their medicines had ever been discussed with them, almost a quarter (24\%) responded ‘no’, with under half (43\%) indicating that possible side effects had ‘definitely’ been discussed with them.
Q21. Have the possible side effects of your medicines ever been discussed with you?

Answered by those who had been receiving any medicines in the last 12 months for their mental health needs. Respondents who stated they did not know/could not remember were excluded. Total number of respondents: 13,292.

When comparing subgroup experiences for this theme, results are similar to those in other themes. People experiencing a first episode of psychosis reported better than average experiences, while those accessing care for non-psychotic chaotic and challenging disorders, or high need cognitive impairment and dementia disorders reported worse than average experiences. In addition, people who had been in contact with services for less than a year reported better than average experiences.

Respondents who indicated they had been receiving medicines for 12 months or longer were asked if an NHS mental health worker had checked with them about how they were getting on with their medicines during this time. Seventy-nine percent of people responded ‘yes’, compared with 21% who responded ‘no’. 
NHS mental health services include a wide variety of therapies, varying in duration and intensity, with the overall aim of providing people with timely and effective care. Some people access multiple types of therapy simultaneously to ensure they are receiving care that is tailored to their specific needs. For example, people with depression can often receive cognitive behavioural therapy (CBT) alongside interpersonal therapy. The charity Mind states that before any therapy is delivered, it should be assessed for each individual, considering the level of risk posed and adjusting the intensity and duration accordingly.

The NHS Long Term Plan set out an aim to increase the types of support available for people, so they are better able to manage their own health. The plan discusses the development of applications (apps) and other online resources to support good mental health, as well as offering online therapies for common mental health conditions. The intention of offering a more diverse range of therapies was to enable a faster and enduring recovery.

Respondents were asked if the therapies they received within the last 12 months were explained to them in a way they could understand. Sixty-five per cent of people responded ‘yes, completely’ with a further 31% responding ‘yes, to some extent’. The same respondents were also asked if they were involved as much as they wanted to be in deciding which NHS therapies to use. Half of people (50%) stated ‘yes, definitely’. However, one in 10 (11%) responded ‘no, but I wanted to be’.
Q27: Were you involved as much as you wanted to be in deciding what NHS therapies to use?

Answered by those who have received any NHS therapies in the last 12 months for their mental health needs.
Respondents who stated that they didn't know / couldn't remember or did not want to be involved have been excluded.
Total number of respondents: 6,084.

Experts believe that demand for NHS mental health services will increase significantly as COVID-19 negatively affects the drivers of good mental health for many people. Respondents were asked how they felt, overall, about the length of time they had to wait before receiving NHS therapies. Forty-four per cent of people felt they waited too long, while just over half reported that the waiting time was appropriate.
Q29: Overall, how did you feel about the length of time you waited before receiving NHS therapies?

Answered by those who had received any NHS therapies in the last 12 months for their mental health needs. Respondents who did not have to wait for NHS therapies have been excluded. Total number of respondents: 5,786.

9: Feedback

The [NHS Constitution](https://www.england.nhs.uk/nhs-constitution/) states that the NHS should aspire to the highest standards of excellence, placing the patient at the heart of everything it does. To achieve this, the NHS encourages people to give feedback on their experiences. This information can then be used to inform service improvement and patient experience.

NHS England highlight the benefits associated with good patient experience. These include: better health outcomes for people who use services; good, organisational reputation; positive impact on staff; and lower care costs.

The [Five Year Forward View for Mental Health](https://www.england.nhs.uk/wp-content/uploads/2018/06/Mapping-Five-Year-Forward-View-mental-health.pdf) further advocates for people to experience care that is flexible to their changing needs and is based on a collaborative and open relationship.
When people were asked if, aside from this questionnaire, they had been asked by NHS mental health services to give their views on the quality of their care within the last 12 months, the majority (76%) responded ‘no’, with the remaining 24% indicating that they had been asked for their views.

10: Support and wellbeing

People who use mental health services often have needs in other areas of their lives that can affect their recovery. These include housing, financial support, employment and physical health needs.

Survey respondents were asked a number of questions about the support provided to them in accessing help for their wider needs. Those who already had active support or felt they did not require support with particular needs were excluded from results.

Physical health needs

As discussed in the Five Year Forward View for Mental Health, physical health problems significantly increase the risk of mental ill-health. The same is true in reverse, with those experiencing severe and prolonged mental illness being at risk of dying on average 10 to 25 years earlier than the general population. Two-thirds of these deaths resulted from avoidable physical illness. An estimated 40,000 early deaths could be prevented if this issue was addressed.78

Long-term conditions, both mental and physical, can have a negative and life-changing impact on a person’s wellbeing, functional capability and quality of life. More than 15 million people have multiple long-term conditions.79 Four million of these people also have mental ill-health. It is therefore important to address both mental and physical long-term conditions equally, as set out in the Improving Access to Psychological Therapies Manual80

A number of national policies have addressed inequality between mental and physical health, and committed to closing the health gap between people with mental ill-health and the population as a whole. The Department of Health and Social Care identified the 2020s as the decade for achieving parity of esteem in how conditions are treated and prevented.81

Respondents were asked if, in the last 12 months, NHS mental health services provided them with support for their physical health needs. Thirty-six per cent of people did not receive support but would have liked it.
Q30: In the last 12 months, did NHS mental health services support you with your physical health needs (this might be an injury, a disability, or a condition such as diabetes, epilepsy, etc)?

![Bar chart showing responses to Q30](chart.png)

Answered by all.
Respondents who stated that they have support and did not need NHS mental health services to provide it, do not need support for this, or do not have physical health needs have been excluded. Total number of respondents: 8,499.

Financial advice, benefits and employment

Stable employment and financial security are key factors in maintaining good mental health. In 2017, *Thriving at work: a review of mental health and employers* found that 300,000 people with a long-term mental health condition lose their jobs each year, which is a much higher proportion than those with physical health conditions.82

The *Five Year Forward View for Mental Health* found that people with mental health conditions are often over-represented in low-paying, high-turnover, temporary roles, indicating higher levels of financial instability for people in this group.

When considering the COVID-19 pandemic and the implications this has for the UK economy and jobs, financial instability is an increasing concern in many households. A study conducted by the Mental Health Foundation, which tracks
the mental health impacts of the pandemic, has found that 34% of surveyed adults who are in full-time employment are worried about losing their job.83

Respondents were asked if, in the last 12 months, they had received help or advice from NHS mental health services with finding support for financial advice or benefits. Forty-three per cent of people reported that they did not receive help and advice but would have liked it.

Q31. In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits?

Answered by all.
Respondents who stated that they have support and did not need help / advice to find it, or do not need support for this have been excluded.
Total number of respondents: 9,680.

