

REDEVELOPMENT OF THE COMMUNITY MENTAL HEALTH SERVICE USERS SURVEY

THE COORDINATION CENTRE FOR THE
NHS PATIENT SURVEY PROGRAMME



Making patients' views count

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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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EXECUTIVE SUMMARY

1.1 Background

The National Community Mental Health Service Users survey has been conducted near-annually since 2004 as part of the National Patient Survey Programme 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 2013 over 13,000 service users from 58 NHS trusts and social enterprises told us about their experiences by taking part in the survey.

Its last major redevelopment was in time for the 2010 survey. The survey has now been updated for 2014 in order to reflect changes in policy, best practice and patterns of service use, i.e. to align the survey with services as they will be provided and experienced in 2014.

1.2 Process

The redevelopment process had two major phases.

In the first phase we established the current landscape of mental health service provision and use, discussed topics important to stakeholders, and examined the 2013 survey in this context. This was conducted largely through a series of consultations between May and September 2013 with service users, service providers, regulators, policy experts and academics, and supported by a literature review and secondary analysis of data from the 2012 and 2013 surveys.

In the second phase we designed and tested the 2014 questionnaire, consulting with stakeholders on drafts and testing the questionnaire with service users in four rounds of cognitive interviews during October and November 2013.

1.3 External context

Developments in current policy and best practice have been guided by the recovery approach (or recovery model) of mental health care. This moves away from a medical, treatment-based model structured around maintenance and the relief of symptoms and towards an individualised approach structured around each person's goals and priorities. This is reflected in the Government's No Health without Mental Health policy^{1,2} and NICE's 2011 guidance on improving the experience of care for people using adult NHS mental health services³.

¹ No Health without Mental Health: Outcomes Strategy (DoH, Feb 2011)
<https://www.gov.uk/government/publications/the-mental-health-strategy-for-england>

² No Health without Mental Health: Implementation Framework (DoH, July 2012)
<https://www.gov.uk/government/publications/national-framework-to-improve-mental-health-and-wellbeing>

³ Service User Experience in Adult Mental Health (NICE, Dec 2011)
<http://www.nice.org.uk/nicemedia/live/13629/57542/57542.pdf>

Data from the survey will be used by CQC for regulation and has the potential to be used in Payment by Results (PbR) quality and outcome monitoring. The needs of both programmes are particularly relevant as CQC is in the process of developing a new regulatory model and the PbR national tariff for mental health is in development.

1.4 Findings

The language used in the 2013 questionnaire came under strong criticism for being dated and disempowering, as well as potentially contributing to low response rates. Changes in patterns of service provision were highlighted, especially integration between primary and secondary services and the existence of multidisciplinary teams providing a suite of services. Administrative and logistical issues with the survey itself were discussed, as were possible reasons for and ways to tackle the survey's low response rate.

Four major areas were raised that are not covered – or not appropriately covered – by the 2013 questionnaire. These were:

- **Interpersonal relationship with care worker:** Continuity of care; key aspects of the relationship; privacy and discretion
- **Coproduction of care:** Goals and goal-setting; responsiveness of services; positive risk-taking; peer support; families
- **Service provision:** Time pressures; transitions and gaps in care; travel; sign-posting; discharge
- **Wider life and needs:** Diversity of needs; “feeling useful”; stigmatised or disregarded needs

1.5 Changes

A full list of changes to the questionnaire is available in *Section 8 - Summary of changes*. Questions have been added to address many of the topics raised in the consultation. The remaining questions are based on or aim to replace directly questions from the 2013 questionnaire. These questions have had their language changed to reflect more empowering, person-centred care, to remove NHS-specific terms that may rapidly become dated, and to make the questionnaire as clear and easy to answer as possible.

The “sampling period” (the time during which service users must have had contact with services in order to be eligible for the survey) has been moved from July-September of the year preceding the survey to September-November of the year preceding the survey.

STAKEHOLDER CONSULTATION

The Coordination Centre carried out stakeholder consultations between May and September 2013 with service users, service providers, regulators, policy experts and academics. This was supported by a review of current policy and best practice literature. The consultation covered service users' priorities and experiences of care; service providers and regulators' uses of the survey and its results; current service structures and pressures; and mental health in the wider current social and political context.

Background covers the history of the survey and gives details of the 2013 survey.

Section 3 - External context covers key current policy drivers, including the recovery approach and its influence on current policy, the new CQC regulatory model, and Payment by Results.

Section 4 - Consultation findings covers those consultation findings not related directly to questionnaire topics. This includes the language of the questionnaire, patterns of service provision and use, and how the survey is used by different stakeholders.

Section 5 - Topic areas covers important aspects of patient experience not covered – or not fully covered – in the 2013 questionnaire.

2. Background

This section provides background on the National Community Mental Health Service Users survey and the stakeholder consultation phase of its redevelopment.

2.1 History of the Community Mental Health Service Users survey

The Community Mental Health Service Users survey was first run as a voluntary survey in 2003, following pilot work conducted by the Picker Institute in 2002/3. The questionnaire and methodology were developed by the Picker Institute for the then regulator, the Commission for Healthcare Improvement. Both organisations contributed to further development of the questions and methodology following the 2003 voluntary survey, and it was introduced in 2004 for all NHS providers of community mental health service in England as part of the National Patient Survey Programme.

The survey has been conducted near-annually since 2004. Its purpose is to understand, monitor and improve service users' experiences of NHS mental health services. In 2013 over 13,000 service users from 58 NHS trusts and social enterprises told us about their experiences by taking part in the survey.

The National Centre for Social Research (NatCen) carried out major redevelopment work on the questionnaire prior to the 2010 survey. This was the most recent major redevelopment, and can be found at <http://www.nhssurveys.org/survey/936>.

2.2 The 2013 survey

The 2013 questionnaire was an eight-page self-completion booklet containing 46 questions about service user experience, and a further nine demographic questions. For an overview of the major topics please see Section 5.1. Each NHS community mental health service provider (largely specialist mental health trusts, community health trusts and social enterprises) sent this questionnaire to a randomly selected sample of 850 eligible service users.

In 2013, the sample of service users surveyed was taken from a list of adults aged 18 and over who had received community mental health services in July-September 2012.⁴ Current mental health inpatients were excluded, as were those primarily receiving drug and alcohol services, learning disability services, forensic services, IAPT and other services that are very different from the typical service user pathway. Older adults, those receiving memory services, and those over 18 years of age receiving CAMHS were included. The full sampling criteria for 2013 can be found at <http://www.nhssurveys.org/survey/1236>.

The national response rate for 2013 was 29%, with trust response rates ranging from 20% to 40%.

⁴ Typically more than 80% of service users in the sample will have also had contact with the trust after this point.

3. External context

The primary reason for redeveloping the Community Mental Health Service Users Survey for 2014 was that the external context had changed considerably since the last major redevelopment. This section outlines the key current policy drivers.

3.1 Key documents

Since the redevelopment of the survey by NatCen in 2010, the Government has produced its No Health without Mental Health outcomes strategy (February 2011)⁵ and implementation framework (July 2012)⁶, and NICE has produced guidance (December 2011)⁷ on improving the experience of care for people using adult NHS mental health services.

Data from the survey will be used by CQC for regulation and has the potential to be used in Payment by Results (PbR) quality and outcome monitoring. The needs of both programmes are particularly relevant as CQC is in the process of developing a new regulatory model and the PbR national tariff for mental health is in development.

3.2 The recovery approach

Both the No Health Without Mental Health and NICE documents are guided by the recovery approach (or recovery model) of mental health care, which moves away from a medical, treatment-centred model structured around maintenance and the relief of symptoms and towards an individualised approach structured around each person's goals and priorities.

Features of this approach include^{8,9}:

- social inclusion and networks of interdependence – the individual supports and is supported by others;
- individual goals and agency – the individual decides their own priorities and what constitutes a meaningful and fulfilled life for them;
- self-management and person-centred care – the individual is the expert on their own experience; professionals are “on tap, not on top”;
- hope, well-being and a sense of identity outside of mental illness – the individual is defined by their positive sense of self, not by their symptoms or diagnosis.

⁵ No Health without Mental Health: Outcomes Strategy (DoH, Feb 2011)

<https://www.gov.uk/government/publications/the-mental-health-strategy-for-england>

⁶ No Health without Mental Health: Implementation Framework (DoH, July 2012)

<https://www.gov.uk/government/publications/national-framework-to-improve-mental-health-and-wellbeing>

⁷ Service User Experience in Adult Mental Health (NICE, Dec 2011)

<http://www.nice.org.uk/nicemedia/live/13629/57542/57542.pdf>

⁸ Leamy, Mary, et al. “Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis.” *The British Journal of Psychiatry* 199.6 (2011): 445-452.

<http://bjp.rcpsych.org/content/199/6/445.long>

⁹ Shepherd, Geoff, et al. “Making recovery a reality.” London: Sainsbury Centre for Mental Health, 2008. http://www.centreformentalhealth.org.uk/pdfs/Making_recovery_a_reality_policy_paper.pdf

3.3 CQC regulatory model

CQC recently consulted on changes to the way it inspects and regulates health and social care.¹⁰ The Quality and Risk Profiles (QRP) will be replaced and the main assessment framework will be based around five key questions, referred to as domains:

- Is care safe?
- Is care effective?
- Is it caring?
- Is care responsive?
- Is care well led?

These five questions form the 'Expected Standards' that set out what anyone using services can expect as a matter of course.

In redeveloping the questionnaire it was necessary to consider whether its questions would be able to feed into CQC's risk monitoring activities. The CQC consultation proposed that indicators will be used to raise questions about quality of care. There are three levels of indicators proposed which will include questions from the patient surveys. The first level ('tier 1') indicators will be used to identify potential concerns and trigger a response from CQC, and it is expected that indicators developed from patient survey questions will be included in this tier.

3.4 Payment by Results

Progress is being made in bringing Mental Health within the scope of Payment by Results (PbR).¹¹ It may be possible to use PbR information in the analysis of the national survey data, and for the national survey data to feed into information needed by PbR.

PbR is the system by which acute hospital trusts are paid for the majority of the healthcare they provide.¹² Hospitals are paid based on the estimated cost of the cases that they treat, with this estimation based on the diagnosis, needs and treatment options for each person treated.

Clustering

A key feature of PbR in mental health is the clustering of service users into needs-based categories. Trusts will have this category information as a mandatory part of their data on service users, which means that, subject to approval under Section 251 of the NHS Act 2006 from the Health Research Authority Confidentiality Advisory Group, they can then provide it when submitting details of their sample to the Patient Survey Co-ordination Centre.¹³

¹⁰ A New Start: Consultation on changes to the way CQC regulates, inspects and monitors care (CQC, June 2013)

http://www.cqc.org.uk/sites/default/files/media/documents/cqc_consultation_2013_tagged_0.pdf

¹¹ Mental Health Payment by Results Guidance for 2013-14 (DoH, Feb 2013)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214907/Mental-Health-PbR-Guidance-for-2013-14.pdf

¹² A Simple Guide to Payment by Results (DoH, Nov 2012)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213150/PbR-Simple-Guide-FINAL.pdf

¹³ Trusts already provide year of birth, gender, CPA status and date of last contact to allow both statistical checks on the samples drawn and additional analysis to be carried out on the final response data.

It is possible that needs-based category information could then be used to analyse survey results by cluster or super cluster to understand how a service user's needs affect both their likelihood of response and their experience of services.

Patient Reported Experience Measures

Some questions in the 2013 questionnaire were identified in the 2013-14 PbR guidance as possible sources of data for Patient Reported Experience Measures (PREMs). If the survey can appropriately measure the areas necessary for PREMS, this will reduce the burden on service users and service providers as experiences will not have to be canvassed twice.

4. Consultation findings

Consultations took place with service users, service providers, regulators, policy experts and academics. The service user involvement included two focus groups with service users, a consultation event with CQC Experts by Experience, a CQC analysis of write-in responses in the “Other Comments” section of the 2013 survey, and the participation of academics and service providers who are also service users. For a full list of those represented in the consultation process, please see Appendix 1 (page 79).

Sections 4.1 to 4.3 below describe the key issues, other than questionnaire topic areas, for the redevelopment of the survey that were identified in the consultation work. These are broadly categorised as question design (specifically language); patterns of service provision; and broader (overarching) issues. Section 5 describes the consultation findings with regard to the questionnaire’s topic areas.

4.1 Question framing and language

The questions in the Community Mental Health Service Users survey must be designed appropriately: we must pay careful attention to the way in which each question is worded and the context in which it is presented, as these can influence how people understand and answer the question itself. Similarly, the questionnaire must use language that is easily understood by service users and that reflects and supports contemporary understandings of best practice - that mental health service provision is individualised, empowering and built on the principles of the recovery approach. The consultation identified several important issues relating to context and language, as described below.

4.1.1 Recovery approach

Stakeholders found some of the questions in the 2013 questionnaire to be problematic in terms of their language and phrasing.

The questions would benefit from a review to embed the modern principle of the active empowered patient, rather than a more passive model of being supported rather than engaged to move to recovery.

- Policy expert

One question highlighted by several stakeholders as typifying this issue was:

Q30 Before the review meeting, were you given a chance to talk to your care coordinator about what would happen?

This implies a passive process, in which best practice is that the service user is allowed to learn what will happen to them, rather than viewing preparation for care reviews as a collaborative process in which the service user and service providers work together in the coproduction of the service user’s care.

A suggested alternative concept was:

Were you helped to prepare for your review and go prepared to get the help you need to achieve your goals?

This underlying concept here implies that best practice sees the service user and their care coordinator working together to help the service user get the most out of their care review. It shows the care review itself as an enabling process, tailored towards the individual's goals.

4.1.2 Language may obscure experience

The 2013 questionnaire asks about the respondent's "care co-ordinator (or lead professional)", "care plan" and "care review". Each of these terms is explained before the first relevant question, but the questions themselves contain only the phrases themselves, as do the section headings.

It's not that [service users] don't know who their main person is or who to make contact with, it's that they don't understand that word.

- Service provider

Trusts raised concerns that service users may well know "who is in charge of their care," "what is going on with their care" and "when they get a chance to talk about what's happened so far and what should happen next" without recognising the terms used in the survey. A further, related concern is that trusts could improve their scores on these questions by improving services users' recognition of the terms, but not necessarily the quality of services.

It's all paperwork and nothing else.

- Service user

This concern was reflected in service users' experiences of receiving copies of doctors' letters with "Care Plan" written on them – this did not help them understand their care, but did mean they had a care plan.

4.1.3 Language may shape local policy

The questionnaire may penalise more progressive language.

One trust reported being asked by a service user group to rename their documentation from "care plan" to "recovery plan" or "self-care management document". The service users said this was paternalistic and medical phrasing that was not in keeping with the trust's stated commitment to recovery-focussed services.

If the questionnaire explicitly refers to "care plans", we may see inappropriately low scores in those trusts that adopt more recovery-focussed terminology. It is therefore appropriate to move towards a question wording that avoids these specific terms.

4.1.4 Impact of language on response rates

Concerns have been raised over the low response rate for the survey (see section 4.3.1 for details); one contributing factor suggested by several stakeholders for the low response rate is that service users who receive the questionnaire do not recognise the services described or find the language formal, intimidating or otherwise off-putting.

