



## NHS Patient Survey Programme

# 2018 community mental health survey Statistical release

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Independent data analysis

# Contents

<b>Summary of findings</b> .....	<b>2</b>
<b>Introduction</b> .....	<b>6</b>
<b>About the community mental health survey</b> .....	<b>8</b>
<b>Results from the survey</b> .....	<b>15</b>
1. Care and treatment.....	17
2: Health and social care workers.....	20
3: Organising care .....	21
4: Planning care.....	23
5: Reviewing care .....	26
6: Changes in the staff who people see.....	27
7: Crisis care.....	28
8: Medicines .....	30
9: NHS Therapies .....	32
10: Support and wellbeing .....	34
11. Overall .....	43
Subgroup analysis summary: how experience varies for different groups of respondents.....	45
<b>Appendix A: Survey methodology</b> .....	<b>49</b>
<b>Appendix B: Other sources of information related to survey results</b> .....	<b>56</b>
<b>Appendix C: Comparisons with other surveys</b> .....	<b>58</b>
<b>Appendix D: Main users of the survey data</b> .....	<b>59</b>
<b>Appendix E: Quality and methodology</b> .....	<b>61</b>
<b>Appendix F: Further information and feedback</b> .....	<b>62</b>
<b>Appendix G: Subgroup analysis</b> .....	<b>64</b>
<b>Appendix H: Care cluster codes</b> .....	<b>81</b>
<b>References</b> .....	<b>82</b>

# Summary of findings

The 2018 community mental health survey received feedback from 12,796 people who were treated for a mental health condition between 1 September and 30 November 2017.

The report shows that people's experience of mental health services has deteriorated across several areas according to this survey. In some areas, this represents a continued negative trend, with a consistent decline in results since 2014. In other areas, the results declined significantly this year, having remained relatively stable between 2014 and 2017.

We analysed results to check for significant variations in experience between different subgroups of people using mental health services. This year, younger respondents aged 18 to 35 and those diagnosed with non-psychotic chaotic and challenging disorders consistently reported worse than average experiences across multiple areas. However, those on the new Care Programme Approach (CPA) and those who had been in contact with NHS mental health services for less than a year often reported better than average experiences.

## Positive results

People's awareness of knowing who to contact out of office hours when having a crisis remained unchanged since last year's survey, as 71% of people responded positively. Analysis of how this has changed over time revealed that between 2014 and 2018 there has been a gradual, but sustained increase in positive experiences for this area (up from 68% in 2014).

Most respondents (96%) knew how to contact the person in charge of organising their care if they had a concern. Nine out of 10 respondents felt this person organised their care and services either 'very well' or 'quite well'. However, there has been a significant decrease in the proportion of respondents that are told who is in charge of their care (decrease from 77% in 2014 to 73% in 2018).

Better than average experiences were identified for respondents that were diagnosed with a psychotic disorder. More specifically, people diagnosed as having a 'first episode in psychosis' reported better than average experiences for the majority of key areas across the care pathway.

## Key areas for improvement

### Accessing care

Only 43% of respondents said they had 'definitely' seen NHS mental health services enough for their needs in the previous 12 months. Results for this question have been declining since 2014, and there was a small, but statistically significant decrease since the previous survey (44% in 2017).

## Staff

Over half (58%) of respondents felt that they were 'definitely' given enough time to discuss their needs with health and social care workers, a decrease of seven percentage points compared with 2014 (65%). The percentage of respondents who 'definitely' felt that staff understood how their mental health affects other areas of their life also decreased from 55% in 2017 to 52% this year (57% in 2014).

## Planning care

In 2017, we highlighted that there is room for improvement in people's experience of how services plan their care. In 2018, results for all three questions asking people about this aspect of their mental health care are at their lowest point since 2014.

The percentage of respondents who said they had 'definitely' agreed on the care they would receive with someone from NHS mental health services further decreased this year to 41%.

In addition, among those who had agreed the care they will receive, there was a significant decrease of three percentage points for those 'definitely' feeling involved in the process (down from 56% in 2017 to 53% in 2018). There was also a significant decrease of four percentage points in those 'definitely' feeling that the agreed care took their personal circumstances into account (down from 59% in 2017 to 55% in 2018).

