

# 2019 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 at Picker on behalf of the Care Quality Commission (CQC). Its purpose is to understand, monitor and improve service users' experiences of NHS community mental health services. In 2018, there was a 28% response rate, with over 12,000 participants from 56 NHS trusts and social enterprises who told us about their experiences by taking part in the survey.

Data collected from the 2019 Community Mental Health Survey (CMH19) will be used by the CQC in its assessment of mental health trusts in England. The results are also used by NHS England and the Department of Health and Social Care for performance assessment, improvement 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 cross-Whitehall Public Services Transparency Framework and NICE Quality Standards.

The survey methodology is identical to that used in the 2018 iteration though survey materials underwent some redevelopment. The questionnaire underwent a phase of redevelopment to reflect current policy and areas identified as important by stakeholders. A review of the NHS Patient Experience Framework was undertaken to identify aspects that were not sufficiently covered by the questionnaire, and as is standard practice, a performance analysis was conducted on the previous year's data to help pinpoint questions for removal. A redesigned questionnaire was then tested with recent service users across several rounds to ensure that the questions were clear, understood and were effective in capturing service users' experiences accurately.

Some small changes were made to the covering letters for CMH19. These changes built on findings from the 2017 pilot and from patient feedback collected during cognitive testing interviews in other surveys within the NPSP. The incoming General Data Protection Regulation meant that information around data sharing also had to be updated.

This report sets out the phases of development in more detail and the changes that were made to materials in the 2019 survey.

## 2. Review of the NHS Patient Experience Framework

The NHS Patient Experience Framework is a working definition of patient experience, to guide its measurement across the NHS. It was agreed on in 2011 by the NHS National Quality Board (NQB) and is based on a modified version of the Picker Institute Principles of Patient-Centred Care (Department of Health and Social Care, 2012)<sup>1</sup>. Accordingly, it is important to regularly re-evaluate questionnaires, such as the NHS Community Mental Health Service User Questionnaire, against the NHS Patient Experience Framework and the

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<sup>1</sup> Department of Health and Social Care. (2012, February 22). *NHS Patient Experience Framework*. Retrieved from GOV.UK: <https://www.gov.uk/government/publications/nhs-patient-experience-framework>

elements it outlines as critical to patient experience. This ensures all indicators are covered and measurable data is collected.

Picker is currently in the process of reviewing and refreshing its person-centred care principles, to ensure they are up to date, relevant and still reflect the expectations of patients and service users. The review is scheduled for completion in summer 2019.

A similar refreshment of the NHS Patient Experience Framework is also recommended. Since its development, there have been changes in policy, as well as upcoming changes to practice which will adopt a more holistic approach to health and integrated physical and mental healthcare services. These changes are a result of new recognition for the equal importance of physical and mental health (Mental Health Taskforce, 2016)<sup>2</sup>.

In particular, point 4, which refers to physical comfort in the NHS Patient Experience Framework discusses physical pain management exclusively, and does not consider psychological pain. For the current review of the framework against the 2018 CMH questionnaire, we approached this topic to refer to emotional pain management, but of course this is deviating from the actual meaning. Looking beyond the CMH survey, the importance of updating the NHS Patient Experience Framework would be perhaps even more relevant to other patient experience questionnaires, as with the shift to a holistic healthcare approach, mental health support should be provided during physical healthcare. For example, recent policies based on robust research findings, advocate the high importance of preventive measures and mental health support during the perinatal period and teenagerhood<sup>3</sup>.

### **Assessment of the 2018 questionnaire vs the NHS Patient Experience Framework**

Overall, most areas of the NHS Patient Experience Framework are covered by the current questionnaire, particularly those detailed below:

- **Coordination and integration of care** across the health and social care system
- **Information, communication and education** on clinical status, progress, prognosis, processes of care in order to facilitate autonomy, self-care and health promotion
- **Physical comfort** including pain management, help with activities of daily living, and clean and comfortable surroundings
- **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transactions
- **Access to care** with attention for example, to time spent waiting for admission or time between admission and placement in a room in an inpatient setting, and waiting time for appointment or visit in the outpatient,

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<sup>2</sup> Mental Health Taskforce. (2016, February). *The Five Year Forward View for Mental Health*. Retrieved from [england.nhs.uk](http://england.nhs.uk):

<sup>3</sup> <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>;  
<https://www.gov.uk/government/publications/a-framework-for-mental-health-research>;  
<https://www.gov.uk/government/collections/prevention-concordat-for-better-mental-health>;

primary care or social care setting  
(Department of Health and Social Care, 2012)<sup>4</sup>.

However, three areas of the NHS Patient Experience Framework (Department of Health and Social Care, 2012) were highlighted as lacking in the 2018 questionnaire:

- **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers
- Only one question (Q35) related to this section of the NHS Patient Experience Framework
- We therefore recommended the addition of a question relating to family / close relation involvement in care, especially as such involvement can be vital in mental health care – from referral to support during treatment.
  
