

SURVEY DEVELOPMENT REPORT

COMMUNITY MENTAL HEALTH SURVEY 2021

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Updates

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Questions and comments

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1. Background

The Community Mental Health Survey (CMH) has been conducted almost every year since 2004 as part of the NHS Patient Survey Programme (NPSP), coordinated by the Survey Coordination Centre for Existing Methods (SCCEM) at Picker on behalf of the Care Quality Commission (CQC). In 2020, the survey was in fieldwork for 18 weeks, between February 2020 and June 2020. A 26% response rate was achieved, with 17601 respondents from 55 Community Mental Health trusts (CMH trusts) and social enterprises taking part in the survey. Those aged 18 and over were eligible to take part if they were receiving care or treatment for a mental health condition between 1 September 2019 and 30 November 2019.

The purpose of the survey is to understand, monitor and improve service users' experiences of NHS community mental health services. Data collected from the 2021 Community Mental Health Survey (CMH21) will be used by the CQC in its assessment of mental health trusts in England. The results are also used by NHS England and NHS Improvement and the Department of Health and Social Care (DHSC) for performance assessment, improvement, governance and regulatory purposes.

The 2021 survey has been developed similarly to the previous Community Mental Health 2020 Survey (CMH20), with the exception of taking into consideration the impact of COVID-19 on the care and treatment provided by community mental health services. The 2021 survey will continue to use the higher sample size of 1250, which was introduced in the 2020 survey.

As part of the development work for the 2021 iteration of the NHS Community Mental Health Survey, the SCCEM undertook a development review exercise. This exercise involved a number of stages:

- A review of survey coverage in relation to the NHS Patient Experience Framework and existing surveys targeted at mental health service users
- A review of current mental health policy and service provision
- A review of NPSP wide developments and learnings
- A review of considerations from the survey development phase of CMH20
- Performance analysis of the CMH20 questionnaire
- Desk research, online survey and consultation with trusts to understand the impact of the COVID-19 pandemic on the services provided by CMH trusts
- Consultation with the CMH survey Advisory Group
- Desk research and interviews with CMH trusts regarding the inclusion of Improving Access to Psychological Therapies (IAPT) services in the survey
- Cognitive testing of the questionnaire with 18 recent service users

This report sets out the phases of development in more detail and the changes that were made for the 2021 survey.



1.1 Summary of changes

The development work resulted in a number of changes to the materials and methods for the 2021 survey. In summary, these are:

- Questionnaire: five questions were added, three were removed and several questions were modified to reflect changes in policy or guidance and circumstances during the Covid-19 pandemic. Minor design changes were made to the front page following feedback during cognitive testing
- Covering letters: the font and colour were changed and wording shortened to be made more approachable and motivating. Note added on how to request accessible versions.
- o Accessibility: questionnaire versions available in Braille, Easy Read and large font on
- Postal reminders: due to delays in the postal service caused by the Covid-19 pandemic, first reminders will be sent out seven working days after the first mailing (rather than five).
- Sampling: Due to the Covid-19 pandemic modes of contact and service delivery have changed. The eligibility criteria has therefore changed to include contact via video conferencing or telephone as well as face to face contact.
- o Sample file: three new variables are collected. Postcode to enable deprivation analysis by mapping to Lower Layer Super Output Areas (LSOA) deprivation indices (such as the English Index of Deprivation or Index of Multiple Deprivation). Email address indictor will flag whether a service user has an email address on record to help us assess possible alternative methods of contact for future surveys. Mode of contact will enable analysis to distinguish between feedback received from different contact types (face to face, via video, by telephone or a mix of modes).

Review of the NHS Patient Experience Framework 2.

The Patient Experience Framework (PEF) was built on a modified version of the Picker Institute Principles of Person Centred Care and is used by the DHSC as a measure of patient experience¹. This is a general patient experience framework and, at face value, appears to align more clearly with acute care than community mental health experience.

The 2020 questionnaire was reviewed against the framework to identify any gaps in coverage. There are a number of themes within the framework that do resonate with mental health care and policy approaches. The CMH20 questionnaire reflected these themes in a number of ways, as shown in table 1.

¹ The Patient experience framework, 2011, NHS National Quality Board (NQB) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/21 5159/dh 132788.pdf



NHS Patient Experience Framework Theme	In questionnaire by:	Example questions
Respect for patient- centred values, preferences and	A number of questions about shared decision making and involvement in care.	Q12. Were you involved as much as you wanted to be in agreeing what care you will receive?
expressed needs		Q15. Did you feel that decisions were made together by you and the person you saw during this discussion?
Coordination and integration of care	In the 'organising your care' section of the questionnaire which included questions on	Q7. Have you been told who is in charge of organising your care and services?
	the coordination of care.	Q16. Would you know who to contact out of office hours within the NHS if you had a crisis?
Information, communication and education	In a number of questions on information given to service users about their medication,	Q20. Has the purpose of your medicines ever been discussed with you?
	therapies and those responsible for care.	Q26. Were these NHS therapies explained to you in a way you could understand?
Emotional support	A number of questions assessed overall well-being support, such as financial support.	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?
Welcoming the involvement of family and friends	Question on 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?
Transition and continuity	Questions on organising the service users care plan.	Q10. How well does this person organise the care and services you need?
Access to care	A number of questions on ability to contact relevant care providers and care	Q29. Overall, how did you feel about the length of time you waited before receiving NHS therapies?



coordinators, one question on	
timely access to care.	

Table 1: NHS Patient Experience Framework and representation of the themes with the CMH20 questionnaire

The NHS Patient Experience Framework defines **emotional support** as 'alleviation of fear and anxiety about such issues as clinical status, prognosis and the impact of illness on patients, their families and their finances'. The 2020 questionnaire contained a number of questions assessing overall well-being support (e.g. 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)?) However, question 32 is in relation to signposting service users to relevant support groups and does not place responsibility on the trust to provide this advice.

In addition, while the **access to care** theme was covered by a number of questions on ability to contact relevant care providers and care coordinators, only one question in the 2020 questionnaire addressed timely access to care. A question was added to the survey in 2020 addressing wait times for receiving NHS therapies (see table above). However, there was no question which addressed wait times for crisis care interventions, or initial access to CMH services or community care services.

2.1 Other mental health surveys

The CQC survey is the most widely used survey in England measuring service user experience in community mental health services. The charity MIND conduct a regular survey called The Big Mental Health Survey. This survey aims to understand people's experiences of mental health support offered by primary care and the voluntary and community sector as well as experiences of discrimination and the support given to individuals whilst they are waiting for access to NHS services². Whilst the MIND survey provides valuable and insightful data, the crossover of items from that survey to the CQC survey is challenging given the different end uses of data.

Another survey of interest in the UK was an online mental health help-seeking questionnaire. This online questionnaire focuses on help-seeking behaviour and barriers to seeking help within mental health³. The survey found that 'feeling embarrassed or ashamed' was the most significant barrier to seeking help for a mental health problem⁴. Of the participants that disclosed that they had experienced a mental health difficulty, 35% did not seek help. Help seeking or barriers to seeking help with mental health is not currently addressed within the CQC CMH questionnaire. Whilst it is vital to understand help seeking behaviours and barriers to seeking help, the CQC questionnaire may not be the appropriate questionnaire for this topic, additionally the data may not be useful for policy makers and CMH trusts (i.e. barriers identified may be out of the trust's control).

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² https://www.mind.org.uk/about-us/our-policy-work/reports-and-guides/our-research/

³ Br J Gen Pract 2016; DOI: 10.3399/bjgp16X687313

⁴ https://bjgp.org/content/bjgp/66/651/e686.full.pdf



For future iterations of the CQC survey, it will be important to continue to reflect on the content of other mental health surveys to ensure that the CQC survey remains comprehensive and covers salient aspects of experience for service users.

Policy and the Community Mental Health Survey 3.

3.1 NHS Long Term Plan and Five-Year Forward View for Mental Health

The NHS Long Term Plan⁵, published in January 2019, sets out NHS England and NHS Improvement's goals for mental health service provision to 2024. Many of these goals carry forward recommendations made in the Five Year Forward View for Mental Health, published in 2016, which identified priority areas for the future of mental health care.