During the consultation we spoke to service users who were familiar with the system (service providers who were also service users, researchers who were also service users, CQC experts by experience) and those who weren't.

Among stakeholders familiar with the system, there were many examples of different people referring to the same thing with different names (eg "multidisciplinary teams" were also "care teams" or "Community Mental Health Teams"/"CMHTs") or different things with the same name (eg "buddies" in peer support, discussed in section 5.3.4). Such ambiguities may mean that different respondents interpret questions using this language differently, or have difficulty responding if they are aware of several different meanings but do not know which one is intended.

Service users who weren't familiar with the system referred to many different types of service as "counselling" and did not draw any distinction between primary and secondary services.

4.2 Patterns of service provision

The full package of care received by a service user is often not provided exclusively by the specialist mental health trust. Care may be shared between primary and secondary services, and the service user's General Practitioner (GP) may coordinate or guide care. Local authorities and third sector organisations may also provide some services.

Service users may not draw a distinction between who provides the services, seeing all of them as part of the NHS. Alternatively, they may draw false distinctions: one trust raised concerns that since their care plans were drawn collaboratively with the local authority and contained local authority branding, service users may not identify this as their "NHS care plan".

Primary and secondary care clinicians, managers and commissioners should work together to design local care pathways that provide an integrated programme of care across both primary and secondary care services.

- 2011 NICE Guidelines on Common mental health disorders: Identification and pathways to care¹⁴

One model of integrated (or "shared") care between primary and secondary services can involve GPs taking a central role in coordinating care. They will be responsible for all referrals and prescriptions, following advice or recommendations from secondary services.

¹⁴ Common mental health disorders: Identification and pathways to care (NICE, May 2011)
<http://www.nice.org.uk/nicemedia/live/13476/54520/54520.pdf>

Care is “stepped” according to needs: when it can be managed entirely within the primary sector it is, with further care from secondary services brought in as and when needed. The service user will continue seeing their GP regularly alongside any secondary services, and will regard their GP as a (or, indeed, the) central professional in their care.

Some trusts said that their services are increasingly aiming to build care around individuals through multidisciplinary teams that allow all of a service user’s needs to be met within the team, rather than having to refer the service user out to specialists. This means that there is continuity of care for the service user, as and when their needs change – so crisis care, for instance, is provided within the team rather than by specialists who are unfamiliar with the service user.

These multidisciplinary teams do not have a fixed structure, and are known by many different names. They may not consist solely of NHS secondary mental health workers, but may include social workers provided by local authorities and voluntary or third sector workers. They may also include “peer specialists” (service users who are recognised as experts through experience and training) as full, paid members of staff, as recommended in the Implementing Recovery Through Organisational Change (IMRoC) proposed methodology¹⁵.

4.3 Broader (overarching) issues

Several overarching issues with the current survey, unrelated to modernisation of services, were highlighted by stakeholders during the consultation. These concerns were: the survey’s response rate; clarity around the purpose or purposes of the survey; the length of time given to trusts to prepare; and the survey’s reporting.

4.3.1 Response rates

The 2013 survey had a response rate of 29%, down from 32% in 2012. This is in comparison with a 51% response rate for the 2012 National Inpatients Survey.

Some stakeholders said that the low response rate and high risk of non-response bias (some types of people being more likely to respond than others) makes it hard for service providers to trust the results and correspondingly easy for them to disregard unwelcome results.

There were a number of suggested reasons for why the response rate was so low, including:

- the breadth of the sample;
- the length of the questionnaire;
- incentives to respond;
- accessibility;
- language use and framing.

The breadth of the sample

We get questionnaires back with “My wife has dementia – she can’t possibly understand these questions, let alone respond to them” written on.

¹⁵ Implementing Recovery – A methodology for organisational change, Shepherd, G., Boardman, J. & Burns, M. (2010), Centre for Mental Health
http://www.centreformentalhealth.org.uk/pdfs/Implementing_recovery_methodology.pdf

- Service provider

A common concern from trusts was that the sample of service users to be sent questionnaires includes those with organic conditions such as dementia. If we are able to collect information about service users' PbR clusters, then we should be able to use this to analyse non-response by service users' conditions and needs. There is no change to sampling criteria proposed in the current redevelopment, but it is important to understand whether conditions and needs do have any effect on non-response, and, if so, what effect this is.

The length of the questionnaire

That overall thing is that it is too long, but all anyone can do is think of things to add rather than delete.

- Academic and service user

Many stakeholders felt that at 8 pages the questionnaire was too long. There is some research¹⁶ indicating that 4 page and 12 page patient experience questionnaires have the same response rates, however, this has not been conducted with mental health service users, who may face different challenges when filling in the questionnaire.

Incentives to respond

Several different incentives to respond were suggested, from localised "You said, we did..." information explaining the positive effects the survey results have already had on improving local trusts, to actual financial incentives such as prize draws. There are strong methodological concerns with some of these suggestions, but the broader message is clear: service users should be given clear reasons why the survey is being carried out and what direct, measurable benefits their contribution will have.

Accessibility

A number of different accessibility concerns were raised by stakeholders. The questionnaire can be completed with the aid of a friend/carer, but this was not considered to be sufficiently clear in the instructions and covering letter. For blind and partially sighted service users, other questionnaire formats were suggested, such as Braille (currently available on request) and large print (not currently available).

Language use

As raised in Section 4.1.4, the disconnect between the language used by service users and the language used in the questionnaire was considered to be an important reason why service users might not respond.

The first few questions in a questionnaire can set the tone for a questionnaire as "easy" or "difficult" to complete¹⁷, and so potential respondents who do not connect with the language

¹⁶ Jenkinson, C, et al, Properties of the Picker Patient Experience questionnaire in a randomized controlled trial of long versus short form survey instruments, Journal of Public Health Medicine Vol. 25, No. 3, pp. 197–201, 2003, <http://jpubhealth.oxfordjournals.org/content/25/3/197.full.pdf>

¹⁷ Dillman, Don A. Mail and internet surveys: The tailored design method. Vol. 2. New York: Wiley, 2000.

on the questionnaire may discontinue at this point. This is particularly important as Q3 in the 2013 survey (which asked who was the most recent care worker seen by the respondent) has the single highest item non-response rate on the questionnaire, suggesting that the list of professionals given does not work for some service users.

4.3.2 The purpose of the survey

A theme throughout our discussions with stakeholders was the variety of different uses they had for the survey. Some trusts devoted much of their improvement planning to areas highlighted by the national survey, whereas others prioritised information they had from other sources, such as local real-time feedback and service user groups. Representatives from service user and advocacy groups said the survey was most useful to them as evidence behind advocacy or long-term strategy.

Nationally, the data feeds into CQC's intelligence and into the NHS National Outcomes Framework. There is potential for the data to form part of the PbR PREMS, as described in Section 2.4.

4.3.3 Time to prepare

One issue raised by several trusts was the short period of time between the release of the guidance and the sampling period.

The timetable for the national survey is constrained by various factors, such as the need to obtain both Ethics approval, and section 251 approval from the Confidentiality Advisory group at the Health Research Agency. This means it is not currently possible to change the time period between release of the finalised criteria and when sampling may begin.

4.3.4 Reporting

All organisations participating in the survey receive two reports from CQC:

- Benchmarking report: trusts receive a score for each question intended to measure quality of experience, based on their responses for these questions, adjusted for demographics. These are compared to national performance in a clear, statistically robust manner that highlights the extremes of good and poor performance. These are published and the comparisons are given on the CQC website.
- Frequency tables of responses: tables giving the frequency of each response option on each question for the trust.

Trusts also receive reports from the contractor who carried out the survey on their behalf. If they carried out the survey in house, they are responsible for their own internal reporting. There are no standard requirements for these reports, and it became clear during discussions that not all trusts received the same information or information breakdowns.

The methodology for the CQC benchmarking reports – the only source of information that allows trusts to compare their performances nationally – is intended to highlight extremes of

score. For this reason, most scores for most trusts are described simply as “about the same” as most other trusts, while appearing in the red (“worse”) or green (“better”) only gives information about comparative performance, not absolute quality. As one trust memorably put it, “Being the cream of rubbish is still not good.”

5. Topic areas

Over the course of the consultation, the following topic areas emerged as important aspects of current service experience that were not covered – or were not fully covered – in the 2013 questionnaire. They are presented here thematically, without comment on relative or absolute importance.

The four key areas are:

- (5.2) Interpersonal relationship with care worker
- (5.3) Coproduction of care
- (5.4) Service provision
- (5.5) Wider life and needs

We present first the topics in the 2013 questionnaire, so that these areas may be understood in the context of what is currently covered.

5.1 The 2013 questionnaire

The major topics covered in the 2013 questionnaire were:

Health and social care workers: Who the service user saw most recently and how they felt about this interaction

Medicines: Information and involvement in decisions around medicine

Talking therapies: Whether the service user received talking therapy and how useful they found it

Care co-ordinator: Can the service user identify and contact their care co-ordinator or lead professional?

Care plan: Information and involvement in decisions around the care plan; goal-setting

Care review: Information and involvement in decisions around the care plan

Crisis care: Can the service user contact someone out of hours?

Day to day living: Are services monitoring and providing support for the services user's physical and social needs?

A copy of the questionnaire is included as Appendix 4 (page 89).

Only one question was changed between the 2012 survey and the 2013 survey – this was Q45, in both cases a question asking respondents to evaluate their overall experience, which appears after the topic-specific questions.

5.2 Interpersonal relationship with care worker

The 2013 questionnaire addresses some aspects of the respondent's interpersonal relationship with their care workers, but other topics have also emerged in stakeholder consultations. In this section we cover analysis of the existing questionnaire (5.2.1); continuity of relationships (5.2.2); quality of relationships (5.2.3); privacy and discretion (5.2.4).

5.2.1 Coverage of relationships in the 2013 questionnaire

The 2013 questionnaire addresses the following aspects of the relationship between the service user and the most recent care worker they saw:

- If the care worker **listened carefully** to the service user (Q5)
- If the care worker **took** the service user's **views into account** (Q6)
- If the service user had **confidence and trust** in the care worker (Q7)
- If the care worker treated the service user with **dignity and respect** (Q8)
- If the service user was given **enough time** to discuss their condition and treatment (Q9)

Responses to these questions show very high correlation with each other.¹⁸ It may be that these questions are measuring the same underlying trait or concept, or it may be that the placement of five similar questions together mean that respondents do not draw a distinction between the different aspects of the relationship being asked about.

It is important to note that removing some of these questions may create the perception that some of these qualities are not as important as others – however, it is clear that these questions do not provide distinct information. Reordering the questionnaire as a whole so that these questions do not appear together may also be a solution.

5.2.2 Continuity of relationships

People using mental health services using community mental health services are normally supported by staff from a single, multidisciplinary community team, familiar to them and with whom they have a continuous relationship.

– NICE Quality Standard #4

Continuity was a strong theme in discussions with service users, who found that it was only through long-term, continuous relationships with staff that they could build up the positive dynamics they found most beneficial to their care.

It is important to service users to feel known and understood as a whole person, not just a collection of symptoms. The examples given were of therapists, counsellors, support

¹⁸ Of the ten pairwise correlations possible, all had polychoric correlation of 0.75 or higher, with eight at 0.8 or higher. The highest correlation was between Q4 and Q5 of 0.93. These two questions had Cohen's Kappa of 0.70, which is on the threshold for inter-rater agreement: that is, Q4 and Q5 are likely to be measuring the same underlying concept on the same scale. In each case, the number of pairwise responses analysed was over 10,000.

workers and others who had taken the time to get to know them and take an interest in their lives over a period of time.

Service users who did not see the same members of staff repeatedly, but instead had their care handled by a series of new people, found this detrimental not just to their relationships with staff but to their health as a whole. They spoke of the demoralising effect of “having to go through it all over again” with each new person – where “it” could be their mental health history, past trauma(s), current difficulties, or other issues – rather than being able to look forward towards what they wanted to achieve from mental health services.

5.2.3 Quality of relationships

It's about my life, not just one little bit.

- Service user

Service users said it was important to them to feel like an equal. They wanted knowledgeable, empathic, non-judgmental care workers, who had time for them and who got them talking. Most important of all was someone who “got” them and treated them as a whole person.

People using mental health services and their families or carers feel they are treated with empathy, dignity and respect.

- NICE Quality Standard #2

The NICE Quality Standards also state that service users should receive emotional support for any sensitive issues (QS7).

Other stakeholders raised issues with the wording of the questionnaire as it stands. They felt that dignity, respect and careful listening, while important, were impersonal; they wanted to know if care workers were friendly, kind and polite. They also felt that the wording of the questions – especially Q4 and Q5 – favoured a paternalistic model of care over a collaborative one.

5.2.4 Privacy and discretion

Trust. I think you've got to trust that person who're speaking to. I used to see [a counsellor] at work and I never trusted him as far as I could throw him, because I'm quite sure when I went out, he went back to my line manager and told her all my problems.

- Service user

Privacy is recognised in the NHS Patient Experience Framework¹⁹ as a critical feature of good service provision. It is presented here as an interpersonal quality because this was how service users conceptualised it: as a personal contract between the individual and their care workers, not a feature of the system as a whole. This suggests that privacy should be addressed through a question treating it as a transactional quality between the respondent

¹⁹ NHS Patient Experience Framework (DoH, Feb 2012), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215159/dh_132788.pdf

and a care worker, rather than through a more general question about NHS mental health services.

5.3 Coproduction of care

When things first start happening, you're not in control of anything [...] so you do need people around you that are experience and strong, so they can guide you. But they need to know when you can start taking control [...] so that you start making decisions for yourself.

- Service user

Coproduction of care is key to the recovery approach. In this section we address goals and goal-setting (5.3.1); responsiveness of care and support (5.3.2); positive risk-taking (5.3.3); peer support (5.3.4) and the inclusion of families (5.3.5).

5.3.1 Goals and goal-setting

Setting and working towards goals are important features of personalised, recovery-focussed care.

Goals can be long-term aims – to quit smoking, to swim in the sea – or much more short-term and immediate – to walk the dog, to cook a meal. Collaborative goal-setting allows the individual to take control of their care and work towards the life that they want to lead; the type of support needed to meet these goals, correspondingly, depend very much on the individual.

The 2013 questionnaire addresses this both through questions that allow a broad range of interpretations (“Q24 Does your NHS care plan set out your goals? This might include the changes you want to make to your life as your care progresses or the things you want to achieve.”) and questions on specific topics such as finances and employment that are written on the understanding they do not apply to everyone.

Whilst the importance of goals and goal-setting are paramount to recovery-focussed care, care must be taken when designing specific questions on this topic. The language of “goals” and “goal-setting” has been criticised by some service users as too formal and too far removed from the actual process of deciding what you want to do/achieve and starting to do so.

Don't use “goal” – ask “What's missing?”

- Expert by Experience

Not all service users benefit from having goals – for some, the simple fact of having a goal can be a stressor in itself, and some find the idea of goals too closely linked to unrealistic ideas of full clinical recovery. We may wish to account for this in the response options to any question about goals.

5.3.2 Responsiveness

An individual is often best placed to notice and evaluate their own stresses and warning signs – service users should be able to access the support they need before they are in crisis, rather than having to wait until they are sufficiently ill to merit emergency care.