- **Respect for patient-centred values, preferences, and expressed needs**, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making
- Although most elements under the point '*respect of patient-centred values*' are covered in the questionnaire, *cultural issues* and *privacy* were identified as areas which are not presently addressed.
  
- **Emotional support** and alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances
- We also found that emotional support for families, i.e. the impact of the service user's illness on families, was not directly captured in the questionnaire.

### 3. Policy and approaches to community mental health services

Mental health continues to maintain a prominent role in the policy and legislative landscape. It has never had a higher profile and priority, with more people than ever receiving treatment for mental health conditions. At the same time there is commitment from the Government to provide the funding to implement '*The Five Year Forward View*', besides separate commitments to improve mental health care (Care Quality Commission, 2017)<sup>5</sup>.

There are some key themes which summarise the current mental health policy landscape and related literature brief summary of these, focusing particularly on trends relevant to community mental health, can be found below:

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<sup>4</sup> Department of Health and Social Care. (2012, February 22). *NHS Patient Experience Framework*. Retrieved from GOV.UK: <https://www.gov.uk/government/publications/nhs-patient-experience-framework>

<sup>5</sup> Care Quality Commission. (2017, July 20). *The state of care in mental health services 2014 to 2017*. Retrieved from CQC.org.uk: <https://www.cqc.org.uk/publications/major-report/state-care-mental-health-services-2014-2017>

- **Recognition of the equal importance of physical and mental health care**

The mental health care system is undergoing a major reform. ‘*The Five Year Forward View for Mental Health*’ outlines the ambitions of the NHS to reform the health care system, advocating its equal importance to physical health care, and recognising the need to increase the *availability* and *quality* of mental health care services (Mental Health Taskforce, 2016)<sup>6</sup>.

- **Holistic approach to health**

One of the key strategies outlined in the ‘*The Five Year Forward View for Mental Health*’ is its goal of an integrated mental and physical health approach. It points to the evidence of interaction between physical and mental health, and the need for a combined approach in order to achieve favourable outcomes. It advocates that on the one hand, mental health support should be made easily available across the NHS, while on the other, people living with severe mental health problems should be offered screening and secondary prevention given their higher risk of poor physical health. The latter is also important to tackle health inequalities (Mental Health Taskforce, 2016)<sup>7</sup> – an issue also highlighted by the CQC’s recent review of the current state of mental health care (Care Quality Commission, 2017)<sup>8</sup>.

- **Focus on prevention: shift away from crisis care and life course approach to mental health**

The ‘*Prevention Concordat for better mental health*,’ published in August 2017, clearly highlights the shift in policy towards a focus on prevention rather than on crisis care. It points out potential social and life stage causes or triggers of mental health illnesses, and advocates the promotion of good mental health and wellbeing, the need for action beyond treatment and for early intervention (Public Health England, 2017)<sup>9</sup>. A recently published independent review of mental health at work also illustrates this shifting approach, by calling for preventive measures and for the promotion of healthy lifestyles (Department for Work and Pensions, 2017)<sup>10</sup>, as does the

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<sup>6</sup> Mental Health Taskforce. (2016, February). *The Five Year Forward View for Mental Health*. Retrieved from england.nhs.uk: <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

<sup>7</sup> Mental Health Taskforce. (2016, February). *The Five Year Forward View for Mental Health*. Retrieved from england.nhs.uk: <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

<sup>8</sup> Care Quality Commission. (2017, July 20). *The state of care in mental health services 2014 to 2017*. Retrieved from CQC.org.uk: <https://www.cqc.org.uk/publications/major-report/state-care-mental-health-services-2014-2017>

<sup>9</sup> Public Health England. (2017, August 30). *Prevention concordat for better mental health*. Retrieved from GOV.UK: <https://www.gov.uk/government/collections/prevention-concordat-for-better-mental-health>

<sup>10</sup> Department of Work and Pensions et al. (2017, November 30). *Improving lives: the future of work, health and disability*. Retrieved from GOV.UK: <https://www.gov.uk/government/publications/improving-lives-the-future-of-work-health-and-disability>

Government's recent policy paper outlining the strategy on the future of work (Department of Work and Pensions et al., 2017).

- **Focus on the importance of timely treatment**

The *'The Five Year Forward View for Mental Health'* sets out the objectives of immediate, 24/7 access to crisis care, as well as access to support early on, to prevent crisis care. Better and timely access to mental health care and support is outlined as one of the top priorities of the reform. Reducing waiting times and providing early access is proven to improve outcomes, and would also alleviate pressure on acute mental health care (Mental Health Taskforce, 2016)<sup>11</sup>. The importance of new, remote assessment and treatment methods in achieving the above objectives is apparent from the literature. Phone support therapies (Testa, 2017)<sup>12</sup> and crisis services (Ivory, 2018)<sup>13</sup> are proving to be a success, primarily as they allow for timely response. The Government's continued investments into such alternative and community-based approaches further highlight their increased importance. For instance, last year the Prime Minister pledged £67.7 million for digital mental health services, including online therapy (Department for Education et al., 2017)<sup>14</sup>, while recently a £15 million fund was announced for clinics, crisis cafés and other community services under the *'Beyond Places of Safety'* scheme, designed to prevent people from reaching crisis point (Department of Health and Social Care, 2018)<sup>15</sup>.