Additionally, respondents were asked if, in the last 12 months, NHS mental health services gave them any help or advice with finding support for finding or keeping work (paid or voluntary). Forty-three per cent of people did not receive this support but would have liked it. Just over a quarter (27%) indicated they had ‘definitely’ received help and advice.
Q32: In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding or keeping work (paid or voluntary)?

Answered by all.
Respondents who stated that they have support and did not need help / advice to find it, do not need support for this, or are not currently in or seeking work have been excluded.
Total number of respondents: 5,016.

Community/social activities
Social interaction has been widely linked to mental wellbeing. Research and insight from national government, mental health charities, academia and think tanks all advocate for social inclusion as a buffer against poor mental health.84,85

NICE quality statement 6: Joint care planning stated that care plans should include activities that promote social inclusion through activity. These activities include education, employment, volunteering, leisure and caring for dependents. This is reinforced by the Improving Access to Psychological Therapies Manual, which highlights the importance for mental health service providers to work as part of a wider system to facilitate links between people and those providing sources of support in the community.

As with financial stability, COVID-19 has also had an impact on people in terms of the amount and quality of social interaction they access daily. The restrictions
and subsequent lockdown have caused profound distress to those in strict isolation. Many people are still experiencing extreme loneliness. In response, the government have launched a £5 million loneliness COVID-19 fund that encourages a community-level response to tackling this issue.86

Considering the importance of social interaction for the maintenance of good mental health, respondents were asked if, in the last 12 months, NHS mental health services had supported them in joining a group or taking part in activities. Thirty-seven per cent of people did not receive support but would have liked it.

**Q33: In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?**

![Bar chart showing responses to Q33](chart.png)

Answered by all. Respondents who stated that they did not want / need this have been excluded.
Total number of respondents: 9,313.

Differences in experience related to support and wellbeing were analysed using a composite of the following questions:

- In the last 12 months, did NHS mental health services support you with your physical health needs (this might be an injury, a disability, or a condition such as diabetes, epilepsy, etc.)?
- In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits?
• In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding or keeping work (paid or voluntary)?

• In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?

As has been evident across almost all themes, people experiencing a first episode of psychosis reported better than average experiences. People accessing care with cognitive impairment or dementia complicated conditions, with high need overall or high physical or engagement needs, reported worse than average experiences for the support and wellbeing theme.

**Involving family or friends**

A person is more likely to feel confident in their ability to deal with mental health conditions if they have the support of family and friends. As a result, NICE guidance encourages mental health providers to actively involve family and carers of people using the service, should the person receiving care want this.\(^7\)

All respondents were asked if NHS mental health services involved a member of their family, or someone close to them, as much as they would have liked. Just over half (53%) of respondents reported that a member of their family or someone close to them was ‘definitely’ involved as much as they wanted. Eighteen per cent of people responded ‘no, not as much as I would like’.
Q34. Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?

Answered by all.
Respondents who stated that their friends or family did not want to be involved, did not want their friends or family to be involved, or that this does not apply to them have been excluded.
Total number of respondents: 11,642.

In summary, many people have not received help, advice or support from NHS mental health services for physical health, social interaction or to support financial stability. These are also the areas that are likely to be affected by COVID-19 as a result of restricted activity during lockdown and economic uncertainty. In particular, people with severe or chaotic and challenging non-psychotic disorders and those with cognitive impairment or dementia disorders with high need overall or high physical or engagement needs, reported worse experiences.

11: Overall

Dignity and respect

NICE quality statement 1: Empathy, dignity and respect recognises that a key component of good experience is being treated with empathy, dignity and
respect. In addition, the **NHS constitution** says that people should expect to be treated in this way as a basic human right. Respect and dignity are fundamental when building good relationships between those providing mental health services and those receiving care and treatment. However, research has found that stigma, or perceived stigma, attached to mental illness can act as a barrier for people needing specialist help.\(^8\) This extends to stigma, or perceived stigma, in the healthcare system too. As earlier sections in this report highlight, positive experiences of the relationship between people using the service and the service provider can improve outcomes, treatment and recovery.

People were asked if overall, in the last 12 months, they felt that they were treated with respect and dignity by NHS mental health services. The majority (73%) responded ‘yes, always’, with 19% responding ‘yes, sometimes’. Eight percent did not feel that they were treated with respect and dignity during the 12-month period.

When comparing the experiences of different groups with regard to respect and dignity, findings are similar to other themes, with people from different age groups and those assigned to different care cluster codes reporting significantly different experiences of care. In addition, people who identify as heterosexual and people who have been in contact with NHS mental health services for five years or less reported better than average experiences. In comparison, those who indicated they were no longer in contact with services or were unsure of the length of their contact with services reported worse than average experiences.

**Overall experience**

Respondents were asked to rate their overall experience of NHS mental health services, with a score of 0 representing a ‘very poor experience’ and a score of 10 representing a ‘very good experience’. Just over half of all people (51%) rated their experience positively, giving it a score of either eight, nine or 10.

When considering the experiences of different groups overall, those reporting better than average experiences were people aged 66 and older, people who identify as heterosexual and people who have been in contact with services for five years or less. As is evident in other themes, people accessing services with a first episode of psychosis also reported better than average experiences, as did those with ongoing recurrent psychosis with low symptoms and ongoing or recurrent psychosis with high disability.

In contrast, people with non-psychotic chaotic and challenging disorders reported worse than average experiences, as did people aged 50 and younger, people who preferred not to disclose their religious beliefs, and people who were no longer in contact with services or were unsure about the length of their contact with services.
Subgroup analysis summary: how experience varies for different groups of respondents

Subgroup analysis has modelled the mean scores of different groups of people using community mental health services, based on their age, sex, religion, ethnicity, sexual orientation, CPA status, diagnosis (care cluster codes), length of contact, long-term conditions and proxy response (‘Q41. Who was the main person or people that filled in this questionnaire?’).

The themes (some using composites of individual survey questions) are:
- overall (Q35)
- access (Q3)
- communication (Q4)
- crisis care (access) (Q16)
- crisis care (care) (Q17)
- involvement of family and friends (Q34)
- information sharing (medicines) (Q20 and Q21)
- information sharing (therapies) (Q26)
- involvement (Q12 and Q15)
- organisation of care (Q7 and Q10)
- respect and dignity (Q36)
- respect for person-centred values (Q5 and Q13)
- support and wellbeing (Q30, Q31, Q32 and Q33)
- treatment history (Q6).

Appendix G: Subgroup analysis contains more information about the questions used, as well as the charts.

In this report, differences that are equivalent to at least 0.1 standard deviations from the overall mean of the target variable are treated as being noteworthy, provided that the confidence interval does not overlap the mean line.