Questions in the 2013 questionnaire on responsiveness cover only crisis support (“someone from your local NHS mental health service that you can phone out of office hours”). There is nothing addressing whether service users can step up care without being in crisis, and indeed some service users expressed frustration at not being able to receive care until their symptoms deteriorated dangerously: “You have to be suicidal, but not too suicidal.”

It is important that crisis support is not neglected however, as the crisis support service users do receive when in crisis can also be unresponsive, with some trusts having crisis support lines that are only available Monday-Friday, 9am-5pm, and other crisis services being limited and over-subscribed.

5.3.3 Positive risk-taking

Positive risk-taking gives service users opportunities to work towards positive outcomes in a supportive, risk-aware manner where it is recognised that many potential rewards carry with them an element of risk. This allows service users to work with staff to collaboratively understand and contain the risk, rather than avoiding it entirely.²⁰

Positive risk-taking is an important feature of the recovery approach, and concerns were raised by stakeholders that a regulatory focus on safe-guarding – already a growing feature of service providers’ workloads – and “zero harm” may discourage trusts from supporting service users’ recovery journeys.

Even among service users very familiar with the jargon of mental health services, the language used to discuss positive risk-taking was conflated with risk-assessment, a formal process that has strict guidelines for safeguarding service users. Care must be taken in phrasing questions clearly to cover the intended ground.

5.3.4 Peer support

The recovery approach encourages interdependence – where the individual both supports and is supported by others. This is an important and empowering approach to care and support, where individuals learn and grow through supporting others, feel more able to accept support themselves, and are supported by people who understand what they are going through.

As discussed in Section 4.2, peer support is a vital aspect of the workforce transformation recommended by the IMRoC group.

However, “peer support” can be understood as many different things. At one extreme is the idea that any friendship or supportive dynamic could be peer support, without any kind of formal system or training. At the other extreme is peer support as a skilled position that requires training and is provided only by those with similar experiences who are in recovery

²⁰ Morgan, S. "Positive risk-taking: an idea whose time has come." *Health Care Risk Report* 10 (2004): 18-19 <http://practicebasedevidence.squarespace.com/storage/pdfs/OpenMind-PositiveRiskTaking.pdf>

themselves. Peer support may be provided by volunteers who don't necessarily have experience of mental health issues, or it could be something that requires training and its own support system but anyone can volunteer to do.

The language of peer support itself must also be considered carefully – the term “peer support” was considered too formal and unfamiliar for use in the survey, and surrounding concepts such as “buddies” meant very different things to different stakeholders.

Not all types of peer support could or should be provided within a mental health trust, but workers can signpost service users towards such schemes in the third/voluntary sector or provide the support needed for an individual to develop their own informal network.

5.3.5 Including families

Families should receive education and support from mental health services, but all family involvement in a service user's care, treatment and support must be only with the consent of the service user.

Expert A: It would be nice to see that when someone is in crisis a member of the CMHT would speak to the family, if necessary educate the family about what the person's going through and how they might be able to help.

Expert B: As well as what to look for.

Expert A: As well as what they're going through. ... So they're coming home to a mental health friendly environment.

Expert C: Yes, but with the permission of the service user. Because I would really object if they had called up my parents.

- Experts by Experience

This is also addressed by NICE.

Bear in mind that service users may be ambivalent or negative towards their family for many different reasons, including as a result of the mental health problem or as a result of prior experience of violence or abuse.

- NICE Guidelines

5.4 Service provision

Topics covered in this section are time pressures; transitions and gaps in care; travel; signposting; discharge from services.

5.4.1 Time pressures

Time pressures are experienced by service users in many different ways.

Appointments with workers can feel rushed. There may not be enough time to cover important points, or service users can be made to feel unimportant. Service users spoke warmly of those workers who had “made time” for them.

Service users may find that there is too long to wait between appointments, especially if they do not also have other forms of support available to them. If service users are receiving only a single type of care from specialist mental health services, rather than care through a team, this can be especially striking.

Limited courses of treatment can affect service users’ attitudes to their care. They may be concerned that the care is not long enough to be effective, that there will be other issues that emerge after the course is over, or that they are inhibited by pressure to make best use of the time.

5.4.2 Transitions and gaps in care

Transitions in care for service users can take place as their circumstances or needs change. Needs-based transitions might be between inpatient and community-based care, between crisis care and more long-term services or between primary and secondary care. Circumstance-based transitions might occur when the service user moves house or when services are restructured. The transitions from child and adolescent mental health services (CAMHS) to adult services, and from adult to older adult services can be seen as both needs- and circumstance-based: It is true that needs change with age, but when there is a strict cut-off between the ages of 17 and 18 or between 64 and 65 this may reflect circumstances more than needs.

National Voices²¹ was commissioned by NHS England to develop a narrative of what care transitions and integrated care mean to service users, carers and practitioners. This provided a framework definition of integrated care and help government and regulators establish policy that promotes service coordination and cross-care collaboration. The re-developed survey aims to capture whether or not service users are experiencing such integrated service provision in part through identifying where the experience of integrated care may break down.

Four key themes emerged when covering transition points:

- waiting times;
- intermediate services;
- handover process;
- communication.

Waiting times

One service user described waiting for two years after moving house to receive services from his new mental health trust. Separate services can have their own waiting lists even within trusts, and so the transition process is strongly hindered by the fact that sometimes, what should be a transition is instead a gap.

When the transition is within a single package of care from the point of view of the commissioning body, this may not be considered a waiting time for the commissioner’s purposes, but is still one from the service user’s point of view.

²¹ See the National Voices website: <http://www.nationalvoices.org.uk/coordinated-care>

Intermediate services

The gap is too big between our services and primary care services.

- Service provider

When the response to changing needs is to move the person between services, rather than build the services around the person, it is possible that neither service will be a good fit. One example that was given repeatedly was that service users may require a service between “crisis” and “long term recovery” – this service may not be accessible or may simply not exist.

Handover process

Handovers may take place between services or within services. Some trusts are working to reduce handovers by keeping services within teams, even when “step-up care” is needed - “You pull in the experts, rather than sending [service users] off to the experts” – but handovers can be unavoidable when services are restructured or staff changes.

Service users said their ideal handover process would involve meetings that included them (and perhaps their family/carers), their old team and their new team. The key example of bad handover practice was lack of information sharing: this tied with concerns over continuity of care and the detrimental effect of having to explain problems repeatedly.

Communication

Communication. Between teams, within your own team. Communication needs to be really highlighted, because I think that is a real problem.

- Expert by Experience

Information-sharing more generally was highlighted as a focus for trusts - “Being able to talk about patients rather than simply referring patients” – and a concern for service users. Service users drew a clear distinction between the difficulty of having to get to know a new care worker and the difficulty of having a new care worker who did not have adequate information about their previous care.

5.4.3 Travel

Several trusts expressed concern that service reorganisation and consolidation meant that service users had further to travel for their services. This places additional burdens on the service user, and they were keen to establish whether there were any links between this and broken engagements/missed appointments.

Service users spoke of the difficulties incurred when they had to travel further for services, such as having to miss work and childcare issues, but did not link it to broken engagements.

5.4.4 Sign-posting

The current questionnaire has a series of questions about service users’ wider needs, such as physical health needs, care responsibilities and employment, with the structure, “In the

last 12 months, have you received support from anyone in NHS mental health services in getting help with [specified need]?”

It is not necessarily the job of mental health services to support service users directly with such needs, but it should be their responsibility to help the service user find the resources, where available, to meet these needs. Similarly, peer support services and third sector services may not be the trust's direct responsibility, but if these services are on offer then it is important that service users are informed about and supported to use them.

They should be knowledgeable enough to say, “Oh, there’s a service down the road that offers that. Shall I contact them or do you want to contact them and get the ball rolling?” . . . They could come with you.

- Expert by Experience

Concerns were raised that the language “support ... in getting help” was confusing, and would be misread as asking if NHS mental health services had provided this support directly.

5.4.5 Discharge

The recovery approach aims to move away from a model of dependency on services towards one of empowerment, where discharge is a realistic long-term aim for service users. However, discharge can be a contentious issue in terms of mental health policy and practice.

Many service users viewed discharge as a positive goal. One said that a good care plan would list the steps required to be discharged; another said that for them, discharge was their strongest motivator.

On the other hand, some service users brought up that for them, this can be a disempowering or disingenuous message: disempowering in that it invalidates the experiences and needs of those who do not reach a place where discharge would be appropriate; disingenuous in that it can be used to justify inappropriate withdrawal or transition of services.

One service user said that he was currently being treated by the adult services, but if he was discharged and readmitted, even for exactly the same issues, then he would go to older adult services simply because of his age. This made him not want to be discharged.

Discharge is further complicated by the wider political climate, an issue brought up by several trusts. As resources for helping people back into work become – or are perceived to be – scarcer, and as targets around “benefit frauds” affect back-to-work health assessments, some service users face compelling reasons to avoid these issues by avoiding discharge.

One trust described service users deliberately sabotaging their own discharge “because of the ATOS [back-to-work] assessments”; this trust was in the process of monitoring suicides and near-misses to see if the service users involved had contacted the service recently due to benefits-related stresses.

5.5 Wider life and needs

Public service recognise the wider determinants of mental health and wellbeing (including employment, housing, poverty, education, school truancy, pollution, or crime), including how these differ for specific groups, and address them accordingly

- No Health without Mental Health desired outcome

Service users' wider lives and needs are not possible – or desirable – to disentangle from the previous topics. However, some aspects of these broad topics did not fit into the above themes. This section covers analysis of the 2013 questionnaire, then moves on to the diversity of needs service users may have; physical health needs; finances; “feeling useful” and sense of role; stigmatised and disregarded needs.

5.5.1 Coverage of wider life and needs in the 2013 questionnaire

The 2013 questionnaire has a series of questions in the “Day To Day Living” with the same format: “In the last 12 months, have you received support from anyone in NHS mental health services in getting help with **[certain needs]**?” The needs are:

Q40: Physical health needs

Q41: Care responsibilities

Q42: Finding or keeping work

Q43: Finding and/or keeping accommodation

Q44: Financial advice or benefits

An analysis of the 2012 data revealed that this section has the highest item non-response rate (proportion of respondents who should provide a response but do not) of any section on the questionnaire. See Appendix 2 (page 80).

It is clear from this that these questions and their response options do not connect well with respondents – especially those over the age of 65, who may not see their experiences reflected in this section.

5.5.2 Diversity of needs

[The] move from asking, “What’s the matter?” to, “What matters to you?”

- Professor Sir Bruce Keogh KBE²²

A brainstorming session with the Experts by Experience of possible aspects of “day to day living” produced seventeen different topics, including sex, religion, employment, housing, holidays and pets. This illustrates how diverse and specific an individual’s priorities and life focusses may be.

This is particularly important to bear in mind when designing response options to any question around support for needs, as there are many ways for a need to be “not applicable”. One possible reason for high non-response in the day to day living section of the existing questionnaire is that the response options are not appropriate for respondents: for instance, the question about support getting help with finding or keeping work has “I did not need any support” and “I am unable to work because of my mental health problems” but no specific option for those who are retired, choose not to work, or are unable to work for a physical health reason.

5.5.3 Physical health

Services address mental health service users’ physical health problems.

Services tackle co-morbidity of physical and mental health problems.

- No Health without Mental Health desired outcomes

The link between physical and mental health is made explicitly in the No Health without Mental Health publications. There are two questions on this in the existing questionnaire, but they are particularly likely to be left unanswered by those over 65, who typically are more likely to have physical health needs. It may be that older service users do not experience integrated care in this area, or that they have other sources of support in getting help with their physical health needs.

5.5.4 Financial needs

The thing with work that’s a constant barrier is if you’re not in work then you’re getting benefits, and if you start work then the benefits get withdrawn and it all becomes a mess. It’s a real preventative barrier, the benefits element.

- Expert by Experience

Key areas of financial concern were benefits and benefit changes, financial planning, and risks around money such as over- or under-spending. These were highlighted both by service users and service providers, who have noted an increased need for support in this area.

²² Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report, Prof Sir Bruce Keogh, July 2013, <http://www.nhs.uk/NHSEngland/bruce-keogh-review/Documents/outcomes/keogh-review-final-report.pdf>

One stakeholder suggested that the current question, which asks about “financial advice or benefits” is too broad, as managing finances and navigating benefits are very different things.

5.5.5 “Feeling useful”

Some service users identified work and employment as a key part of their sense of identity and self-respect, whereas others felt judged and stigmatised for not being able to work or not seeing fulltime employment as their ultimate goal. This means that any question which addresses this point must be careful not to imply a judgement as to the relative value of those who do and don’t work.

Older adults, in particular, did not like the conflation of “working” and “feeling useful”.

Family is important, and community. I would call it preservation of role within the family and within the community. It may be important to an older adult to still have a perceived role as the head of the family, to be very active in voluntary work and engaged with society at large, in ways actually that they may take for granted – they may be doing more than they realise. [...] It’s about role, it’s about community and it’s about family.

- Service provider

5.5.6 Stigmatised or disregarded needs

Sex is a really important thing. Just because I’m mentally ill doesn’t mean I don’t want a relationship.

- Expert by Experience

Sex and religion were two needs that some service users felt were under-supported by services, but others did not want to be considered in their care.

Religion and spirituality were very important to some service users, who felt like an overly medical model of mental health care devalued the benefits of faith. Others felt their religious beliefs were private, and some did not want to feel pressured to consider something they felt had no role in their lives.

These topics are sensitive, which may in itself be a justification for not including them on the questionnaire, but they are also important to some service users.

COGNITIVE TESTING

Following the development of a draft survey, cognitive interviews were carried out to test the questionnaire and refine the questions. Service users with a range of mental health needs participated in one-to-one interviews, in which they completed the questionnaire and answered probes about their thought processes and the context of their answers. This process ensures that the questions are clear, relevant and consistently understood.²³

Section 6 - Participants gives a demographic breakdown of the service users who took part.

Section 7 - Distinguishing between primary and secondary care outlines key challenges in ensuring that the questionnaire adequately captures the experience of those whose services are integrated across primary and secondary care.

Section 8 - Summary of changes gives a table of all questions in the 2014 questionnaire, a table of all new questions tested but not included in the 2014 questionnaire, and a table of all questions removed with no replacement from the 2013 questionnaire.

Section 9 - Question testing covers the findings of the process, including the details of all changes made and recommendations for each question.

²³ See, for instance, Pam Campanelli, *Testing Survey Questions: New Directions in Cognitive Interviewing* (1997) *Bulletin de Methodologie Sociologique*, 55, 5-17
<http://www.ccsr.ac.uk/courses/congnitiveInterviewing/documents/CampanelliArticle.doc>

6. Participants

44 cognitive interviews were carried out between 21st October and 28th November 2013 in Oxford, London and Daventry with service users with a range of mental health needs.

Participants were recruited by advertisements in local papers, online at Gumtree and in visits to Mind drop-in centres. We would like to thank Daventry Mind and Oxfordshire Mind for their help and support with this.

