

# 2020 Community Mental Health Survey: Survey Development Report

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## 1. Background

The Community Mental Health Survey 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 2019, the survey was in fieldwork for 18 weeks and achieved a 27% response rate, with over 12,500 respondents from 56 NHS trusts and social enterprises taking part in the survey.

The purpose of the survey is to understand, monitor and improve service users' experiences of NHS community mental health services. Data collected from the 2020 Community Mental Health Survey (CMH20) will be used by the CQC in its assessment of mental health trusts in England. The results are also used by NHS England NHS Improvement and the Department of Health and Social Care for performance assessment, improvement, governance and regulatory purposes. These include the NHS Outcomes Framework (Domain 4: Ensuring patients have a positive experience), the NHS England overall patient experience measure, the NHS Performance Framework, the NHS Oversight Model, the cross-Whitehall Public Services Transparency Framework and NICE Quality Standards.

As part of the development work for the 2020 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
- 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 CMH19
- Interviews with six key stakeholder organisations
- Analysis of the CMH19 questionnaire performance
- Consultation with the Community Mental Health Survey Advisory Group
- Cognitive testing of the questionnaire with 19 recent service users.

This report sets out the phases of development in more detail and the changes that were made for the 2020 survey.

## 2. Review of the NHS Patient Experience Framework

This framework was adopted by the NHS National Quality Board (NQB), and built on a modified version of the Picker Institute Principles of Person Centred Care. However, it should be noted that this is a general patient experience framework and on face value, appears to align more clearly with acute care than community mental health experience. However, there are a number of themes within the framework that do resonate with mental health care and policy approaches. The main themes within the framework are:

- Respect for patient-centred values, preferences and expressed needs
- Coordination and integration of care
- Information, communication and education
- Emotional support
- Welcoming the involvement of family and friends
- Transition and continuity

- o Access to care

For the most part, the 2019 questionnaire content aligned relatively well with the current themes of the framework. For example, a number of question items covered aspects of patient-centred values or preferences such as shared decision making (e.g. Q13: “Does this agreement on what care you will receive take your personal circumstances into account?”; Q27 “Were you involved as much as you wanted to be in deciding what NHS therapies to use?”). However, the questionnaire was not felt to cover ‘*cultural issues, privacy and independence of patients and service users*’. In the development of the 2019 iteration of the questionnaire, these topics were identified as being missing from the current scope of the survey but no new question was tested to cover this topic. Consideration was given to including a question on this topic area during the 2020 survey development. However this was balanced against key considerations such as other priority areas of focus (such as waiting times), maintaining longitudinal data as far as possible and overall questionnaire length. Whilst an item was not added to the 2020 survey, future iterations should revisit this aspect of care and new items be considered.

In addition, the theme of ‘emotional support’ has not been as well covered in the questionnaire which may seem odd for a questionnaire focussing on mental health care. However, the theme specifically mentions ‘*alleviation of fear and anxiety about such issues as clinical status, prognosis and the impact of illness on patients, their families and their finances*’. It was noted that there was a question about support for financial matters in the 2019 survey (Q30), however the main focus of that item was around the signposting provided by the trusts to service users about where they can get the support they need, rather than a direct responsibility on the trust to provide that type of financial advice and guidance. The questionnaire also did not cover any clinical aspects such as diagnosis itself or prognosis of the condition nor touch on the emotional impact of diagnosis or living with the condition for the service user. However, it did ask about the holistic approach to care with a focus on trusts supporting participation in local activities and building relationships/contact with people experiencing the same mental health condition.

### 3. Policy and the Community Mental Health Survey

#### 3.1 NHS Long Term Plan

The key developments in mental health policy in the NHS Long Term Plan, published in January 2019, set out NHS England’s goals for the next decade. Many of the policy areas outlined in the Long Term Plan are pledges from the *Five Year Forward View for Mental Health*, which set out priority areas for NHS mental health improvement in 2016, which have been built on and expanded.

The Long Term Plan commits to expanding the overall investment in adult mental health services faster than the NHS budget overall (£2.3 billion a year by 2023/24), in accordance with the Lancet Commission on Global Mental Health that sets a goal for high income countries to spend at least 10% of their total health budget on supporting mental health (National Health Service, 2019a). In addition to big-picture principles for improving mental health care through increased funding and an expanded work force, there are several specific commitments to improve care. These are:

o **Prevention and personalisation**

A recurring theme in the Long Term Plan that has been apparent in mental health policy for some years now, is the focus on prevention rather than crisis care. In the Long Term Plan, this takes the form of targeting weight management for service users with a high BMI and a smoking cessation offer for long-term users of specialist mental health services (Centre for Mental Health, 2019b). The Long Term Plan also references allowing people to have greater choice and control over their care by 2023/24 (National Health Service, 2019a).

o **Ease of accessing mental healthcare**

Possibly the most talked-about goal in the media introduced by the Long Term Plan is the introduction of four-week waiting time targets for generic adult and older adult mental health care (National Health Service, 2019b). This has been a priority for third sector organisations for years now, as they are often relied upon to fill the gap while service users are awaiting NHS treatment (MIND, 2013): timely access to mental health services and wait times for appointments are themes in other mental health surveys (MIND, 2019). Waiting-time targets are already well-established in emergency departments and cancer care and similar targets for mental health help to take steps towards parity between physical and mental health care (Centre for Mental Health, 2019a). The Mental Health Taskforce introduced a wait time standard for early intervention in psychosis in 2016. The fact that these targets are being implemented points to the issues people have faced for years in accessing mental health services, particularly those waiting for psychological therapies.

o **An integrated approach to mental and physical healthcare**

Integration of community mental health services and primary care has numerous mentions in policy. According to research, mental health service users receive inferior medical care and as a result, service users with severe mental illnesses have a high rate of physical illnesses and cardio metabolic complications, resulting in premature death 10-20 years before those without mental health conditions (Mitchel, Hardy and Shiers, 2017). As such, the Long Term Plan has increased the target from the *Five Year Forward View* for the total number of people receiving physical health checks annually during mental health appointments from 280,000 by 2020/21 to 390,000 by 2023/24 (Mental Health Taskforce, 2016).

o **Inequality in mental healthcare**

In order to address the disparity between mental and physical healthcare, the NHS will have to address the inequalities between different demographic groups. People living in poverty; Black, Asian and Minority Ethnic (BAME) communities; and people with learning disabilities experience higher rates of poor mental health (Mental Health Foundation, 2018) and also experience inequalities in accessing mental health treatment. For example, people of Black and African Caribbean heritage are more than twice as likely to access mental health services through the criminal justice system rather than healthcare pathways (HM Government, 2018). An independent review into the Mental Health Act (1983) recommended that, in order to tackle these inequalities there would need to be a change in the structure of existing systems (HM Government, 2018).

- o **Improved access to crisis care and improved crisis care coverage nationwide**

While there is a focus on prevention that is not to say that crisis care is ignored in policy. Building on from the commitments in the *Five Year Forward View*, the Long Term Plan pledges 100% coverage of 24/7 crisis care via NHS 111 in addition to increasing the presence of mental health liaison services at all general hospitals (National Health Service, 2019b). Additionally, they are committed to 24/7 community support as well as improved ambulance services and alternatives to hospital admission during crisis (Centre for Mental Health, 2019b). The Long Term Plan, drawing on conclusions from an independent review, concluded that the Mental Health Act (1983) is “out of step” with the modern mental health system and that there is a need for better crisis services for people with serious mental illnesses (National Health Service, 2019a).