- **Reducing inequalities around mental health and access to care**

Inequalities in access to mental health care remain an issue as well as inequalities in the use of the Mental Health Act 1983 (MHA). The latter is currently the subject of an independent review with the goal to address apparent inequalities in how it is applied, and to make it work better for everyone. The interim report published this year highlights that legislative changes of the MHA alone will not achieve improvements, and stresses that any change in legislation must be underpinned by mental health service improvements, and greater access to services (Department of Health and

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<sup>11</sup> Mental Health Taskforce. (2016, February). *The Five Year Forward View for Mental Health*. Retrieved from [england.nhs.uk: https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf](https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf)

<sup>12</sup> Testa, A. (2017, July 24). *England's Mental Health Experiment: No-Cost Talk Therapy*. Retrieved from The New York Times: <https://www.nytimes.com/2017/07/24/health/england-mental-health-treatment-therapy.html>

<sup>13</sup> Ivory, M. (2018, May 30). *'A&E is no place for a crisis': Bradford leads the way in mental health care*. Retrieved from The Guardian: <https://www.theguardian.com/healthcare-network/2018/may/30/crisis-bradford-mental-health-care>

<sup>14</sup> Department for Education et al. (2017, January 9). *The shared society: Prime Minister's speech at the Charity Commission annual meeting*. Retrieved from GOV.UK: <https://www.gov.uk/government/speeches/the-shared-society-prime-ministers-speech-at-the-charity-commission-annual-meeting>

<sup>15</sup> Department of Health and Social Care. (2018, May 25). *£15 million boost for local mental health crisis services*. Retrieved from GOV.UK: <https://www.gov.uk/government/news/15-million-boost-for-local-mental-health-crisis-services>



Social Care, 2018). Racial and locational inequalities affect access to care, with Black, Asian and Minority Ethnic groups having poorer access, and the availability of care services varying greatly across postcodes (Telegraph Reporters, 2017; Mental Health Taskforce, 2016)<sup>16</sup>.

- **Importance of complaints handling procedures**

The '*Maintaining momentum: driving improvements in mental health care*' report published by the Parliamentary and Health Service Ombudsman in 2018, stipulates that there are serious failings in the NHS mental health services and highlights failure for local NHS organisations to investigate complaints effectively. In 2016-17, from 14,106 complaints made to NHS mental health trusts, 65% were upheld or partly upheld by the local organisation. In 2016-17, 352 investigations in to NHS mental health trusts found failings in 140 (37%) of these cases.

'*The Five Year Forward View for Mental Health*' sets out the need for a costed multi-disciplinary workforce strategy to ensure the right number of people with the right skills. However, the Ombudsman's report (which was published two years into the implementation plan for The Five Year Forward View) suggests that unless workforce challenges are addressed, the transformation of mental healthcare envisioned in the '*The Five Year Forward View*' cannot be realised. It further stipulates that good complaint handling is integral to good patient experience. Although no system wide recommendations resulted from the review, it has been used to highlight the impact of service failure and make sure momentum is maintained in the implementation of the '*The Five Year Forward View for Mental Health*' (Parliamentary and Health Service Ombudsman, 2018)<sup>17</sup>.

The above overview clearly highlights that mental health care is undergoing a major reform and there are a number of fresh policy initiatives which will hopefully bring about a welcome improvement of the system. Although not all of the above points can be directly addressed in the community mental health questionnaire, it is still important to provide the legislative and policy context. For instance, while inequalities in access cannot be measured as this mechanism occurs before people become service users, a number of other points raised in the literature review were identified as possible areas of interest in the questionnaire. These are presented below, split by if they can be measured by modifying an existing question or if a new question would need to be included.

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<sup>16</sup> Telegraph Reporters. (2017, September 11). *Patients face mental health post-code lottery as psychiatrists twice as available in some parts of country*. Retrieved from The Telegraph: <https://www.telegraph.co.uk/news/2017/09/11/patients-face-mental-health-post-code-lottery-psychiatrists/>

<sup>17</sup> Parliamentary and Health Service Ombudsman. (2018, March 21). *Maintaining momentum: driving improvements in mental health care*. Retrieved from GOV.UK: <https://www.gov.uk/government/publications/maintaining-momentum-driving-improvements-in-mental-health-care>

## **Suggested amendments to CMH18 questions**

**Q31.** *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 patients *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)<sup>18</sup>. There is clear evidence in the available literature that suggests this problem needs to be tackled by offering patients with severe mental health problems screening and secondary prevention due to their higher risk of poor physical health (Mental Health Taskforce, 2016)<sup>19</sup>.

## **Suggested new questions / areas of interest**

As well as the questions suggested for addition in the NHS Patient Experience Framework Review section, a few additional areas of interest were identified based on the literature review.