The Long Term Plan commits to growing investment in mental health services faster than the NHS budget overall for each of the next five years. This pledge means mental health will receive a growing share of the NHS budget, over £2.3 billion a year by 2023/24, and that services will grow faster in the next 5 years than in the past 5 years. A number of priorities and commitments made in the Long Term Plan are detailed below.

Personalised care and control over care

The NHS Long Term Plan sets out provisions for people to take more responsibility for managing their own physical and mental health. This increased personal responsibility for health will be supplemented by advice and peer support in the community and online. For mental health in particular, the Long Term Plan supports the development of apps and online resources to support good mental health and enable recovery. The Long Term Plan also references allowing people to have greater choice and control over their care by 2023/24.

Prevention and integration of physical and mental health

The Kings Fund recognises that physical and mental health are closely interdependent, and that neglecting one can damage the other⁶. There is currently a lack of access to physical healthcare for people with mental health conditions. Indeed people with severe mental illness are at risk of dying on average 15 to 20 years earlier than those without a mental health condition⁷. The Long Term Plan sets out plans to integrate healthcare systems, by delivering 'triple integration' of primary and specialist care, physical and mental health services. As part of this integrated care the Long Term Plan has increased the target from

⁵ The NHS Long Term Plan, 2019. https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhslong-term-plan-version-1.2.pdf

⁶ https://www.kingsfund.org.uk/projects/integrating-physical-mental-health

⁷ Five Year Forward View, 2016, Independent Mental Health Taskforce. https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf



the Five Year Forward View for the total number of people receiving physical health checks annually during mental health treatment.

Additionally, the Long Term Plan commits to increased funding of prevention programs to help people get and stay healthy. The Plan also sets out specific action, for example to: cut smoking in people with long term mental health problems and targeting weight management for people with a high BMI.

Access to mental health care

Increased funding as set out in the NHS Long Term Plan aims to provide faster access to mental health services, both in the community and crisis care. A four week waiting time for access to adult and older adult community mental health teams will be trialled, with the ambition to roll this standard out across the NHS over the next decade.

The Five Year Forward View for Mental Health acknowledges that too often those in mental health crisis are accessing mental health care via contact with the police or attendance at A&E⁸. The Long Term Plan has committed to ensuring that a 24/7 community-based mental health crisis response will be available across England by 2020/21. Additionally, they aim for a mental health liaison service to be in every acute hospital, with at least 50% of these providing 24/7 care by 2020/21, and 100% providing this service by 2023/24.

Inequality

The Five Year Forward View for Mental Health places particular focus on tackling inequality⁹. Mental health problems disproportionately affect those in marginalised groups, including Black, Asian and Minority Ethnic (BAME) people, lesbian, gay, bisexual and transgender people, disabled people, and those who have had contact with the criminal justice system. The report calls for routine data to be made available to ensure local CMH services are addressing age, gender, ethnicity, disability and sexuality inequalities in access to services.

Demographic data is collected in the CMH survey and subgroup analysis is undertaken to look at the experience of mental health care for those in marginalised groups, and how experience differs between groups. Additionally, the 2021 survey will collect service user postcode data, mapping postcodes to the Lower Layer Super Output Areas (LSOA) deprivation indices (such as the English Index of Deprivation or Index of Multiple Deprivation). This mapping will enable us to examine whether there is a link between deprivation and experiences of community mental health service users. This is discussed further in section 8.2.

Five Year Forward View, 2016, Independent Mental Health Taskforce.
 https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf
 Five Year Forward View, 2016, Independent Mental Health Taskforce.
 https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf



3.2 Impact of the COVID-19 pandemic on community mental health services

The coronavirus (COVID-19) pandemic hit England in early 2020, resulting in action being taken to delay the spread of the virus. The pandemic has significantly impacted services across the NHS, and has resulted in many services adapting to cope with the demand and capacity to continue delivering support.

NHS England and NHS Improvement released guidance¹⁰ in managing the capacity and demand within community mental health services. This guidance touches on the need to consider risk stratification, to determine who are most at risk physically and mentally and how to coordinate care accordingly. Continuity of care for service users is extremely important in these circumstances, however for the safety of staff and service users, face to face interaction was limited and other delivery methods such as telephone and video consultations were implemented. The Royal College of Psychiatrists¹¹ guidance suggested using Red/ Amber/ Green (RAG) rating risk assessments to determine appropriate delivery methods.

In response to COVID-19, NHS England and NHS Improvement requested that 24/7 urgent NHS mental health telephone support¹², advice and triage was established as a priority. This was expected to be rolled out in March 2021 as part of the Long Term Plan, however was brought forward in light of the pandemic.

A recent study conducted by Rethink Mental Illness¹³, explains the impact the pandemic has had on those living with mental health illness during this time. Findings highlighted that 80% of respondents said their mental health had worsened, with 47% saying this was due to receiving less support from mental health services. Thirty nine percent of respondents also said that they did not book or attend medical appointments due to worries of catching the virus, concern of burdening the NHS or due to lack of available appointments.

COVID-19 Trust Consultation

To understand the impact of COVID-19 directly on CMH trusts and service provision an online survey was undertaken in July 2020. Invites were sent to all 55 CMH trusts expected to be involved in the 2021 survey. A total of 26 responses were received, a response rate of 47%.

The results of the COVID-19 survey indicated that the majority of services offered by CMH trusts changed 'a lot' due to COVID-19 and these changes were expected to remain for at

¹⁰ https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/Managing-demand-and-capacity-across-MH-LDA-services_25-March-final-1.pdf

https://www.rcpsych.ac.uk/about-us/responding-to-covid-19/responding-to-covid-19-guidance-for-clinicians/community-and-inpatient-services/covid-19-working-in-community-mental-health-settings
 https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0130-Urgent-NHS-mental-health-telephone-lines-03.04.20.pdf

¹³ https://www.rethink.org/news-and-stories/news/2020/04/80-of-people-living-with-mental-illness-say-current-crisis-has-made-their-mental-health-worse/



least three months or longer. Many of these changes resulted in a reduction in face-to-face contact and an increase in remote methods such as via video conference or telephone. This change was identified as highly relevant as it impacted the eligibility criteria for the survey.

The CMH20 sampling instructions stated for trusts to only include service users that had a face-to-face contact during the sampling frame (September to November). Due to the reduction in face-to-face contacts during 2020 as a result of the pandemic and the change in service provision, if the sample criteria was to remain the same for 2021 this could cause a) difficulty for smaller trusts to meet the 1250 sample size and b) have an impact on comparability since changes to face-to-face contact appear to vary across services.

The decision was made to change the 2021 survey sampling criteria to capture this change in care and treatment delivery methods. Therefore the 2021 sampling criteria will not only include service users who had face to face contact during the sampling period, but will also include contact via video and telephone. For more information on this, please see section 8.1.

3.3 Performance of the 2020 questionnaire

Ahead of the advisory group, analysis was conducted on the 2020 survey data, including item non-response, ceiling effects and question correlations to highlight potential questions for removal.

Item non-response refers to questions that were not answered (i.e. left blank) but were applicable to the respondent. A high level of item non-response on a particular question may indicate that either respondents did not understand the question, the question is not relevant to them, or that the response options listed did not fit their experience. High levels of item non-response can lead to data being supressed at trust and/or national level (suppression occurs when <30 respondents answer a question) when results are reported.

Ceiling effects occur when a question is answered the same by nearly all respondents. For instance, if 95% of respondents answered 'yes' to a question then this can be an indication that the question may not be providing useful insight.

Question correlations were conducted to identify any questions that are statistically similar to one another. This may lead to questions being removed if several questions appear to be measuring the same thing.

While reviewing the analysis of the 2020 data, consideration is given to how the data from the questionnaire is used and how historical comparability might be affected by any proposed changes. For example, some questions contribute to Overall Patient Experience Scores (OPES)¹⁴ used by NHS England and NHS Improvement in their assessments of care and services provided by the NHS. Generally, OPES questions are not removed or altered to maintain the way the scores are calculated across survey years; however if there is

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¹⁴ Overall Patient Experience Scores. https://www.england.nhs.uk/statistics/statistical-work-areas/patexp/



substantial evidence that an OPES question is not performing correctly or as well as expected, changes can be made accordingly.