The participant breakdown was as follows:

Gender:

- 22 women
- 21 men
- 1 person who identified as both male and female

Age:

- 7 people aged 18-35
- 16 people aged 36-50
- 16 people aged 51-65
- 2 people aged 66+
- 3 not stated

Ethnic background:

- 38 white
- 1 black
- 1 Indian
- 1 Middle Eastern
- 3 not stated

Location:

- 27 Oxford
- 10 Daventry
- 7 London

7. Distinguishing between primary and secondary care

An individual's mental health care can be integrated between primary and secondary providers in a variety of ways, depending on their needs, the structure of the providers, and local policy and best practice. (*Section 4.2 - Patterns of service provision.*)

Many service users do not distinguish easily between primary and secondary mental health services. We encountered this problem when screening people for participation: many service users correctly regarded their GP as an important part of their NHS care for mental health, and in two cases it was not clear even after detailed discussion whether certain non-GP services received at a GP surgery were primary or secondary.

Even after the screening process, which may have focussed the participants on the distinction between their GP and other services, many participants talked about services from their GP and from secondary providers interchangeably, depending on which they thought was most appropriate.

We have added instructions at the start of each section (apart from the two discussed below and the demographic section, "About You") to remind people not to include their GP. These were successful with those participants who noticed them, and did not confuse or mislead anyone, but were not read by all participants.

7.1 Organising your care

Some service users have their care coordinated by their GP. We feel it is appropriate to take this into account and make sure that we gather information about whether or not the person under discussion is the GP or another health professional.

To this end, the section begins with the instruction "In this section, **you may** include contact with your GP." One question asks what role the lead professional/care coordinator has, with GP being one of the response options.

7.2 Medicines

Prescription and monitoring of medicines is extremely integrated for some service users. Many participants described having their medicines decided or suggested by someone from secondary services but actually prescribed by their GP. Some participants said their GP was responsible for all decisions about their medicines, but had to inform their secondary service staff about any decisions made. Some people had their medicines prescribed exclusively in a secondary setting, some in a primary setting. One participant had regular injections from a primary care nurse of medicine which had been prescribed in a secondary setting.

We have introduced the instruction "Please **do not** include medicines prescribed only by your GP in this section." This was well understood by those participants who noticed it, but not all did.

Even if the instruction is perfectly understood, there is still an attribution issue here: whose responsibility is it to make sure that the service users are involved in decisions about medicines, are given understandable information, and have their medicines reviewed? A decision must be made if and how secondary providers can be scored on these questions.

8. Summary of changes

8.1 Introduction

The majority of questions in the proposed 2014 questionnaire (Appendix 3, page 81) are new or have been modified from the 2013 questionnaire (Appendix 4, page 89) to reflect concerns about language highlighted in *Section 4.1 - Question framing and language*.

Filtering instructions are not included in the text below, but can be seen in the proposed questionnaire. These were noticed by some but not all of the participants. This is often observed in cognitive testing and reflected in the raw data collected; data cleaning ensures that answers are not counted where respondents have indicated the question is not applicable²⁴.

8.2 Questions recommended for the 2014 questionnaire

Question number in 2014	Related question(s) in 2013	Question text 2014	See page
1	1	When was the last time you saw someone from NHS mental health services ?	
2	2	Overall, how long have you been in contact with NHS mental health services?	
3	NEW	In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs?	40
4	NEW	How easy was the actual journey to see this person or people?	41
5	4	Did the person or people you saw listen carefully to you?	
6	8	Were you given enough time to discuss your needs and treatment?	
7	NEW	Did the person or people you saw understand how your mental health needs affect other areas of your life ?	42
8	19	Have you been told who is in charge of organising your care and services?	43
9	NEW	Is the person in charge of organising your care and services...	44
10	20	Do you know how to contact this person if you have a concern about your care?	45
11	21	How well does this person organise the care and services you need?	
12	22-25,27	Have you agreed with someone from NHS mental health services what care you will receive?	46
13	22-25,27	Were you involved as much as you wanted to be in agreeing what care you will receive?	46

²⁴ See, for example, *Guidance on Data Cleaning for the NHS Community Mental Health Service Users Survey 2013*: <http://www.nhssurveys.org/survey/1320>

14	22-25,27	Does this agreement on what care you will receive take your personal circumstances into account?	47
15	28	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?	48
16	29-33	Were you involved as much as you wanted to be in discussing how your care is working?	49
17	29-33	Did you feel that decisions were made together by you and the person you saw during this discussion?	49
18	NEW	In the last 12 months , have the people you see for your care or services changed?	50
19	NEW	What impact has this had on the care you receive?	51
20	NEW	Did you know who was in charge of organising your care while this change was taking place?	51
21	34	Do you know who to contact out of office hours if you have a crisis?	52
22	35	In the last 12 months , have you tried to contact this person or team because your condition was getting worse?	
23	36	When you tried to contact them, did you get the help you needed?	
24	9	In the last 12 months, have you been receiving any medicines for your mental health needs?	53
25	10	Were you involved as much as you wanted to be in decisions about which medicines you receive?	54
26	11	In the last 12 months, have you been prescribed any new medicines for your mental health needs?	55
27	12-14	The last time you had a new medicine prescribed for your mental health needs, were you given information about it in a way that you were able to understand?	55
28	15	Have you been receiving any medicines for your mental health needs for 12 months or longer?	56
29	16	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?)	57
30	17-18	In the last 12 months, have you received any treatments or therapies for your mental health needs that do not involve medicines?	58
31	NEW	Were you involved as much as you wanted to be in deciding what treatments or therapies to use?	59
32	39-40	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)?	60
33	44	In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits ?	60

34	42	In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding or keeping work ?	60
35	43	In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding or keeping accommodation ?	60
36	NEW	Has someone from NHS mental health services supported you in taking part in an activity locally?	65
37	46	Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?	67
38	NEW	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?	66
39	NEW	Do the people you see through NHS mental health services understand what is important to you in your life?	68
40	NEW	Do the people you see through NHS mental health services help you with what is important to you?	68
41	NEW	Do the people you see through NHS mental health services help you feel hopeful about the things that are important to you?	68
42	45	Overall...	69
43	7	Overall in the last 12 months, did you feel that you were treated with respect and dignity by NHS mental health services?	69
44	47	Who was the main person or people that filled in this questionnaire?	72
45	48	Are you male or female?	
46	49	What was your year of birth ?	
47	53	What is your religion?	
48	54	Which of the following best describes how you think of yourself?	
49	55	What is your ethnic group?	

8.3 New questions tested but not included

Question topic	Question text	See page
Care transitions	Did the new person or people know your care history?	52
Therapies and treatments	How did you feel about the length of time it took before you started the treatments or therapies?	59

Integrated care	To what extent do you agree or disagree with the following statement... 'Health and social care staff always ensure I know what will happen next'	70
Integrated care	Do all the different people treating and caring for you work well together to give you the best possible care and support?	70

8.4 Questions removed from the 2013 questionnaire with no replacement

Question number in 2013	Question text	Reason for removal
3	Which of the following NHS healthcare workers or social care workers have you seen most recently for your mental health condition ?	This has a very high item non-response rate, indicating it does not connect well with respondents. It does not reflect the current structure of service provision.
5	Did this person take your views into account?	Very high (polychoric) correlation between answers to Q4-Q8 (in 2013): These questions are measuring the same underlying concept, so some are redundant. Moving them apart may help reduce the correlation if this is partly an effect of their appearing together. Q4(2013) and Q8(2013) are now Q5(2014) and Q6(2014); Q7(2013) has been moved to the end of the questionnaire.
6	Did you have trust and confidence in this person?	
26	Does your NHS care plan cover what you should do if you have a crisis (e.g. if you are not coping or if you may need to be admitted to a mental health ward)?	This was understood by participants during cognitive testing to refer to a phone number or other contact details rather than a crisis plan. It is redundant given Q21(2014). See page 47.
37	Has anyone in NHS mental health services ever asked you about your alcohol intake?	The only two (scored) questions in 2013 with absolutely no correlation between their score and the overall satisfaction score.
38	Has anyone in NHS mental health services ever asked you about your use of non-prescription drugs?	
41	In the last 12 months, have you received support from anyone in NHS mental health services in getting help with your care responsibilities (including looking after children)?	Some participants during cognitive testing understood this question to refer to care of themselves rather than care they provide for others. While this is an important topic for service users, the question cannot be included without further redesign.

50	In general, how is your mental health right now ?	This question is of a sensitive nature and is not used in routine CQC analysis. It does not provide useable information, as a single self-reported scale question is unlikely to be an accurate assessment.
51	Have you been admitted to a hospital as a mental health patient in the last 12 months?	This is an extremely sensitive question with no clear use. In 2013, only 13% of respondents said they had been admitted once or more, so trust-level disaggregation of results by this answer would not be appropriate.
52	Are you currently in paid work?	In 2013, 40% (a plurality) picked "No, other reason" -- the response options are clearly not effective, and this is a sensitive question

9. Question testing

Most questions underwent three rounds of testing (Rounds 1-3). However, a fourth round of testing was recommended for the “Other Areas of Life” questions, as these questions were not working as intended but had been highlighted as a very important area in the consultation work.

Changes made as a result of testing have been highlighted in underlined red text.

Q3: Frequency of contact (new)

Service users feel that their contact with NHS mental health services can be too limited in terms of frequency, length of appointments and number of instances of contact (eg only six or only twelve sessions of therapy). See *Section 5.4.1 - Time pressures* for more details.

This question is intended to address the first of the three, which is that people do not have contact often enough.

Round 1:

Do you feel your contact with NHS mental health services is **often enough** for your needs?

- Yes, definitely
- Yes, to some extent
- No
- It is too often
- Don't know

This question was generally understood well, with participants thinking about how frequently they felt they personally needed to be seen for services to be effective and helpful. However, two participants understood this to be asking about how good services were at **contacting** them.

Rounds 2 & 3:

Do you feel you see NHS mental health services **often enough** for your needs?

[No change to response options]

The wording worked well, but in this round some respondents answered over their entire experience of mental health care. To make this question usable by regulators and service providers, we recommend focussing the question on the last 12 months. The proposed change in wording will, in our experience, not alter how service users connect with the question.

Recommendation:

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

[No change to response options]

Q4: Ease of travel (new)

Service users and service providers both raised concerns that reorganisation and consolidation of services might make it harder for service users to get to them. (*Section 5.4.3 - Travel.*)

This question is intended to allow us to track this issue over future changes.

Round 1:

How long did it take you to travel to see this person or people?

- I did not have to travel
- Less than 30 minutes
- More than 30 minutes but less than 1 hour
- More than 1 hour but less than 2 hours
- More than 2 hours
- Don't know / can't remember

Concerns were raised by stakeholders that this question might reflect service user choice rather than ease of travel. This was confirmed in testing: one participant chose to be seen further away; several participants chose modes of travel that added to the length of their journey.

Round 2:

How easy was the journey to see this person or people?

- I found it easy to get there
- I found it somewhat easy to get there
- I found it hard to get there
- I did not have to travel
- Don't know / can't remember

One participant connected this explicitly with the figurative “patient journey”, asking whether the question meant literal travel or the entire process. Another connected this to the “patient journey” implicitly, thinking about how hard it had been for her doctor to understand her needs.

Round 3:

How easy was the actual journey to see this person or people?

[No change to response options]

This question tested well and was easily understood by all participants.

Recommendation: Keep as in Round 3.

Please note: We do not recommend that this question is “scored” – it is not fair to compare providers on this, as they have very different geographic and demographic features which cannot be controlled for. This is not a performance issue and is not actionable by providers, but it is important to monitor over time to understand how service users are actually experiencing changes to services.

Q7: Staff understanding of the service user as a “whole person” (new)

An important aspect of the relationship between service users and staff was staff’s understanding of service users’ lives as a whole, with the interaction between their mental health and the rest of their life clearly understood. (*Section 5.2.3 - Quality of relationships.*)

Two versions of this question were tested each round – half of the questionnaires had Version A, half had Version B. The different versions were proposed because concerns were raised that people might relate Version A to issues of social stigma even if this is not a priority for them.

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

- Yes, definitely
- Yes, to some extent
- No
- Don’t know/ can’t remember

B. Did the person or people you saw **understand** how your treatment affects other areas of your life?

- Yes, definitely
- Yes, to some extent
- No
- Don’t know/ can’t remember

“Other areas of your life” connected well with participants: each person thought of those parts of their life that were most important to them, such as family, housing, aspirations or “getting my life back”.

In some cases, Version B was connected explicitly with medicines or therapy, with participants talking about how their medicines’ side effects affected their life, or how timetabling therapy was difficult; whereas in other cases it was more generally understood to refer to their mental health as a whole.

Version A was consistently understood to refer to the participants’ mental health as a whole and how this affected what was important to them personally; stigma was not referenced.

Recommendation: Version A.

Introduction to “Organising Your Care”

The introductory text for this section has been tested with both

Version A: “In this section, **you may** include your GP” (Rounds 2 & 3)

and

Version B: “In this section, **you should** include your GP” (Round 4)

There were no problems identified with Version A. However, one participant in the additional round noticed this text and said that she could not answer this section because she did not have a GP.

Recommendation: Version A.

Q8: Care coordination(1) (modified)

This question is intended to replace the 2013 question on care coordinators (Q19) with language that is easier to understand and not linked to NHS terminology.

Round 1

Do you know 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”.)

- Yes
- No
- Not sure

Some participants understood this to refer to their service provider such as the NHS trust or other organisation that overall “organised” their services.

Some participants tried to guess who their care coordinator might be. One asked if it might be her as she had self-referred to her current service.

Round 2

Added “In this section, **you may** include contact with your GP.” (See discussion in *Section 7.1 - Organising your care* for more details.)

Do you know **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”.)

[No change to response options]

Participants now understood this to be referring to a single person, but many of them tried to guess who it might be based on their knowledge of their services.

Round 3

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”.)

[No change to response options]

We are conscious that the language here of “being told” might be seen as part of a top-down model of care. However, this wording worked well for the participants, who did not try to guess who this person might be, and appeared to be happier selecting the “No” and “Not sure” options.

One participant understood the person in charge to be a practice manager rather than an individual care coordinator, but otherwise this was consistently understood to refer to a care coordinator/lead professional.

Recommendation: Keep as in Round 3.

Q9: Care coordination(2) (new)

This question is intended to understand whether responsibility for organising service user's care lies in the primary or secondary sphere, as described in *Section 7.1 - Organising your care* above. It is unlikely that further subdivision of result for analysis will be practical or useful, as the expected size of response groups would be too small to allow for appropriate statistical analysis.

Round 1 & 2

Is this person...

- A CPN (Community Psychiatric Nurse)
- A psychotherapist / counsellor
- A social worker
- A psychiatrist
- A mental health support worker
- A GP
- Another type of NHS health or social care worker
- Don't know

One participant in Round 2 ticked multiple boxes, reflecting all the staff she saw.

Round 3

Is the person in charge of organising your care and services...

[No change to response options]

The question was consistently understood to refer only to care coordinator/lead professionals, but one respondent still selected two boxes, reflecting the fact that he saw both his GP and his therapist as leading on his care.

Recommendation: Keep as in Round 3, but ask survey providers to enter the data for this question as a multicode / multiple response (that is, providers record all boxes that have been ticked), so we can understand how the question is being answered by those who tick more than one box.

Please note: In the 2013 questionnaire, the response options of Q3 have a similar format and the instruction to “tick one box only” is prominently displayed – however, over 10% of respondents still tick more than one box. We therefore do not think that adding the instruction here will prevent the same.