### ***Question around complaints procedure***

The importance of effectively dealing with complaints has been highlighted in the Parliamentary and Health Service Ombudsman report (2018)<sup>20</sup>, as a significant problem within local NHS trusts. Whilst the majority of complaints discussed in this report refer to mental health inpatients, there are also examples of complaints made against community mental health teams. The report appropriately suggests that ‘good complaint handling is integral to good patient experience’. Additionally, complaints can be a good opportunity for organisations to learn and develop their services. As with all health and social services, community mental health services by law, must have a procedure to deal efficiently with complaints. Therefore, it seems appropriate to capture if service users are aware of the official procedure by including the relevant question in CMH19.

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<sup>18</sup> Mental Health Taskforce. (2016, February). *The Five Year Forward View for Mental Health*. Retrieved from england.nhs.uk: <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

<sup>19</sup> Mental Health Taskforce. (2016, February). *The Five Year Forward View for Mental Health*. Retrieved from england.nhs.uk: <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

<sup>20</sup> Parliamentary and Health Service Ombudsman. (2018, March 21). *Maintaining momentum: driving improvements in mental health care*. Retrieved from GOV.UK: <https://www.gov.uk/government/publications/maintaining-momentum-driving-improvements-in-mental-health-care>

Slight variations of the question below have been included in the Inpatient Survey since the 2006 iteration:

Did you see, or were you given, any information explaining how to complain to the hospital about the care you received?

- 1  Yes
- 2  No
- 3  Not sure / don't know

Potentially this could be adjusted to read: 'Did you see, or were you given, any information explaining how to complain to the service about the treatment you received there?'

***Question around facilitating access to support and therapies:***

In the 2018 questionnaire there is only one question (Q30) around waiting times for therapy, but this could be followed up with a question around what support took place in the meantime. Such a question would be relevant to understand any efforts made to achieve timely treatment or support, and the approach to shift away from crisis care – objectives very relevant to current policies. Therefore, it would be important to measure if the alternative support (telephone, digital or community networks) is offered to patients who face waiting times. The question could address if contact details were provided for alternative sources of support (i.e. telephone, digital or support services) on initial contact and before patients started therapy. It is acknowledged that some difficulty arises around the introduction of such a question. Firstly, some service users might be thinking of interaction with GP, rather than interaction the community mental health service. Secondly, the eligibility criteria of the survey means that participants will already be enrolled in the service, quite possibly for a number of years and so recall around access may be difficult. In the 2018 iteration of the survey 39 percent of respondents said they had been in contact with NHS mental health services for between 1-5 years and 29 percent had been in contact for 10 years or more.

***Question around waiting time to community mental health services***

Considering the apparent importance of providing an accessible service, it should be considered whether a question capturing the waiting time or ease of access to the community mental health service should be included.

***Question about clinical information management and access***

The CQC report on the state of mental health services highlights the poor clinical information systems as being an issue across trusts: "*too often staff were unable to locate or retrieve information that others had recorded*" (Care Quality Commission, 2017, p. 34)<sup>21</sup>. This problem is something that can be noticed by patients (i.e. if they are asked to repeat symptoms, experiences, problems etc.), and particularly for mental health service users it

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<sup>21</sup> Care Quality Commission. (2017, July 20). *The state of care in mental health services 2014 to 2017*. Retrieved from CQC.org.uk: <https://www.cqc.org.uk/publications/major-report/state-care-mental-health-services-2014-2017>

could be a very damaging experience (as opening up about mental health problems is typically not an easy process).

Information already recorded but not locatable or accessible to others is an issue in continuity of care. It however would not necessarily be captured under the section 'Organising your care' (Q6-9) which contains the questions currently focused on continuity of care, as these questions focus on the person in charge of organising the care of the service user. Therefore, it is recommended that a new question is added which would capture such information.

## 4. Review of the 2018 survey

### **Main stage survey**

#### ***Introduction of coloured questionnaire and updated covering letters***

In 2018, redesigned covering letters and redesigned questionnaires were implemented as standard materials in the survey, following their successful trial in a 2017 pilot. Response data from the 2018 survey showed these as being effective in boosting response rates both overall and from key demographic sub-groups, including among those aged 18-35. The overall response rate increased by two percentage points from 26% in 2017 to 28% in 2018 and by one percentage point among 18-35's, increasing from 17% to 18%. This is welcome news considering that response rates fall by one or two percentage points each year without any significant changes to method or materials.

#### ***Increasing sample sizes***

As part of the development review for the CMH18 survey, a larger sample size of 1,250 service users per trust, up from 850, was considered. It was however felt to be too burdensome on trusts in terms of cost, due to the introduction of coloured mailing materials that same year.

For the CMH18 survey, the smallest eligible population has approximately 1,600 eligible service users. The overall mean number of eligible service users from across all participating trusts for CMH18 was 9,264 (SD=5,285). This suggests that, based on figures from CMH18, that an increase in sample size to 1,250 service users as of CMH19 would be viable. However, the fewer number of trusts who participate in the community mental health survey (approx. 56) compared to the acute surveys (approx. 130-150), will likely have a larger impact on the viability of undertaking secondary analysis. However, considering the CQC's ambitions for a mixed-mode approach in future survey iterations, sample size increases would be feasible with little or no additional expense for trusts, since electronic means are generally cheaper to administer and process than paper-based methods.