## Crisis care

While there has been a positive trend in the proportion of respondents knowing who to contact out of office hours when having a crisis, 18% of respondents who tried to make contact when experiencing a crisis said they did not get the help they needed. An additional 3% were unable to make contact at all. Although results for this question are not comparable with previous iterations of the survey, this remains an area in need of improvement.

## Support and wellbeing

When reporting on the 2017 community mental health survey results, we identified that only a small proportion of respondents felt sufficiently supported in other areas of their life. This year, there have been multiple statistically significant decreases in the percentage of respondents answering positively on their experiences in this area.

Only 30% of respondents said they 'definitely' received help or advice with finding support for their physical health needs. These results have significantly decreased by five percentage points compared with 2017 (35%), after a four-year period of relatively stable results.

Similarly, the percentage of respondents who 'definitely' received help or advice with finding support to get financial advice or benefits significantly decreased by three percentage points in 2018 to 29%, having remained stable at 32% each year between 2014 and 2017.

Over a third (38%) of respondents said they did not receive any support from NHS mental health services in joining a group or taking part in an activity, but they would have liked this.

## Overall experience

Seventy-one per cent of respondents felt they were 'always' treated with respect and dignity by NHS mental health services. Comparing this with other surveys across the NHS Patient Survey Programme, there is a large discrepancy with results from the 2017 adult inpatient survey, where 82% of inpatients in acute hospitals (physical health) felt they were 'always' treated with respect and dignity.

Thirty per cent of respondents rated their overall experience as nine or above out of 10. This figure has not changed beyond expected limits since 2014. However, there is a large disparity compared with the adult inpatient survey, with 50% of acute inpatients answering nine or above out of 10.

## How experience varies for different groups of people

Results were analysed according to a number of demographic and other characteristics, for example, seeing how results varied according to the gender of people using services, their ethnicity or diagnosis type. There were consistent differences for different 'subgroups' of people using services. Respondents diagnosed with non-psychotic chaotic and challenging disorders (care cluster code 8) reported worse than average experiences for:

- respect and dignity
- access
- communication
- respect for patient centred values
- involvement
- support and wellbeing
- crisis care
- information sharing: medicines
- involvement of family and friends
- overall experience.

Younger respondents aged 18 to 35 reported poorer than average experiences for the following themes: respect and dignity, access, communication, organisation, respect for patient centred values, involvement, crisis care, peer support and overall experience. Reported experiences for those aged 36-50 were also found to be worse than average across: respect and dignity, access, communication and overall experience.

Those respondents who had been in contact with NHS mental health services for less than a year reported better than average experiences for: respect and dignity, access, communication, respect for patient centred values, involvement and overall experience.

Respondents on a new CPA reported better than average experiences for: access, crisis care access, organisation, and support and wellbeing.

# Introduction

Community mental health services provide care and treatment for people who need mental health care over and above the services provided by primary care. Community mental health teams (CMHTs) support people in the community who have complex or serious presentations of mental health conditions. A CMHT can include: psychiatrists, psychologists, community psychiatric nurses, social workers, and occupational therapists.<sup>1</sup> Most community mental health care is provided by staff who visit people in their own homes, though some specialist outpatient clinics may involve people visiting clinics based in community mental health centres or on a hospital site. Mental health services in England care for people with a wide range of conditions.

Public Health England states that in any given year, one in six adults experience at least one diagnosable mental health condition and that mental health conditions are the second leading cause of morbidity in England.<sup>2</sup>

The most prevalent mental health conditions often are grouped under the 'common mental health' category.<sup>3</sup> According to the National Institute for Health and Care Excellence (NICE), 'common mental health' conditions include: depression, generalised anxiety disorder (GAD), social anxiety disorder, panic disorder, obsessive compulsive disorder (OCD) and post-traumatic stress disorder (PTSD).<sup>4</sup> In the UK, mixed anxiety and depression is the most common mental health condition, with 8% of people meeting criteria for diagnosis. Between four and 10% of people in England will experience depression in their lifetime.<sup>5</sup>

The [Mental Health Foundation](#) tells us that other less prevalent mental health conditions include psychotic mental health conditions, bipolar disorder, autism spectrum disorder, personality disorders and attention deficit hyperactivity disorder.

Research has shown that certain subgroups are more likely to experience a mental health problem. These subgroups include: those from Black, Asian and minority ethnic groups, refugees/asylum-seeking/stateless people, people with disabilities (both learning and physical), lesbian/gay/bisexual/transgender people, carers, people affected by domestic violence, prisoners, homeless people and people affected by substance misuse or dependence.