Additionally, the overall order of questions remains broadly similar to the previous survey iteration as the inclusion of new items can impact the context or answering of a following question. Finally, the wording of existing questions is occasionally altered where there is strong evidence from the cognitive interviews for doing so, however this usually means that historical comparisons for these questions are not advisable.

The analyses revealed several questions requiring review. Question numbers below relate to those reported in the 2020 survey.

Question 9 was found to have a ceiling effect, with 97% of service users knowing how to contact the main person in charge of their care if they had a concern.

Two questions were highly correlated with each other (i.e., r > .60). Questions 31 and 32 ask whether NHS mental health services have given service users any help or advice for financial advice and finding or keeping work.

There were nine questions identified with high item non-response. All of these questions were filtered questions, meaning respondents had been routed past these questions due to the response option selected at a preceding question. Questions with high non-response included:

- Questions 9 and 10 which asked service users if they knew how to contact the person in charge of their care if they had any concerns and how well this person organised their care;
- Question 15 asked whether service users felt decisions were made together by them and the person they saw;
- Question 17 asks whether the service user got the help needed when they contacted the crisis team;
- Question 24 which asked if a mental health worker had checked how the service user was getting on with their medicines;
- Questions 26 to 29 which asks the service user about their experience with NHS Therapies.

4. Advisory Group

Following the completion of desk research and a review of the 2020 questionnaire as detailed in the sections above, an Advisory Group met in August 2020, to discuss the redevelopment of the 2021 survey. Contributors were asked to advise on questions that were no longer relevant, potential new questions, service provision changes as a result of the COVID-19 pandemic, as well as recent policy changes in NHS mental health services.

The Advisory Group consisted of key stakeholders, including NHS CMH trusts, current service users recruited from MIND's Lived Experience Leaders, policy makers, research charities and other official bodies. These members were consulted with throughout survey development to ensure the questionnaire aligns with current procedures and that the data



can be used effectively by NHS CMH trusts to implement improvements to service user experience.

Five areas were flagged for discussion with the advisory group:

o COVID-19 impact on services and servicer user experience

The impact of the pandemic on CMH trusts and the services they provide to service users was discussed with members of the advisory group. Stakeholders provided guidance on how care and services had changed, the relevance of current items included in the questionnaire were discussed and new question topics were agreed to capture the impact changes have had on service user experience.

Access to care

As highlighted in the Patient Experience Framework and the NHS Long Term Plan access to care is of high importance in mental health services and was therefore raised during the advisory group. Members agreed to add a new question on whether service users were able to access the services they needed when they needed them. This question was agreed upon rather than a question on waiting times as this data is held elsewhere and it was noted recall may be an issue for some respondents.

o Personalised care and control over care

With the commitment to personalised care noted within the NHS Long Term Plan, this theme was raised for discussion. The addition of a question on this topic was considered in the 2021 questionnaire, however, while some mental health online tools are endorsed by the NHS¹⁵, not all have been developed by the NHS, making it difficult to attribute outcomes. Additionally, online tools are likely to be developed centrally, with local CMH trusts having little to no control over their content or delivery. This means data received at trust level on this aspect of care cannot be used to make changes and drive improvement.

o Integration of physical and mental healthcare

Within the 2020 questionnaire, one question addresses physical health care (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)?). However, this question may be seen only to apply to those with an established physical health condition. This topic was raised in the advisory group and while it was noted to be of particular importance, it was not flagged during the subsequent prioritisation task (described below) completed by advisory group members, where other topics took precedence.

o Emotional support

As emotional support is one domain within the Patient Experience Framework and there had been acknowledgment about the absence of questions in relation to this topic in the 2020 questionnaire, it was discussed within the advisory group. While this topic was

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¹⁵ https://www.nhs.uk/apps-library/category/mental-health/?page=1



discussed to be crucial in the delivery of mental health care and services, it was felt to be quite abstract and that currently other topics would take prioritisation.

Each of these themes are discussed further in sections 2 and 3 above.

A number of topic areas were identified during the advisory group meeting. To keep questionnaire length at eight pages it was not possible to include all suggestions. We therefore undertook a prioritisation exercise to identify questions for removal and new question areas.

As a result of the advisory group consultation and a subsequent prioritisation task completed by advisory group members, three questions were added to the questionnaire, all of which were added to the 'Your care and treatment' section. One of the new questions is in relation to access to care, while the other two new questions are regarding the coronavirus pandemic. Furthermore, two questions were removed, and several amendments were made. Details of these changes can be found in section 6 and Appendix A below.

Feasibility of including Improving Access to Psychological Therapies service users in the CMH survey

The CMH survey had been running for four years before the Improving Access to Psychological Therapies (IAPT) programme was introduced in 2008. IAPT services comprise of a mix of talking therapies, sessions with a well-being practitioner or self-directed online courses. Those using IAPT services were added to the exclusion criteria for the CMH survey in 2011 because IAPT services were primarily provided through primary care trusts at the time¹⁶. The SCCEM undertook desk research and conducted stakeholder interviews to investigate whether this exclusion was still appropriate for the 2021 survey.

Four CMH trusts were interviewed, in September 2020, to further investigate a range of aspects of IAPT services: commissioning and day-to-day service delivery, as well as how IAPT service users' data are held and excluded from the CMH survey. Each interview consisted of at least two experts: an IAPT service lead and a member of the data information team.

Findings indicated that stakeholders from CMH trusts were overall in favour of including IAPT service users in the CMH survey, with it being feasible to draw a sample containing both secondary mental health care service users and IAPT service users. It was found that large sections of the current CMH questionnaire would not be appropriate for IAPT service users and would therefore need significantly adapting. IAPT service users' data is captured on a separate database to secondary mental health care service users and therefore there had been no issue in excluding these service users in the past iterations of the survey. Additionally, it was found that the large majority of IAPT services across the country are provided by CMH trusts, while third sector organisations provide a much smaller proportion.

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¹⁶ The CMH Survey did not run in 2009, and Picker did not run the survey in 2010.



Based on both the desk research and the interviews held with stakeholders, the SCCEM recommended including IAPT service users in the CMH survey from the 2022 iteration onwards. This recommendation was provided given the favourable inclusion of IAPT service users by CMH trusts and feasibility of doing so. However, given the questionnaire and sampling process would need to be re-developed implementing changes ahead of the 2022 survey was recommended to ensure quality was not compromised.

6. Cognitive testing

6.1 Recruitment

Taking into account all of the above evidence and feedback, a questionnaire was drafted for testing with recent service users. 'Cognitive testing' involves holding interviews with recent users of NHS community mental health services and asking them to answer the questionnaire, reading out loud and explaining the reasoning behind their answers. The interviewer observes the responses that the participant makes and periodically asks questions such as whether the question was easy to answer, what their circumstances were and what they were thinking about when considering their answer. The interviewer also pays attention to whether the respondent appears to struggle when answering certain questions, and whether instructions were read and followed correctly. Cognitive testing ensures that as far as possible, the instructions, questions and response options are relevant and understood. For this survey the covering letters were also tested since they had undergone significant changes since the previous survey. Refinements are made to the survey materials following each round of testing in accordance with any issues that are evidenced by the interviews.

Service users were screened upon registering their interest to participate to identify the mental health service they had used, their demographics and location. Additionally, we wanted to ensure we interviewed service users who had used secondary care mental health services, as opposed to IAPT services, as currently IAPT service users are ineligible for the main survey.

Recruitment for cognitive testing underwent significant changes compared to previous surveys. This was due to COVID-19 restrictions with social distancing measures still in place at the time of cognitive testing. Therefore recruitment was conducted online, with interviews taking place online and over the phone, instead of face-to-face. Although, participants were offered face-to-face interviews as restrictions eased, service users chose their preferred method and what they felt most comfortable with. Throughout the pandemic many service users received regular contact from their community mental health team via video and/or phone and therefore service users were familiar with this way of interacting. One of the advantages using online recruitment channels and video calls was that a wider geographical reach could be achieved than in previous surveys.