## 5. Analysis and consultation

As in previous years, a consultation was undertaken in order to update the questionnaire for 2019. Amendments were made based on the following:

- Consultation in June 2018 with the Advisory Group (representatives from CQC, NHSE and the Survey Coordination Centre plus two Patient Experience leads at mental health trusts, two Experts by Experience, and a representative from the mental health charity MIND) regarding any topics that should be addressed either from a policy or service user perspective.
- Analysis of the 2018 survey data to examine item non-response i.e. questions that were not answered but were applicable to the respondent and items that were inapplicable to respondents as they were routed past.
- Analysis of the 2018 survey data to examine ceiling or floor effects i.e. when the vast majority of respondents report a very positive or negative experience.
- Analysis of the 2018 survey data to examine statistical correlations to identify any questions that respondents tend to answer in the same way, suggesting a similar or the same underlying concept.

The Survey Coordination Centre presented the findings from the above analyses to stakeholders for discussion on which questions to remove or change.

## 6. Cognitive testing and 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.

### **Changes in eligibility criteria**

The eligibility criteria to participate in cognitive testing included friends or relatives of service users. This was due to results from the survey suggesting that over a third of people completing the questionnaire were not the service user alone.

### **Advertising**

The respondents were recruited using a number of means, such as local and national online and printed advertisements and on social media. Adverts were placed on Daily Info (an Oxford-based newsletter) online and in print between August and October 2018.

Adverts were placed on local Gumtree pages in the following locations, Oxford, Bicester, Banbury, Henley-on-Thames, Reading, Leamington Spa, Gloucester, Swindon, Cheltenham, Milton Keynes, Bristol, Birmingham, Coventry, Abingdon, Farringdon, Chipping Norton,

Aylesbury, High Wycombe, Evesham, Wokingham 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 your category. Additionally, on the Oxford advert the web address link was added.

Additionally, recruitment was promoted via Picker's own Twitter account and adverts were placed on 'spotted' sites on Facebook, these were places in Oxford and numerous surrounding towns. Additional adverts were placed in a number of towns and cities in Warwickshire, Buckinghamshire, Berkshire and the Midlands.

### **Additional recruitment approaches**

The following trusts were emailed and agreed to share the request for volunteers amongst their service users; Camden and Islington NHS Foundation Trust, South London and Maudsley NHS Foundation Trust, Coventry and Warwickshire Partnership NHS Trust and Dudley and Walsall Mental Health Partnership NHS Trust.

Advisory Group contacts were also contacted to ask if they could share the advert in newsfeeds, webpages and on social media.

In the final round of interviewing Dudley and Walsall Mental Health Partnership NHS Trust kindly assisted in arranging interviews with some of their service users.

### **Responses for cognitive testing**

There was a very good response overall, with 68 replies to our adverts. Unfortunately, 17 of these people were not able to take part due to them not meeting the eligibility requirements: four people were parents of children accessing CAMHS, however their children were under 18 years of age and so did not meet the criteria; four people were receiving care through their GP and not through community mental health services; five people were only accessing IAPT (Improving Access to Psychological Therapies) services such as Talking Space in Oxford; two people had not accessed the services in the last 12 months and two people had not accessed mental services ever.

### **Respondents recruited**

In total 24 respondents were interviewed; 19 testing the CMH19 main stage survey and five testing a shorter version of the questionnaire (for a pilot study to run alongside the CMH19 survey, though this pilot was later cancelled). It was essential to test how the shorter questionnaire worked, as removing questions and changing the format can potentially affect the way in which people respond, since preceding questions can help frame the one that follows for example.

The respondents represented service users from a wide demographic, geographic and experience profiles:

- Nine males and 15 females
- Age range: 29 to 61
- Geographic locations: Oxfordshire, Berkshire, London, and the Midlands



- o Ethnic backgrounds: White British, White Scottish, Black British, Black African, Pakistani, Gypsy and Swedish

The main stage and shorter questionnaire was tested during September, October and November 2018. Three waves of cognitive 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 submitted for a final round of stakeholder feedback, finalised and then submitted for ethical approval alongside the other service user facing materials.

## 7. Changes to the questionnaire

For the 2019 questionnaire, three questions were added, four were removed and one question was modified. The details of these changes are listed below.

### New questions for 2019

The following questions are new and were thoroughly tested with service users during cognitive interviews:

**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

This question was added following a CQC report on the state of mental health services, highlighting that poor clinical information systems were an issue across trusts and that service user's medical history may not be known to relevant members of staff. This can result in service users being asked to repeat symptoms or experiences, which can potentially cause distress. Where multiple healthcare professionals are involved in someone's care, it is important that care remains personalised and joined up.

