

DEVELOPMENT REPORT FOR THE COMMUNITY MENTAL HEALTH SURVEY 2016

THE COORDINATION CENTRE FOR THE
NHS PATIENT SURVEY PROGRAMME

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About the National Patient Survey Coordination Centre

The National Patient Survey Coordination is managed by the Picker Institute on behalf of the Care Quality Commission (CQC). We are responsible for designing, coordinating, and reporting on the findings of surveys of NHS patients and service users conducted as part of the national patient survey programme for England.

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1 Introduction

The Community Mental Health survey has been conducted almost every year since 2004 as part of the National Patient Survey Programme (NPSP) coordinated by Picker Institute Europe on behalf of the Care Quality Commission (CQC). Its purpose is to understand, monitor and improve service users' experiences of NHS mental health services. In 2015 over 13,000 participants from 55 NHS trusts and social enterprises told us about their experiences by taking part in the survey.

Information drawn from the questions in the survey will be used by the Care Quality Commission in its assessment of trusts in England. The results are also used by NHS England and the Department of Health 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.

This year the survey had a minor review to consider whether any changes were needed to the questionnaire, to ensure it remains up to date. Its last major redevelopment took place in 2014¹ when the survey was updated in order to reflect changes in policy, best practice and patterns of service use.

The methodological approach remains unchanged from the 2015 survey. Trusts submitted a randomly drawn sample of 850 service users who were seen during the sampling period of 1st September to 30th November of that year and who adhered to the additional inclusion and exclusion criteria set out in the survey instruction manual.

Alongside updating the questionnaire for 2016, changes were made to the three mailing letters that accompany the questionnaires. These were re-written in a more informal tone, whilst retaining all key information around confidentiality, data protection and so on. Of all surveys in the NPSP, the Community Mental Health Survey has historically generated the lowest response rate. In tandem with this, response rates to all the surveys within the programme have dwindled since its inception. Response to the 2015 Community Mental Health Survey was 29%; in the first survey undertaken it stood at 41%. It was hoped that this relatively minor modification may encourage response, without the need for the survey to undergo any radical methodological change. Also discussed was the Arial font and whether it was feasible to change this to another, more inviting, font. Arial font is often used in official documents and in keeping with the new, informal tone of the letters it was proposed that an alternative font, equivalent in clarity and size could be used. Whilst there are no specific references to other acceptable fonts - see http://www.sensorytrust.org.uk/resources/connect/infosheet_clearlargeprint.pdf - some alternative suggestions were looked at, eg size 13 Calibri, which appeared to meet the requirements. However, following advice from the editorial team at CQC, the decision was made to keep the original font. This does not rule out the possibility of testing new fonts for the 2017 Mental Health survey or another survey within the programme, when time may not be such a constraint.

At the time of writing, the 2016 survey is still in field so it is too early to gauge whether the change to the letter wording has had a beneficial effect.

¹ Report available at: www.nhssurveys.org/surveys/750

Summary of Development

Consultation was undertaken in order to update the questionnaire for 2016. Amendments were made on the basis of the following:

- Analysis of the 2015 survey data to examine question non-response rates (questions people have not answered, for example, because it was not relevant to them), floor/ceiling effects (questions where the vast majority of respondents report a very positive or negative experience), and correlations (questions that people tend to answer in the same way suggesting a similar or the same underlying concept), and;
- Consultation with stakeholders at CQC, NHS England, and the Department of Health regarding any other topics that should be addressed either from a policy or service user perspective.

As is common practice in the NPSP, the revision and re-development of all questionnaires follows best practice. All question changes, regardless of the extent, are cognitively tested with a group of recent and current NHS mental health service users. 'Cognitive testing' is a process which tests both new questions, and questions used in previous years, to check if they are understood as intended by participants and that they are able to answer them appropriately with the response options provided. The respondents are recruited via different mechanisms such as local advertisements in newspapers, public buildings (shops, cafes, libraries, community centres, community noticeboards), online forums and websites (such as Gumtree) and social media. A number of different respondents were recruited to cover a wide demographic base and service user experience. For the 2016 survey fourteen respondents participated:

- 7 men
- 7 women
- Aged 18 - 57 years old
- A mix of ethnic backgrounds
- A variety of different services and delivery teams

Cognitive interviews were conducted in Oxford during the two-week period 10th to 20th November 2015. Following a review of the feedback from the first week, which did not highlight any necessary changes to the cognitive questionnaires used, the second week of interviews continued with the same 'round' of questioning and prompts.

2 Amendments to the questionnaire for 2016

The 2016 questionnaire has been kept as similar as possible to the 2015 version to allow for year-on-year comparisons.