- o **Improvements to children and young people’s and perinatal mental healthcare**

Research has found that 50% of mental health problems are established by age 14 and 75% by age 24 (Royal College of Paediatrics and Child Health, 2019) and one in four women experience mental health problems during pregnancy or in the following two years after birth (National Health Service 2019a). Funding for children and young people’s mental health will increase faster than adult mental health and the average for the NHS (Centre for Mental Health, 2019b). The NHS is also increasing mental health support to expecting and new mothers (National Health Service, 2019a).

The above summary of the current state of mental health policy demonstrates that there is currently an attempt to redress the imbalance between physical and mental health care within the NHS, with a number of strengthened commitments to reforming the system and introducing new policy initiatives.

### 3.2 Other mental health surveys

The CQC survey is the most widely used survey in this area (i.e. measuring service user experience in community mental health services). MIND conduct a regular survey called The Big Mental Health Survey but the content of this is not very well aligned with the CQC survey, given the different end uses of the data. For example, the MIND survey focuses on primary care services, transitions, mental health conditions (severity/symptoms, etc.) and the support given to individuals whilst they are waiting for access to NHS services. 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. 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.

## 4. Stakeholder interviews

Interviews were conducted with the following six stakeholders in August 2019:

- o CQC (data analyst)
- o CQC Expert by Experience
- o NHS England & Improvement (analyst)
- o MIND



- North Staffordshire Combined Healthcare NHS Trust (conducted CMH19 in-house)
- Oxford Health NHS Foundation Trust (conducted CMH19 using a contractor)

## 4.1 Survey coverage

Feedback from these interviews highlighted a number of areas that it was felt the survey should cover. It is worth noting, however, that some stakeholders were very keen to keep the question items consistent between survey years to ensure longitudinal comparability.

Overall, there was positive feedback for the questionnaire content. Stakeholders felt the survey content gave a good overview of:

- Care planning
- Medicines, including side effects
- Care review
- Crisis care
- Total wellbeing: additional support services items
- Care coordinator

However, there were a number of areas that stakeholders felt the questionnaire was lacking:

### **Access to care**

Local based research, cited during one of the interviews, suggests that the recovery from mental health conditions is much improved when family are involved and community support is available. This suggests that there is potentially a need to understand access to mental health services in terms of the geographical proximity of service provision in relation to service users' own community and family support networks. However, in previous CMH surveys, there were questions aimed at understanding how far a service user had to travel to attend their appointments. These items were removed as it was felt that this was outside of the jurisdiction of a trust and therefore unfair to hold them accountable for this.

### **Waiting times**

Waiting times are a key theme in the NHS Long Term Plan as well as stakeholder interviews. The NHS is introducing four-week waiting time targets for generic adult and older adult mental health care because waiting times around therapies are a particular challenge at the moment. It was highlighted by stakeholders that waiting times around therapies were a particular challenge (i.e. they are particularly long as there is not enough space available on services to meet needs). Stakeholders felt a question about how long a service user waited before accessing a service was important.

### **Third sector involvement**

It was also acknowledged by stakeholders that a number of service users have to access third sector provisions for support with their mental health whilst waiting to gain access to NHS provided services. A question about signposting service users to interim support available, in particular for social functioning and inclusion, was suggested and that a question covering peer support would also be beneficial. Whilst there is already a question regarding contact with others with the same mental health condition, this would not be a

suitable proxy for understanding peer support as the focus of the item is concerned with information provision.

### **Transition of care**

Another aspect mentioned during the interviews was the interplay between primary and community care within mental health. The real focus of these discussions was around the early intervention and diagnosis of conditions, and the handover or transition of care between services (namely moving from primary to community care). Transition and continuity are also a main theme in the NHS Patient Experience Framework. However, whilst important, a key consideration needs to be how useful data in this area would be to those focussed on improvement of services.

### **Physical health**

Questions on physical health and the management of any conditions or illnesses are missing from the current survey. There is often an interplay between mental and physical health for service users and the impact of physical health conditions on an individual's mental health is noticeably absent. It was felt that the relationship between the two and the support given to manage physical health should be covered somewhere in the survey.

### **Choice**

Whilst service user involvement is very much reflected throughout, stakeholders would like to see more of a focus on person centred 'choice'. In addition, it was also specifically noted that the questionnaire covers compassionate care and involvement in decision making in a number of ways, which is very important, but that consideration could be given to whether these items could be reduced. This is echoed by the NHS Long Term Plan, which talks about also allowing people to have greater choice and control over their care by 2023/24.

### **Children and Young People**

Children and young people's mental health care is currently receiving a lot of attention in policy. Some stakeholders noted that there is a lack of research into the experience of children and young people and they felt they would benefit from additional data about their experiences. Whilst the age range for the community mental health survey could be lowered to include 16 and 17 year olds, this may not necessarily fill the gap in the measurement of Children and Young Peoples Mental Health Services (CAMHS). However, it may enable questions on the transition between CAMHS and adult services to be included. It was noted however, that it would not be possible to design just one or two items to measure transitions between services unless the focus were on the integration of those services.

In addition, whilst a number of these areas were already covered in the 2019 questionnaire, stakeholders wanted to see specific items that focussed on particular aspects of the following themes:

- **Medication:** it was suggested that there should be a new item that asks about follow up medication meetings; for example, medications are often prescribed during crisis periods and it is not always possible for the service user to take the information in at the time, so it would be beneficial to understand whether a follow up meeting happened and how informative this was.



- **Additional support:** whilst there are questions regarding additional support and signposting provided by trusts, there is not an item that focuses on support for further education.
- **Appointments:** there was interest in understanding more about the appointments themselves and not just the care planning or review meetings; it was suggested that there be items included on whether the general/regular appointments are kept, punctuality of clinicians and how useful they are.
- **Feedback:** it was suggested that the focus needs to be on complaints and not just on giving feedback on the quality of care. It was also mentioned that a question on whether service users were able to switch teams (or even request a switch) should be included.
- **Holistic/recovery model approach:** it was felt that there needs to be an item on whether service users are being supported to reach their full potential.
- **Care coordinator:** it was suggested that there needs to be an item that captures any changes in care coordinator so that it is possible for trusts to compare outcomes of care with the frequency by which care coordinator changes or the experiences when the care coordinator changes.

More contextual data was also requested from stakeholders. Areas that stakeholders would like included were:

- Details of the mental health condition and severity
- A question on symptoms being experienced
- Choice of treatment options and referrals
- Which health professional the service user last saw

## 4.2 Suggestions relating to specific questions

Additionally stakeholders provided the feedback on the following four specific questions:

- It felt that the term NHS Therapies (used at Q25) was not specific enough and it would be useful to understand what type of therapy someone received, e.g. CBT/ DBT, a regular conversation with the care coordinator or social intervention.
- It was suggested that Q32 (*In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?*) does not currently add any data value as the language is too vague, with 'group' and 'activity' not clearly defined.
- The placement of Q33 (regarding the involvement of family members) was felt to be a little odd
- The gender question (Q42) in its current form was seen as outdated. Some stakeholders felt strongly that the question should be reworked to be more inclusive due to the links between mental health diagnoses and people who identify as transgender.