Q10: Care coordination(3) (modified)

This question is intended to replace Q20 in the 2013 questionnaire.

Round 1

Do you know how to contact this person if you have a problem?

- Yes
- No
- Not sure

Some participants understood “a problem” to mean a crisis or other sudden deterioration in their mental health, rather than a problem with the organisation of their care.

While it was not raised by any participants in the first round, we noted that it was possible someone could know how to contact their care coordinator – for instance, having a phone number for them – but not actually be able to do so when needed. We therefore decided to explore the possibility of accounting for this in the response options.

Round 2 & 3

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

- Yes
- Yes, but they are not always available
- No
- Not sure

The wording “a concern about your care” was well-understood by participants to mean a problem with care organisation or care provision.

The new response option, however, was inconsistently understood by participants. Of those who could only contact their care coordinator within office hours, some selected “Yes” and some selected “Yes, but they are not always available”.

Recommendation: Keep question wording from Round 2& 3 but response options as in Round 1.

Q12: Plan of care(1) (new)

This question is intended to replace the question about care plans (Q22) on the 2013 questionnaire. During the consultation phase of the redevelopment work, we found it was extremely problematic to refer explicitly to care plans. For example, some service users received documents with the title 'care plan' meaning that they technically had a care plan but did not mean that they understood them or knew what was included. From the consultation it was clear that what was important to service users was knowing what care they would receive. (*Sections 4.1.2-4.1.4 on language use.*)

Round 1 & 2

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

- Yes, definitely
- Yes, to some extent
- No

Some participants answered thinking of an agreement with their GP or a voluntary sector organisation.

Round 3

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

[No change to response options]

This question was well understood by participants, although one participant selected "No" because he had not agreed with what had been decided for him.

It must be noted that it is not equivalent to a question about care plans: service users can have a care plan but not know what care they will receive or service users can have had a verbal plan of care. The new question reflects service user priorities as revealed in the consultation work.

Recommendation: Keep as in Round 3.

Q13: Plan of care(2) (modified)

This question worked well in all rounds. It is intended to replace Q23 of the 2013 questionnaire, but instead of asking if the service user's views were "taken into account", it reflects a more collaborative and person-centred approach. (*Section 4.1.1 - Recovery approach.*)

Rounds 1, 2 & 3:

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

- Yes, definitely
- Yes, to some extent
- No but I wanted to be
- No but I did not want to be
- Don't know / can't remember

Recommendation: Keep as in Round 1.

Q14: Personalisation of plan of care (new)

This question is modelled on question F9 from the 2013 Maternity questionnaire. In the first two rounds, it followed the question on crisis planning (below); in the third, it was adapted to follow the questions on more general plans of care, to test if it would work if the crisis planning question that originally preceded it was removed.

Round 1

Does this agreement on what to do in a crisis take your personal circumstances into account?

- Yes, definitely
- Yes, to some extent
- No

Round 3

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

- Yes, definitely
- Yes, to some extent
- No
- Don't know / can't remember

In all cases, the question tested well and reflected an issue of importance to the participants. Personal circumstances included family responsibilities and childcare, housing and homelessness, individual reactions to stressful situations, preferred methods of communication and many other diverse concerns.

Recommendation: Keep as in Round 3.

N/A: Crisis planning (remove)

Q26 in the 2013 questionnaire asks if the respondent's care plan covers what to do in a crisis. The proposed 2014 questionnaire explicitly does not consider care plans, but this question attempted to capture the same information: whether there was an agreed plan in place in case of a crisis, even if this was not a formal crisis plan.

Round 1, 2 & 3

Have you agreed with someone from NHS mental health services what will happen if you have a crisis?

A crisis is if you need urgent help because your mental or emotional state is getting worse very quickly.

- Yes, definitely
- Yes, to some extent
- No

This question was not consistently understood by participants. Most referred simply to whether or not they had a phone number to call (which is covered in Q21-23 of the proposed questionnaire), but some referred to a more formal crisis plan or access to a crisis refuge.

Recommendation: Remove.

Q15: Care review(1) (modified)

This question has been adapted from Q28 in the 2013 questionnaire, which is on formal care reviews.

Round 1

In the last 12 months have you met with someone from NHS mental health services to review the care you receive?

- Yes
- No
- Don't know / can't remember

Participants associated this question with any discussion of care and, in some cases, with any discussion of their own health and well-being, including assessments.

Round 2

Added "REVIEWING YOUR CARE" heading.

In the last 12 months have you met with someone from NHS mental health services to discuss how your care is working?

[No change to response options]

Participants no longer associated this with assessments or reviews of their own health, but did still identify this as any discussion of how care was working, rather than a formal care review process.

Round 3

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?

[No change to response options]

This connected better with a care review process for those participants who had either had a care review in the past or knew about them. However, it did not connect well with all participants: two still answered “yes” thinking only of discussions of how care was working, rather than an actual care review meeting.

Note that the 2013 question wording is:

A care review is a meeting between you and staff from NHS mental health services to discuss how your care has been working.

In the last 12 months have you had a care review meeting to discuss your care?

Given the way participants thought about the questions we trialled, we do not think they would connect better with this, and it runs more risk of becoming dated if service providers stop using the term “care review.”

Recommendation: Keep as in Round 3.

Q16 & Q17: Care review(2,3) (modified/new)

These questions are intended to replace Q29-Q33 of the 2013 questionnaire, but – as with Q13 above – instead of asking if the service user’s views were “taken into account”, they reflect a more collaborative and person-centred approach. (*Section 4.1.1 - Recovery approach.*)

Round 1

Were you involved as much as you wanted to be in reviewing your care?

- Yes, definitely
- Yes, to some extent
- No but I wanted to be
- No but I did not want to be
- Don't know / can't remember

Did you feel that decisions were made **together** by you and the person you saw during your review?

- Yes, definitely

- Yes, to some extent
- No
- I did not want to be involved in making decisions
- Don't know / can't remember

These questions worked well in all rounds, but were adapted in rounds 2 and 3 to fit the wording of Q16 (above).

Round 2 & 3

Were you involved as much as you wanted to be in discussing how your care is working?

[No change to response options]

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

[No change to response options]

Recommendation: Keep as in Round 3.

Q18: Care transitions(1) (new)

The questions on transitions and other changes to who is seen for care have been introduced following the stakeholder consultation. (*Section 5.2.2 - Continuity of relationships; Section 5.4.2 - Transitions and gaps in care.*)

Round 1

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

- Yes
- Yes, but this was because I moved home
- No

Some participants did not know if starting care counted as a change. Not all participants answered this question thinking about the last twelve months.

Round 2

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

- Yes
- Yes, but this was because I moved home
- No
- My care has started but not changed

Two participants asked if stopping care counted as a change.

Round 3

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

Please **do not** include stopping care completely.

[No change to response options]

This question was largely well-understood, but one participant did not see all members of his team regularly enough to know if some of them had changed.

Recommendation: Keep as in Round 3, but add a “Don’t know” response option.

Please note: We do not recommend this question is scored, as the reasons for changing may be positive (transition of care as appropriate) or at the service user’s request.

Q19: Care transitions(2) (new)

Rounds 1, 2, 3

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

- It got better
- It stayed the same
- It got worse
- Not sure

This question was well-understood by participants, and did not require any changes.

Recommendation: Keep as in Round 1.

Q20: Care transitions(3) (new)

Rounds 1, 2, 3

Did you know who was in charge of organising your care while this change was taking place?

- Yes
- No
- Not sure

This question was well-understood by participants, and did not require any changes.

Recommendation: Keep as in Round 1.

N/A: Care transitions(3) (do not include)

During the consultation process, service users highlighted the problem of having to tell their story again every time they saw a new member of staff. This question was intended to address this problem.

However, the question was generally understood by participants to be connected to whether the care worker had access to their notes – several people said they assumed this must be the case, as everything was on computer now.

Rounds 1 & 2

Did the new person or people know your care history?

- Yes, definitely
- Yes, to some extent
- No
- Not sure

Round 3

Did the new person or people know your care history?

- Yes, definitely
- Yes, to some extent
- No
- Not sure / don't know

Recommendation: Do not include.

Q21: Crisis care(1) (modified)

This question is adapted from Q34 in the 2013 questionnaire to be about all forms of access to crisis care, rather than just a phone number. This connected well with those participants who had access to walk-in crisis care, and continued to work well for those who had a phone number.

Round 1

IF YOUR CONDITION GETS WORSE

These questions are about what happens if you are having urgent problems. You may have been given a number to contact, such as a “Crisis Helpline” or a “Crisis Resolution Team”

Do you know who to contact out of office hours if your condition is getting worse?

This could be a person or a team.

- Yes
- No
- Not sure

Some participants did not refer exclusively to mental health services, for example, some thought of the Samaritans and, in one case, a family member.

Round 2

Do you know who to contact out of office hours if your condition is getting worse?

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

[No change to response options]

This question was not understood to be referring exclusively to crisis care, but to more general deterioration in symptoms. One participant who was over 70 associated this with her “red button” crisis contact for physical crises such as falls.

Round 3

CRISIS CARE

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”.

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**.

[No change to response options]

This question was well understood.

Recommendation: Keep as in Round 3.

Q24: Medicines(1) (modified)

This question has been adapted from Q9 in the 2013 questionnaire, which asks if participants have taken prescribed medicines. Stakeholders raised the issue that not everyone who is prescribed medicines takes them although it should be noted that 89% of respondents answered “yes” to the 2013 question.

References to “medications” have been changed to “medicines” as this was viewed by stakeholders as less stigmatising. Participants understood this wording easily.

Please see *Section 7.2 - Medicines* for more notes on integrated care and medicine.

Round 1

In the last 12 months, have you been prescribed any medicines for your mental health needs?

Yes

No

Participants answered this question largely thinking about if they had been **first** prescribed these medicines in the last twelve months – so, for instance, did not include medicines they had been taking for longer than a year.

Round 2

Please **do not** include medicines prescribed by your GP in this section.

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

[No change to response options]

Participants now understood the question to refer to all medicines they were prescribed, including those that had been first prescribed over a year ago. However, some participants had medicines prescribed jointly by primary and secondary services (as discussed in *Section 7.2 - Medicines*) and so did not know whether they should include these.

Round 3

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

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

[No change to response options]

This question was well understood by participants, with one participant noticing the word “only” in the instruction and connecting this with his experiences of joint prescription. However, not all participants noticed the instruction.

In no rounds did any participants include non-prescription medicines.

Recommendation: Keep as in Round 3.

Q25: Medicines(2) (modified)

This question was modified to work with Q26 (above) in Rounds 2 & 3. It tested well and was easily understood.

Round 1

Were you **involved** as much as you wanted to be in decisions about which medicines were prescribed?

- Yes, definitely
- Yes, to some extent
- No but I wanted to be
- No but I did not want to be
- Don't know/ can't remember

Rounds 2 & 3

Were you **involved** as much as you wanted to be in decisions about which medicines you received?

[No change to response options]

Recommendation: Keep as in Round 3.

Note: In the final questionnaire, this has been amended to “Were you **involved** as much as you wanted to be in decisions about which medicines you **receive**?”

Q26 & Q27: New medicines(1,2) (modified)

The 2013 questionnaire contained four questions on new medicines: one filter question (Q11) asking if new medicines had been prescribed in the last 12 months, and three (Q12-14) asking if the purpose was explained, information about side effects was given, and if the information was given in a way that was “easy to understand”. These questions were extremely highly correlated, implying they were measuring the same underlying concept.

It was also noted that asking people if something is “easy to understand” asks them to guess how other people might view the information, whereas we are most interested in their personal experience of whether or not they could understand it.

Round 1

The last time you had a new medicine prescribed for your mental health needs, were you given **information** about it in a way that you were able to understand?

- Yes, definitely
- Yes, to some extent
- No
- I was not given any information
- I have not been prescribed any new medicines

This question attempted to condense all four questions on the 2013 questionnaire into one. However, it did not put a time constraint on the last time a new medicine was prescribed and so some participants referred to instances more than a year ago.

Round 2

In the last 12 months, have you been prescribed any **new medicines**?

Yes _____

No _____

The last time you had a new medicine prescribed for your mental health needs, were you given **information** about it in a way that you were able to understand?

Yes, definitely

Yes, to some extent

No

I was not given any information

I have not been prescribed any new medicines

Some participants thought of medicines not prescribed for mental health needs.

Round 3

In the last 12 months, have you been prescribed any **new medicines** for your mental health needs?

Yes

No

The last time you had a new medicine prescribed for your mental health needs, were you given **information** about it in a way that you were able to understand?

Yes, definitely

Yes, to some extent

No

I was not given any information

~~I have not been prescribed any new medicines~~

This question tested well.

Recommendation: Keep as in Round 3.

Q28: Ongoing medicines(1) (modified)

This question was adapted to be consistent with previous questions. It tested well in all rounds.

Round 1

Have you been prescribed any medicines for your mental health condition for 12 months or longer?

- Yes
- No
- Not sure

Round 2

Have you been receiving any medicines for your mental health condition for 12 months or longer?

[No change to response options]

Round 3

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

[No change to response options]

Recommendation: Keep as in Round 3.

Q29: Ongoing medicines(2) (modified)

Round 1 & 2

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?)

- Yes
- No
- Don't know / can't remember

This was well understood, but some participants thought of their GPs.

Round 3

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?)

[No change to response options]

This was well understood, but one participant thought of his GP.

Recommendation: Keep as in Round 3.

Q30: Therapies and treatments(1) (new)

The 2013 questionnaire has two questions on talking therapies (Q17, Q18). Q17 asks if respondents have had any talking therapy through the NHS; Q18 asks if they found it was helpful. These are not considered actionable by service providers, and are inconsistent with the rest of the questionnaire, which does not cover outcomes.

The proposed questions on therapies and treatments are intended to cover all therapies and treatments that are not medication, not simply talking therapies. This was well understood by participants, although they largely thought of talking therapies such as CBT and counselling.

Round 1

In the last 12 months, have you been offered any treatments or therapies that do not involve medicines?

- Yes
- No but I would have liked this
- No but I did not mind
- This was not appropriate for me
- Don't know / can't remember

Participants asked what they should put if they had started to receive therapy in the last 12 months, but were originally put on the waiting list more than 12 months ago. We therefore tried to incorporate this into the next round.

Round 2

In the last 12 months, have you been offered or received any treatments or therapies that do not involve medicines?

[No change to response options]

One participant connected this question with physical therapy for an injured wrist.

The question in Round 2 asks about two different concepts at the same time – being offered treatments or therapies and receiving treatments or therapies. This reduces the usability of any data gathered from it, and so we removed “offered” from the question, as it was revealed to be problematic in Round 1.

Round 3

In the last 12 months, have you ~~been offered or~~ received any **treatments or therapies** for your mental health needs that do not involve medicines?

[No change to response options]

This question tested well – indeed, one participant who had received physical therapy explicitly commented that this question was not asking about that.

Recommendation: Keep as in Round 3.

Please note: The above questions do not explicitly mention NHS mental health services. However, there was no evidence of participants thinking of private therapy or treatments, and we believe that adding “from NHS mental health services” will make the question sufficiently longer and more complicated that it may distract from the three key features of the question: time period, what the therapy/treatment was for, not involving medicines.