According to [Public Health England](#) guidance, wider determinants of mental health conditions include: poverty/disadvantage (including factors such as debt, unemployment and housing), level of social support and relationships (including family/childhood, couple relationships and community), and discrimination (based on age, ethnicity and sexual orientation).

Everybody has a different experience of a mental health condition. Some people may have a single, one-off episode of a mental health issue and have short-term contact with mental health services. Others may have multiple or long-term experiences of varying severity throughout their lives, which may involve either

on-going or intermittent contact with mental health services. It is likely that the group that has been in contact with mental health services for more than a year will include a higher proportion of people with a severe and enduring mental health problem.

Mental health conditions often go untreated and, historically, treatment options for mental health conditions are less effective than for physical conditions.<sup>6</sup> Across mental health services, there is evidence of demographic inequalities in who is receiving treatment.<sup>a</sup> Those most likely to report having treatment were female, White British, and aged between 35 and 54. People from Black, Asian and minority ethnic groups are less likely to access mental health treatment than the general population.<sup>7</sup>

a. These inequalities remain after controlling for differences in prevalence of mental health conditions between groups.

# The community mental health survey

This survey is part of a wider programme of NHS surveys, which covers a range of topics including adult inpatient services, children's inpatient and day-case services, urgent and emergency care services and maternity services. To find out more about the NHS Patient Survey Programme and to see the results from previous surveys, please see the links in the further information section ([Appendix F](#)).

The survey of people who use community mental health services has been conducted annually since 2004.<sup>b</sup> The 2018 survey involved 56 providers of NHS mental health services in England (including combined mental health and social care trusts, foundation trusts and community healthcare social enterprises that provide mental health services). People aged 18 and over were eligible to take part if they were receiving specialist care or treatment for a mental health condition and had been seen by the trust between 1 September and 30 November 2017, and were not a current inpatient. Fieldwork took place between February and June 2018. In total, we sent a questionnaire to 47,600 people. We received responses from 12,796 people, a response rate of 28%.<sup>c</sup> This is an increase from last year's response rate of 26%.

Wherever possible, the questions remain the same over time to measure change. However, they are amended to reflect changes in policy, methodological best practice, and to reflect feedback from stakeholders to make sure that questions stay relevant. The 'Treatments' section of the 2018 questionnaire was separated into two sections – 'Medicines' and 'NHS Therapies'. Doing so provides a more granular assessment of people's experiences of medicine and non-medicine based treatments.

For more information about changes to the questionnaire and survey development, see the 2018 community mental health [survey development report](#) on the NHS Surveys website. [Appendix A](#) provides more information on the methodology, which covers how we developed the survey, the analysis of data, and comparability of results with previous surveys. More detailed information on the limitations of the data is available in the quality and methodology report (see link in [Appendix E](#)).

The survey collected basic demographic information from all people who took part, and this is available in the 'About you' section in the [Open data published on CQC's website](#). The basic demographic characteristics of respondents in 2018 remain similar to the 2014, 2015, 2016 and 2017 surveys for age, gender and ethnicity.

b. In 2009, we conducted a mental health inpatient survey instead of a community mental health survey.

c. We report the 'adjusted' response rate. The adjusted base is calculated by subtracting the number of questionnaires returned as undeliverable, or if someone had died, from the total number of questionnaires sent out. The adjusted response rate is then calculated by dividing the number of returned useable questionnaires by the adjusted base.

## The importance of people's experiences

Alongside clinical effectiveness and safety, a good experience for people is seen as an essential part of an excellent health and social care service according to the [Patient Experience Improvement Framework](#) and [NHS Outcomes Framework](#).<sup>8,9</sup>

The [NHS Constitution](#), published in 2012 and updated in 2015, commits the NHS to encourage people to give feedback about their experiences and to use this to improve services.<sup>10</sup> People's experiences provide key information about the quality of services across England. This information is used to encourage improvements both nationally and locally among providers and commissioners of services. The 2012 [NHS Patient Experience Framework](#) outlines elements that are important to people's experiences of NHS services. This includes: respect and involvement, coordinated and integrated care, information and communication, and the involvement of family or friends.<sup>11</sup>