Age

People in the younger age groups consistently reported less positive experiences than older people, with the exception of access to crisis care in which those over 80 years old reported worse than average experiences.
Specifically, respondents in the 18 to 35 age group reported worse than average experiences across almost all themes. These were:

- access
- communication
- crisis care (care)
- involvement of friends and family
- involvement
- organisation of care
- respect and dignity
- respect for person-centred values
- support and wellbeing
- treatment history
- overall experience.

In contrast, people in the older age groups consistently reported better than average experiences for the same themes.

**Religion**

Analysis shows Muslim respondents reported better than average experiences in the communication theme, whereas those who selected ‘other’ as their religion reported worse than average experiences in three theme areas. These were: communication, involvement of friends and families, and respect for person-centred values. In addition, people who preferred not to disclose their religion reported worse than average experiences across five themes. These were: communication, involvement of friends and family, respect for person-centred values, treatment history and overall experience.

**Sexual orientation**

Those respondents who identified as heterosexual or straight reported better than average experiences in six key theme areas. These were: access, crisis care (care), involvement of friends and family, involvement, respect and dignity, and overall experience.

**Ethnicity**

There were no ethnic groups that reported better or worse experiences in any of the themes analysed.
CPA status

Respondents on a new CPA reported better experiences across three themes. These were: access, organisation of care, and support and wellbeing.

Diagnosis/care cluster codes

Analysis found that respondents diagnosed with non-psychotic disorders and those diagnosed with cognitive impairment and dementia disorders typically reported worse than average experiences across multiple themes. In contrast, respondents with psychotic disorders, particularly those with a first episode of psychosis, reported better than average experiences across most themes. CQC’s *The state of health care and adult social care in England 2018/19* report highlighted concerns that an increase in access to early intervention services, such as talking therapies, had negatively affected those with more challenging mental health issues. Organisations representing people who use services believe that funding is diverted away from some community mental health services to meet early intervention targets.

Non-psychotic disorders

Respondents diagnosed with non-psychotic chaotic and challenging disorders (care cluster code 8), such as personality disorder, reported worse than average experiences across 10 of the 14 themes. These themes were:

- access
- communication
- crisis care (care)
- involvement of friends and family
- information sharing (medicines)
- involvement
- respect and dignity
- respect for person-centred values
- treatment history
- overall experience.

Psychotic disorders

In comparison, respondents diagnosed with a first episode of psychosis (care cluster code 10) reported better than average experiences across 13 of the 14 themes. These were:

- access
- communication
- crisis care (access)
• crisis care (care)
• involvement of friends and family
• information sharing (medicines)
• involvement
• organisation of care
• respect and dignity
• respect for person-centred values
• support and wellbeing
• treatment history
• overall experience.

Comparably, respondents assigned to care cluster code 11 (ongoing recurrent psychosis – low symptoms) and care cluster code 12 (ongoing or recurrent psychosis – high disability) both reported better than average experiences across multiple themes.

**Cognitive impairments and dementia**
Respondents assigned to cognitive impairment and dementia care codes generally experienced worse than average experiences. However, respondents diagnosed with cognitive impairment or dementia complicated (high need) (care cluster code 20) reported worse than average experiences across six themes. These were:

• access
• crisis care (access)
• information sharing (medicines)
• organisation of care
• respect for values
• support and wellbeing.

**Length of contact**
Generally, respondents with a shorter length of contact with NHS mental health services reported better experiences across most themes. For instance, those who have been in contact with services for less a year reported better than average experiences in 11 of the 14 themes. These were:

• access
• communication
• crisis care (access)
• information sharing medicines
• involvement
• organisation of care
• respect and dignity
• respect for person-centred values
• support and wellbeing
• treatment history
• overall experience.

Those who were unsure how long they had been in contact with NHS mental health services reported worse than average experiences for nine themes.

**Long-term conditions**

No long-term condition groups reported significantly better or worse than average experiences.

**Proxy response (response to ‘Q41. Who was the main person or people that filled in this questionnaire?’)**

• Respondents completing the questionnaire with the help of a professional reported better than average experiences across six themes. These were: access, information sharing (medicines), involvement, organisation of care, respect for person-centred values, and support and wellbeing.

See [Appendix G: Subgroup analysis](#) for charts and [Appendix H: Care cluster codes](#) for the definition of each code.
Appendix A: Survey methodology

Survey method

As with most surveys in the NHS Patient Survey Programme, the community mental health survey adopted a postal methodology.

Sample members received their first survey pack containing a questionnaire, covering letter and a leaflet offering guidance on multi-language options for completing the questionnaire. This was followed by a reminder letter, then a final survey pack containing a questionnaire, reminder letter and multi-language sheet.

This iteration of the survey continued the use of a ‘faster first reminder’, with the first reminder being mailed five working days after the first mailing. The second reminder maintained the standard interval of two to three weeks, allowing time to remove those who had since died or had opted-out from mailings.

People aged 18 and over were eligible to take part in the survey if they received specialist care or treatment for a mental health condition and had been seen by an NHS trust between 1 September 2019 and 30 November 2019. Trusts drew a random sample from their records of 1,250 people who had been seen at the trust during the sampling period. The sample size is sufficient to allow analysis of results at individual trust level. Full details of the sampling are available in the sampling instructions for the survey (see links to further information in Appendix F: Further information and feedback).

All providers of NHS community mental health services were eligible to take part in the survey.

Certain groups of people were excluded from the survey before providers drew their samples, including:

- anyone who was a current mental health inpatient
- anyone seen only once for an assessment
- anyone seen for assessment only through a liaison service
- anyone primarily receiving the following services: drug and alcohol, learning disability, forensic, psychological treatments from Improving Access to Psychological Therapies (IAPT), chronic fatigue/ME, psychosexual medicine (sexual dysfunction) and gender identity
- people who have only been in contact with services by telephone or email and have not been seen in person at all.

Fieldwork for the survey (the time during which questionnaires were sent out and returned) took place between February and June 2019. Unexpectedly, a national
lockdown was implemented from 23 March 2020 in response to the COVID-19 pandemic.

For more detailed information on the inclusion and exclusion criteria, please see the sampling instructions for the survey. For further information about how the COVID-19 lockdown affected survey results, please see appendix I: COVID-19.

The age profile of respondents has not changed meaningfully between the 2019 and 2020 surveys, however we can see a gradual shift in the age profile since 2014.