Q31: Therapies and treatments(2) (NEW)

Round 1:

Were you involved as much as you wanted to be in deciding what treatments or therapies to use?

- Yes, definitely
- Yes, to some extent
- No but I wanted to be
- No but I did not want to be
- Don't know / Can't remember

This question was well-understood by participants, and did not require any changes.

Recommendation: Keep as in Round 1.

N/A: Therapies and treatments(3) (do not include)

Waiting times and access are important issues to service users, regulators and policy makers. (*Section 5.4.2 - Transitions and gaps in care.*) However, the following question could not measure well how service users experience waiting times for therapy and other treatments for two reasons.

Firstly and most importantly, this question appears to be measuring a complicated interplay between attitudes towards the NHS and service users' own experiences of care – some participants said they were lucky to even be on a waiting list and knew they had to be patient; one even altered his response so it wasn't seen as a “grumble”.

Secondly, this question does not work well within a timeframe. Some participants were on waiting lists for well over a year.

Round 1 & 2

How did you feel about the length of time it took before you started the treatments or therapies?

- It was as soon as I felt was necessary
- I felt it should have been a bit sooner
- I felt it should have been a lot sooner
- I have not started any treatments/therapies yet
- I did not start any treatments/therapies

Don't know / can't remember

Round 3

How did you feel about the length of time it took before you started the treatments or therapies?

- It was as soon as I felt was necessary
- I felt it should have been a bit sooner
- I felt it should have been a lot sooner
- I have not started any treatments/therapies yet
- I did not start any treatments/therapies
- Don't know / can't remember

Recommendation: Do not include.

Q32-36: Other areas of life (modified)

These questions have been adapted from Q40-44 to be clear and consistent. For a full discussion of these questions, please see *Section 5.5 - Wider life and needs*.

Round 1

The following are areas of life where some people need help or support. For each area, NHS mental health services may have helped you to find any support you needed.

In the last 12 months, did NHS mental health services help you **to find support** with...

...**care responsibilities** (including looking after children)?

- Yes, definitely
- Yes, to some extent
- No, but I would have liked support
- I did not need support
- This does not apply to me

...**physical health needs**?

- Yes, definitely
- Yes, to some extent
- No, but I would have liked support
- I did not need support

This does not apply to me

...**finding or keeping work?**

- Yes, definitely
- Yes, to some extent
- No, but I would have liked support
- I did not need support
- This does not apply to me

...**finding or keeping accommodation?**

- Yes, definitely
- Yes, to some extent
- No, but I would have liked support
- I did not need support
- This does not apply to me

...**financial advice or benefits?**

- Yes, definitely
- Yes, to some extent
- No, but I would have liked support
- I did not need support
- This does not apply to me

Participants did not always understand the term “physical health needs”.

Round 2

...**physical health needs** (including illness, disability and long term physical conditions)?

[No change to response options]

One participant explicitly connected the word “illness” with her mental ill health.

Round 3

The following are areas of life where some people need help or support. For each area, NHS mental health services may have helped you to **find** any support you needed.

In the last 12 months, did NHS mental health services **help with finding support** for ...

...**care responsibilities** (including looking after children)?

[No change to response options]

...**physical health needs** (this might be an injury, a disability, or a condition such as diabetes, epilepsy, etc)?

[No change to response options]

...**financial advice or benefits**?

[No change to response options]

Still thinking in the last 12 months, did NHS mental health services help with finding support for...

...**finding or keeping work**?

[No change to response options]

...**finding or keeping accommodation**?

[No change to response options]

The intention of these questions is to measure how well trusts **signpost** their service users to resources – helping them find state and third sector organisations that can help them, or indeed affordable and practical private solutions. However, participants in the first three rounds responded thinking of times when NHS mental health services had supported them directly – and often selected “This does not apply to me” when they did not think the support they needed was within NHS mental health services’ remit.

There was only one instance in all 37 interviews over the first three rounds where a participant referenced signposting – she had been helped to find childcare to cover her therapy sessions. This is striking because even then she did not think of the possibility of signposting when addressing the physical health question. When asked if she needed support for a physical health issue she’d mentioned earlier, she said, “Not from mental health [services], no.”

In the first three rounds, some participants did not limit themselves to thinking of the last year. It is possible that adding the stem to each question might help, but this would require further testing. It is certainly the case that the 2013 questionnaire presented each question complete with stem (eg “Q43 In the last 12 months, have you received support from anyone in NHS mental health services in getting help with **finding and/or keeping your accommodation**?”) and this did not ensure that respondents thought about signposting.

Round 4

Introductory Text

OTHER AREAS OF LIFE

Please **do not** include help from your GP in this section.

The following are areas of life where some people need help or support. For each area, NHS mental health services may have helped you to **find** any support you needed.

Support might have been provided by NHS mental health services, or it might have been provided by another organisation – such as social services, a charity or a community group. If support was provided by someone else, we are interested in whether NHS mental health services **helped you to find this support** from them.

The majority of the participants appeared to read the instructions carefully, although some participants skipped them. No one asked for help understanding or interpreting the wording.

Care Responsibilities

In the last 12 months, did NHS mental health services give you any **help or advice** with **finding support** for **care responsibilities** (including looking after children)?

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

None of the participants had care responsibilities, such as looking after children, parents, partners or other family members. However, three of the seven participants answered this question explicitly thinking of care for themselves as a care responsibility, with another two selecting answers that implied they did have care responsibilities, although it was not clear why. Two participants answered the question explicitly thinking about childcare.

However, participants did understand this question to refer to help or advice they had been given in order to get support, rather than direct support. Two participants who had been encouraged by NHS services to seek support (for themselves) through MIND selected, “Yes, definitely”; two more who would have liked more help in finding support (for themselves) selected, “No, but I would have liked help or advice with finding support”.

Recommendation: Do not include.

Physical Health Needs

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)?

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

- I do not have physical health needs

Participants understood this question to refer to help or advice they had been given in order to get support, rather than direct support. They thought about such things as being given information about support groups and being told who to contact to get help.

The non-scored answer options were not appropriately used: one person who had physical health needs for which he acquired his own support selected “I do not have physical health needs”; one person who did not have physical health needs selected “I do not need support”.

Recommendation: Include.

Financial Advice and Benefits

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

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

This question was very well understood. Participants answered thinking of being told who to contact to apply for benefits, being told that MIND could help them with benefits, help dealing with agencies, help with navigating the system, and help finding out which benefits they were entitled to.

One participant who had received direct help from her (NHS) counsellor selected “Yes, definitely”. Some participants were not sure whether the signposting they had received had been from the NHS – this was the case where they were receiving integrated services that had NHS and non-NHS components.

Recommendation: Include.

Finding or Keeping Work

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

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

This question was very well understood. Participants answered thinking of being told who to contact to find out their options, being directly told what options were available to them, and help understanding their legal position.

The non-scored responses were not always appropriately selected. One person who was retired selected “I do not need support for this”; one person who had support already selected “I do not need support with this”. Two people selected “I am not currently in or seeking work”; neither of them showed hesitation about selecting this.

Recommendation: Include.

Finding or Keeping Accommodation

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

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

This question was very well understood. Participants answered thinking either of direct help they had been given or signposting to other services which supported them.

Two participants selected “No, but I would have liked help or advice with finding support” because they were not happy with the support that they had.

One participant wrote in “Doesn’t apply” as he still lived “at home” (with one or both parents) and so did not consider this applicable to him.

Recommendation: Include.

Please note: We recommend that the non-scored²⁵ response data from these questions should not be used for secondary analysis. Participants who selected a non-scored response did not always select the “correct” one, although it was clear they were right to select a non-scored one.

Q37: Community involvement (new)

This question is designed to measure how well services are supporting people to be an active part of their community. It is specifically designed to allow service users to connect it with whichever activities are most relevant to them. This was confirmed in testing, where participants were thinking of such things as sports, volunteering, museum trips, music and

²⁵ “Non-scored” responses are those that do not evaluate the service. Here, they are “I have support and did not need help/advice to find it”, “I do not need support for this” and (for some questions) “I do not have [this need]” or “I am not currently in or seeking work”.

fundraising for charities. (Section 3.2 - *The recovery approach*; Section 5.5.5 - “*Feeling useful*”.)

Rounds 1 & 2

Has someone from NHS mental health services supported you in taking part in an activity locally?

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

One participant said that he understood “I did not want this” to mean he had to have been explicitly asked if he wanted it and then refused, rather than it simply not having been mentioned. He had not wanted/needed support.

Round 3

Has someone from NHS mental health services supported you in taking part in an activity locally?

- Yes, definitely
- Yes, to some extent
- No but I would have liked this
- I did not want this / I did not need this

This question tested well. In particular, it was very well-received by those who wanted support (both those who had received it and those who hadn’t but would have wanted to).

Recommendation: Keep as in Round 3.

Q38: Peer support (new)

This question is designed to measure service users’ access to peer support. The level of support asked about – providing information about support– was calibrated against the NICE guidelines²⁶: “Service users should be informed of appropriate local user-led support organisations or options for peer support.” The wording “peer support” was avoided on advice from CQC Experts By Experience. (Section 5.3.4 - *Peer support*.)

Round 1 & 2

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?

- Yes, definitely

²⁶ Service User Experience in Adult Mental Health (NICE, Dec 2011)
<http://www.nice.org.uk/nicemedia/live/13629/57542/57542.pdf>

- Yes, to some extent
- No but I would have liked this
- I did not want this

Not all participants noticed this was about information provision.

Round 3

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?

[No change to response options]

This tested well.

Recommendation: Keep as in Round 3.

Q39: Family involvement (modified)

A version of this question appears as Q46 in the 2013 questionnaire. The option of saying family members were involved too much has been added. (*Section 5.3.5 - Including families.*)

Round 1

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

- Yes, definitely
- Yes, to some extent
- No, not as much as I would like
- No, they have involved them too much
- This does not apply to me

The option “This does not apply to me” was intended to replace two options in the 2013 question (“My friends or family did not want to be involved” / “I did not want my friends or family to be involved”) to encompass these options and also the possibility of not having friends/family. However, participants did not readily connect “This does not apply to me” to not wanting their family involved or their family not wanting to be involved.

Rounds 2 & 3

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

- Yes, definitely

- Yes, to some extent
- No, not as much as I would like
- No, they have involved them too much
- My friends or family did not want to be involved
- I did not want my friends or family to be involved

One participant did not have family or a partner, and so left the question blank.

Recommendation:

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

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

Please note: “This does not apply to me” would be excluded from any scoring or analysis of specific responses, and so is functionally equivalent to user-missing for most purposes. Therefore it could be omitted if preferred.

Q40-42: Person-centred prioritisation and the Recovery Approach (new)

These questions were designed to capture elements of the Recovery Approach. (*Section 3.2 - The recovery approach: Section 5.5.2 - Diversity of needs; Section 5.5.6 - Stigmatised or disregarded needs.*)

They were extremely well-received by participants, several of whom remarked that this was what they were most looking for from mental health services. The three different questions appear to capture three different concepts.

Rounds 1, 2 & 3

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

- Yes, always
- Yes, sometimes
- No

Do the people you see through NHS mental health services **help you** with what is important to you?

- Yes, always
- Yes, sometimes
- No

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

- Yes, always
- Yes, sometimes
- No

Recommendation: Keep as in Round 1.

Q43: Overall (moved)

This existing question showed a potential order effect when directly following the question on respect and dignity, with many participants asking if this question was asking just about respect and dignity, and two explicitly saying that the question must be about respect and dignity.

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

I had a very poor experience

I had a very good experience

0	1	2	3	4	5	6	7	8	9	10
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Recommendation: Move before the question on respect and dignity, so it is the first in the "Overall" section.

Q44: Respect and dignity (modified)

A version of this question appears as Q7 of the 2013 questionnaire.

Round 1 & 2

Overall, did you feel that you were treated with **respect and dignity** by NHS mental health services?

- Yes, always
- Yes, sometimes

No

Most participants connected this to their entire experience of NHS mental health services, not just the last 12 months. We are aiming to measure providers' performances annually, so would like responses to be focussed on this time period.

Round 3

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

[No change to response options]

This worked well.

Recommendation: Keep as in Round 3.

N/A: Integrated care questions (do not include)

These questions were presented at the end of the questionnaire, after the "Overall" section but before the demographic ("About you") section. They were in a separate section titled "All services" and were preceded by the text:

Please include contact with your GP in this section.

Thinking about all the health and social care services you have used over the last 12 months...

Rounds 1 & 2

To what extent do you agree or disagree with the following statement...

'Health and social care staff always ensure I know what will happen next'

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Do all the different people treating and caring for you work well together to give you the best possible care and support?

- Yes, all of them work well together
- Most of them work well together
- Some of them work well together

- No, they do not work well together
- Don't know / not sure

For the final round these questions were tested in reverse order, since earlier rounds indicated that respondents were more likely to connect with the phrase “all the different people treating and caring for you.”

Round 3

[Order reversed, otherwise no change.]

These questions tested extremely poorly throughout the cognitive interviewing process.

Despite the change in question order, the majority of participants did not recognise that these questions referred to all health and social care staff. Specifically they did not associate this phrase with services provided for their physical health. Probing indicated that many respondents had been inpatients or outpatients at hospital for reasons other than their mental health, but they did not think of these experiences when answering the question.

One respondent who replied referring only to mental health services, stated after probing that his answers would have been different if he'd noticed the “all health and social care services” instruction. Several respondents did refer to their GP in answering this question, but probing indicated that this was understood in terms of the mental health care they received from their GP; responses indicated the patients' association of their GP with their mental health care, rather than their association of these questions with physical healthcare.

Only a few participants understood these questions as intended. As such, data gathered from these questions would not be useable. It would be extremely misleading to include these questions without extensive testing to find a way to frame these questions so as to collect the intended information.

Recommendation: Do not include.

Please note that question had two different versions tested – half of the questionnaires had version A, half had version B:

A: To what extent do you agree or disagree with the following statement...

‘Health and social care staff always tell me what will happen next’

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

B: To what extent do you agree or disagree with the following statement...

'Health and social care staff always ensure I know what will happen next'

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

We did not see significant difference between the two versions of the former question. however, there were some indications that respondents were interpreting the phrase "tell me" negatively, in terms of not making *shared* decisions, so if this question is to be included, we recommend Version B.

Q45: Self or proxy response (modified)

This is an existing question (Q47) on the 2013 questionnaire.

Round 1

Who was the main person or people that filled in this questionnaire?

- The **service user/client** (named on the front of the envelope)
- A **friend or relative** of the service user/client
- Both** service user/client and friend/relative together
- The service user/client with the help of a health professional

One participant did not recognise the term "service user"; another said he would prefer "patient" or "person". However, both participants selected the correct option.

Round 2 & 3

Who was the main person or people that filled in this questionnaire?

- The person named on the front of the envelope (the **service user/client**)
- A **friend or relative** of the service user/client
- Both** service user/client and friend/relative together
- The service user/client with the help of a health professional

This tested well.

Recommendation: Keep as in Round 3.

N/A: Current mental health (remove)

This question appears as Q50 in the 2013 questionnaire. The phrase “right now” was not consistently understood by participants, who stated that their mental health varied on a daily basis depending on any number of factors: some participants felt better in the morning or in the evening, depending on the effects of their medications; some participants found the act of filling in the questionnaire (and focussing on their experiences of mental health services) to be difficult and so have an effect on their mood. One participant indeed wrote in her own option: “Volatile.”