The Department of Health and Social Care's [NHS Mandate for 2018/19](#) includes a goal for NHS England "to ensure that the NHS meet the needs of each individual with a service where people's experience of their care is seen as an integral part of overall quality".<sup>12</sup> Domain 4 of the [NHS outcomes framework](#) also highlights the need to ensure that people have a positive experience of care.<sup>13</sup>

NHS England sees shared decision-making as key to improving experience for those who use services.<sup>14</sup> The [Health and Social Care Act 2012](#) states that those who commission services must promote and facilitate the involvement of people who use services and carers in decisions about their care and treatment.<sup>15</sup>

Recent research, including that carried out in the development work for the NHS Patient Survey Programme, has identified many aspects of care that are important to people using services. These include being informed and offered options, being listened to by staff and having enough time with them, and being involved in their own care.<sup>16</sup>

Evidence from academic research suggests that when people are involved in their care, decisions are made more effectively and health outcomes improve.<sup>17</sup> Studies in this area also suggest that experience is positively associated with safety and clinical effectiveness.<sup>18</sup> All questionnaires used in the NHS Patient Survey Programme are designed to reflect these themes.

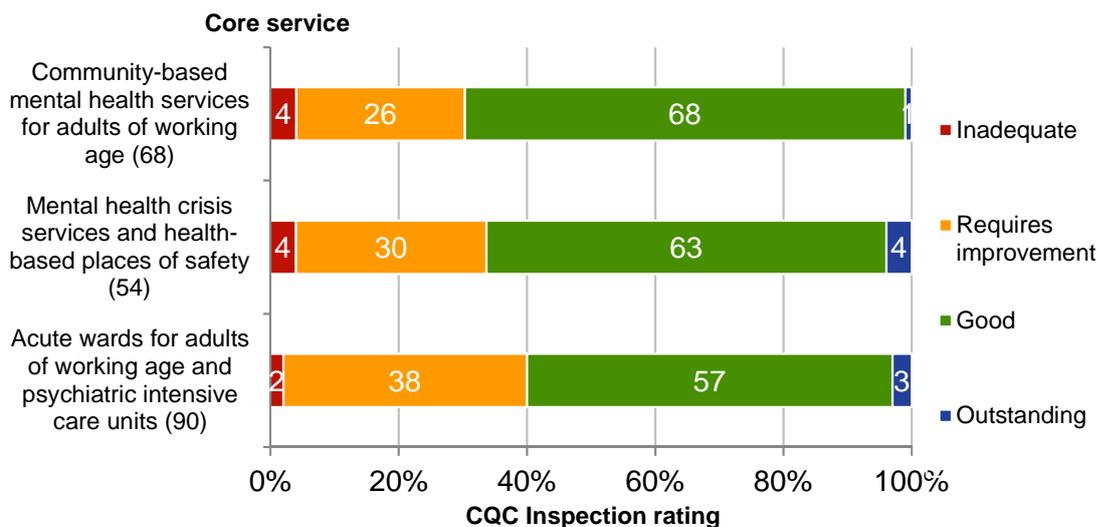
# Mental health policy

This section sets out some of the broader policy and contextual issues relevant to community mental health care in England.

In February 2016, the independent Mental Health Taskforce to the NHS in England set out NHS England’s plans for improving and expanding mental health care in the *Five Year Forward View for Mental Health*.<sup>19</sup> NHS England published an [implementation plan](#) in July 2016 detailing how it will deliver the recommendations of the Taskforce working with its partner arms-length bodies.<sup>20</sup> The Taskforce reported ‘one year on’ about mental health service provision in England and made recommendations in all service areas.<sup>21</sup>

The implementation plan set specific objectives that focus on specific groups and outcomes in the chapter ‘Adult mental health: community, acute and crisis care’.

According to CQC’s 2018 State of care report, the three core service types that the respondents to this survey are most likely to be in contact with are those that CQC most often rates as requires improvement or inadequate.<sup>22</sup>



## Crisis and acute care

In its [Five Year Forward View for Mental Health Implementation plan](#), NHS England found that the majority of crisis resolution and home treatment teams (CRHTTs) are not currently sufficiently resourced to operate 24 hours, seven days a week. Caseloads are above levels that allow teams to fulfil their core functions of providing treatment to prevent people from being admitted to acute inpatient services and being treated with out of area treatments (OAT). NHS England’s aim is to deliver a 24/7 community-based crisis response and intensive home treatment services as an alternative to acute inpatient admissions by 2020/21. This aim also includes eliminating inappropriate OAT for acute mental health care for adults.