Following analysis of the 2015 survey data and consultation with colleagues from the CQC, NHS England and the Department of Health, three questions included in 2015 have been removed, two questions added, a minor amendment made to one question and the title changed for one of the questionnaire sections.

2.1 Removal of three questions

Three questions were removed from the 'Other areas of Life' section of the 2015 questionnaire for this year's survey as outlined below.

Two questions were highlighted for possible removal:

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

- 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

And:

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

These questions were included in the 2015 survey in the 'Other areas of life' section of the questionnaire. During re-development work undertaken for the 2014 survey, signposting by mental health services for support or advice was identified by service users as being a particularly important aspect their care.

During the cognitive testing of the questionnaire for the 2016 survey, both of these questions were only relevant to a small number of participants. Most of the participants understood the questions and could answer them, but were selecting the 'I did not need support for this' response option. To determine whether this may be reflected in the service user population on a wider scale, data from the 2015 questionnaire was analysed. The analysis of the 2015 data found that : a) regarding the subject of finding or keeping work, 75% already had support, did not need support or were not in or seeking work; b) in relation to accommodation, 78% already had support or did not need support for this.

While the questions demonstrated construct validity and were easily understood by those respondents to whom they applied, low numbers of respondents actually required this signposting. From the cognitive interviews, there was no strong indication as to which question to remove, however stakeholders highlighted the 'accommodation' question for removal from the 2016 survey.

Do the people you see through NHS mental health services understand **what is important to you** in your life?

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

Do the people you see through NHS mental health services help you **feel hopeful** about the things that are important to you?

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

During the development of the 2016 survey, analysis was undertaken on the data from the 2015 survey to identify patterns of response at item level. This analysis helps to identify how questions are performing in practice and to identify potential candidates for improvement or removal. The questions above ask about similar concepts and were identified as being well correlated with another question.

Consultation with stakeholders resulted in the retention of the question asking 'Do the people you see through NHS mental health services help you with what is important to you?' as this question is an example of trusts actively helping service users.

2.2 Addition of two new questions

Two new questions were added to the questionnaire for the 2016 survey to reflect emerging areas of interest from stakeholders. Both questions focus on the theme of ‘explanations’ regarding different aspects of care delivery. Due to the current structure and the desire to maintain as much comparability with the 2015 questionnaire as possible, two questions were added to different sections of the questionnaire.

The first of these questions was added into the ‘Changes in who you see’ section and is as follows:

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

During the development of the 2014 survey, changes in key mental health staff delivering a service user’s care was identified as a key area of concern amongst stakeholders and service users alike. The 2014 and 2015 questionnaire focussed on establishing whether someone’s care had changed with respect to who was involved in care delivery for a service user and the subsequent impact of that change. One important element that was not explored focussed on whether the reasons for change were explained to the service user at the time. As a result it was considered an important addition to the 2016 questionnaire.

This question tested well with those respondents that it applied to though it should be noted that for a number of people this question did not apply. For those who did answer the question it was easily understood, with no changes required during the testing stage. One respondent did suggest adding an additional response option to cover when explanations were given but the quality of those explanations was unsatisfactory. Due to the multi-faceted nature of the quality of explanations it would not be feasible to have included this response option to that particular question. Instead for this data to be gathered it would be necessary to develop an additional item. As a result, this question was recommended for inclusion as tested, with no changes.

The second question that was added to the questionnaire focussed on explanations of non-medicine based treatments or therapies. This section in the questionnaire lent itself to inclusion of a question about explanations. The following question was added:

Were these treatments or 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

This question tested well with all of the respondents who had received treatments and therapies that did not involve medicines in the last 12 months. The majority of the respondents answered ‘yes, completely’ and were able to expand on why they had come to that evaluation. For the most part, this was because the person working with the service user

on their treatments or therapies talked the service user through the options and explained what was involved in each. In addition, all respondents understood the question well and were able to answer it easily with no hesitation or ambiguity over what it was asking of them.

2.3 Minor amendment made to one question

One question had a minor amendment made in the addition of a new response option:

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

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

The second response option was added to distinguish between changes in care teams being initiated by the service provider or by the service user themselves. During testing it became apparent that a change in the care team could have been driven from the service user perspective. Where this is the case, it would not be appropriate to ask the service user the follow up questions regarding whether changes were explained to the service user and who was in charge of their care when the change was taking place.

This question tested well with all respondents and the additional response option was easily understood. When probed during testing, respondents could easily differentiate between the different options for the question and felt that the distinction between whether the service user requested this or whether it was a change made by the service itself was very clear. It should be noted that this additional response option means that the 2016 data will not be comparable to previous years' data.