6.2 Advertising

The recruitment advert was redesigned for 2021 to be visually appealing and was linked to Picker's website providing service users with more information about the interviews and survey.

Respondents were recruited using several recruitment channels. A new avenue explored this year was the use of paid Facebook boosted posts following the success of this recruitment method for the 2020 Urgent and Emergency Care Survey. This service allows you to advertise a regular Facebook post to a wider audience in relation to the amount of money invested. Adverts were also posted on Facebook community groups and local spotted pages. The Facebook boosted posts had limited success for CMH21 with only two of the respondents being recruited via this channel.

Adverts were also placed in three local newspapers across the country, (online and/or in print) between September and November 2020. There were large differences in success by newspaper, however an older population was reached through this channel.

Further, the advert was posted on Gumtree and on Picker's own Twitter and LinkedIn accounts. Gumtree had the highest success rate across all avenues, and was also the channel with the highest share of BAME respondents which are also historically a group more difficult to reach.

Central and North West London NHS Foundation Trust (CNWL) were also contacted during recruitment and the advert was shared with the trusts register of Patients and Carers for Involvement. This proved successful with a number of participants registering their interest to take part in the interviews.

The same broad eligibility criteria were applied as for the main survey which was that participants must be aged 18 or over and have used NHS community mental health services in the last 12 months. Additionally, the 2020 data showed 21% of questionnaires were completed by a friend or relative of the service user and 11% by both the service user and friend or relative together. Therefore, we also advertised to friends and relatives of service users, who could participate and answer the questions on behalf of the service user.

6.3 Interviews

Three rounds of cognitive interviews were carried out using video or phone calls in October and November 2020. Respondents were given £40 in 'Love2shop' or Amazon vouchers for the one-hour interview as a thank-you. This had been £25 for the 2020 iteration survey, but was increased in 2021 given the circumstances and the additional barriers in place due to social distancing in the context of Covid-19.

Eighteen cognitive interviews were carried out across three rounds:

- o Gender: 12 women, 6 men;
- Age: ranged from 18 to 69 years old, average age was 47;



- Residence: 4 respondents from Oxfordshire, 3 respondents from Birmingham, 3 from London, 2 from the Liverpool, 2 from Kent, 1 from Hayes, 1 from Sheffield, 1 from Oldham and 1 from Bilston;
- Ethnic background: 10 White British, 8 non-White British (Asian Indian, Asian Bangladeshi, Black Caribbean, Romany Gypsy, and White other);
- o 15 participants with long-term conditions;
- 2 service users completed the interview with the assistance of their carer (friend or relative).

Upon completion of cognitive testing, the questionnaire was finalised and then submitted for ethical approval alongside the other service user facing materials. A section 251 application was also submitted for the approval of sharing confidential patient information without consent.

7. Changes to the questionnaire

Following consultation with key stakeholders at the advisory group and cognitive interviews with service users, a number of amendments were made to the questionnaire. In total, 3 questions were removed from the questionnaire, 5 questions were added, and 12 questions were amended.

7.1 Questions removed from the questionnaire

Three questions were removed and are no longer present in the 2021 questionnaire (the numbering in this section refers to the numbering in the questionnaire for the 2020 Community Mental Health Survey).

Question 19 on involvement in decisions about which medicines to receive was removed as it was identified by key stakeholders as of lower priority. During testing respondents noted that while they were happy to be involved in decisions about medicines, the final decision was with the healthcare professional.

19.	Were you involved as much as you wanted to be in decisions about which medicines you receive?
1	Yes, definitely
2	Yes, to some extent
3	No, but I wanted to be
4	No, but I did not want to be
5	Don't know / can't remember

In the 'support and wellbeing' section, question 33 was removed. During cognitive testing it became apparent that face-to-face peer group support was not running and there was very limited online peer support available for service users to attend. Additionally, this was flagged by key stakeholders as of lower priority given the circumstances of COVID-19. There



were no concerns about this question, apart from its applicability during the COVID-19 pandemic.

33. In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?
1 Yes, definitely
² Yes, to some extent
3 No, but I would have liked this
4 I did not want this / I did not need this

In the 'About you' section, question 42 on sex was removed and replaced with two new questions following a redevelopment of the sex question on the <u>Adult Inpatients Survey 2020</u>.

42. Are you male or female?	
¹	
² Female	

7.2 Questions added to the questionnaire

Three questions were added in the care and treatment section of the questionnaire, one asking about access to care and two related to changes to care due to the COVID-19 pandemic.

Access to care was prioritised by key stakeholders at the survey advisory group as an important topic to add into the questionnaire this year. Therefore, question four was introduced to capture whether service users were able to access the care and services they needed when they needed them.

4. In the last 12 months, were care and services available when you needed them?
¹ Yes, always ² Yes, sometimes
³☐ No
Service(s) were available, but not the service I needed
5 ☐ Don't know / can't remember

To measure communication about service changes due to the coronavirus pandemic, question 5 was introduced following the consultation with the survey advisory group. The advisory group members had highlighted communication about service changes as an important indicator of the quality of care. During cognitive testing, the response option 'I did

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not receive care and treatment before the pandemic' was added which routes respondents past question 6 as this question did not apply to service users who had only started receiving treatment after the beginning of the pandemic in the England.

5. Were you informed how the treatment you were receivin change due to the coronavir	g would
¹ Yes, definitely	→ Go to 6
² Yes, to some extent	→ Go to 6
3 No	→ Go to 6
4 My care and treatment	
did not change	→ Go to 7
5 I did not receive care and	treatment
before the pandemic	→ Go to 7
6 Don't know / can't	
remember	→ Go to 7

In addition, question 6 was introduced to measure how changes to services due to the pandemic affected service users' mental health.

6. Do you feel changes in your care and treatment due to the coronavirus pandemic affected your mental health?
¹ Yes, my mental health improved
2 Yes, my mental health got worse
₃ No, the changes did not affect my
mental health
⁴ ☐ Don't know / not sure

In the 'About you' section, two new questions were added following redevelopment of the question on sex and gender in the Adult Inpatients 2020 Survey. The first new question asks about sex at birth, and the second question addresses the service user's gender identity. These questions include an additional disclaimer on confidentiality. The questions were added to the CMH21 questionnaire after the end of cognitive testing.



The following two questions ask about your sex and gender. Your answers will help us understand whether experiences vary between different groups of the population. Your answers will be kept confidential and not linked to your medical records.

44. At birth were you registered as
1
45. Is your gender the same as the sex you were registered as at birth?
Yes No, please write your gender below
3 Nould prefer not to say

7.3 Questions modified

Several questions were amended to reflect changes in the sample criteria where phone, video call appointments were included as service provision had changed due to the COVID-19 pandemic. A note to say that contact may have been via phone, video call or in person was added to all questions with the terms 'saw' or 'seen' in the wording to avoid misunderstanding. The disclaimer was added ahead of round 3 testing after feedback from service users during rounds 1 and 2 of the cognitive interviews. This note was added to questions 1, 3, 8, 9 and 18. Please see an example of this shown on question 1 below.

The timeframe 'In the last 12 months' was removed from Q20 (Q17 in 2020 questionnaire) and has been updated to 'Thinking about the last time you tried to contact this person or team, did you get the help needed?' This was flagged in the advisory group for consideration by a service user who didn't feel the timeframe was necessary and thought it would be more important to know whether help was provided in the last contact they had.

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20. Thinking about the last time you tried to contact this person or team, did you get the help you needed?
¹ ☐ Yes, definitely
² Yes, to some extent
3 No
⁴ ☐ I could not contact them
5 I have not tried contacting them
6 Don't know / can't remember

The NHS Therapies section has been updated to 'NHS Talking Therapies' following feedback from NHS England and NHS Improvement, to align with their goals in delivering the NHS Long Term Plan and the National Institute for Health and Care Excellence's (NICE) guidance. All questions within this section, questions 27 to Q31, have been amended to reflect this change.