**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

In the CMH18 questionnaire, Q22 asked whether service users were given information about their medicines in a way they could understand. For the 2019 questionnaire, Q20 and Q21 were introduced to provide more information. Exploring side effects specifically was noted as an area of interest by the CMH19 advisory group members as problems can have a significant impact on someone's health and wellbeing.

**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

Q37 was introduced following the findings of the Parliamentary and Health Service Ombudsman report (2018) which highlighted the importance of effectively dealing with complaints. Following discussion at the advisory group, it was felt that 'complaints' can denote negative connotations. Instead it was agreed that a question exploring whether service users are being asked for the views on their care would be more suitable. This enables exploration of whether service user feedback is being sought by trusts.



## Questions removed for 2019

The following questions were removed for 2019. The item numbers shown are from the 2018 questionnaire.

**15. In the last 12 months, have the people you see for your care or services changed?**

Please do not include stopping care completely.

- 1  Yes → Go to 16
- 2  Yes, but this was because I requested the change → Go to 18
- 3  Yes, but this was because I moved home → Go to 18
- 4  No → Go to 18
- 5  My care has started but not changed → Go to 18
- 6  Don't know / not sure → Go to 18

**16. Were the reasons for this change explained to you at the time?**

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  No explanation was needed

**17. What impact has this had on the care you receive?**

- 1  It got better
- 2  It stayed the same
- 3  It got worse
- 4  Not sure

Following analysis of the CMH18 data, only 40% of respondents were eligible to answer Q16 and Q17 therefore these questions were removed. Following requests to incorporate new questions, and the relevance of Q15 as a standalone item, the decision was taken to remove Q15 as well.

**22. Were you given information about your medicines in a way that you were able to understand?**

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I was not given any information
- 5  I did not need any information

Q22 was removed in order to incorporate new questions 20 and 21 in the medicines section of the questionnaire.

**30. How long were you on the waiting list before your NHS therapy began?**

- 1  Less than 1 month
- 2  Between 1 and 2 months
- 3  Between 2 and 6 months
- 4  Between 6 months and 1 year
- 5  More than 1 year
- 6  Don't know / can't remember

Q30 which asked about waiting before therapies began was removed as some service users may wait longer to get the therapy of their choice. The question is not scored and it would be unfair to relate findings from this question to the trust.

### **Questions tested that were not included**

All new questions that were tested during cognitive testing were included in the final 2019 questionnaire.

### **Changes to instructions**

During cognitive testing it was apparent that some service users were missing some of the instructions and therefore potentially referencing their experience with their GP rather than with community mental health services. Instructions were shortened where possible with only key messages made bold rather than the whole instruction.

## 8. Results from cognitive testing

### Round one

Instructions which precede each section of the questionnaire help to frame respondent's interpretation of subsequent questions. During cognitive testing it was noticed that a number of respondents were skipping the instructions to exclude their GP when answering questions. This meant they were missing key information on how to correctly answer questions. Previously, during development of the MH18 questionnaire, the instructions were made bold. It was decided it would be clearer if some words were not bold, thereby highlighting the key messages in the instructions.

Original instruction

**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.**

Modified instruction

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.**

Whilst testing, it was discovered that a number of service users found the wording of Q6 problematic. One service user suggested mental health needs and treatment history are two different aspects so it was difficult to answer one question in relation to both. It was decided, in order to try and simplify the question, the words 'mental health needs' would be removed for round two of testing.

Original question

**6. Did the person or people you saw appear to be aware of your mental health needs and 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

Additionally, in round one it became apparent that a number of respondents when answering Q16 were referring to a person or team that were not within the NHS. For example, two respondents referred to the Samaritans when answering and another referred to contacting their pastor from the local church. Due to these findings, the wording of Q16 was changed for round two, in order to clarify that the question was trying to ask specifically about NHS crisis services.

Original question

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

**This could 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. 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

## Round two

In round two it was clear from interviewing respondents that the instructions about not including their GP were still being missed. Some respondents commented that the instructions were easy to miss as they did not stand out. However, no real suggestions were

made to make instructions clearer. It was decided to keep the instruction in bold but to shorten the wording and underline the word 'not'.

**Example one:**

Original instruction

**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.**

Modified instruction

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.

Additionally, in Q37 the words 'in the last 12 months' and 'give your views' have been bolded. The word 'quality of care' was un-bolded to help clarify to people that they were being asked if they've had a chance to give their views.

For Q33, respondents reported missing the second part of the question referring to the 'someone close to you' option. In order to make this clearer, it was decided to make the words 'member of your family' and 'someone close to you' bold.

### **Round three**

In round three, respondents continued to have difficulty reading the instructions in the questionnaire. One respondent commented that they missed the writing in purple due to being drawn to the black of the question text. Other respondents missed instructions completely or found them confusing. One respondent commented that switching between 'you can include GP' and 'do not include GP' was off putting.

Changing the colour of the instruction text was discussed, for example, making this in a contrasting colour. However, it was decided to leave the instructions unchanged as additional colours could make the questionnaire busier. Additionally, it was debated whether adding the word 'only' to the instruction in the 'Organising your care' section might help. However, at this late stage in the cognitive interviewing there would be no opportunity to test any more changes that were made, so the decision was made for the instructions to remain the same for the final questionnaire.