### 4.3 Stakeholder views on survey methodology

Additionally, stakeholders provided the feedback on the following four specific areas:

#### **Eligibility criteria**

Given the desire to keep longitudinal comparability, for some stakeholders, keeping the sampling criteria the same as previous years is preferable. However, there is potential interest in including the views of younger people due to the relevance of the NHS Long Term Plan. It is noted that NHS Digital have run a national survey measuring the health and wellbeing of children and young people, which includes topic areas on mental health. Previous iterations of the CQC survey included 16 and 17 year olds but this was changed in 2012 due to concerns raised by the ethics committee. Any changes to the age threshold for the survey would affect comparability longitudinally.

It was suggested that service users diagnosed with severe dementia should be excluded as standard from the survey due to feedback received from service users and carers highlighting that it is distressing to receive the survey.

There was also a suggestion to consider the importance of including service users who may be in prison at the time of the questionnaires being mailed out and having greater publicity in prisons as standard. Whilst not a group that is currently excluded from sampling, anecdotal feedback was given to suggest that when service users are in prison at the time of the survey being mailed, the prison staff have reported not being able to find the named individual in order for them to complete the survey.

#### **Additional sampling variables**

Greater granularity with regards to data analysis is of particular interest of secondary data users. It was felt that being able to map data back to particular mental health conditions or at service level (compared to the current trust level approach) would allow a greater focus on improvement initiatives for teams and trusts.

Consideration could be given to the collection of full postcode data. For the 2019 Maternity survey, we have successfully achieved Section 251 support to receive full postcode for each patient in the sample. This is to allow for deprivation analysis to be undertaken. Currently, CCG is collected, however no analysis is undertaken at this level due to low response rates. Increasing the sample size overall would potentially increase the likelihood of CCG analysis being feasible.

#### **Reporting**

Feedback from stakeholders said that the way data is reported currently is not particularly useful to identify and develop action plans for improvement initiatives. The data may be more useful to stakeholders if presented better such as knowing what particular sub-groups of the population thought (e.g. "men under 25 felt that they are not involved") or if it were broken down to service level rather than just trust-level.

Free text comments were also mentioned as an untapped source of feedback that is not routinely used as part of reporting for the survey.

## 5. Analysis of the 2019 Community Mental Health Survey

Analysis of the 2019 survey data was undertaken to examine:

- Item non-response rates (questions respondents have not answered, for example because they felt they did not apply to them)
- Floor/ceiling effects (questions where the vast majority of respondents report a very positive or negative experience)
- Correlations (questions that people tend to answer in the same way, suggesting a similar or the same underlying concept)

The performance analysis identified the following items for consideration:

*Q9: Do you know how to contact this person if you have a concern about your care?*

- This question, which refers to main person in charge of organising care and services and which was introduced into the survey in 2018, has a high ceiling effect with the majority of respondents in 2019 (>95%) responding 'Yes'.

*Q13: Does this agreement on what care you will receive take your personal circumstances into account?*

- Responses to Q13 tend to correlate with responses to the previous question (Q12 *Were you involved as much as you wanted to be in agreeing what care you will receive?*), with a correlation coefficient of 0.617 in 2019. Since Q12 is included in the calculation of the composite *involvement* indicator, consideration might be given to the additional value of continuing to ask Q13.

*Q30: In the last 12 months, did NHS mental health services give you any **help or advice** with **finding support** for **financial advice or benefits**?*

and

*Q31: In the last 12 months, did NHS mental health services give you any **help or advice** with **finding support** for **finding or keeping work**?*

- Responses to these two questions tend to correlate (correlation coefficient 0.637 in 2019). Both have been included in the questionnaire since 2014 but it may be worth considering whether both questions are required, or whether a composite question might be developed.

NOTE: Stakeholders stressed the importance of protecting the questions on wellbeing and support and felt quite strongly that these need to be included in future iterations.

Consideration was also given to the following question:

***Q29** In the last 12 months, did NHS mental health services give you any help or advice with finding support for physical health needs (this might be an injury, a disability, or a condition such as diabetes, epilepsy, etc.)?*

This question assesses if support was provided for physical health needs, however it only captures answers if service users perceive they had physical health needs. However, "People with severe and prolonged mental illness are at risk of dying on average 15 to 20 years earlier than other people – one of the greatest health inequalities in England. [...]"

There is also a lack of access to physical healthcare for people with mental health problems” (Mental Health Taskforce, 2016, p. 6). There are clear objectives in the available literature that this problem needs to be tackled by offering service users with severe mental health problems screening and secondary prevention due to their higher risk of poor physical health (Care Quality Commission, 2017). It was therefore suggested that the question could either be updated to ask if service users were encouraged to have a yearly health check (the data can then be filtered on severe problems to assess if this is offered), or an additional question could be added in to measure this issue. However, it is noted that there are challenges with an item focussing on a yearly health check with regards to attribution and measurement error. A respondent may have had a yearly health check but this was conducted by the GP, so outside the jurisdiction of the NHS Trust providing the mental health support, which would need to be considered when analysing the data (and may require an additional item to ascertain who undertook the yearly review). The wording of an item may also be a challenge with regards to a standard definition. The language used around care plans and care reviews have changed within mental health services over time and in previous survey iterations there were concerns over understanding of formal terms such as care reviews. It is likely that it will be difficult to provide a standard, universal definition of a yearly health check which may result in respondents either over or under reporting this.

## 6. Advisory Group

The Community Mental Health Survey Advisory Group met on 9 September 2019 to discuss the redevelopment of the 2020 survey. Present were representatives from the Care Quality Commission (CQC), Survey Coordination Centre for Existing Methods (SCCEM), NHS England, Oxford Health NHS Foundation Trust and two CQC Experts by Experience.

Members were updated by CQC on the plans to implement a mixed mode methodology (paper and online) for all surveys in the NPSP over the next three years. It was noted that CQC is aiming to move the Community Mental Health Survey to mixed mode for the 2021 iteration.

Key points from the discussion of the survey questionnaire are detailed below:

At the beginning of the questionnaire, there was a suggestion that Q1 and Q2 might be removed, combined or condensed to shorten the questionnaire and because this data is available elsewhere.

There was extensive discussion around the inclusion of questions relating to access to services and waiting times, which would fit best in this section. However, there are a number of considerations regarding these topics:

- There is felt to be extensive and potentially more accurate data on waiting times available elsewhere.
- Around eight in ten respondents have been mental health service users for more than 12 months and so waiting times for initial referral would not necessarily be representative of the current survey period (and also recall may be low).
- However, since access to services and waiting times are a key area of focus currently, it was felt there may be some value in including a question here, so long as it refers to the past 12 months. It was suggested the team investigate whether any

other surveys use questions around access/waiting times that might be appropriate. Perhaps something along the lines of 'In the past 12 months have you been able to access services when you wanted to/as quickly as you would have liked to?'