NHS TALKING THERAPIES

Talking therapies include any NHS treatment for your mental health that involve working with a trained therapist and **do not involve medicines.**

27. In the last 12 months, have you received any NHS talking therapies for your mental health needs that do not involve medicines?		
¹ Yes	→ Go to 28	
No, but I would have liked	→ Go to 32	
³ No, but I did not mind	→ Go to 32	
This was not appropriate for me	→ Go to 32	
5 Don't know / can't remember	→ Go to 32	

In the 'About you' section, a question on long-term conditions was amended in line with changes on other surveys across the wider NPSP. Two further long-term conditions, autism and stroke, were added as additional response options to question 40.



40. Do you have any of the following?
Select ALL conditions you have that have lasted or are expected to last for 12 months or more.
☐ Autism or autism spectrum condition
² Breathing problem, such as asthma
3 Blindness or partial sight
4 Cancer in the last 5 years
5 Dementia or Alzheimer's disease
6 Deafness or hearing loss
7 Diabetes
8 Heart problem, such as angina
Joint problem, such as arthritis
10 Kidney or liver disease
11 Learning disability
12 Mental health condition
13 Neurological condition
14 Stroke (that affects your day-to-day life)
15 Another long-term condition

The comment section disclaimer at the end of the questionnaire was amended to clarify to whom and in which situation service user comments and/or personal data of the respondent would be provided back to CMH trusts. This amendment was made in line with changes on other surveys on the NPSP. The text 'Your details will only be passed back to the NHS Trust if your comments in this section raise concerns for your own or others' safety and wellbeing' was added.

OTHER COMMENTS

If there is anything else you would like to tell us about your experiences of mental health care in the last 12 months, please do so here.

Please note that the comments you provide will be looked at in full by the NHS Trust, CQC and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback. Your details will **only** be passed back to the NHS Trust if **your comments in this section** raise concerns for your own or others' safety and wellbeing.

Lastly, the year of birth question was moved to sit below question 42 – 'Who was the main person or people that filled in this questionnaire?' to allow room for the new gender questions.



8. Changes to the design of service user facing materials

8.1 Redesigned questionnaire

Two minor amendments to the front page of the questionnaire were made, following service user feedback during cognitive interviews. The words 'confidential' and 'voluntary' were formatted bold. Additionally the font colour in the 'What to do' and 'Need more help' sections were changed from purple to black.

8.2 Redesigned covering letters

The covering letters have been redesigned to take account of developments across the wider NPSP. The design adopted was based on cognitive testing findings and according to best practice principles of design. The changes to the CMH21 survey covering letters include:

- Using NHS blue colour to highlight key words and phrases in the letter, reinforcing the recognisability of the NHS.
- Using one of the NHS official fonts (Arial).
- Removing superfluous and repetitive text on the front page.
- Incorporating potentially motivating and empowering messages.
- Adding a note to all three cover letters to notify service users on how to request a copy of the questionnaire in Easy Read, large print or braille.

As per the 2020 survey, there are three mailing letters, the first initial invite to complete the questionnaire and two reminders.

8.3 Accessible questionnaire versions

The 2021 questionnaire will also be available in braille, large print and Easy Read for the first time. Service users will be able to request an accessible version of the questionnaire by contacting either the approved contractor or in-house trust using the freephone helpline.

Electronic versions of the Easy Read and large print questionnaires will be provided to contractors and in-house trusts so they can directly send a version upon request from a respondent. A braille questionnaire has been set up by a subcontractor who will print a version and send back to the contractor upon request. The Easy Read and large print versions will be returned to contractors or in-house trusts via the free post envelope. While service users completing a braille questionnaire will need to call the contractor or in-house trust helpline to complete the questionnaire over the phone.



9. Changes to the methodology and sample variables

9.1 Changes to methodology

Sampling Criteria

Due to the COVID-19 pandemic and the impact on the provision of NHS community mental health services (services now having to deliver care and treatment via remote setting mechanisms and not just face to face appointments), the sampling criteria for the CMH21 survey has been amended.

Like previous years, the sample for the survey is a random sample of eligible service users aged 18 years old and above. In previous iterations of the survey (up to and including 2020), eligibility was determined by whether a service user had a face to face contact (i.e: assessment, treatment, care in person) with the mental health service during September to November. Given that the modes of contact and delivery of services have changed due to the pandemic, we have amended the eligibility statement to include not only face to face contact but also contact via video conferencing or telephone.

CMH trusts were consulted with to determine whether the above change is needed and what the implications of this amendment would be for sample eligibility. Trusts who participated in the consultation reviewed the amended eligibility statement and agreed that the change would be required for the 2021 survey. Without this amendment, sample sizes would be significantly affected resulting in an impact on the availability of data for some trusts.

Therefore, the amended sampling criteria is as follows:

- Eligible service users are aged 18 and over at the time of drawing the sample; AND
- Were seen by someone face-to-face at the trust, via video-conference (e.g. using Attend Anywhere, MS Teams, Zoom, etc.) or telephone call between 1st September and 30th November 2020 (the sampling period); AND
- Had at least one other contact (face-to-face, video conference, phone or email) either before, during or after the sampling period.

Postal reminders

For CMH21 survey, the time between the initial contact (first mailing letter) and first reminder (second mailing letter) will be seven working days. Due to coronavirus pandemic Royal Mail have been experiencing postal delays and therefore instead of the previous five working days, the first reminder will be sent out seven working days after the initial mailing to allow service users time to opt out of the survey.

9.2 Additional sample variables

Additional sample variable: Service user full postcode



In addition to the standard sample information collected from CMH trusts, the sample file in 2021 will also include the service user's full postcode. The decision to collect this variable was made as there is interest in examining whether there is a link between deprivation and experiences of NHS community mental health services. Full postcodes will allow the mapping of case level postcodes to the Lower Layer Super Output Areas (LSOA) deprivation indices (such as the English Index of Deprivation or Index of Multiple Deprivation).

Research has shown that mental health is shaped by a variation of socio-economic factors and physical environments, and that poverty can be both a causal factor of mental ill health and a consequence of mental ill health¹⁷. Recent statistics have shown those living in the most deprived areas are more likely to have a severe mental illness compared to those who live in the least deprived areas¹⁸, with social stress and poverty being the main contributing factors. Furthermore, a research study¹⁹ found that difficult life events such as job loss, relationship breakdown, and evictions can harm both mental health and residential opportunities, which increases the likelihood that people with poor mental health will live in socio-economically deprived areas.

Mapping respondent postcodes to LSOA deprivation indices will allow the SCCEM, and other analysis teams, to examine whether deprivation is similarly associated with service user experience and, moreover, which areas of community mental health services are most strongly associated with deprivation. Similarly, sustainability and transformation partnerships (STPs) and CMH trusts will be able to use the data provided by the deprivation analysis to better understand local populations and how to improve service provision.

To comply with data protection and specific Section 251 approval, the postcode information will be stripped out of the final dataset provided to CQC, leaving only the LSOA variable included. All postcode data will be removed by the SCCEM from the dataset produced during cleaning and analysis.

Additional sample variable: Email address indicator

Following the inclusion of mobile phone indicator in the 2020 survey, we have asked trusts to include an email address indicator to flag service users the trust has a complete email address for.

There is an aspiration for the NPSP that over time, each individual survey within the programme will transition from a purely paper based approach to a mixed mode design where respondents will have the option of providing their feedback either via a paper based questionnaire or online. This information provided as part of the sample file will help inform

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¹⁷ Fell, B. and Hewstone, M. (June 2015) Psychological Perspectives on Poverty. Available at: https://www.jrf.org.uk/report/ psychological-perspectives-poverty

¹⁸ https://www.gov.uk/government/publications/severe-mental-illness-smi-physical-health-inequalities/severe-mental-illness-and-physical-health-inequalities-briefing

¹⁹ Tunstall et al. (2015) 'Difficult Life Events, Selective Migration – Spatial Inequalities in Mental Health in the UK'. PLOS ONE, 10(5): e0126567. Doi:10.1371/journal.pone.0126567. Available at: http://www.plosone.org/article/ fetchObject.action?uri=info:doi/10.1371/journal.pone.0126567&representation=PDF



the feasibility of whether the national community mental health survey could be transitioned to mixed mode in the future.

This variable will be numeric and will be a flag variable rather than actual contact information and will simply indicate whether the trusts has a complete email address for each sampled service user. No email addresses will be shared with either approved contractors or the SCCEM.