### Respondent age profile for 2014 to 2020

<table>
<thead>
<tr>
<th></th>
<th>18-35</th>
<th>36-50</th>
<th>51-65</th>
<th>66+</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>14%</td>
<td>23%</td>
<td>25%</td>
<td>38%</td>
</tr>
<tr>
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<td>2018</td>
<td>15%</td>
<td>20%</td>
<td>25%</td>
<td>39%</td>
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<tr>
<td>2019</td>
<td>15%</td>
<td>19%</td>
<td>25%</td>
<td>40%</td>
</tr>
<tr>
<td>2020</td>
<td>15%</td>
<td>18%</td>
<td>26%</td>
<td>40%</td>
</tr>
</tbody>
</table>

In comparison to the sample profile, we had a lower proportion of younger service users and a higher proportion of older service users responding to our survey. To account for this, we apply weights to our data that are discussed below in the analysis methodology section.

Further information about the sample profile can be found in the quality and methodology report on CQC’s website.

### Questionnaire design

Wherever possible, the questions remain the same over time to measure change. However, questions are amended, added or removed to reflect changes in policy or survey best practice. We also seek guidance from an external advisory group to make sure the questions remain relevant. For this survey iteration, members included representatives from CQC, NHS England, NHS mental health trusts and people who use mental health services.

For this 2020 survey, seven questions were modified to improve clarity, one question was removed and another question was added.
For more detailed information please see the Community mental health 2020 survey development report and the final questionnaire for the 2020 survey.

**Analysis methodology**

**Weighting**

The data presented in this report has been weighted with two weights:

1. A ‘trust weight’, which weights responses from each trust to ensure that each trust has an equal influence on England results. As some trusts have a higher response rate than others, they have a larger share of respondents in the total respondent’s population for England. Without weighting, the views of respondents from these trusts would be over-represented in the England-level results. The weighting is therefore designed so that each trust that participated contributes equally to the overall results for England, regardless of differences in response rates.

2. A ‘population weight’, which aims to weight responses for each individual to make sure it is representative of the trust’s own population (based on the initial eligible sample). This involves weighting based on variables that are related to how people respond: age group and sex.

Both sets of weights are then multiplied together to produce a single combined weight for the data tables that underpin the analysis.

This weighting has been applied to all questions except for demographic questions. The demographic questions are presented without weights applied, as it is more appropriate to present the real percentages to describe the profile of respondents, rather than adjust figures.

**Rounding**

The results present percentage figures rounded to the nearest whole number, so the values given for any question will not always add up to 100%. Please note that rounding up or down may make differences between survey years appear bigger or smaller than they actually are.

**Notes on specific questions**

**Q8**: Is the main person in charge of organising your care and services…?

Some respondents are not sure who is in charge of their care and therefore may have ticked more than one option to this question. Results are presented as percentages for each option, out of all those eligible to answer that question, because some respondents will have selected more than one category. This

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k The questionnaire did not instruct respondents to ‘tick all that apply’. However, as a large number of respondents did this, data has been treated as multiple response.
means that the results may add up to over 100%. Though this question is not included in this report, you can find the results to question 8 in the Open data available on CQC’s website.

Q9 Do you know how to contact this person if you have a concern about your care?
Respondents who stated at Q8 that their GP is in charge of organising their care and services have been removed from the analysis for these questions. This is because results will not be attributable to the mental health trust.

Q10 How well does this person organise the care and services you need?
Respondents who stated at Q8 that their GP is in charge of organising their care and services have been removed from the analysis for these questions. This is because results will not be attributable to the mental health trust.

Q14: In the last 12 months have you had a specific meeting with someone from NHS mental health services to discuss how your care is working?
As the question specifies a time period of ‘the last 12 months’ we have removed people who said they have been in contact with mental health services for less than a year (based on their responses to Q2) from the data set, and they are therefore not included in the analysis for this question. This is because they have not been in contact with services long enough to reasonably expect them to have had a care review.

Q15: Did you feel that decisions were made together by you and the person you saw during this discussion?
We have revised the analysis rules for Q15 to be consistent with that applied to Q14. This approach removes respondents from the dataset who stated at Q2 they had been in contact with mental health services for less than a year, and they are therefore not included in the results for Q15 (as well as for Q14) because we cannot be certain that they were referring to a care review.

I. Respondents who selected option one (‘less than a year’) at Q2 (Overall, how long have you been in touch with NHS mental health services?) were removed from the analysis of Q14 and Q15 as reported in this section.
Appendix B: Other sources of information related to survey results

This section summarises other sources of data related to mental health services in England. Please note that, as they do not measure experience of those using services, they are not directly comparable with the findings presented in this report.

Statistics on the use of mental health services

The Mental Health Services Data Set (MHSDS) contains record-level data about the care of children, young people and adults who are in contact with mental health, learning disability or autism spectrum disorder services.

Data in the latest publication (June/July 2020) is caveated to note that, due to the ongoing disruption caused by the COVID-19 pandemic, there is an impact on the quality and coverage of some statistics. Therefore, they advise readers to interpret data with care during this period.

The latest data shows:

- At the end of June, there were 1,302,903 people in contact with services; the majority of these (928,206) were in adult mental health services. Both of these figures are lower than those in June/July 2019. There were 272,167 people in contact with children and young people’s mental health services and 143,585 in learning disability and autism services.
- 311,393 new referrals were received into services during June and 2,062,570 care contacts were attended.
- 20,854 people were subject to the Mental Health Act in June, including 15,002 people detained in hospital. 89

Mental Health Five Year Forward View dashboard

This dashboard is intended to help monitor progress against the delivery of the Five Year Forward View for Mental Health and is published quarterly. Please see the NHS England website for more information about the Five Year Forward View for Mental Health dashboard.

Staffing

Statistics on staffing numbers are provided in NHS Digital’s statistical release on NHS Workforce Statistics. Please note this data covers all trust types, such as acute and community trusts, as well as mental health providers. For more information on NHS Workforce statistics, please visit the NHS Digital website.
Waiting times

The government has committed to introducing access and waiting time standards for mental health services. For more information about access and waiting time standards, please visit the NHS England website.
Appendix C: Comparisons with other surveys

There are very few surveys related to community mental health services and this is the only survey of community mental health services currently conducted in the UK. Other surveys tend to establish prevalence of mental health issues rather than focus on experiences of care received.

The Big Mental Health Survey

This is a relatively new survey carried out by Mind, the mental health charity. The survey is designed to measure people’s experiences of mental health support offered by primary care and the voluntary and community sector, as well as experiences of discrimination in the community.

Data collected as part of the Big Mental Health Survey is not comparable with this survey due to the differing methodologies being used. The themes covered in the questionnaire, such as information sharing, communication around medicines and support for physical health conditions, are in line with the themes adopted in our survey.

The latest survey was carried out between July and September 2017, with results published in 2018. The survey, which was available to complete online and in paper format, was promoted using social media channels, supporter lists of leading mental health charities as well as paper forms being distributed by local Minds and Mind retail outlets.