It was raised that although there are questions on timing and frequency, there were some concerns from the advisory group that current questions do not measure the overall quality of the appointment, including what matters to the service user or whether the service met their expectations. It was felt that consideration should also be given to including a question or questions about whether the respondent felt that their latest appointment met their personal needs, and/or whether they felt the person they saw was the right person/best person for them to see (i.e. had the skills, expertise, experience, personal qualities, authority and resources to address their particular needs). In order to include a new question or suite of questions in the survey, it is necessary to consider which existing items can be removed. Otherwise the overall length of the questionnaire would be increased, which may affect response rates. Whilst understanding the quality of the appointment is an important aspect of care, and the data may provide interesting findings, there are potential measurement concerns. For example, without understanding which service a respondent was accessing there would be limits around the usability and value of that data to NHS providers. Whilst an overall question on quality of appointments may highlight that there was variation at trust level, it would be difficult for providers to highlight exactly which services were better than others in this regard.

A question on waiting times was included in the questionnaire taken to cognitive testing (see section 7.2 below). However, this is specific to access for NHS therapies rather than access to the community mental health service more broadly. Designing a question to focus solely on access to the service itself would be challenging for a number of reasons:

- The survey itself does not gather specific data on which service a respondent accessed and so perceived waits for particular services could not be identified in the survey data. This would limit the benefits to NHS providers to identify where the barriers might be for particular services, to enable targeted improvement actions;
- Measuring access to the service as a whole may be complicated by problems in clearly defining the start and end points of the wait (e.g. whether from first episode of illness to assessment, or from referral to treatment etc.). Furthermore, many service users are now offered interim support while waiting for mental health services, via self-referral to IAPT and other third party provision.
- There may be recall issues with regards to the time a respondent waited to access the service. The sampling period for the survey can include individuals who have been using a service for more than 12 months which may introduce accuracy concerns over the data for an item of this nature if a respondent is trying to recall the wait they had prior to using a service more than 12 months ago.

## **Involvement**

There are three questions concerned with shared decision making and the service user feeling involved in agreeing the care they will receive, decisions regarding medicines and decisions regarding NHS therapies (Q12, Q19, Q27). As the questions are similar, and showed moderate correlation in the performance analysis of the 2019 survey (correlation coefficients of between 0.43 and 0.51), there was some concern that it may not be possible



for service users to differentiate between what is being asked in each question. Given concerns that these three items may be measuring either the same concept from a respondent's perspective or overlapping concepts, changes were not made to these questions but explored fully during cognitive testing.

### **Crisis Care**

There was general agreement from the group that the Crisis Care section was important. Some members of the group were interested in going through these questions with Crisis colleagues due to policy changes following the NHS Long Term Plan. It is noted that the NHS Long Term plan sets out the current and future priorities around crisis care. However, it was felt that the changes could only be reflected in the survey once the translation of those priorities into practice nationally is clearer. Given that there was a strong interest in maintaining longitudinal comparability and that the 2020 survey may be slightly too early to measure crisis care in more depth, at this stage no fundamental changes (i.e. a shift in focus) were made to these questions and no additional items were added to this section.

### **Medicines**

There was some uncertainty around how providers would use data gained from Q22 regarding whether the service user felt medicines had helped their mental health. This is mainly due to there being no record of what medicines had been administered and whether the service user had taken medication correctly. However, CQC felt the current question has value in helping to build a picture of whether a service user feels that the care they receive meets their needs, even if without clinical data it may not be particularly helpful at the local level. Consideration could be given to whether any alternative question would be more useful to other data users, since any amendments would compromise trend analysis.

### **NHS Therapies**

There was some discussion in the group that the term 'NHS therapies' may be too broad and therefore make it difficult for providers to use the results effectively. It was acknowledged that it would be difficult to identify the specific therapy used as it would not be possible to construct an exhaustive list of the therapies included. Furthermore, any attempt to include examples of what is meant by the term might result in high non-response or a change in response patterns, as services users may only consider the examples when answering.

Discussion centred around what therapies the questionnaire should be asking about, with arts and music therapies mentioned as well as online therapies, which are becoming more widespread but not necessarily available consistently at the national level. A view was put forward that questions should focus on psychological and talking therapy, as in previous versions of the survey. Members of the group were interested in discussing this further with policy colleagues to understand what they would want to be measured regarding provider-managed and wrap-around services. Given that it would be difficult to provide an exhaustive list of all therapies that may be considered within this section, that there is variability in what therapies are offered by NHS Trusts at the local level and the interest in maintaining longitudinal comparability, it was decided to keep the terminology used throughout this section as 'NHS Therapies'. As further work is done in providing different therapies by NHS trusts, the terminology of this section may require review for future iterations of the survey.



## **Support and Wellbeing**

There is a clear direction in policy that states that signposting alone is no longer enough and that trusts should be taking responsibility for both physical and mental health. Stakeholders would like a more explicit question about physical and mental healthcare, not just signposting. Overall, members of the advisory group thought the questions in this section worked well and were important to assess. There was a suggestion that Q30<sup>1</sup> might include voluntary/unpaid work and education as well as paid work. There was also discussion of Q31 and what types of groups/activities this is designed to cover. There was a similar discussion around Q34 regarding whether it is the case that trusts are expected to signpost service users to support groups with “the same mental health needs”.

Changes were made to the questions regarding physical health and work. For Q29 (which focusses on physical health), the question focus was redefined to be specifically on the NHS Trust providing the support rather than signposting the service user to other services. For Q31, changes were made to include voluntary work.

At Q32, regarding support in joining a group or taking part in activities, it was felt unclear what type of activities were being referred to and some felt it may be difficult for service users to answer accurately. As such members of the group were unclear to what extent this question would measure activities which are under the remit of a trust to deliver. While no changes to the questionnaire were proposed for testing, service users’ understanding was probed during testing to assess what types of activities they felt this question covered.

## **Gender question**

The gender question includes male and female only, and there was consensus amongst the group that this needs to be updated. CQC informed the group that they are looking into using the proposed Office of National Statistics (ONS) question that will be used in the next Census, although this has not yet received ministerial approval. Any changes to the gender question, regardless of whether this is the ONS version, would require full and robust testing to ensure that the redesigned question is suitable for this service user population specifically rather than a general population more broadly.

# **7. Cognitive testing**

## **7.1 Recruitment**

As is common practice in the NPSP, the revision and redevelopment of all questionnaires follows best practice. All questions are tested with recent service users, with a particular emphasis on new or amended questions or response options. Cognitive testing (or interviewing) is a research method which tests new questions and questions used in previous years to check if they are interpreted and understood as intended by respondents. It also tests whether respondents are able to answer them appropriately with the response options provided.

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<sup>1</sup> NB question numbering relates to the CMH19 survey questionnaire

## **Advertising**

The respondents were recruited using a number of means, such as local and national online and printed advertisements and social media. Adverts were placed on Daily Info (an Oxford-based newsletter) online and in print between September and November 2019. Adverts were placed on local Gumtree pages in the following locations: Reading, Slough, Abingdon, Banbury, Birmingham, Witney, Leamington Spa, Bicester, Newbury, Oxford, Southampton, High Wycombe, Bristol, Didcot, Temple Meads, Aylesbury, Milton Keynes and London. Some of these adverts were subsequently advertised as urgent or 'bumped up', meaning the advert goes back to the top of the listings in the category.