Additional sample variable: Mode of contact

While consulting on the new sampling criteria, CMH trusts revealed there would be value in being able to report results broken down by the mode used to deliver care and treatment. Several of the trusts expressed an interest in being able to distinguish between the feedback received from those primarily receiving care face to face, via video, by telephone or a mix of modes.

This variable will be used within England-level and trust-level analysis, with the latter dependent on there being enough responses to adhere to the <30 suppression rule²⁰. It is also anticipated that this information will have value during the sample checking process conducted by the SCCEM when ensuring the new sampling criteria has been correctly implemented.

Trusts will need to provide data for each service user, based on the most commonly used mode of contact since 1st March 2020. CMH trusts would populate this information using service user record notes where mode of contact is recorded. CMH trusts have been asked to conduct a simple count of the different modes used for each contact to determine the most commonly used mode for that service user. CMH trusts have been asked to only include contacts where a service user received care, treatment or assessment. Contacts where a service user was simply querying an appointment time for example, should not be included.

10. Further information

For further information and documents for the Community Mental Health 2021 survey, please visit the <u>NHS Survey website</u>.

For any questions, please contact the Survey Coordination Centre for Existing Methods at:

mentalhealth@surveycoordination.com

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²⁰ Quantitative response data with fewer than 30 valid (specific) responses per trust is supressed and recoded to '996 – Cleaned responses'. This procedure is implemented across the NHS Patient Survey Programme to preserve trust-level precision and protect against respondents potentially being identified.



Appendix 1 - Question mapping 2021 vs. 2020 and summary of changes to questionnaire

The following table provides a summary of changes for 2021 questionnaire in comparison with the 2020 Community Mental Health questionnaire.

CMH21 questionnaire mapping with summary of changes

2020	2021	Changes made	Reasons for change
Covering page	Covering page	The words 'voluntary' and 'confidential' were highlighted by making them bold.	To highlight that the survey is voluntary and confidential
		The font colour of text on the front page was changed from purple to black.	To improve legibility.
Your care and treatment	Your care and treatment		
Q1: When was the last time you saw someone from NHS mental health services?	Q1: When was the last time you saw someone from NHS mental health services? (This includes contact in person, via video call and telephone).	Disclaimer on mode of contact added.	A note to say that contact may have been via phone, video call or in person was added to all questions with the terms 'saw' or 'seen' in the wording to avoid misunderstanding.
Q2: Overall, how long have you been in contact with NHS mental health services?	Q2: Overall, how long have you been in contact with NHS mental health services?		
Q3: In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs?	Q3: In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs? (This includes contact in person, via video call and telephone).	Disclaimer on mode of contact added.	A note to say that contact may have been via phone, video call or in person was added to all questions with the terms 'saw' or 'seen' in the wording to avoid misunderstanding.



-	Q4: In the last 12 months, were care and services available when you needed them?	NEW QUESTION	Q4 was introduced to capture whether service users were able to access the care and services they needed when they needed them. (see also Access to Care in NHS Long-Term Plan and NHS Patient Experience Framework).
-	Q5: Were you informed how the care and treatment you were receiving would change due to the coronavirus pandemic?	NEW QUESTION	Q5 was introduced to measure communication about service changes due to the coronavirus pandemic.
-	Q6: Do you feel changes in your care and treatment due to the coronavirus pandemic affected your mental health?	NEW QUESTION	Q6 was introduced to measure how changes to services due to the pandemic affected mental health.
Your health and social care workers	Your health and social care workers		
Q4: Were you given enough time to discuss your needs and treatment?	Q7: Were you given enough time to discuss your needs and treatment?		
Q5: Did the person or people you saw understand how your mental health needs affect other areas of your life?	Q8: Did the person or people you saw understand how your mental health needs affect other areas of your life? (This includes contact in person, via video call and telephone).	Disclaimer on mode of contact added.	A note to say that contact may have been via phone, video call or in person was added to all questions with the terms 'saw' or 'seen' in the wording to avoid misunderstanding.
Q6: Did the person or people you saw appear	Q9: Did the person or people you saw appear to be aware of your	Disclaimer on mode of contact added.	A note to say that contact may have been via phone, video call or



to be aware of your treatment history?	treatment history? (This includes contact in person, via video call and telephone).	in person was added to all questions with the terms 'saw' or 'seen' in the wording to avoid misunderstanding.
Organising your care	Organising your care	
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").	Q10: 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").	
Q8: Is the main person in charge of organising your care and services	Q11: Is the main person in charge of organising your care and services	
Q9: Do you know how to contact this person if you have a concern about your care?	Q12: Do you know how to contact this person if you have a concern about your care?	
Q10: How well does this person organise the care and services you need?	Q13: How well does this person organise the care and services you need?	
Planning your care	Planning your care	
Q11: Have you agreed with someone from NHS mental health services what care you will receive?	Q14: Have you agreed with someone from NHS mental health services what care you will receive?	
Q12: Were you involved as much as you wanted to be in agreeing what care you will receive?	Q15: Were you involved as much as you wanted to be in agreeing what care you will receive?	



Q13: Does this agreement on what care you will receive take into account your needs in other areas of your life?	Q16: Does this agreement on what care you will receive take into account your needs in other areas of your life?		
Reviewing you care	Reviewing your care		
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?	Q17: 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?		
Q15: Did you feel that decisions were made together by you and the person you saw during this discussion?	Q18: Did you feel that decisions were made together by you and the person you saw during this discussion? (This includes contact in person, via video call and telephone).	Disclaimer on mode of contact added.	A note to say that contact may have been via phone, video call or in person was added to all questions with the terms 'saw' or 'seen' in the wording to avoid misunderstanding.
Crisis care	Crisis care		
Q16: Would you know who to contact out of office hours within the NHS if you had a crisis? This should be a person or a team within NHS mental health services.	Q19: Would you know who to contact out of office hours within the NHS if you had a crisis? This should be a person or a team within NHS mental health services.		
Q17: In the last 12 months, did you get the help you needed when you tried contacting this person or team?	Q20: Thinking about the last time you tried to contact this person or team, did you get the help you needed?	'In the last 12 months' was removed and question was reworded.	This change was made to refer specifically to the last time the respondent tried accessing crisis care.
Medicines	Medicines		
Q18: In the last 12 months, have you been	Q21: In the last 12 months, have you been		



receiving any medicines for your mental health needs?	receiving any medicines for your mental health needs?		
Q19: Were you involved as much as you wanted to be in decisions about which medicines you receive?		Removed	Question was identified by key stakeholders as of lower priority. During testing respondents noted that while they were happy to be involved in decisions about medicines, the final decision was with the healthcare professional.
Q20: Has the purpose of your medicines ever been discussed with you?	Q22: 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?	Q23: Have the possible side effects of your medicines ever been discussed with you?		
Q22: Do you feel your medicines have helped your mental health?	Q24: Do you feel your medicines have helped your mental health?		
Q23: Have you been receiving any medicines for your mental health needs for 12 months or longer?	Q25: Have you been receiving any medicines for your mental health needs for 12 months or longer?		
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?).	Q26: 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?).		



NHS Therapies Therapies include any NHS treatment for your mental health that does not involve medicines.	Talking Therapies Talking therapies include any NHS treatment for your mental health that involve working with a trained therapist and do not involve medicines.	Terminology was changed from 'NHS therapies' to 'NHS talking therapies'. Section note was amended to say that trained therapist provides therapy.	Align with NHS Long Term Plan and NICE guidance.
Q25: In the last 12 months, have you received any NHS therapies for your mental health needs that do not involve medicines?	Q27: In the last 12 months, have you received any NHS talking therapies for your mental health needs that do not involve medicines?	Terminology was changed from 'NHS therapies' to 'NHS talking therapies'.	Align with NHS Long Term Plan and NICE guidance.
Q26: Were these NHS therapies explained to you in a way you could understand?	Q28: Were these NHS talking therapies explained to you in a way you could understand?	Terminology was changed from 'NHS therapies' to 'NHS talking therapies'.	Align with NHS Long Term Plan and NICE guidance.
Q27: Were you involved as much as you wanted to be in deciding what NHS therapies to use?	Q29: Were you involved as much as you wanted to be in deciding what NHS talking therapies to use?	Terminology was changed from 'NHS therapies' to 'NHS talking therapies'.	Align with NHS Long Term Plan and NICE guidance.
Q28: Do you feel your NHS therapies have helped your mental health?	Q30: Do you feel your NHS talking therapies have helped your mental health?	Terminology was changed from 'NHS therapies' to 'NHS talking therapies'.	Align with NHS Long Term Plan and NICE guidance.
Q29: Overall, how did you feel about the length of time you waited before receiving NHS therapies?	Q31: Overall, how did you feel about the length of time you waited before receiving NHS talking therapies?	Terminology was changed from 'NHS therapies' to 'NHS talking therapies'.	Align with NHS Long Term Plan and NICE guidance.