This question is of a sensitive nature and is not used in routine CQC analysis. It does not provide useable information, as a single self-reported scale question is unlikely to be an accurate assessment.

Round 1

In general, how is your mental health **right now**?

- Excellent
- Very good
- Good
- Fair
- Poor
- Very poor

Not included, Rounds 2 & 3.

Recommendation: Remove.

N/A: Admission to hospital as a mental health patient (remove)

This is an extremely sensitive question with no clear use. Nationally, only 13% of respondents said they had been admitted once or more, so trust-level disaggregation of results by this answer would not be appropriate.

Round 1

Have you been admitted to a hospital as a mental health patient in the last 12 months?

- No
- Yes, once
- Yes, 2 or 3 times
- Yes, more than 3 times

Not included, Rounds 2 & 3.

Recommendation: Remove.

CHANGES TO METHODOLOGY

10. Changing the “sampling period”

For this survey, the sample is compiled by taking all service users who had contact with services within a certain time period (the “sampling period”) and applying various exclusion criteria. The criteria remain the same for 2014, but the sampling period has been changed from the three month period July-September of the year preceding the survey to the three month period September-November of the year preceding the survey. The sampling period for the 2014 survey will therefore be 1st September 2013 to 30th November 2013.

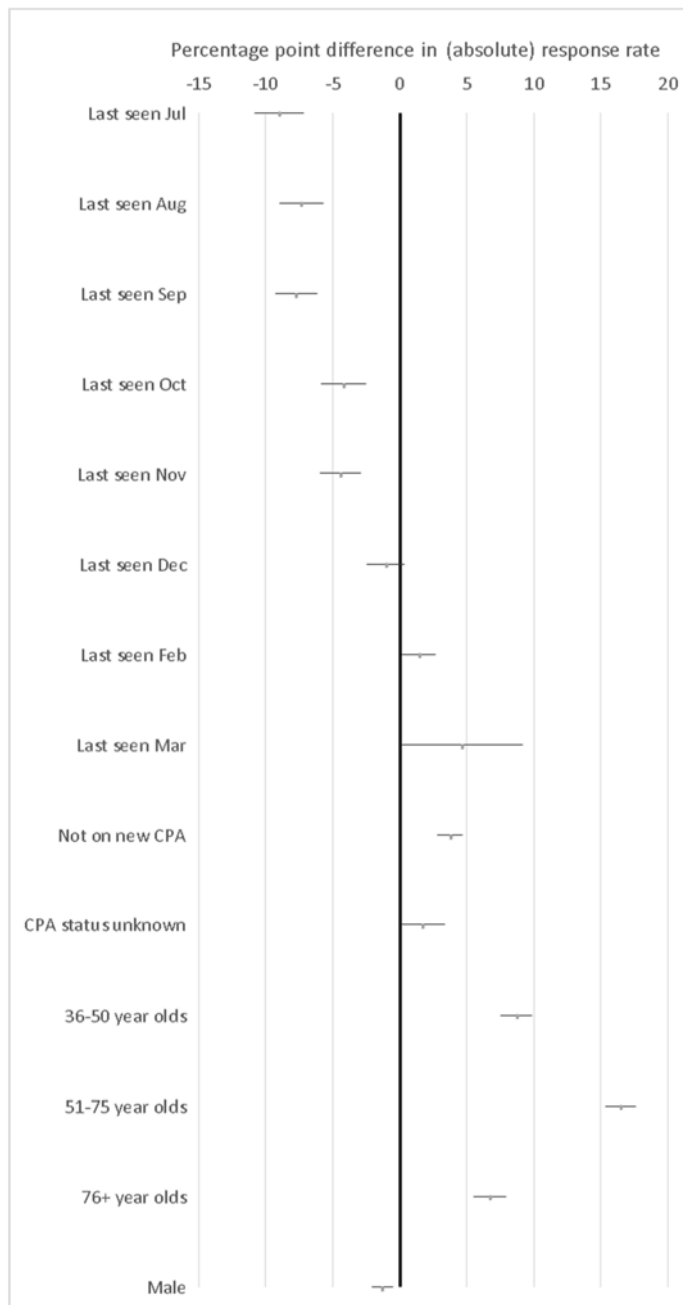
The fieldwork for the survey itself is typically carried out February-June of the year of the survey. It is hoped that moving the sampling months closer to the time of the survey will increase response rates and improve service providers’ views of the relevance of the survey.

Providers participating in the survey currently draw their sample in late January or early February of the survey year, so the latest possible month in the sample period is December. However, December may have atypical service use, as it falls over Christmas and the New Year, which sees a pronounced drop in service activity. The latest possible typical month is therefore November.

10.1 Relationship between date of last contact and response rate

There is a clear relationship between how recent the service user's date of last contact is and their likelihood to receive the survey and respond to it.

The below chart looks at response rate including those whose questionnaires were returned undelivered and those who died in the denominator – this is because we are interested in the absolute return on sending out questionnaires, not the proportion of those who receive the questionnaire who then complete them.



The reference category above (the zero line) is female, 18-35 year old service users on CPA last seen in January. The point estimates for each category are given with 95% confidence intervals. This multilevel model was produced using MLwiN using the two levels of trust and respondent to control for differences in response rate for trusts with different demographics.

10.2 Perceived timeliness of survey

Some service providers expressed concerns during consultation that each survey cycle takes a full year for completion, with the sampling months July-September of the preceding year and the results officially published in September of the survey year itself. This means that by the time the results come out, they cannot act to improve services before the sampling months for the next survey are already over.

Moving the sampling months closer to the time of the survey fieldwork may help to improve the perception of relevance for service providers.²⁷

11. Additions to the Sample Frame

As part of the redevelopment work for the survey, we considered if there is any further information that could usefully be collected in the sample frame. The 'sample frame' includes all service users who have been selected to be sent a questionnaire. In 2013 this included the following information:

- Service user Record Number
- Year of birth
- Gender
- Ethnic category
- Day of last contact
- Month of last contact
- Year of last contact
- CPA status
- GP practice code

²⁷ In fact, this perception does not reflect the reality of the survey. In 2013, only 22% of those sampled had their date of most recent contact (at the time of the sample being drawn) in the sampling months, with the majority (52%) having their date of most recent contact in January-March of the year of the survey. Since these are the dates of most recent contact at the point when the sample is drawn (typically February/March), and trusts do not have high service user turnover, it is reasonable to assume that most service users being sent the questionnaire will have had contact with the trust within the previous two to three months.

Of those who respond to the survey, thus whose responses contribute to the trusts' scores, 51% have had contact within a month of responding, and another 22% in the 1-3 months before.

11.1 PbR Trust Cluster

During the consultation stage of the redevelopment work, it was clear that Payment by Results (PbR) trust cluster was felt to be a useful addition to the sample frame.

Care Clusters are groupings of service users based on their needs and characteristics. They are a way of classifying individuals using Mental Health services that is intended to form the basis for payment. There are 21 possible Care Clusters. There are also three 'super classes' which can be used by staff to help the clustering decision, these are: psychosis, non-psychotic and organic.

Payment by Results (PbR) trust cluster was identified by key stakeholders as a useful addition to the sample frame as data from the survey has the potential to be used in PbR quality and outcome monitoring. Collecting this would also enable increased opportunities for secondary analysis. For example, we could look at the response rates for service users with different needs, and, analyse survey results to understand how a service user's needs affect their experience of services.

Recommendation: Apply for approval under section 251 of the NHS Act 2006 from the Confidentiality and Advisory Group at the Health Research Authority to include this in the sample frame for the survey.

11.2 Location Information

Stakeholders within CQC expressed interest in knowing location information about respondents, as it was felt that this lower level information could be of use to the CQC regulatory model. We therefore explored the possibility of collecting: Site Code, Local Authority of Residence and the Team seen by the service user.

Site code: The coordination centre contacted a number of trusts to ask if they hold this information on their records system, and if this would be useful to them to collect. Feedback from trusts suggests this would not be viable, for example:

- One trust said that site code is an existing but non-mandatory field. One trust supplied a breakdown of some of their data, which has site and location type: 86% had site not specified. Location type was much better completed, with only 20% not specified, but the categories are "Patient's home" / "Health Clinic (NHS)" / "Health organisation" / "Other organisation" etc. rather than anything usable.
- Another trust said it was doable but "would create a lot of work" – and said that within the Clinical Audit Team, the consensus was that this would not be useful for them internally. They also raised the concern that different trusts are so differently organised (both in terms of site type and team structure) that any kind of comparison between different trusts would not work.

Local Authority of Residence: Stakeholders within CQC had thought this was submitted by trusts to MHMDS (the Mental Health Minimum Data set). However, investigations revealed that it is not something trusts submit themselves but the Health and Social Care Information Centre (HSCIC) derive it from postcode details. Therefore this does not seem to be a variable we can collect.

Team: In order to assess the viability of collecting the Team seen by a service user, a request was put in to receive data MHMDS for the period June-August 2012, to match the sampling period for the 2013 survey. The intention of this was to get a feel for the data and base sizes to help form a view on whether this could be usefully collected on the sample file.

Unfortunately even including the full population of service users seen during this period (though with the sampling exclusions as specified in the guidance applied as far as possible) much of the data would need to be suppressed due to low cell counts (of less than 5). It was therefore necessary to aggregate this up to three broad categories: General Mental Health Services, Specialist Mental Health Services and Other Mental health Services. It was therefore felt not possible to collect this information in the survey, as numbers at trust level would likely be far too low to use as the survey has a sample of 850, and a national response rate of around 30%, though this varies at trust level. It is also questionable how useful such high level information could be.

Recommendation: It is not recommended to collect Site Code, Local Authority of Residence or Team for the reasons set out above.

Apply for approval under section 251 of the NHS Act 2006 from the Confidentiality and Advisory Group at the Health Research Authority to collect GP Code in the sample frame for the survey for the purposes of further analysis. Currently permission is only granted for conversion of GP Code to CCG code.

APPENDIX 1: List of stakeholders consulted

The Coordination Centre would like to thank everyone who very generously gave their time and considerable expertise to help with this project.

This includes the service users who attended focus groups in London and Leeds and representatives from:

Avon and Wiltshire Mental Health Partnership NHS Trust
Care Pathways and Packages Project
Care Quality Commission
CQC Experts by Experience
CQC Mental Health Expert Reference Group
Foundation Trust Network
Greater Manchester West Mental Health NHS Foundation Trust
Implementing Recovery through Organisational Change (ImROC)
Mental Health Foundation
MIND
NHS Confederation
NHS England
North East London NHS Foundation Trust
North Staffordshire Combined Healthcare NHS Trust
Northumberland, Tyne and Wear NHS Foundation Trust
Oxford Health NHS Foundation Trust
Oxleas NHS Foundation Trust
Payment by Results
Quality Health
Service User Research Enterprise (SURE)
South Essex Partnership University NHS Foundation Trust
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
Southern Health NHS Foundation Trust
Southwest Yorkshire Partnership NHS Foundation Trust
Tees, Esk and Wear Valleys NHS Foundation Trust

We are particularly grateful to South Staffordshire & Shropshire Foundation Trust and CQC for hosting the consultation events.

APPENDIX 2: Item non-response in the 2012 Day To Day Living section of the questionnaire

The average item non-response rate for questions outside this section is 3.8%. For the full day-to-day living section, average item non-response is 7.9%, which rises to 9.6% when restricted to the five questions described above.

When broken down by age group, it becomes clear that these questions work particularly badly for those over the age of 65, who formed 33% of respondents in 2012. This group has an average item non-response rate of 17.7% on the five questions above, compared to 6.1% outside this section. Those aged 18-65 had an average item non-response rate of 5.6%, which is still high compared to their average of 2.8% outside this section.

Question	Overall non-response (N=15878)	Age 18-65 non-response (N=10620)	Age 66+ non-response (N=5258)
Questionnaire mean (excluding Day To Day Living section)	3.8%	2.8%	6.1%
<i>In the last 12 months, have you received support from anyone in NHS mental health services in getting help with...</i>			
Q40 ...your physical health needs?	8.9%	5.9%	14.8%
Q41 ...your care responsibilities?	9.6%	6.7%	15.7%
Q42 ...finding or keeping work?	12.6%	5.6%	26.7%
Q43 ...finding and/or keeping your accommodation	8.9%	5.1%	16.6%
Q44 ...financial advice or benefits?	8.2%	4.8%	15.0%



Service User Questionnaire

What is the survey about?

This survey is about **your experiences** of the health and social care you receive through NHS mental health services. We're interested in your views of that experience, even if your contact has only been limited or has now finished.

Your feedback is very important in helping us gain a picture of the care you received. The information will be used to help improve NHS mental health services.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his/her point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please cross clearly inside one box using a black or blue pen. If you prefer not to answer a question, simply leave it blank.

Sometimes you will find the box you have crossed has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

Don't worry if you make a mistake; simply fill in the box and put a cross in the correct box.

Please **do not** write your name or address anywhere on the questionnaire. All your answers will be kept confidential. It will not be possible to identify you in any report of the results.

Questions or help?

If you have any queries about the questionnaire, please call the helpline number given in the letter enclosed with this questionnaire.



Taking part in this survey is voluntary.

Your answers will be treated in confidence.

YOUR CARE AND TREATMENT

Please **do not** include contact with your GP when answering questions in this section.

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

- In the last month
- 1 to 3 months ago
- 4 to 6 months ago
- 7 to 12 months ago
- More than 12 months ago
- Don't know / can't remember
- I have never seen anyone from NHS mental health services → **Please go to Q44 on Page 7**

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

- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- More than 10 years
- I am no longer in contact with NHS mental health services
- 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?

- Yes, definitely
- Yes, to some extent
- No
- It is too often
- 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. How easy was the actual **journey** to see this person or people?

- I found it easy to get there
- I found it somewhat easy to get there
- I found it hard to get there
- I did not have to travel
- Don't know / can't remember

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

5. Did the person or people you saw **listen carefully** to you?

- Yes, definitely
- Yes, to some extent
- No
- Don't know/ can't remember

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

- Yes, definitely
- Yes, to some extent
- No
- Don't know/ can't remember

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

- Yes, definitely
- Yes, to some extent
- No
- Don't know/ can't remember

ORGANISING YOUR CARE

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

8. 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”.)

- Yes → **Go to 9**
 No → **Go to 12**
 Not sure → **Go to 12**

9. Is the person in charge of organising your care and services...

- A CPN (Community Psychiatric Nurse)
 A psychotherapist / counsellor
 A social worker
 A psychiatrist
 A mental health support worker
 A GP
 Another type of NHS health or social care worker
 Don't know

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

- Yes
 No
 Not sure

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

- Very well
 Quite well
 Not very well
 Not at all well

PLANNING YOUR CARE

Please **do not** include contact with your GP when answering questions in this section.

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

- Yes, definitely → **Go to 13**
 Yes, to some extent → **Go to 13**
 No → **Go to 15**

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

- Yes, definitely
 Yes, to some extent
 No but I wanted to be
 No but I did not want to be
 Don't know / can't remember

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

- Yes, definitely
 Yes, to some extent
 No
 Don't know / can't remember

REVIEWING YOUR CARE

Please **do not** include contact with your GP when answering questions in this section.