The headline results from 2017 stated that:

- Survey participants reported a better overall experience of care provided by voluntary organisations than primary care services.
- One in six people who were prescribed medication reported not being given enough information about their purpose.
- Two in five people prescribed medication were not given information about potential side effects.
- One in three people who were referred to talking therapies or specialist services were not given enough information.
- Less than half of respondents did not feel able to discuss physical health conditions during mental health appointments.

For more information about the Big Mental Health Survey, please visit Mind’s website.
Coronavirus: Mental health in the pandemic

The Mental Health Foundation (MHF) is leading an ongoing, UK-wide, long-term survey of how the pandemic is affecting people’s mental health. All participants are aged 18 or older. Not all participants have pre-existing mental health conditions.

Working in partnership with a number of universities, the MHF has released key findings of the study in different waves which are approximately 6 weeks apart. This allows for comparisons to be made between waves. Wave 1 began in mid-March, before the lockdown. The latest statistics from wave seven (late August 2020) show:

- Almost half (45%) of the UK population had felt anxious or worried in the previous two weeks
- Nearly one in five people (18%) reported feeling lonely in the previous two weeks.
- 10% of the overall UK adult population reported having experienced suicidal thoughts or feelings in the previous two weeks.

While this survey does not monitor mental health care, it does provide insight into the growing demand for services as a result of COVID-19.

Information about the long-term COVID-19 study can be found on the Mental Health Foundation website.

CQC survey: Inpatient experience during the COVID-19 pandemic

In 2020, the Care Quality Commission undertook a survey which asked people about their experiences of inpatient care during the peak of the COVID-19 pandemic. The survey received feedback from 10,336 people (a 42% unadjusted response rate) who had received inpatient care in an NHS hospital in England and were discharged between 1 April and 31 May 2020.

While the results show that people’s experiences of inpatient care were generally positive, people with dementia or Alzheimer’s, people with a mental health condition, and people with a neurological condition consistently reported poorer experiences of most aspects of inpatient care. In particular, poorer experiences were reported for the ‘staff and communications’ theme. Key findings in this area are:

- people with dementia or Alzheimer’s, autistic people and those with a learning disability reported difficulties in communication with staff in PPE
- people with a learning disability and people with a mental health condition or neurological impairment were less likely to feel they were about to keep in touch with family and friends ‘often’.

More information about the Inpatient experience during the COVID-19 pandemic can be found on the CQC website.
Appendix D: Main users of the survey data

This appendix lists known users of data from the Community mental health survey and how they use the data.

**Care Quality Commission (CQC)**

CQC uses the results from the survey in the regulation, monitoring and inspection of NHS trusts in England. Survey data is used in our CQC Insight monitoring tool, which provides inspectors with an assessment of how trusts are performing. The survey data will also be used to inform our inspections and as a key source of evidence to support the judgements and ratings for trusts.

**NHS England and NHS Improvement**

NHS England and NHS Improvement will use the data to inform how it addresses the challenges currently facing the NHS across the country.

Questions from the NHS Patient Survey Programme (specifically the inpatient, community mental health and urgent and emergency care surveys) are used to produce a separate index measure called the **Overall Patient Experience Score (OPES)**. The score forms part of a regular statistical series that is updated alongside the publication of each respective survey. Due to pressures of COVID-19 work, the OPES update following the publication of this survey has been suspended.

For [more information about NHS England and NHS Improvement](#), please visit their website.

**NHS trusts and commissioners**

NHS trusts, and those who commission services, use the results to identify where they need to improve to provide a better experience for people who use their services.

**People who use services, their supporters and representative groups**

CQC publishes the survey results for each participating NHS trust. This appears on the trust’s profile page on CQC’s website. You can find this by searching for the name of the organisation using the search function. The data is presented in an accessible format alongside inspection results to enable the public to examine how services are performing.
Appendix E: Quality and methodology

All detail on data limitations can be found in the Quality and methodology document, available on CQC’s website.

Revisions and corrections

CQC publishes a Revisions and Corrections Policy relating to these statistics. The NHS Patient Survey Programme data is not subject to any scheduled revision as they capture the views of people about their experiences of care at a specific point in time. All new survey results are therefore published on CQC’s website and the NHS Surveys website, as appropriate, and previously published results for the same survey are not revised.

This policy sets out how CQC will respond if an error is identified and it becomes necessary to correct published data or reports.

Further information about changes to the questionnaire and overall survey development can be found in the 2020 community mental health survey development report, on the NHS Surveys website. Appendix A provides information on the survey methodology, which covers survey development and the analysis approach.
Appendix F: Further information and feedback

Further information
This report, together with the trust level results, is available on CQC’s website. You can also find a ‘technical document’ there, which describes the methodology for analysing trust level results, and a ‘quality and methodology’ document, which provides information about the survey development and methodology.

All survey reports, instructions and documents created as part of the survey can be found on the NHS Surveys website. These include full details of the methodology for the survey, questionnaires, letters sent to people who use services, instructions on how to carry out the survey and the survey development report.

There is more information on the NHS Patient Survey Programme, including results from other surveys and a programme of current and forthcoming surveys on the NHS Surveys website.

Further questions
This summary was produced by CQC’s Survey Team and reflects the findings of the 2020 community mental health survey. The guidance on our website should help answer any questions you have about the programme. However, if you wish to contact the Team directly, please contact Tamatha Webster, Survey Manager, at Patient.Survey@cqc.org.uk.

Feedback
We welcome all feedback on the survey findings and the approach we have used to report the results, particularly from people using services, their representatives, and those providing services. If you have any views, comments or suggestions on how we can improve this publication, please contact Tamatha Webster, Survey Manager, at Patient.Survey@cqc.org.uk.

We will review your information and use it, as appropriate, to improve the statistics that we publish across the NHS Patient Survey Programme.

If you would like to be involved in consultations or receive updates on the NHS Patient Survey Programme, please subscribe to our newsletter.

National Statistics status
National Statistics status means that official statistics meet the highest standards of trustworthiness, quality and public value.
All official statistics should comply with all aspects of the Code of Practice for Official Statistics. They are awarded National Statistics status following an assessment by the Authority’s regulatory arm. The Authority considers whether the statistics meet the highest standards of Code compliance, including the value they add to public decisions and debate.

It is a producer’s responsibility to maintain compliance with the standards expected of National Statistics, and to improve its statistics on a continuous basis. If a producer becomes concerned about whether its statistics are still meeting the appropriate standards, it should discuss its concerns with the authority promptly. National Statistics status can be removed at any point when the highest standards are not maintained, and reinstated when standards are restored.
Appendix G: Subgroup analysis

The Equality Act 2010 requires that public bodies have due regard to eliminate discrimination, and to advance equality of opportunity by fostering good relations between people who share certain protected characteristics and those who do not. The protected characteristics are age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation, marriage, and civil partnership. The Act provides an important legal framework that should improve the experience of all people using NHS services.