Additionally, recruitment was promoted via Picker's own LinkedIn account and adverts were placed on 'spotted' sites on Facebook for locations in Oxford and surrounding towns. SCCM also reached out to Mental Health Charities including MIND and Restore, of which Restore put the adverts on their social media accounts.

## **Additional recruitment approaches**

The following trusts were emailed and agreed to share the request for volunteers amongst their service users:

- Oxford Health NHS Foundation Trust
- Worcestershire Health and Care NHS Trust
- West London Mental Health NHS Trust
- Northamptonshire Healthcare NHS Foundation Trust
- South London and Maudsley NHS Foundation Trust
- Coventry and Warwickshire Partnership NHS Trust
- Dudley and Walsall Mental Health Partnership NHS Trust
- Black Country Partnership NHS Foundation Trust

## **Responses for cognitive testing**

In total 19 respondents tested the questionnaire. The respondents represented service users from a wide demographic and experience profile and various geographic locations:

- Gender: Eight males and eleven females
- Age range: 28 to 68 years
- Geographic locations: Oxfordshire, Birmingham, Berkshire and London
- Ethnic backgrounds: Caribbean, Indian, Mixed European, White British, Mixed White and Black Caribbean and White other

Cognitive interviews took place during October and November 2019. Three waves of interviews were completed. After each wave findings were analysed and, where necessary, changes were made and tested in the subsequent wave of interviews. Upon completion of cognitive testing, the questionnaire was finalised and then submitted for ethical approval alongside the other service user facing materials.

## 7.2 Changes to the questionnaire before and during cognitive testing

Prior to the first round of testing and as a result of the survey development work, the following changes were made to the questionnaire used for CMH19:

- The scale used at Q1 was condensed, as the full scale is not used in the analysis and it may not be easy for service users to recall with this level of accuracy.

Original question:

**1. When was the last time you saw someone from NHS mental health services?**

1  In the last month

2  1 to 3 months ago

3  4 to 6 months ago

4  7 to 12 months ago

5  More than 12 months ago

6  Don't know / can't remember

7  I have never seen anyone from NHS mental health services → Please go to Q38 on page 7

Modified question:

**1. When was the last time you saw someone from NHS mental health services?**

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 Q38 on page 7

- An additional answer option was added at Q6 to account for service users with no prior treatment history.

Original question:

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

1  Yes, completely

2  Yes, to some extent

3  No

4  Don't know / can't remember

Modified question:

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

1  Yes, completely

2  Yes, to some extent

3  No

4  Don't know / can't remember

5  Not applicable - I had no treatment prior to this

- Q13 was amended to refer to “*your needs in other areas of your life*”, rather than “*your personal circumstances*”, in order to better measure the delivery of personalised care.

Original question:

**13. Does this agreement on what care you will receive take your personal circumstances into account?**

1  Yes, definitely

2  Yes, to some extent

3  No

4  Don't know / can't remember

Modified question:

**13. 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

- A new question relating to waiting time was added at the end of the NHS Therapies section:

**29. How did you feel about the length of time you waited before receiving NHS therapy?**

1  The waiting time was appropriate

2  The waiting time was too long

3  The waiting time was too short

4  I did not have to wait for NHS therapy

- o The introduction to the Support and Wellbeing section and the wording of Q30 were amended to reflect the growing importance of the voluntary and community sector as an integral part of the mental health offering, and the increased focus on mental health trusts providing, rather than signposting to, physical health support:

Original question and introductory text:

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 from them**. This may be through posters, flyers and leaflets.

29. In the last 12 months, did NHS mental health services give you any **help or advice with finding support for physical health needs** (this might be an injury, a disability, or a condition such as diabetes, epilepsy, etc)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked help or advice with finding support
- 4  I have support and did not need help / advice to find it
- 5  I do not need support for this
- 6  I do not have physical health needs

Modified question and introductory text:

Please include support provided either **directly by NHS mental health services or by any charities/other organisations that NHS mental health services directed you to**.

30. 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)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked support
- 4  I have support and did not need NHS mental health services to provide it
- 5  I do not need support for this
- 6  I do not have physical health needs

- o The wording of Q31 was updated to include specific reference to voluntary work:

Original question:

**31. In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding or keeping work?**

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked help or advice with finding support
- 4  I have support and did not need help / advice to find it
- 5  I do not need support for this
- 6  I am not currently in or seeking work

Modified question:

**32. 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)?**

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked help or advice with finding support
- 4  I have support and did not need help / advice to find it
- 5  I do not need support for this
- 6  I am not currently in or seeking work

- o The original Q34 (below) was removed, as it is not clear that trust signpost or offer peer support tailored to those “with the same mental health needs”. This was supported by the Advisory Group due to the results not being available by condition:

**34. Have you been given information by NHS mental health services about getting support from people who have experience of the same mental health needs as you?**

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked this
- 4  I did not want this



## Round one

- At the first round of cognitive testing it was noted that a number of respondents were confused by the instruction 'If you make a mistake, just fill in the box'. It was decided it would be clearer if the word 'completely' was added, to read 'If you make a mistake, just fill in the box completely'.

Original instruction:

### 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 ■ and put a cross ☒ in the correct box.

Modified instruction:

### 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 ■ and put a cross ☒ in the correct box.

- A number of service users found the wording of Q14 confusing. This question was designed to determine whether service users have had a care review meeting in the last year, but some of those interviewed appeared to be referring to less formal discussions regarding their care, while others appeared to have had a care review, but did not consider this a 'formal' meeting. As a result, the word 'formal' was removed from the question text and it was agreed to test understanding of the phrase 'care plan' as an alternative to 'how your care is working'.

Original question

**14. In the last 12 months, have you had a formal meeting with someone from NHS mental health services to discuss how your care is working?**

- 1  Yes → Go to 15
- 2  No → Go to 16
- 3  Don't know / can't remember → Go to 16

Modified question

**14. In the last 12 months, have you had a meeting with someone from NHS mental health services to review your care plan?**

- 1  Yes → Go to 15
- 2  No → Go to 16
- 3  Don't know / can't remember → Go to 16

- Prior to cognitive testing, the instruction text at the start of the 'Support and Wellbeing' section was changed. However, when this was tested in round one it became apparent that the introductory text was confusing and overly long for the respondents. It was decided to revert back to the 2019 text.

Original instruction

Please include support provided either **directly by NHS mental health services** or by **any charities/other organisations that NHS mental health services directed you to.**

Modified instruction

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 from them.** This may be through posters, flyers and leaflets.

- Probing was used to assess reactions to the three questions relating to service user involved and shared decision making (Q12, Q19 and Q27). It was felt that while these questions were similar, there was no perceived overlap as far as respondents were concerned, and no concerns were expressed about these questions.
- Probing around 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?'*) established that respondents were thinking about a wide range of activities in answering this question, from group activities for those with mental health problems to a range of hobbies and social activities unrelated to their mental health status. Probing continued for the remaining rounds of interviewing but it was felt that there was no need to make any changes or clarifications to the question wording.