15. 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?

- Yes → **Go to 16**
 No → **Go to 18**
 Don't know / can't remember → **Go to 18**

16. Were you involved as much as you wanted to be in discussing how your care is working?

- Yes, definitely
- Yes, to some extent
- No but I wanted to be
- No but I did not want to be
- Don't know / can't remember

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

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

CHANGES IN WHO YOU SEE

Please **do not** include contact with your GP when answering questions in this section.

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

Please **do not** include stopping care completely.

- Yes → **Go to 19**
- Yes, but this was because I moved home → **Go to 21**
- No → **Go to 21**
- My care has started but not changed → **Go to 21**
- Don't know / not sure → **Go to 21**

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

- It got better
- It stayed the same
- It got worse
- Not sure

20. Did you know who was in charge of organising your care while this change was taking place?

- Yes
- No
- Not sure

CRISIS CARE

Please **do not** include contact with your GP when answering questions in this section.

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".

21. 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**.

- Yes → **Go to 22**
- No → **Go to 24**
- Not sure → **Go to 24**

22. **In the last 12 months**, have you tried to contact this person or team because your condition was getting worse?

- Yes → **Go to 23**
- No → **Go to 24**
- Can't remember → **Go to 24**

23. When you tried to contact them, did you get the help you needed?

- Yes, definitely
- Yes, to some extent
- No
- I could not contact them

TREATMENTS

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

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

- Yes → **Go to 25**
 No → **Go to 30**

25. Were you **involved** as much as you wanted to be in decisions about which medicines you receive?

- Yes, definitely
 Yes, to some extent
 No but I wanted to be
 No but I did not want to be
 Don't know/ can't remember

26. In the last 12 months, have you been prescribed any **new medicines** for your mental health needs?

- Yes → **Go to 27**
 No → **Go to 28**

27. The last time you had a new medicine prescribed for your mental health needs, were you given **information** about it in a way that you were able to understand?

- Yes, definitely
 Yes, to some extent
 No
 I was not given any information

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

- Yes → **Go to 29**
 No → **Go to 30**
 Not sure → **Go to 30**

29. 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?)

- Yes
 No
 Don't know / can't remember

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

- Yes → **Go to 31**
 No but I would have liked this → **Go to 32**
 No but I did not mind → **Go to 32**
 This was not appropriate for me → **Go to 32**
 Don't know / can't remember → **Go to 32**

31. Were you involved as much as you wanted to be in deciding what treatments or therapies to use?

- Yes, definitely
 Yes, to some extent
 No but I wanted to be
 No but I did not want to be
 Don't know / can't remember

OTHER AREAS OF LIFE

Please **do not** include help from your GP in this section.

The following are areas of life where some people need help or support. For each area, NHS mental health services may have helped you to **find** any support you needed.

Support might have been provided by NHS mental health services, or it might have been provided by another organisation – such as social services, a charity or a community group. If support was provided by someone else, we are interested in whether NHS mental health services **helped you to find this support** from them.

32. 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)?

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

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

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

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

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

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

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

36. Has someone from NHS mental health services supported you in taking part in an activity locally?

- Yes, definitely
- Yes, to some extent
- No but I would have liked this
- I did not want this / I did not need this

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

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

38. 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?

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

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

- Yes, always
- Yes, sometimes
- No

40. Do the people you see through NHS mental health services **help you** with what is important to you?

- Yes, always
- Yes, sometimes
- No

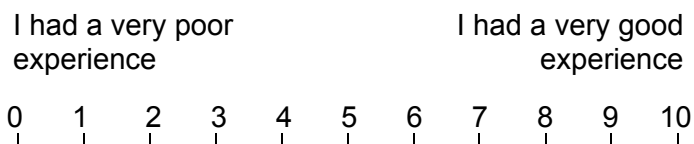
41. Do the people you see through NHS mental health services help you **feel hopeful** about the things that are important to you?

- Yes, always
- Yes, sometimes
- No

OVERALL

Please **do not** include contact with your GP in this section.

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



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

- Yes, always
- Yes, sometimes
- No

ABOUT YOU

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

44. Who was the main person or people that filled in this questionnaire?

- The person named on the front of the envelope (the **service user/client**)
- A **friend or relative** of the service user/client
- Both** service user/client and friend/relative together
- The service user/client with the help of a health professional

Reminder: 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.

45. Are you male or female?

- Male
- Female

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

e.g.

1	9	3	4
---	---	---	---

1	9		
---	---	--	--

47. What is your religion?

- No religion
- Buddhist
- Christian (including Church of England, Catholic, Protestant, and other Christian denominations)
- Hindu
- Jewish
- Muslim
- Sikh
- Other
- I would prefer not to say

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

- Heterosexual / Straight
- Gay / Lesbian
- Bisexual
- Other
- I would prefer not to say

49. What is your ethnic group? **(Tick ONE only)**

a. WHITE

- English/Welsh/Scottish/Northern Irish/ British
- Irish
- Gypsy or Irish Traveller
- Any other White background, **write in...**

b. MIXED /MULTIPLE ETHNIC GROUPS

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed/multiple ethnic background, **write in...**

b. ASIAN / ASIAN BRITISH

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, **write in...**

d. BLACK / AFRICAN /CARIBBEAN/BLACK BRITISH

- African
- Caribbean
- Any other Black / African / Caribbean background, **write in...**

e. OTHER ETHNIC GROUP

- Arab
- 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.

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.



Service User Questionnaire

What is the survey about?

This survey is about the health and social care you receive through NHS mental health services. This might include contact with psychiatrists or psychiatric nurses, social workers, mental health support workers, occupational therapists, psychologists, psychotherapists or other mental health or social care workers, including those helping people with dementia, depression or other types of mental health problem.

The information will be used to help improve NHS mental health services.

Who should complete the questionnaire?

This questionnaire is being sent to a random sample of people who have had contact with the NHS mental health service during the period July-September 2012. We're interested in your views of that experience, even if your contact has only been limited or has now finished.

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his/her point of view – not the point of view of the person who is helping.

Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen. If you prefer not to answer a question, simply leave it blank.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will only answer the questions that apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please do not write your name or address anywhere on the questionnaire. All your answers will be kept confidential. It will not be possible to identify you in any report of the results.

Questions or help?

If you have any queries about the questionnaire, please call the helpline number given in the letter enclosed with this questionnaire.

Your participation in this survey is voluntary.
If you choose to take part, your answers will be treated in confidence.

YOUR CARE AND TREATMENT

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

This may have been a psychiatrist, psychiatric nurse, social worker, mental health support worker, occupational therapist, psychologist, psychotherapist or other mental health or social care worker. (Please do not include your GP.)

- 1 In the last month
- 2 1-3 months ago
- 3 4-6 months ago
- 4 7-12 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 → **Go to Question 44 on Page 87**

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

HEALTH AND SOCIAL CARE WORKERS

3. Which of the following **NHS** healthcare workers or social care workers have you seen **most recently for your mental health condition?** (Please do not include your GP)

If your most recent contact involved more than one health or social care worker, please tick the person you have seen most frequently

(Tick ONE box only)

- 1 CPN – Community Psychiatric Nurse
- 2 Social Worker
- 3 Psychiatrist
- 4 Mental Health Support Worker
- 5 Occupational Therapist
- 6 Psychologist
- 7 Psychotherapist
- 8 Other NHS healthcare worker or social care worker
- 9 Don't know/can't remember

Thinking about the last time you saw this NHS healthcare worker or social care worker for your mental health condition...

4. Did **this** person listen carefully to you?

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

5. Did **this** person take your views into account?

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

Still thinking about the last time you saw this NHS healthcare worker or social care worker for your mental health condition...

6. Did you have **trust and confidence** in **this** person?

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

7. Did **this** person treat you with **respect and dignity**?

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

8. Were you given **enough time** to discuss your condition and treatment?

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

MEDICATIONS

9. In the last 12 months, have you taken any prescribed medication for your mental health condition?

- 1 Yes → Go to 10
- 2 No → Go to 17

10. Do you think your views were taken into account in deciding which medication to take?

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

11. In the last 12 months, has any **new** medication (e.g. tablets, injections, liquid medicines, etc.) been prescribed for you by an NHS mental health worker such as a psychiatrist or a community psychiatric nurse? (Please do not include prescriptions from your GP.)

- 1 Yes → Go to 12
- 2 No → Go to 15
- 3 Can't remember → Go to 15

The LAST time you had a new medication prescribed for you...

12. Were the **purposes** of the medication explained to you?

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

13. Were you told about possible **side effects** of the medication?

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

14. The last time you had a new medication prescribed for your mental health condition, were you given information about it in a way that was **easy to understand**?

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

15. Have you been on any prescribed medication for 12 months or longer for your mental health condition?

- 1 Yes → Go to 16
- 2 No → Go to 17

16. In the last 12 months, has an NHS mental health worker or social care worker checked with you about **how you are getting on with your medication** - i.e. have your medicines been reviewed? (Please do not include reviews by your GP.)

- 1 Yes
- 2 No

TALKING THERAPIES

The next two questions are about **talking therapies**. By talking therapies we mean therapies such as counselling, cognitive behavioural therapy (CBT) and anxiety management.

17. In the last 12 months have you received any of these sorts of talking therapies from NHS mental health services?

- 1 Yes → Go to 18
- 2 No → Go to 19

18. Did you find the NHS talking therapy you received in the last 12 months helpful?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Too early to say

YOUR CARE CO-ORDINATOR

A **Care Co-ordinator** (or lead professional) is someone from NHS Mental Health Services who keeps in regular contact with you. This person could be a Community Psychiatric Nurse (CPN), a Psychiatrist or a Social Worker.

19. Do you know who your Care Co-ordinator (or lead professional) is?

- 1 Yes → Go to 20
- 2 No → Go to 22
- 3 Not sure → Go to 22

20. Can you contact your Care Co-ordinator (or lead professional) if you have a problem?

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

21. How well does your Care Co-ordinator (or lead professional) organise the care and services you need?

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

YOUR CARE PLAN

A **care plan** (or recovery plan) is a document or letter, drawn up by NHS mental health services, that sets out your mental health needs and explains how your care has been planned.

22. Do you **understand** what is in your NHS care plan?

- 1 Yes, definitely → Go to 23
- 2 Yes, to some extent → Go to 23
- 3 No, I don't understand it → Go to 23
- 4 I don't know/can't remember what is in my care plan → Go to 27
- 5 I do not have a care plan → Go to 28

23. Do you think your views were taken into account when deciding what was in your NHS care plan?

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

24. Does your NHS care plan set out your **goals**? This might include the changes you want to make to your life as your care progresses or the things you want to achieve.

- 1 Yes, definitely → Go to 25
- 2 Yes, to some extent → Go to 25
- 3 No → Go to 26

25. Have NHS mental health services helped you start achieving these goals?

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

26. Does your NHS care plan cover what you should do if you have a crisis (e.g. if you are not coping or if you may need to be admitted to a mental health ward)?

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

27. Have you been given (or offered) a **written or printed** copy of your NHS care plan? (**Tick ONE box only**)

- 1 Yes, in the last year
- 2 Yes, more than one year ago
- 3 No
- 4 Don't know/ Not sure

YOUR CARE REVIEW

A care review is a meeting between you and staff from NHS mental health services to discuss how your care has been working.

28. **In the last 12 months** have you had a care review meeting to discuss your care?

- 1 Yes, I have had more than one → **Go to 29**
- 2 Yes, I have had one → **Go to 29**
- 3 No, I have not had a care review in the last 12 months → **Go to 34**
- 4 Don't know / Can't remember

→ **Go to 34**

29. Were you **told** that you could bring a friend, relative or advocate to your care review meetings?

- 1 Yes
- 2 No
- 3 Don't know / Can't remember

30. Before the review meeting, were you given a chance to talk to your care co-ordinator about what would happen?

- 1 Yes
- 2 No
- 3 Don't know / Can't remember

The LAST time you had a care review meeting to discuss your care...

31. Were you given a chance to express your views at the meeting?

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

32. Did you find the care review helpful?

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

33. Did you discuss whether you needed to continue using NHS mental health services?

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

CRISIS CARE

34. Do you have the number of someone from your local NHS mental health service that you can phone out of office hours?

- 1 Yes → **Go to 35**
- 2 No → **Go to 37**
- 3 Not sure / Don't know → **Go to 37**

35. In the last 12 months, have you called this number?

- 1 Yes → **Go to 36**
- 2 No → **Go to 37**

36. **The last time** you called the number, did you get the help you wanted?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I could not get through to anyone

DAY TO DAY LIVING

37. Has anyone in NHS mental health services **ever** asked you about your alcohol intake?

- 1 Yes
- 2 No
- 3 Don't know/ Can't remember

38. Has anyone in NHS mental health services **ever** asked you about your use of non-prescription drugs?

- 1 Yes
- 2 No
- 3 Don't know/ Can't remember

39. In the last 12 months, did anyone in NHS mental health services ask you about any physical health needs you might have?

- 1 Yes
- 2 No
- 3 Don't know/ Can't remember

40. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with your **physical health needs**?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked support
- 4 I do not have any physical health needs

41. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with your **care responsibilities** (including looking after children)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked support
- 4 I did not need any support
- 5 I do not have any caring responsibilities

42. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with **finding or keeping work** (e.g. being referred to an employment scheme)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked support
- 4 I did not need any support
- 6 I am unable to work because of my mental health problems

43. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with **finding and/or keeping your accommodation**?

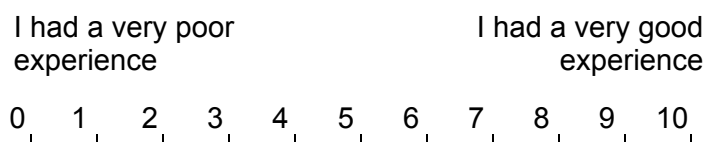
- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked support
- 4 I did not need any support

44. In the last 12 months, have you received support from anyone in NHS mental health services in getting help with **financial advice or benefits** (e.g. Housing Benefit, Income Support, Disability Living Allowance)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but I would have liked support
- 4 I did not need any support

OVERALL

45. Overall... (Please circle a number)



46. 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
- 4 My family or friends did not want or need to be involved
- 5 I did not want my family or friends to be involved

ABOUT YOU

47. Who was the main person or people that filled in this questionnaire?

- 1 The **service user/client** (named on the front of the envelope)
- 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

Reminder: 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.

48. Are you male or female?

- 1 Male
- 2 Female

49. What was your **year of birth**?

(Please write in) e.g.

1	9	3	4
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1	9		
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50. In general, how is your mental health **right now**?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

51. Have you been admitted to a hospital as a mental health patient in the last 12 months?

- 1 No
- 2 Yes, once
- 3 Yes, 2 or 3 times
- 4 Yes, more than 3 times

52. Are you currently in paid work?

TICK ALL THAT APPLY

- 1 Yes, I am working between 1-15 hours a week
- 2 Yes, I am working 16 or more hours a week
- 3 No, I am retired
- 4 No, I do voluntary work
- 5 No, but I am a full time student
- 6 No, other reason

53. 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

54. 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

55. What is your ethnic group? (Tick ONE 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.

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.

No stamp is needed.