## Mental health liaison

Specialist liaison mental health services provide mental health care in settings providing physical health care. They support the work of clinicians working in general health care, enabling emergency departments and wards in general hospitals to assess and manage mental health conditions as they present or arise among people being cared for in the general health pathway. In its [Five Year Forward View for Mental Health Implementation plan](#), NHS England's ambition is to ensure that all acute hospitals have all-age mental health liaison teams in place by 2020/21, and that at least 50% of these will meet the 'Core 24' service standard as a minimum, which sets an appropriate mix of staffing.<sup>23</sup>

## Early intervention

A national access and waiting time standard was introduced for Early Intervention in Psychosis (EIP) services in April 2016.<sup>24</sup> The standard requires that at least 50% of people with a first episode of psychosis start treatment with a NICE-recommended package of care within two weeks of referral, rising to 60% of people by 2020/21.

For the wider cohort of adults receiving treatment from community mental health services, [NHS England](#) has commissioned a new three-year programme of work to deliver the first set of treatment pathways to define high-quality care for adults with more severe or complex mental health needs in the community. This will build on the approach taken for EIP services.

## Physical health interventions

Academic research tells us that mental health disorders increase the risk of diseases and contribute to physical injury, and also that many physical health conditions increase the risk for mental disorder. Furthermore, co-morbidity makes it harder to seek help, be diagnosed and receive treatment, and influences prognosis. The research concludes that health care systems should be strengthened to improve delivery of mental health care, by focusing on existing programmes and activities, such as those that address the prevention and treatment of physical health conditions.<sup>25</sup>

According to [NHS England](#), primary care staff do not always feel confident in actively supporting people with severe mental illness to access relevant physical health screenings and interventions. This often means that the physical health needs of this group of people are not fully met so they suffer from poorer health compared with other groups, and die prematurely. [Implementing the Five Year Forward View](#) set out NHS England's ambition to reduce premature mortality of people living with severe mental illness (SMI), and that the physical health needs of 280,000 more people will be met by increasing early detection and expanding access to evidence-based physical care assessment and intervention each year by 2020/21.

## Finding and keeping work

The Five Year Forward View for Mental Health recommended that people with severe mental health illness need help to find and keep work. In response, NHS England committed to doubling access to Individual Placement and Support (IPS) services by 2020/21. IPS is a vocational rehabilitation intervention for people with severe mental disabilities.<sup>26,27</sup>

## Access to therapies for serious mental health illness

Improving Access to Psychological Therapies (IAPT) started in 2006 to support the provision of talking therapies for people of working age with depression and anxiety. In 2011, the government made a commitment to expand access to psychological therapies in England to treat people with different types of mental health conditions. This expanded access now includes people with a severe mental illness (SMI), specifically, diagnoses of psychotic disorders, bipolar disorder and personality disorders.<sup>28</sup>

In its [Five Year Forward View for Mental Health Implementation plan](#), NHS England aims to improve access to psychological therapies for these people by 2020/21. In November 2012, six demonstration sites were selected and funded to deliver IAPT for people with SMI. The IAPT-SMI sites have shown the positive impact of access to NICE-recommended psychological interventions. The evaluation found that satisfaction with the IAPT for SMI services was generally very high on experience, outcomes and reduced healthcare use and that the service should be rolled out further.<sup>29</sup>

## Mental health data

NHS England has developed a [dashboard](#) that monitors key data from across mental health services. The dashboard aims to help monitor progress against the delivery of the Five Year Forward View for Mental Health and is published quarterly.<sup>30</sup>

A new Mental Health Services Data Set (MHSDS) is being developed by [NHS England](#) to enable the routine capture and reporting of information about referral to response, assessment and treatment times, interventions delivered (and whether in line with NICE recommendations) and outcomes (clinician and patient reported). NHS Digital, NHS Improvement and NHS England will focus to improve the completeness and quality of data submitted.

## Equality between physical and mental health services

[No Health Without Mental Health](#) outlined the government's objective to give equal priority to mental and physical health, stating "...we are clear that we expect parity of esteem between mental and physical health services".<sup>31</sup>

Parity of esteem was enshrined in law in the [Health and Social Care Act 2012](#), and has become a central objective for all recent government policy. The government's aims to achieve parity of esteem is reflected in the [Mandate to NHS England](#) and [NHS Constitution](#), as well as in policy publications such as [Closing the Gap](#) and the [Five Year Forward View for Mental Health](#).