## Round two

- The change made to Q14 in round one was tested in round two and it was found that respondents were still finding this question confusing. Many were unclear what the terminology 'care plan' was referring to which made it hard for them to understand whether a meeting had taken place to discuss this. As a result, it was decided to revert to the 2019 wording of this question 'how your care is working' and also add the word 'specific' in place of the word 'formal' which had been used in 2019.

Original question

**14. In the last 12 months, have you had a meeting with someone from NHS mental health services to review your care plan?**

1  Yes → Go to 15

2  No → Go to 16

3  Don't know / can't remember → Go to 16

Modified question

**14. 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?**

1  Yes → Go to 15

2  No → Go to 16

3  Don't know / can't remember → Go to 16

- o It was noted at Q16 that some respondents were answering 'no', to suggest that they did not know who to contact out of office hours in a crisis, but when probed were clarifying that they had been provided with details of who to contact, and could access them easily if required (for example, they had a card or leaflet at home). They were saying 'no' because they could not, at the point of being asked, recall the name of the team or the phone number, but they were confident that they had been given this information and could access it if needed. It was felt that these service users would ideally be answering 'yes' to the question, since the trust had clearly provided the necessary information. The question wording was therefore amended to "Would you know..." rather than "Do you know..." to encourage an accurate response in this situation.

Original question

**16. Do you know who to contact out of office hours within the NHS if you have a crisis?**

**This should be a person or a team within NHS mental health services.**

1  Yes → Go to 17

2  No → Go to 18

3  Not sure → Go to 18

Modified question

**16. 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.**

1  Yes → Go to 17

2  No → Go to 18

3  Not sure → Go to 18

- o Finally, in round two it became apparent that Q29 was causing a problem where respondents who were receiving multiple therapies felt differently about the waiting times for the different therapies. Therefore, the question text was changed to account for those receiving multiple therapies by adding the word 'Overall' at the start of the question text to encourage respondents to give an overall judgement.

Original question

29. How did you feel about the length of time you waited before receiving **NHS therapy**?

- 1  The waiting time was appropriate
- 2  The waiting time was too long
- 3  The waiting time was too short
- 4  I did not have to wait for NHS therapy

Modified question

29. Overall, how did you feel about the length of time you waited before receiving **NHS therapies**?

- 1  The waiting time was appropriate
- 2  The waiting time was too long
- 3  The waiting time was too short
- 4  I did not have to wait for NHS therapies

### Round three

- o During round three of testing, it was discovered that some respondents were confused by the positioning of the instruction text in the 'Support and Wellbeing' section. It was agreed that it no longer made sense to provide this instruction before Q30 since this question had been amended to ask about direct support, rather than signposting to other organisations. The instruction was therefore moved to before the following question (Q31), to which it remained relevant.

Original positioning

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 from them**. This may be through posters, flyers and leaflets.

30. 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)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked support
- 4  I have support and did not need NHS mental health services to provide it
- 5  I do not need support for this
- 6  I do not have physical health needs

## Modified positioning

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.

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

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked help or advice with finding support
- 4  I have support and did not need help / advice to find it
- 5  I do not need support for this

## 8. Summary of changes to the questionnaire

For the 2020 questionnaire, one question was added, one question was removed and seven questions were modified. The details of these changes are listed below.

### 8.1 New question for 2020

The following question was thoroughly tested with service users during cognitive interviews:

**29. Overall, how did you feel about the length of time you waited before receiving NHS therapies?**

- 1  The waiting time was appropriate
- 2  The waiting time was too long
- 3  The waiting time was too short
- 4  I did not have to wait for NHS therapies

This was added to the 'NHS Therapies' section to reflect an increasing focus on waiting times for NHS mental health therapies.

### 8.2 Question removed for 2020

The following question was removed from the 'Support and Wellbeing' section:

**34. Have you been given information by NHS mental health services about getting support from people who have experience of the same mental health needs as you?**

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked this
- 4  I did not want this

It was felt that trusts did not necessarily signpost or offer peer support groups tailored to service users with the same mental health needs, so the question did not provide valuable insight.

### 8.3 Amended questions for 2020

In Q1, the first four response options were condensed into one response option: 'In the last 12 months' as they were not used during analysis and in order to save space.

**1. When was the last time you saw someone from NHS mental health services?**

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 Q38 on page 7

A 'not applicable' response option was added to Q6 for service users with no treatment history.

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

1  Yes, completely  
 2  Yes, to some extent  
 3  No  
 4  Don't know / can't remember  
 5  Not applicable - I had no treatment prior to this

At Q13, the wording 'personal circumstances' was changed to 'your needs in other areas of your life' in order to better capture the theme of personalised care.

**13. 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

The wording of Q14 was changed due to respondent confusion around the use of the wording 'formal meeting' in cognitive testing. Respondents interpreted 'formal meeting' in different ways and the use of the word 'formal' resulted in respondents answering 'no' if they considered care review meetings informal. Therefore the wording was modified to 'specific meeting'.



**14. 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?**

1  Yes → Go to 15  
 2  No → Go to 16  
 3  Don't know / can't remember → Go to 16

The text in Q16 was changed from 'Do you know' to 'Would you know' as during cognitive testing respondents would often choose 'No' if they could not remember the name of the person or team on the spot, but were confident that they had been provided with this information and could access it easily if they needed it.

**16. 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.**

1  Yes → Go to 17  
 2  No → Go to 18  
 3  Not sure → Go to 18

The wording of Q30 was modified in order to better reflect changing expectations of how NHS Community Mental Health care should support service users with physical health needs. Previously, the wording of this question corresponded to Q31: 'did NHS mental health services give you any **help or advice** with **finding support**'. The instruction before this question, which referred to signposting to other agencies, was also moved to after Q30 as it was no longer felt to apply to the question.

**30. 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)?**

1  Yes, definitely  
 2  Yes, to some extent  
 3  No, but I would have liked support  
 4  I have support and did not need NHS mental health services to provide it  
 5  I do not need support for this  
 6  I do not have physical health needs

In Q32 the phrase '(paid or voluntary)' was added to make it clear that finding or keeping employment could refer to either of these.

32. 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)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked help or advice with finding support
- 4  I have support and did not need help / advice to find it
- 5  I do not need support for this
- 6  I am not currently in or seeking work

## 8.4 Changes to the front cover

The instruction around how to indicate a mistake in a tick box was clarified with the addition of the word 'completely' to the instruction 'If you make a mistake, just fill in the box'.

A helpline email address, in addition to a telephone number, was included on the front page.

## 9. Changes to the other service user facing materials

Only one minor change was made to the covering letters for the 2020 iteration of the survey. Contractors and in-house trusts must now provide a contact email address on the covering letter, as well as a Freephone number. This was deemed necessary to give service users another mode of contact should they need any assistance with the survey.