We include additional analysis to compare how different groups of people using mental health services rated their experience by using a multi-level model analysis.

This subgroup analysis compares the mean scores for a subset of questions by different groups. With this model, we can more effectively explore the relationships between respondent characteristics and their experiences.

Methodology

Results for each demographic subgroup were generated as adjusted means (also known as estimated marginal means or population marginal means) using a linear mixed effects model. These means were compared on composites of questions, illustrated in the subgroup charts. Each question was centred by subtracting its overall mean score from the results before the questions were combined into composites. This was to remove any differences in composite scores that might potentially be caused by different patterns of response between questions.

This model takes into account trust clustering, as trusts are likely to have a big impact on reported experience at a national level. To assess whether experience differs by demographic factors, we used statistical significance tests. Variables were also checked for multicollinearity to ensure co-efficient estimates were not being influenced by ‘additional factors’ (these would be chance associations in the sample that wouldn’t be reproduced in another sample).

Differences that are equivalent to at least 0.1 standard deviations from the overall mean of the target variable are treated as being noteworthy in this report, provided that the confidence interval does not overlap the mean line.

The analysis modelled the mean scores of different subgroups: age, gender, ethnicity, religion, sexual orientation, CPA status, diagnosis (care cluster codes), length of contact, long-term conditions and ‘proxy response’ (whether the

m. The sum of question scores divided by the number of questions in the composite.
questionnaire was completed by someone other than the patient) – for a set of questions based on the NHS Patient Experience Framework.

Overall
Q35. Overall…

Access
Q3. In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs?

Communication
Q4. Were you given enough time to discuss your needs and treatment?

Crisis care (access)
Q16. Would you know who to contact out of office hours within the NHS if you had a crisis?

Crisis care (care)
Q17. In the last 12 months, did you get the help you needed when you tried contacting this person or team?

Involvement of family and friends
Q34. Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?

Information sharing (medicines)
Q20. Has the purpose of your medicines ever been discussed with you?

Q21. Have the possible side effects of your medicines ever been discussed with you?

Information sharing (therapies)
Q26. Were these NHS therapies explained to you in a way you could understand?

Involvement
Q12. Were you involved as much as you wanted to be in agreeing what care you will receive?

Q15. Did you feel that decisions were made together by you and the person you saw during this discussion?

Organisation of care
Q7. Have you been told who is in charge of organising your care and services?

Q10. How well does this person organise the care and services you receive?
Respect and dignity
Q36. Overall, in the last 12 months, did you feel that you were treated with respect and dignity by NHS mental health services?

Support and wellbeing
Q30. In the last 12 months, did NHS mental health services support you with your physical health needs (this might be an injury, a disability, or a condition such as diabetes, epilepsy, etc.)?

Q31. In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits?

Q32. In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding or keeping work (paid or voluntary)?

Q33. In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?

Treatment history
Q6. Did the person or people you saw appear to be aware of your treatment history?

Respect for person-centred values
Q5. Did the person or people you saw understand how your mental health needs affect other areas of your life?

Q13. Does this agreement on what care you will receive take into account your needs in other areas of your life?

In this report, differences that are equivalent to at least 0.1 standard deviations from the overall mean of the target variable are treated as being noteworthy, provided that the confidence interval does not overlap the mean line.

The graphs in this section highlight better than average experiences that are significant in green. Significantly worse than average experiences are highlighted in orange for all charts. The cluster code definitions are in Appendix H.
2020 Community mental health survey: Statistical release
Appendix H: Care cluster codes

Care cluster codes enable people using mental health services to see which care and treatments are most likely to meet their needs. Created by clinicians and people who use mental health services, each care cluster considers the level of need and risk that someone has, as well as their diagnosis. There are 20 clusters in total and these fall into one of three main groups:

Non-psychotic (Codes 00 to 08)

This group includes people diagnosed with anxiety, depression, obsessive compulsive disorder, phobic disorders and eating disorders.

Psychotic (Codes 10 to 17)

This group includes people diagnosed with forms of psychosis, such as bi-polar disorder and schizophrenia.

Cognitive impairment and dementia (Codes 18 to 21)

This group includes people diagnosed with dementia, including Alzheimer’s disease and other types of brain injury impacting peoples’ mental health.

The care cluster codes are as follows:

Non-psychotic
Care Cluster 0: Variance (unable to assign adult mental health care cluster code)
Care Cluster 1: Common Mental Health Problems (Low Severity)
Care Cluster 2: Common Mental Health Problems (Low Severity with Greater Need)
Care Cluster 3: Non-Psychotic (Moderate Severity)
Care Cluster 4: Non-Psychotic (Severe)
Care Cluster 5: Non-Psychotic Disorders (Very Severe)
Care Cluster 6: Non-Psychotic Disorder of Over-Valued Ideas
Care Cluster 7: Enduring Non-Psychotic Disorders (High Disability)
Care Cluster 8: Non-Psychotic Chaotic and Challenging Disorders

Psychotic
Care Cluster 10: First Episode Psychosis
Care Cluster 11: Ongoing Recurrent Psychosis (Low Symptoms)
Care Cluster 12: Ongoing or Recurrent Psychosis (High Disability)
Care Cluster 13: Ongoing or Recurrent Psychosis (High Symptoms and disability)
Care Cluster 14: Psychotic Crisis
Care Cluster 15: Severe Psychotic Depression
Care Cluster 16: Dual Diagnosis
Care Cluster 17: Psychosis and Affective Disorder (Difficult to Engage)
Cognitive impairment and dementia
Care Cluster 18: Cognitive Impairment (Low Need)
Care Cluster 19: Cognitive Impairment or Dementia Complicated (Moderate Need)
Care Cluster 20: Cognitive Impairment or Dementia Complicated (High Need)
Care Cluster 21: Cognitive Impairment or Dementia Complicated (High Physical or Engagement)

For more information, visit the NHS Data model and dictionary.
Appendix I: COVID-19

The national lockdown resulting from the COVID-19 pandemic began midway through the community mental health survey fieldwork period. The diagram below details national events in relation to this period.

Diagram showing a survey timeline detailing key COVID-19 events

We carried out a series of analyses to determine if the pandemic and subsequent lockdown had an impact on the way people responded to the community mental health survey.