2.4 Section name change

Following a request from NHS England, the section in the questionnaire titled 'Other areas of life' was replaced by 'Support and Wellbeing'. It was thought in retrospect that the original title may suggest that the questions in this section pertained to aspects not related to the person's mental health. On reviewing the question topics and how they fitted together, it was felt that 'Support & Wellbeing' effectively covered the theme of the questions covered in this section and was recommended for testing. In addition, on reviewing the section title, it was felt that 'Other areas of life' might suggest aspects that had little in common and had been grouped together as they did not fit neatly into any of the other sections, which was not the case. The section asks about people's experiences of mental health services providing direct support, or signposting service users to services provided by outside organisations, such as helping service users to find work or accommodation, take part in activities locally or be put in touch with other people with similar experiences.

Renaming the section 'Support & Wellbeing' was thought to be a good fit by stakeholders and tested well with participants and was therefore included in the 2016 questionnaire.

2.5 Other proposed changes that were not made

The following question was tested during the cognitive interviews because examination of the 2015 data showed a ceiling effect with 96% of respondents indicating 'yes':

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

- 1 Yes
- 2 No
- 3 Not sure

Similarly, of those participants who were routed to this question, the majority responded 'yes'. The final person interviewed replied 'not sure' and perhaps because of this, felt that it was important that service users did know this information and the question therefore kept. In addition, stakeholders had latterly advised that this question could not be removed as it was a national indicator.

At stakeholder request, two alternative questions were drafted around the topic of self-management:

Did you find the treatments or therapies you received in the last 12 months helpful?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

And:

How helpful were the treatments and therapies you received in the last 12 months in helping you to manage your condition?

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

Both questions were asked of all participants (normally only respondents who had received treatments or therapies that did not involve medicines in the last 12 months would answer these questions). Because the questions were asking a very similar point but in a different way, two versions of the questionnaire were produced so that each of these questions in the pair was asked first an equal number of times. Rotating the order of the questions also helps lessen the impact of any order effects, for example, of the second asked question being deemed the inferior 'second-choice' option.

A mix of feedback was gathered with some participants preferring the format of one question but the response options of the alternative. The second option above was perhaps the preferred option overall; it is more suggestive of self-management, however it does not

follow the standard 'experience' scale format and also contains both the terms 'helpful' and 'helping' in the question text.

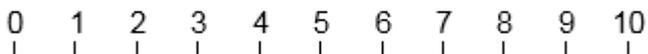
Because other questions tested better amongst participants and needed no further refinement, it was concluded that the topic of self-management be revisited for the next survey iteration.

Each survey in the NPSP utilises an overall rating scale towards the end of the questionnaire, asking respondents to sum up their overall experience of care. In the Community Mental Health Survey it appears as follows:

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

I had a very
poor experience

I had a very good
experience



At the request of CQC, an alternative 'overall' question was tested:

Overall, how satisfied or dissatisfied are you with the care and support services you receive?

- 1 I am extremely satisfied
- 2 I am very satisfied
- 3 I am quite satisfied
- 4 I am neither satisfied nor dissatisfied
- 5 I am quite dissatisfied
- 6 I am very dissatisfied
- 7 I am extremely dissatisfied

As with the approach used for the two alternative questions above, all participants were asked both questions with either option being presented an equal number of times. Whilst there was a split preference amongst the cognitive interview participants, the Coordination Centre strongly advised against the adoption of the 'satisfaction' scale for various reasons:

- There are inherent limitations in the use of service user satisfaction because satisfaction itself is multiply defined and because evaluations of satisfaction are subjective, vulnerable to bias and difficult to interpret (Cleary, 1998);
- The overall rating scale in use across the NPSP was extensively researched in 2012 (Graham & MacCormick) and provides some alignment of measures across all the patient survey questionnaires.

For these reasons the existing 'overall' experience rating was retained for inclusion in the 2016 survey.

3 Additional changes to the 2016 survey

A small number of other changes were made to the survey this year as outlined below.

3.1 Sample declaration form

The sample declaration form has been updated since the 2015 survey. For this year, whilst the majority of the form itself and the process for completing the form remains unchanged, there have been some useful additions made. The most significant change is the inclusion of an additional signatory, who counter signs the form to indicate that the sample has been checked by someone other than the person who drew the sample.

The second change relates to the inclusion of a new Section A on the form, which asks providers to indicate the total number of service users from their total population who have specifically indicated that they do not wish to take part in a survey. This was introduced to help identify where providers have large proportions of their service users indicating dissent (who are therefore not eligible to participate in the survey due to information governance approvals). Where there are large proportions of dissenters there can be issues with the representativeness of a provider's sample, which will in turn impact the response data collected. Providing this information at the very early stages of the sampling process allows the Coordination Centre and CQC to explore potential concerns with providers and safeguard their participation in the national survey.