Some respondents found answering Q7 difficult, they reported that it was not just one person in charge of their care, in turn they were unsure how to answer this question. It became apparent that people were thinking of who was 'in charge of their care' and not who was 'in charge of organising their care'. It was discussed if bolding the word 'organising' as well as 'who is in charge' would assist people in answering this question correctly. It was

decided that it was too late into cognitive testing to make changes, but perhaps a wider discussion around the whole 'Organising your care' section would be appropriate moving forward for the 2020 survey.

Since 8% of respondents had not answered the 'Overall' question (Q35) in 2018, the question was probed more thoroughly in the cognitive testing phase. Some service users commented that it was not specific enough about what time period or aspect of treatment the question was referring to. One respondent suggested the question could read 'In the last 12 months overall...' They noted that a lot of previous questions had referred to this explicit time period, so it would be in keeping with the rest of the questionnaire.

Although it was acknowledged that there are potential improvements that could be made to the wording of this question, this would need a lot more time and consideration before any decisions were made. This is also a consistent measure across the surveys within the programme and so any changes to the question would need to be considered programme-wide.

One respondent noted that the text above the free text boxes were italicised, whereas all other text is regular text. The decision was made to remove the italicised text for consistency. This was the only change made moving forward from the round three questionnaire to the final questionnaire.

## **Questions for review**

### **Long-term condition questions**

With recent policy highlighting a significant link between physical and mental health, three new questions (question 39, 40 and 41) were added to the 2018 questionnaire to try and capture the prevalence of this amongst service users. Question 40 lists some common long-term conditions, including 'mental health condition', but it was thought that this had the potential to confuse service users. Therefore, it was decided to probe further on this question in cognitive testing for the 2019 questionnaire. We wanted to gain an insight into people's understanding of it, particularly with regard to the response option of 'mental health condition'.

After three rounds of cognitive testing it was found that overall people had a clear understanding of this question and had no problem with 'mental health condition' being included. However, a couple of participants did suggest they found it slightly confusing as they assumed everyone that would be filling in the questionnaire would automatically have a mental health condition.

### **Ethnicity question**

This question was explored further in cognitive testing as the layout had previously proven to be problematic for some cognitive testing participants in other national surveys. Broad ethnic groups are headed in bold with specific ethnicities detailed below these. Feedback from a number of participants was that the question layout was confusing as it can be misinterpreted to look like five separate questions. For people who both do or do not identify

as White, the layout of the categories can present problems. For people identifying as White British, they can easily find their ethnic group as this is the top box in the column. Participants not identifying as White sometimes hesitated over answering the top section, thinking that it was a question they had to answer.

Therefore, it is recommended that this question needs more development and examination, in order to potentially make a programme-wide change. The layout is not user-friendly and causes people to hesitate before answering. For many, the current question (which takes up a column of space on the back page) looks like multiple questions. Additionally, the need for multiple free-text boxes is questioned as one box could perhaps suffice.

## 9. Changes to the covering letters

The three covering letters for the survey had some changes made to them, though changes were minor and in some cases brought about by service user feedback from other surveys in the programme. Therefore, it was deemed not necessary to test them during a cognitive testing phase.

As part of a programme-wide introduction, the first reminder letter was updated to include the trust logo and Chief Executive signatory. Not only would this bring it in line with the first and third letters, it was felt that this would give more credence to the letter – something that had been highlighted by patients in cognitive interviews in other surveys.

Secondly, the text of the first reminder letter was changed as it did not generate the uplift in response that the initial covering letter did and did not perform as well as the control. Though there is no evidence to suggest why the letter did not perform well, it was felt that it was different in style to the other two. An additional change was made to all three letters in that only one coloured font was used, so the purple replaced the blue font that was used in the introductory text. The original 2018 first reminder letter and the updated version for 2019 are below:

### First reminder letter as used in the 2018 survey:

[Date]

Dear [Insert first name and surname here]

**Don't forget to tell us about your experience of NHS services.**

We recently sent you a questionnaire about your experience of community mental health services at [NHS trust name], but we haven't received your response yet.

Your views are very important so we would like to hear from you. The results of the survey will **help us find out what we do well and what changes we need to make.**



## First reminder letter amended for the 2019 survey:

[Date]

### Don't forget to tell us about your experiences.

We recently sent you a questionnaire about your experiences of community mental health services at [NHS trust name], but we haven't received your response yet. Please send us your feedback as soon as you can so **your voice can be heard**.

Many people have already responded to the questionnaire and we would really appreciate your contribution. The results of this survey will help improve services at your local trust and nationally. **You can be a part of this**.

Finally, the reverse of the first and third letter includes a set of questions and answers relating to the survey. In line with the incoming General Data Protection Regulation which replaced the Data Protection Act in May 2018, the information relating to how data is shared was updated to reflect this.