The text in blue shows the addition of an email helpline contact in the covering letters:

Please see the back of this letter for more information or call [our Freephone helpline /us] on [phone number] [free of charge] if you have any questions and [they/we] will do our best to help. The line is open between [opening time] and [closing time], [days]. You can also email us on [XXXXXXXXXX@XXXXXX.XXX] if you would prefer.

## 10. Changes to the methodology and design of guidance materials

There have been two main changes to the methodology for the 2020 iteration of the survey.

### Increased sample size

In the development of the CMH19 survey, it was proposed to increase the sample size from 850 service users to 1,250 services users. There were three main reasons for making this change:

1. Alignment of the Community Mental Health Survey with the acute surveys in the NPSP, most of which use a total sample 1,250 patients per survey.
2. In response to steadily declining response rates. As response rates fall, the ability to make meaningful and robust comparisons between different service user groups becomes more challenging. With small sample sizes, we would need to see big

differences in experience to be able to determine whether those changes were statistically significant, e.g. whether the change in experience was a 'true' change and unlikely to have happened by chance.

3. Increased data for trusts and service providers. A larger sample size allows for more data to be provided back to services and increases the possibility of more detailed reporting to help identify service improvements and to support with action planning at the local level.

The main consideration for increasing the overall sample size was the potential impact this had on NHS trusts who participate in the survey. While larger sample size provide more robust results and potentially greater granularity, both of which were issues raised in the stakeholder interviews, increasing the sample size also increases the overall cost for a trust to participate. It was decided for the CMH19 survey that because trust costs had increased due to the change in colour printing of the materials, the increase in sample size would be too great an additional burden on trusts if implemented at the same time. For the 2020 survey, trusts were consulted on the increase in sample size and the decision was taken to implement the increase for this iteration.

### **Additional sample variable: mobile phone indicator**

During the advisory group meeting that took place in September 2019 (see Section 3), there was discussion of future plans in transitioning the survey to an online response mode due to the potential benefits this can bring.

Over the past few years, there have been a number of methodological pilots undertaken across the wider NPSP looking at ways of increasing response rates and encouraging feedback from those groups that tend to be 'harder to reach'. One way in which this has been done is to look at the use of different ways to invite people to respond to surveys and offering different response modes. As progress is made in this area, it is important to understand what information is available at provider level to make these changes possible.

To support this work, trusts will provide an additional sample variable: a mobile phone indicator. This is a numeric indicator that will indicate whether a trust has a mobile number on record for each sampled service user. Whilst contractors and the SCCM will not receive details of the actual mobile number for a service user, this data will be particularly valuable in determining coverage of contact details held by providers.

## **Further information**

For further information and documents for the Community Mental Health 2020 survey, please visit:

<https://nhssurveys.org/surveys/survey/05-community-mental-health/year/2020/>

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

[mentalhealth@surveycoordination.com](mailto:mentalhealth@surveycoordination.com)

01865 208 127

Appendix 1 - Question mapping 2020 vs. 2019

2019	2020	Changes made	Reasons for change
Covering page	Covering page	Inclusion of an email address in addition to a telephone helpline.  Addition of the word 'completely' to make it clear what to do if a mistake is made.	To offer service users assistance.  To clarify the answer box should be completely filled in to indicate a mistake.
Title	Title		
Instructions	Instructions	The content of the instruction text in the 'Support and Wellbeing' section has remained the same, but it has moved from the start of this section to immediately before Q31.	The change to Q30 (previously Q29) means that the instruction text no longer applies to Q30.
<b>Your care and treatment</b>	<b>Your care and treatment</b>		
Q1	Q1	The first four response options were condensed into a single answer option 'In the last 12 months'.	These answers were condensed as the previous four responses were not used in analysis and in order to save space in the questionnaire.
Q2	Q2		
Q3	Q3		
<b>Your health and social care workers</b>	<b>Your health and social care workers</b>		
Q4	Q4		
Q5	Q5		
Q6	Q6	'Not applicable' option added.	For service users who do not have a treatment history.
<b>Organising your care</b>	<b>Organising your care</b>		
Q7	Q7		

Q8	Q8		
Q9	Q9		
Q10	Q10		
<b>Planning your care</b>	<b>Planning your care</b>		
Q11	Q11		
Q12	Q12		
Q13	Q13	'Personal circumstances' was changed to 'your needs in other areas of your life'.	It was thought this would better capture the theme of personalised care.
<b>Reviewing you care</b>	<b>Reviewing your care</b>		
Q14	Q14	'Formal meeting' was changed to 'specific meeting'.	In cognitive testing there was confusion surrounding the definition of a formal meeting.
Q15	Q15		
<b>Crisis care</b>	<b>Crisis care</b>		
Q16	Q16	'Do you know' was modified to 'Would you know'.	To encourage respondents who had been provided with this information and were able easily to access it from responding 'no' because they were unable to recall the name of the person or team spontaneously.
Q17	Q17		
<b>Medicines</b>	<b>Medicines</b>		
Q18	Q18		
Q19	Q19		
Q20	Q20		
Q21	Q21		
Q22	Q22		
Q23	Q23		

Q24	Q24		
<b>NHS Therapies</b>	<b>NHS Therapies</b>		
Q25	Q25		
Q26	Q26		
Q27	Q27		
Q28	Q28		
	Q29	NEW QUESTION 'How did you feel about the length of time you waited before receiving <b>NHS therapy?</b> '	To reflect an increasing focus on NHS therapy waiting times.
<b>Support and Wellbeing</b>	<b>Support and Wellbeing</b>	Instruction text was moved to before Q31.	Due to the question changes, the instruction text is no longer applicable to Q30.
Q29	Q30	The text was modified to ' <b>...mental health services support you with your physical health needs</b> '.	In order to better reflect how NHS Mental Health care should support those with physical health needs.
Q30	Q31		
Q31	Q32	'(Paid or voluntary)' was added to Q32.	To clarify that both forms of employment are applicable.
Q32	Q33		
Q33	Q34		
Q34	Removed	Q34 from the 2019 survey – 'Have you been given <b>information</b> by NHS mental health services about getting support from people who have experience of the same mental health needs as you?'- was removed.	After discussion it was felt that trusts do not necessarily signpost support groups for service users with similar mental health needs, so the question did not provide valuable insight.
<b>Overall</b>	<b>Overall</b>		
Q35	Q35		



Q36	Q36		
Q37	Q37		
<b>About you</b>	<b>About you</b>		
Q38	Q38		
Q39	Q39		
Q40	Q40		
Q41	Q41		
Q42	Q42		
Q43	Q43		
Q44	Q44		
Q45	Q45		
Q46	Q46		

## Appendix 2 - Main questionnaire

## 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  and put a cross  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 **not** include contact with your GP.

1. When was the **last time** you saw someone from **NHS mental health services**?

- 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 Q38 on page 7

2. Overall, how long have you been in contact with NHS mental health services?

- 1  Less than 1 year
- 2  1 to 5 years
- 3  6 to 10 years
- 4  More than 10 years
- 5  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?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  It is too often
- 5  Don't know

## YOUR HEALTH AND SOCIAL CARE WORKERS

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

**This does not include your GP.**

4. Were you given **enough time** to discuss your needs and treatment?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  Don't know / can't remember

5. Did the person or people you saw **understand** how your mental health needs affect **other areas of your life**?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  Don't know / can't remember

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

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  Don't know / can't remember
- 5  Not applicable - I had no treatment prior to this

## ORGANISING YOUR CARE

In this section, you may **include** contact with your GP.