Support and Wellbeing	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)?	Q32: 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?	Q33: 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)?	Q34: 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?		Removed	During the cognitive testing it became apparent that face to face peer group support was not running and there was very limited online peer support available for service users to attend. Additionally, this was flagged by key stakeholders as of lower priority given the current circumstances of COVID-19.



Q34: Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?	Q35: Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?		
Q35: Overall	Q36: Overall		
Q36: Overall, in the last 12 months, did you feel that you were treated with respect and dignity by NHS mental health services?	Q37: Overall, in the last 12 months, did you feel that you were treated with respect and dignity by NHS mental health services?		
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?	Q38: 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?		
About you	About you		
Q38: Do you have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last for 12 months or more? Include problems related to old age.	Q39: Do you have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last for 12 months or more? Include problems related to old age.		
Q39: Do you have any of the following? Select ALL conditions you have that have lasted or are expected to last for 12 months or more.	Q40: Do you have any of the following? Select ALL conditions you have that have lasted or are expected to last for 12 months or more.	Two additional response options were added: - Autism or autism spectrum condition	Response options added for consistency across the NHS Patient Survey programme.



		- Stroke (that affects your day-	
Q40: Do any of these reduce your ability to carry out day-to-day activities?	Q41: Do any of these reduce your ability to carry out day-to-day activities?	to-day life)	
Q41: Who was the main person or people that filled in this questionnaire?	Q42: Who was the main person or people that filled in this questionnaire?		
Q43: What was your year of birth?	Q43: What was your year of birth?		
Q42: Are you male or female?	Q44: At birth, were you registered as	Previous question on sex removed, and 2 questions on sex and gender added as well as disclaimer on data confidentiality before Q44.	New gender questions have been included following redevelopment work on the Adult Inpatients 2020 Survey.
	Q45: Is your gender the same as the sex you were registered as at birth?	NEW QUESTION	New gender questions have been included following redevelopment work on the Adult Inpatients 2020 Survey.
Q44: What is your religion?	Q46: What is your religion?		
Q45: Which of the following best describes how you think of yourself?	Q47: Which of the following best describes how you think of yourself?		
Q46: What is your ethnic group?	Q48: What is your ethnic group?		
Other Comments	Other Comments		
If there is anything else you would like to tell us about your experiences of mental health care in	If there is anything else you would like to tell us about your experiences of mental health care in	Disclaimer on safeguarding added.	To ensure it is clear to service users when their comments may be



the last 12 months,	the last 12 months,	passed back to NHS
please do so here.	please do so here.	trusts.
Please note that the comments you provide will be looked at in full by the NHS Trust, Care Quality Commission and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback.	Please note that the comments you provide will be looked at in full by the NHS Trust, Care Quality Commission and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback. Your details will only be passed back to the NHS Trust if your comments in this section raise concerns for your own or others' safety and wellbeing.	



Appendix 2 - Main questionnaire

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NHS Community Mental Health Service User Questionnaire

Your experience matters, please tell us what your care is really like

This survey is about your experience of the health and social care you receive through NHS mental health services. We would like to hear from you, even if your contact has only been limited or has now finished.

What you tell us is **confidential** and taking part is **voluntary**.

WHAT TO DO

Put a cross 🗷 clearly inside one box using a black or blue pen.

If you make a mistake, just fill in the box completely \blacksquare and put a cross \boxtimes in the correct box.

If you cannot answer a question, or do not want to answer it, just leave it blank and go to the next question.

Please remember not to write your name or address anywhere on the questionnaire.

When you have filled in as much as you can, please return it in the Freepost envelope provided. **Thank you.**

NEED MORE HELP?

For help completing this questionnaire, please call the survey helpline on <insert helpline number> or, if you would prefer, email <insert email address>.

If you have concerns about the care you or others have received please contact the Care Quality Commission (CQC) on 03000 61 61 61.

YOUR CARE AND TREATMENT

Please do <u>not</u> include contact with your GP.

1. When was the last time you saw someone from NHS mental health services? (This includes contact in person, via video call and telephone). 1 ☐ In the last 12 months 2 ☐ More than 12 months ago 3 ☐ Don't know / can't remember 4 ☐ I have never seen anyone from NHS mental health services → Please go to Q39 on page 6
2. Overall, how long have you been in contact with NHS mental health services?
Less than 1 year
² 1 to 5 years
³ 6 to 10 years
⁴ More than 10 years
I am no longer in contact with NHS mental health services
⁶ ☐ Don't know / can't remember
3. In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs? (This includes contact in person, via video call and telephone).
¹ Yes, definitely
Yes, to some extent No
⁴ ☐ It is too often
⁵ □ Don't know
4. In the last 12 months, were care and services available when you needed them?
1 Yes, always
Yes, sometimes
3 No
Service(s) were available, but not the
service I needed
5 Don't know / can't remember

5. Were you informed how the treatment you were receivin change due to the coronavir	g would
Yes, definitely Yes, to some extent No My care and treatment did not change I did not receive care and before the pandemic Don't know / can't remember	 → Go to 6 → Go to 6 → Go to 7 treatment → Go to 7
6. Do you feel changes in your treatment due to the corona pandemic affected your mer 1 Yes, my mental health implemental health good when the changes did not a mental health 4 Don't know / not sure	virus ntal health? proved t worse
YOUR HEALTH AND SOCIAL	CARE

Thinking about the **most recent time** you saw someone from **NHS mental health services** for your mental health needs...

This does <u>not</u> include your GP.

7. Were you given enough time to discuss your needs and treatment?
1 Yes, definitely
² Yes, to some extent
3 No
Don't know / can't remember

 8. Did the person or people you saw understand how your mental health needs affect other areas of your life? (This includes contact in person, via video call and telephone). 1 Yes, definitely 2 Yes, to some extent 3 No 4 Don't know / can't remember 	 12. Do you know how to contact this person if you have a concern about your care? 1 Yes 2 No 3 Not sure 13. How well does this person organise the care and services you need? 1 Very well
 9. Did the person or people you saw appear to be aware of your treatment history? (This includes contact in person, via video call and telephone). 1 Yes, completely 	2 Quite well 3 Not very well 4 Not at all well
² Yes, to some extent ³ No	PLANNING YOUR CARE
4 Don't know / can't remember	Please do <u>not</u> include contact with your GP.
Not applicable - I had no treatment prior to this	14. Have you agreed with someone from NHS mental health services what care you will receive?
ORGANISING YOUR CARE	¹ ☐ Yes, definitely → Go to 15
In this section, you may <u>include</u> contact with your GP.	 Yes, to some extent → Go to 15 → Go to 17
 10. 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"). 1 Yes	 15. Were you involved as much as you wanted to be in agreeing what care you will receive? 1 Yes, definitely 2 Yes, to some extent 3 No, but I wanted to be 4 No, but I did not want to be 5 Don't know / can't remember
 11. Is the main person in charge of organising your care and services 1 A GP 2 Another type of NHS health or social care worker (e.g. a community psychiatric nurse, psychotherapist, mental health support worker etc). 3 Don't know / not sure 	 16. Does this agreement on what care you will receive take into account your needs in other areas of your life? 1 Yes, definitely 2 Yes, to some extent 3 No 4 Don't know / can't remember