## 10. Changes introduced to the 2019 survey

### Faster postal reminder

The time frame has been reduced between the first, initial mailing and the second mailing (first reminder letter) from two to three weeks, to five working days. This follows a methodological pilot that was undertaken alongside the Adult Inpatient Survey 2017. The pilot investigated the impact of reducing the time gap between the first and second mailing on overall response rates. The pilot found that there was a significant increase in response rate of three percentage points when the time gap was reduced. First reminders are a covering letter only, whereas second reminder mailings are full survey packs and therefore more expensive. It was anticipated that the faster first reminder would increase response rates earlier on and make the survey less expensive overall, by reducing the amount of paper needed. Though the intervention only resulted in marginally fewer second reminders but significantly more first reminders, it did result in a higher response rate overall (44% versus 40.8% in the control) and among 16-35's (15.5% versus 12.9%). The decision was therefore made to adopt this approach in the mainstage survey.

### Translated dissent posters

This year, the dissent poster was made available in the ten most commonly spoken languages in England. Trusts may choose the posters suitable to their population profile, so people whose first language is not English are aware of the survey and have an equal opportunity to opt out.

Additionally, the inclusion of relevant trust email and postal address information is to be included, if available, alongside a contact telephone number.



Appendix 1 - Main questionnaire – question mapping 2019 vs. 2018

2018	2019	Changes made	Reasons for change
Covering page	Covering page	In intro box, 'We would like to hear from you...' rather than 'We'd...'	Less informal.
Title	Title		
Instructions	Instructions	Instructions were in bold with stressed elements italicised. Instructions were shortened where possible and fonts were amended to regular font with important elements in bold, and words for particular emphasis e.g. 'not' in bold and underlined.	During cognitive testing a number of people were missing the instructions not to include their GP. It was felt shorter instructions were more effective. Also as all instructions were in bold previously it was thought that the key elements were not standing out.
<b>Your care and treatment</b>	<b>Your care and treatment</b>		
Q1	Q1		
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	New question added.	This question was added following a CQC report on the state of mental health services, highlighting that poor clinical information systems were an issue across trusts and that service user's medical history may not be known to relevant members of staff.

2018	2019	Changes made	Reasons for change
<b>Organising your care</b>	<b>Organising your care</b>		
Q6	Q7		
Q7	Q8		
Q8	Q9		
Q9	Q10		
<b>Planning your care</b>	<b>Planning your care</b>		
Q10	Q11		
Q11	Q12		
Q12	Q13		
<b>Reviewing you care</b>	<b>Reviewing you care</b>		
Q13	Q14		
Q14	Q15		
<b>Changes in who you see</b>			Following analysis of the CMH18 data, only 40% of respondents were eligible to answer Q16 and Q17 once routed from Q15, therefore these questions were removed. Following demand to incorporate new questions, and the usefulness of Q15 without the accompanying filter questions, the decision was taken to remove Q15 as well.
Q15		removed	
Q16		removed	
Q17		removed	

2018	2019	Changes made	Reasons for change
<b>Crisis care</b>	<b>Crisis care</b>		
Q18	Q16	'Do you know who to contact out of office hours if you have a crisis? 'Within the NHS' was added to this question to clarify.	There was some earlier feedback that service users may be referencing non-NHS resources such as the Samaritans.
Q19	Q17		
<b>Medicines</b>	<b>Medicines</b>		
Q20	Q18		
Q21	Q19		
Q22		Removed.	Q22 only enquired if service users were given information about their medicines in a way they could understand. It was felt more insight was needed to what information they were being given.
	Q20	New question.	Q20 and Q21 were introduced to provide more information than was gathered from Q22. Q20 asks about the purpose of medicines.
	Q21	New question	Q20 and Q21 were introduced to provide more information than was gathered from Q22. Exploring side effects specifically was noted as an area for exploration by the CMH19 advisory group members.
Q23	Q22		
Q24	Q23		
Q25	Q24		
<b>NHS Therapies</b>	<b>NHS Therapies</b>		
Q26	Q25		
Q27	Q26		
Q28	Q27		

2018	2019	Changes made	Reasons for change
Q29	Q28		
Q30	Q29	removed	
<b>Support and Wellbeing</b>	<b>Support and Wellbeing</b>		
Q31	Q29		
Q32	Q30		
Q33	Q31	'Have NHS mental health services involved <b>a member of your family or someone else close to you</b> as much as you would like?'	Text made bold to highlight that this did not necessarily have to be a family member.
Q34	Q32		
Q35	Q33		
Q36	Q34		
<b>Overall</b>	<b>Overall</b>		
Q37	Q35		
Q38	Q36		
	Q37	New question.	Following ongoing discussion, a question exploring whether service users are asked for the views on their care was agreed. This will be used as a way of exploring whether service user feedback is being sought by trusts.
<b>About you</b>	<b>About you</b>		
Q39	Q38		
Q40	Q39		
Q41	Q40		
Q42	Q41		
Q43	Q42		
Q44	Q43		
Q45	Q44		

<b>2018</b>	<b>2019</b>	<b>Changes made</b>	<b>Reasons for change</b>
Q46	Q45		
Q47	Q46		