7. 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 → Go to 8
- 2  No → Go to 11
- 3  Not sure → Go to 11

8. 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

9. Do you know how to contact this person if you have a concern about your care?

- 1  Yes
- 2  No
- 3  Not sure

10. How well does this person organise the care and services you need?

- 1  Very well
- 2  Quite well
- 3  Not very well
- 4  Not at all well

## PLANNING YOUR CARE

Please do not include contact with your GP.

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

- 1  Yes, definitely → Go to 12
- 2  Yes, to some extent → Go to 12
- 3  No → Go to 14

12. 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

13. 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

Please do not include contact with your GP.

14. 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?

- 1  Yes → Go to 15
- 2  No → Go to 16
- 3  Don't know / can't remember → Go to 16

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

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I did not want to be involved in making decisions
- 5  Don't know / can't remember

## CRISIS CARE

Please do **not** include contact with your GP.

A crisis is if you need urgent help because 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'.**

16. 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.**

- 1  Yes → **Go to 17**  
2  No → **Go to 18**  
3  Not sure → **Go to 18**

17. **In the last 12 months**, did you get the help you needed when you tried contacting this person or team?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No  
4  I could not contact them  
5  I have not tried contacting them in the last 12 months  
6  Can't remember

## MEDICINES

Please do **not** include medicines prescribed only by your GP.

18. In the last 12 months, have you been receiving any **medicines** for your mental health needs?

- 1  Yes → **Go to 19**  
2  No → **Go to 25**

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

20. Has the **purpose** of your medicines ever been discussed with you?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No  
4  Don't know / can't remember

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

- 1  Yes, definitely  
2  Yes, to some extent  
3  No  
4  Don't know / can't remember

22. Do you feel your **medicines** have helped your mental health?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No  
4  Not sure

23. Have you been receiving any **medicines** for your mental health needs for 12 months or longer?

- 1  Yes → **Go to 24**  
2  No → **Go to 25**  
3  Not sure → **Go to 25**



24. 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
- 2  No
- 3  Don't know / can't remember

## NHS THERAPIES

Therapies include any NHS treatment for your mental health that **does not involve medicines**.

25. In the last 12 months, have you received any **NHS therapies** for your mental health needs that do not involve medicines?

- 1  Yes → Go to 26
- 2  No, but I would have liked this → Go to 30
- 3  No, but I did not mind → Go to 30
- 4  This was not appropriate for me → Go to 30
- 5  Don't know / can't remember → Go to 30

26. Were these **NHS 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

27. Were you **involved** as much as you wanted to be in deciding what **NHS therapies** to use?

- 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

28. Do you feel your **NHS therapies** have helped your mental health?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  Not sure

29. Overall, how did you feel about the length of time you waited before receiving **NHS therapies**?

- 1  The waiting time was appropriate
- 2  The waiting time was too long
- 3  The waiting time was too short
- 4  I did not have to wait for NHS therapies

## SUPPORT AND WELLBEING

Please do **not** include help from your GP.

30. 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)?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked support
- 4  I have support and did not need NHS mental health services to provide it
- 5  I do not need support for this
- 6  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.

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

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked help or advice with finding support
- 4  I have support and did not need help / advice to find it
- 5  I do not need support for this

**32. 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)?**

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, but I would have liked help or advice with finding support
- 4  I have support and did not need help / advice to find it
- 5  I do not need support for this
- 6  I am not currently in or seeking work

**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

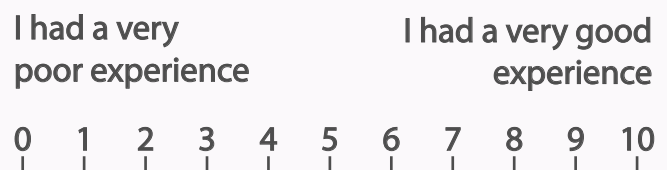
**34. Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?**

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No, not as much as I would like
- 4  No, they have involved them too much
- 5  My friends or family did not want to be involved
- 6  I did not want my friends or family to be involved
- 7  This does not apply to me

## OVERALL

Please do not include contact with your GP.

**35. Overall... (Please circle a number)**



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

- 1  Yes, always
- 2  Yes, sometimes
- 3  No

**37. 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?**

- 1  Yes
- 2  No
- 3  Not sure

## ABOUT YOU

**This information will not be used to identify you.** We use it to monitor whether different people are having different experiences of NHS services.

All the questions should be answered **from the point of view of the person named on the envelope**. This includes the following background questions on gender and date of birth.

**38.** 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.

- 1  Yes **→ Go to 39**  
2  No **→ Go to 41**

**39.** 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.

- 1  Breathing problem, such as asthma  
2  Blindness or partial sight  
3  Cancer in the last 5 years  
4  Dementia or Alzheimer's disease  
5  Deafness or hearing loss  
6  Diabetes  
7  Heart problem, such as angina  
8  Joint problem, such as arthritis  
9  Kidney or liver disease  
10  Learning disability  
11  Mental health condition  
12  Neurological condition  
13  Another long-term condition

**40.** 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

**41.** 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  
3  **Both** service user / client and friend / relative together  
4  The service user / client with the help of a health professional

**42.** Are you male or female?

- 1  Male  
2  Female

**43.** What was your **year of birth**?  
(Please write in)

e.g. 

1	9	6	8
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**44.** What is your religion?

- 1  No religion  
2  Buddhist  
3  Christian (including Church of England, Catholic, Protestant, and other Christian denominations)  
4  Hindu  
5  Jewish  
6  Muslim  
7  Sikh  
8  Other  
9  I would prefer not to say

**45.** Which of the following best describes how you think of yourself?

- 1  Heterosexual / Straight  
2  Gay / Lesbian  
3  Bisexual  
4  Other  
5  I would prefer not to say

46. What is your ethnic group? (Cross ONE box only)

**a. WHITE**

- 1  English / Welsh / Scottish / Northern Irish / British
- 2  Irish
- 3  Gypsy or Irish Traveller
- 4  Any other White background, write in...

**b. MIXED / MULTIPLE ETHNIC GROUPS**

- 5  White and Black Caribbean
- 6  White and Black African
- 7  White and Asian
- 8  Any other Mixed / multiple ethnic background, write in...

**c. ASIAN / ASIAN BRITISH**

- 9  Indian
- 10  Pakistani
- 11  Bangladeshi
- 12  Chinese
- 13  Any other Asian background, write in...

**d. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH**

- 14  African
- 15  Caribbean
- 16  Any other Black / African / Caribbean background, write in...

**e. OTHER ETHNIC GROUP**

- 17  Arab
- 18  Any other ethnic group, write in...

**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, Care Quality Commission and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback.

Is there anything particularly good about your care?

Is there anything that could be improved?

Any other comments?

**THANK YOU VERY MUCH FOR YOUR HELP**

**Please check that you answered all the questions that apply to you.**

**Please post this questionnaire back in the FREEPOST envelope provided.**