**Multi-year impact analysis**

To establish if results were more positive or negative than would be expected, it was important to compare results for the period of time both before and after lockdown, and to also compare results from 2020 with those of 2019. All comparable scored questions that were applicable to all respondents were included in the analysis. The table below shows the unweighted results for early and later responders. Early responders were established as being those whose responses were recorded as received up to and including 31 March 2020. Although the COVID-19 lockdown started on 23 March 2020, the community mental health survey is paper-based, therefore this date was adopted to accommodate for the interval between posting and receipt of completed survey forms. However, postal delays over this period may have affected further the time for receipt to be recorded.
<table>
<thead>
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<th>Scored questions</th>
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<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 Feb to 31 Mar</td>
<td>1 Apr to 30 Jun</td>
</tr>
<tr>
<td>Q3 In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs?</td>
<td>6.2</td>
<td>5.9</td>
</tr>
<tr>
<td>Q4 Were you given enough time to discuss your needs and treatment?</td>
<td>7.5</td>
<td>7.3</td>
</tr>
<tr>
<td>Q5 Did the person or people you saw understand how your mental health needs affect other areas of your life?</td>
<td>7.2</td>
<td>6.9</td>
</tr>
<tr>
<td>Q7 Have you been told who is in charge of organising your care and services?</td>
<td>7.5</td>
<td>7.1</td>
</tr>
<tr>
<td>Q11 Have you agreed with someone from NHS mental health services what care you will receive?</td>
<td>6.0</td>
<td>5.7</td>
</tr>
<tr>
<td>Q20 Has the purpose of your medicines ever been discussed with you?</td>
<td>7.5</td>
<td>7.4</td>
</tr>
<tr>
<td>Q35 Overall…</td>
<td>7.0</td>
<td>6.8</td>
</tr>
<tr>
<td>Q37 Aside from in this questionnaire, in the last 12 months, have you been asked by NHS mental health services to give your views on the quality of your care?</td>
<td>2.3</td>
<td>2.1</td>
</tr>
</tbody>
</table>

Table 1: Comparison of response patterns in 2019 and 2020 for the period before and after lockdown.

Analysis found that those responding later in the fieldwork period tended to report more negative experiences across both years. However, while this is still evident in the 2020 results, negative responses were less pronounced than those for 2019. Analysis also found some statistically significant changes in later responses between 2019 and 2020. This phenomenon implied that results were more positive in 2020.
Long-term trend analysis

To further investigate the potential increase in positivity and estimate the scale of any impact on survey results, it was important to consider the most recent findings alongside long-term trend data.

Twelve evaluative questions had trend data covering six data points from 2014 to 2019. As shown in the p-charts in the ‘Trends over time’ section below, 11 of these charts show general trends of decline between 2014 and 2019, with five showing scores to be lower than we would expect, based on past data, for two consecutive years. All 11 of these charts, which display questions covering multiple themes and service areas, now show an end to the trend of decline.

Twenty evaluative questions have data for one or more years. All of these questions show an increase in the most positive response for 2020, with 12 having increases that are statistically significant. The maximum percentage increase is 2.5%. This is a noticeable break from trends in previous years and suggests that the pandemic might have had an influence on results.

Respondent profile analysis

Past surveys have shown that some demographic groups will typically report more positively or negatively than others. This is also true of people receiving different types of care. To ensure that any unexpected changes in results were not a result of significant changes to the demographic structure of our respondents, analysis was carried out to compare the respondent profile of 2020 with that of 2019.

In comparing the number of respondents in different age and gender groups, there were no notable differences between 2020 and 2019. There were also no distinct changes in the respondent profile when comparing care cluster codes. This indicates than any phenomenon should not be attributed to changes in the survey respondent profile.

In addition, subgroup analysis has shown no real difference in the groups reporting better or worse than average experiences when comparing between 2019 and 2020.

Pattern of responses

Analysis also found that, in 2020, 57% of responses were received in March, compared with 41% in the same month of 2019. This is the month that saw households across the country participate in the weekly ‘clap for carers’, to show appreciation for frontline workers. This is also the month that many services started to adapt to COVID-19 conditions, changing service delivery.
<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th></th>
<th>2020</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of</td>
<td></td>
<td>%</td>
<td>Number of</td>
<td>%</td>
</tr>
<tr>
<td>responses</td>
<td></td>
<td></td>
<td>responses</td>
<td></td>
</tr>
<tr>
<td>February</td>
<td>1,001</td>
<td>8%</td>
<td>767</td>
<td>4%</td>
</tr>
<tr>
<td>March</td>
<td>5,150</td>
<td>41%</td>
<td>10,107</td>
<td>57%</td>
</tr>
<tr>
<td>April</td>
<td>4,667</td>
<td>37%</td>
<td>5,089</td>
<td>29%</td>
</tr>
<tr>
<td>May</td>
<td>1,434</td>
<td>11%</td>
<td>1,420</td>
<td>8%</td>
</tr>
<tr>
<td>June</td>
<td>299</td>
<td>2%</td>
<td>218</td>
<td>1%</td>
</tr>
<tr>
<td>Total</td>
<td>12,551</td>
<td>100%</td>
<td>17,601</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 2: Comparison of response patterns in 2019 and 2020

A total of four trusts received all of their survey responses during the lockdown, while seven others received the majority of their responses during this period. The remaining 44 trusts received the majority of their responses before lockdown began.

**Community mental health service review**

As part of the development of the community mental health survey 2021, a review of services was carried out with NHS trusts to establish if services had changed as a result of the pandemic, and to what extent. All 55 trusts offering community mental health services were asked to participate in the review. Twenty-one trusts participated. The review found:

- 95% (20 trusts) made changes to services.
- Changes were first introduced in March 2020.
- The majority of trusts reported that services changed ‘a lot’, while very few had stayed the same.

The most common changes reported were:

- the way in which care is delivered (90%), such as over the phone rather than face-to-face appointments
- postponing new patient referrals and appointments (57%)
- increased frequency of contact (52%)
- increased number of staff to help with the demand (52%)

It is clear from research that there are some inconsistencies in the type and scale of changes across trusts.

Another noteworthy finding is that the majority of services have seen a decrease in service users, with the exception of crisis care and home treatment teams.

**Factual and attitudinal question analysis**

Anecdotal evidence has shown the general public to be more supportive of the NHS and its staff than before the pandemic. To find out if, and to what scale, the increased positivity of responses was due to a ‘NHS gratitude effect’,
comparisons were made between the percentage increases of factual and attitudinal questions.

The survey contains 13 attitudinal and 15 factual questions that are used for evaluative purposes. Analysis showed no significant differences between the two types of questions, with both showing similar mean, median, minimum and maximum percentage increases.

**Assumptions**

Based on the investigative work described above, it is assumed that the COVID-19 pandemic and subsequent lockdown has affected the results of this survey.