REVIEWING YOUR CARE			•	last time you tried to
Please do <u>not</u> include contact	with your GP.	contact this person or team, did you ge the help you needed?		
17. In the last 12 months, have y specific meeting with some mental health services to disyour care is working? 1 Yes 2 No 3 Don't know / can't remember	ne from NHS	2 3 4 5 6	Yes, definitely Yes, to some ext No I could not conta I have not tried of Don't know / car	act them contacting them
		MED	ICINES	
18. Did you feel that decisions we together by you and the perduring this discussion? (This contact in person, via video of	son you saw includes		se do <u>not</u> include cribed only by yo	
telephone).	an and	re		hs, have you been i cines for your mental
² Yes, to some extent		1	Yes	→ Go to 22
3 No			No	→ Go to 27
⁴ I did not want to be involved	ed in making			2 00 00 27
decisions 5 Don't know / can't remem	ber		las the purpose of een discussed wit	f your medicines ever h you?
		1	Yes, definitely	
CRISIS CARE		2	Yes, to some ext	ent
Please do <u>not</u> include contact	with your GP.	3	□ No	
	,	4	□ Non't know / cai	n't remember
A crisis is if you need urgent help				
your mental or emotional state is getting worse very quickly. You may have been given a number to contact, such as a 'Crisis Helpline' or a 'Crisis Resolution Team'.			•	side effects of your en discussed with you?
		1	Yes, definitely	
19. Would you know who to cor	tact out of	2	Yes, to some ext	ent
office hours within the NHS		3	No	
crisis?		4	Don't know / cai	n't remember
This should be a person or a NHS mental health service	team within s.	24 . D	o vou feel vour m	edicines have helped
¹ Yes	→ Go to 20		our mental health	
¹ Tes ² No	→ Go to 20	1 [_	
3 Not sure	→ Go to 21	2	<pre> Yes, definitely Yes, to some out</pre>	ont
- INOL Sule	7 00 10 21	3	J Yes, to some ext	ent
		3 L	∐No □Not our	
		• 4	Not sure	

25. Have you been receiving any medicines for your mental health needs for 12 months or longer?	29. Were you involved as much as you wanted to be in deciding what NHS talking therapies to use?	
 Yes → Go to 26 No → Go to 27 Not sure → Go to 27 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?). 	1 Yes, definitely 2 Yes, to some extent 3 No, but I wanted to be 4 No, but I did not want to be 5 Don't know / can't remember 30. Do you feel your NHS talking therapie have helped your mental health? 1 Yes, definitely	
Yes No Don't know / can't remember	Yes, to some extent No No Not sure	
NHS TALKING THERAPIES Talking therapies include any NHS treatment for your mental health that involves working with a trained therapist and do not involve medicines.	 31. Overall, how did you feel about the length of time you waited before receiving NHS talking therapies? 1 The waiting time was appropriate 2 The waiting time was too long 	
27. In the last 12 months, have you received any NHS talking therapies for your mental health needs that do not involve medicines?	The waiting time was too short I did not have to wait for NHS talking therapies	
1	SUPPORT AND WELLBEING	
No, but I would have liked this → Go to 32	Please do <u>not</u> include help from your GP.	
 No, but I did not mind → Go to 32 This was not appropriate for me → Go to 32 Don't know / can't remember → Go to 32 	32. 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)?	
28. Were these NHS talking therapies explained to you in a way you could understand? 1 Yes, completely 2 Yes, to some extent 3 No 4 No explanation was needed	Yes, definitely Yes, to some extent No, but I would have liked support I have support and did not need NHS mental health services to provide it I do not need support for this I do not have physical health needs	

If support was provided by a non-NHS organisation, we are interested to know **if NHS mental health services helped you to find this support.** This may be through posters, flyers and leaflets.

36. Overall... (Please circle a number) 33. In the last 12 months, did NHS mental I had a very I had a very good health services give you any help or poor experience experience advice with finding support for financial advice or benefits? Yes, definitely Yes, to some extent No, but I would have liked help or 37. Overall, in the last 12 months, did you feel that you were treated with respect and advice with finding support dignity by NHS mental health services? ☐ I have support and did not need help / advice to find it Yes, always ¬I do not need support for this Yes, sometimes 3 **No 34.** In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding 38. Aside from in this questionnaire, in the or keeping work (paid or voluntary)? last 12 months, have you been asked by NHS mental health services to give your ¹ Yes, definitely views on the quality of your care? 2 Yes, to some extent 1 Yes No, but I would have liked help or 2 No advice with finding support 3 Not sure 4 I have support and did not need help / advice to find it 5 I do not need support for this **ABOUT YOU** 6 I am not currently in or seeking work This information will not be used to identify you. We use it to monitor whether 35. Have NHS mental health services involved different people are having different a member of your family or someone experiences of NHS services. else close to you as much as you would All the questions should be answered **from** like? the point of view of the person named on ¹ Yes, definitely the envelope. This includes the following background questions on gender and date of Yes, to some extent 3 No, not as much as I would like **39.** Do you have any physical or mental health 4 No, they have involved them too much conditions, disabilities or illnesses that 5 My friends or family did not want to be have lasted or are expected to last for 12 involved months or more? Include problems related to old age. 6 I did not want my friends or family to be involved → Go to 40 1 Yes \Box This does not apply to me → Go to 42 2 **No**

OVERALL

Please do not include contact with your

Select ALL conditions you have that have lasted or are expected to last for 12 months or more. 1 Autism or autism spectrum condition 2 Breathing problem, such as asthma 3 Blindness or partial sight 4 Cancer in the last 5 years 5 Dementia or Alzheimer's disease	your sex and gender. Your answers will help us understand whether experiences vary between different groups of the population. Your answers will be kept confidential and not linked to your medical records. 44. At birth were you registered as 1 Male 2 Female
 Deafness or hearing loss Diabetes 	IntersexI would prefer not to say
Heart problem, such as angina Joint problem, such as arthritis Kidney or liver disease Learning disability Mental health condition Neurological condition Stroke (that affects your day-to-day life) Another long-term condition	45. Is your gender the same as the sex you were registered as at birth? 1 Yes 2 No, please write your gender below 3 I would prefer not to say
41. Do any of these reduce your ability to carry out day-to-day activities? 1 Yes, a lot 2 Yes, a little 3 No, not at all	46. What is your religion? 1 No religion 2 Buddhist 3 Christian (including Church of England, Catholic, Protestant, and other Christian denominations) 4 Hindu
 42. Who was the main person or people that filled in this questionnaire? 1 The person named on the front of the envelope (the service user / client) 2 A friend or relative of the service user / client 	Jewish Muslim Sikh Other I would prefer not to say
 Both service user / client and friend / relative together The service user / client with the help of a health professional 	47. Which of the following best describes how you think of yourself?1 Heterosexual / Straight
43. What was your year of birth? (Please write in) e.g. 1 9 6 8	Gay / Lesbian

48. What is your ethnic group? (Cross ONE	OTHER COMMENTS
box only) a. WHITE English / Wolsh / Scottish / Northern	If there is anything else you would like to tell us about your experiences of mental health care in the last 12 months, please do so here.
English / Welsh / Scottish / NorthernIrish / British	
² Irish	Please note that the comments you provide will be looked at in full by the NHS Trust, CQC
∃ Gypsy or Irish Traveller	and researchers analysing the data. We will
4 Any other White background, write in	remove any information that could identify you before publishing any of your feedback. Your details will only be passed back to the NHS Trust if your comments in this section
	raise concerns for your own or others' safety and wellbeing.
b. MIXED / MULTIPLE ETHNIC GROUPS	
5 White and Black Caribbean	Is there anything particularly good about your care?
6 White and Black African	
White and Asian	
8 Any other Mixed / multiple ethnic background, write in	
c. ASIAN / ASIAN BRITISH	
9 Indian	Is there anything that could be improved?
10 Pakistani	
11 Bangladeshi	
12 Chinese	
13 Any other Asian background, write in	
write III	
d. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH	Any other comments?
14 African	
15 Caribbean	
Any other Black / African / Caribbean background, write in	
e. OTHER ETHNIC GROUP	
17 Arab	THANK YOU VERY MUCH FOR YOUR HELP
Any other ethnic group, write in	Please check that you answered all the questions that apply to you.
	Please post this questionnaire back in the FREEPOST envelope provided.