There are inconsistencies in the scale of changes made to services by trusts, as well as the type of changes, with some services temporarily closing while others report very little change. Analysis found additional inconsistencies in that some trusts received all of their responses during the lockdown, while others received the majority of their responses beforehand.

We cannot rule out that a ‘NHS gratitude effect’ has resulted in respondents reporting more positively when asked about their experiences of community mental health services. Likewise, the changes made to services, including more frequent contact with people using the service in some cases, will be more favourable to some of those people. Analysis of subgroups in previous surveys has indicated that those with more recent contact with mental health services report better experiences across many themes. Therefore, the changes made to service delivery may have prompted more positive responses.

For the reasons detailed above, we conclude that the 2020 survey results are not comparable to those of previous years and trend analysis is not recommended for this survey.

For the purpose of transparency, we include trend data for evaluative questions, where available, below. However, 2020 should be treated as an anomalous year and not compared to previous years.

**Trends over time**

Results that have changed noticeably over time and identify long-term trends where appropriate are presented using ‘p-charts’. We plot the percentage of the most positive responses to questions and show the expected limits of variation in survey results.

An assumption is made that there has been no ‘real’ or meaningful change since the baseline period unless the results go outside of expected limits. Viewing long-term trends in survey results allows for greater confidence in interpreting relationships within the data. Where results do not fall outside of expected limits...
or it is not possible to compare questions over time, no p-chart results are reported.

The following example shows a p-chart in a normal year, with results that fluctuate from above expected limits in 2014, to below expected limits in 2018 and 2019; suggesting a deterioration in results.

**Example of a p-chart 2014 to 2019**

![Image of a p-chart example](image)

However, as discussed, the results for 2020 are not comparable to results from previous survey iterations. Therefore, in this year's p-charts, the upper and lower control limits will run up to 2019 only. A vertical line will score the 2020 result, indicating incomparability.

In our analysis we have retained the control limits for the 2014-2018 period as our baseline. This means the upper and lower control limits for each question will now remain the same for each future survey iteration. Adopting this approach avoids a scenario whereby results identified as being outside control limits in previous reports, fall within limits when we update the time series.

As the volume of respondents in each time period is relatively large, the control limits can be very small. Therefore, it is important to consider the extent of change when results exceed the expected limits, as this could be the result of a small change.

**P-charts for 2020**

Please note, the number of people included in the sample for each trust increased in 2020 to 1,250 from 850 in previous years. This accounts for the sharp increase in the number of people responding to each question this year compared with others.
Q3: In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs?

Answered by all.
Respondents who stated that they didn't know have been excluded.
Total number of respondents: 2014 (13,061), 2015 (11,072), 2016 (12,587), 2017 (11,474), 2018 (12,179), 2019 (11,883) and 2020 (16,738)

Q4: Were you given enough time to discuss your needs and treatment?

Answered by all.
Respondents who stated that they didn't know / couldn't remember have been excluded.
Total number of respondents: 2014 (13,085), 2015 (10,925), 2016 (12,507), 2017 (11,454), 2018 (12,149), 2019 (11,860) and 2020 (16,738)
Q5: Did the person or people you saw understand how your mental health needs affect other areas of your life?

Answer percentage (%)

Answered by all.
Respondents who stated that they didn’t know/couldn’t remember have been excluded.
Number of respondents: 2014 (12,777), 2015 (10,799), 2016 (12,312), 2017 (11,102), 2018 (11,937), 2019 (11,738) and 2020 (16,508)

Q7: Have you been told who is in charge of organising your care and services? (This person can be anyone providing your care, and may be called a “care coordinator” or “lead professional”).

Answer percentage (%)

Answered by all.
Respondents who stated that they weren’t sure have been excluded.
Number of respondents: 2014 (11,314), 2015 (9,589), 2016 (10,838), 2017 (9,863), 2018 (10,358), 2019 (9,982) and 2020 (13,978)
Q11: Have you agreed with someone from NHS mental health services what care you will receive?

Answer percentage (%)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%


Answered by all.
Number of respondents: 2014 (13,223), 2015 (11,178), 2016 (12,728), 2017 (11,569), 2018 (12,342), 2019 (12,035) and 2020 (16,969)

Q12: Were you involved as much as you wanted to be in agreeing what care you will receive?

Answer percentage (%)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%


Answered by those who have agreed with someone from NHS mental health services what care they will receive.
Respondents who stated that they did not know or did not want to be involved have been excluded.
Number of respondents: 2014 (9,821), 2015 (8,242), 2016 (9,412), 2017 (8,395), 2018 (9,208), 2019 (8,832) and 2020 (12,794).
Q19: Were you involved as much as you wanted to be in decisions about which medicines you receive?

Answered by those who have been receiving any medicines in the last 12 months for their mental health needs.
Respondents who stated that they didn't know / couldn't remember or did not want to be involved have been excluded.
Number of respondents: 2014 (10,083), 2015 (8,612), 2016 (9,788), 2017 (8,944), 2018 (9,361), 2019 (9,155) and 2020 (12,866).

Q24: In the last 12 months, has an NHS mental health worker checked with you about how you are getting on with your medicines? (That is, have your medicines been reviewed?).

Answered by those who have been receiving any medicines for 12 months or longer for their mental health needs.
Respondents who stated that they didn't know / couldn't remember have been excluded.
Number of respondents: 2014 (9,052), 2015 (7,575), 2016 (8,522), 2017 (7,812), 2018 (7,897), 2019 (7,859) and 2020 (10,909).
Q31: In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits?

Answer percentage (%)

Answered by all.
Respondents who stated that they have active support and did not need help/advice to find it, or do not need support for this have been excluded.
Number of respondents: 2014 (7,315), 2015 (6,294), 2016 (7,028), 2017 (6,420), 2018 (6,897), 2019 (7,049) and 2020 (9,680).

Q34: Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?

Answer percentage (%)

Answered by all.
Respondents who stated that their friends or family did not want to be involved, did not want their friends or family to be involved, or that this does not apply to them have been excluded.
Number of respondents: 2014 (8,870), 2015 (7,448), 2016 (8,718), 2017 (7,978), 2018 (8,231), 2019 (8,284) and 2020 (11,624).
Q35: Overall question grouped into two categories

Answered by all.
Number of respondents: 2014 (12,698), 2015 (10,703), 2016 (12,273), 2017 (11,202), 2018 (11,738), 2019 (11,599) and 2020 (16,309).

Q36: Overall, in the last 12 months, did you feel that you were treated with respect and dignity by NHS mental health services?

Answered by all.
Number of respondents: 2014 (13,164), 2015 (11,169), 2016 (12,712), 2017 (11,620), 2018 (12,292), 2019 (12,031) and 2020 (16,963).
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