The Mental Health Five Year Forward View [implementation plan](#) also aims to provide equal status to mental and physical health, staff working in mental health services and to provide equal funding for mental health services. To put these plans into action, NHS England committed to funding reaching the front line, recruiting and retaining highly-trained staff and tackling inequalities so that everyone can access mental health care regardless of their age, location, revenue or ethnicity.

## Funding

According to the analysis of official figures by the Royal College of Psychiatrists, “mental health trusts have less money to spend on patient care in real terms than they did in 2012”. In England, 62% of mental health trusts (34 out of 55) at the end of 2016-17 reported lower income than the amount for 2011-12, only one trust saw their income rise all five financial years, and nine mental health trusts saw their income fall all five years.<sup>32</sup>

It was announced in June 2018 that the NHS will receive an average 3.4% per year real-term increase in funding over the next five years that will support a new 10-year long-term plan. A proportion of this funding will be used to create better access to mental health services and to help achieve the government’s commitment to parity of esteem.<sup>33</sup>

More specifically, [NHS England](#) has set funding aside for community mental health services to: help develop a programme to increase delivery of Individual Placement and Support, reach more people with severe mental illness, and increase access to psychological therapies for people with serious mental health conditions. Additional investment will be needed to support delivery of the objectives in the Implementation plan for Community Mental Health. Indicative figures for the period 2018-21 are: £13 million (2018/19), £33 million (2019/20) and £50 million (2020/21).

## Staffing

In [The state of care in mental health services 2014 to 2017](#), CQC highlighted staffing shortages in mental health services and the impact of this on quality and safety of care as one of its key areas of concern.<sup>34</sup>

According to [The King’s Fund](#), approximately 10% of all posts in specialist mental health services in England are vacant. The most commonly reported factors affecting safe staffing levels were staff vacancies, sickness rates and the acuity of patients.

The King’s Fund also found that between August 2014 and 2017 there has been an increase in the number of nursing staff in community services (14,946 in 2014 to 16,658 in 2017), but a slight decrease in the number of nursing support staff in the same period (1,821 in 2014 to 1,675 in 2017).<sup>35</sup>

## Prevention

In terms of prevention, the government launched the [Prevention Concordat for Better Mental Health](#) to provide a focus for cross-sector action to increase adoption of public mental health approaches across local authorities, the NHS, third sector organisations, educational settings and employers.

The programme was launched in 2017 and aims to facilitate local and national action around preventing mental health problems and promoting good mental health.<sup>36</sup> For example, Public Health England and the UCL Institute of Health Equity published a [report](#) that highlights the relationship between social determinants, psychosocial factors and health outcomes. Among other things, the report discusses the effects of adverse factors on health outcomes and promoting protective factors among a population.<sup>37</sup>

As part of this, [Public Health England](#) published resources to help local authorities and their partners take action to promote better mental health and prevent mental ill health in their communities.<sup>38</sup>

## The Care Programme Approach (CPA)

The [Care Programme Approach](#) (CPA) is a care package that helps to treat mental ill health. People that have more complex needs and need ongoing support are put on the CPA, and the approach is used to assess needs and to support recovery from mental illness. Although the [policy](#) has been revised over time, the CPA remains the central approach for coordinating care for people in contact with these services who have more complex mental health needs and who need the support of a multi-disciplinary team.<sup>39,40</sup>

Twenty-six per cent of people who responded to the 2018 survey had their care coordinated on the CPA. This is broadly similar to previous years. However, there is variation in the proportion of people on the CPA between NHS trusts, which suggests that there are systematic differences in how trusts individually interpret and apply the CPA policy.

# Results from the survey

This section presents key results for the 2018 community mental health survey.<sup>d</sup> It highlights statistically significant<sup>e</sup> differences between the results from the most recent survey (2018) and the results from the previous 2017 survey.

We also present the results that have changed noticeably over time and identify long-term trends where appropriate. For the first time this year we have used 'p-charts' to display trends from 2014 onwards to help us see where there have been notable changes in results over time. Following the re-development of the survey in 2014, this type of analysis can only be used from 2014 onwards.

The p-charts in this report plot the percentage of the most positive responses to questions (top box responses), and show the 'expected limits' of variation in survey results, with the assumption that there has been no 'real' or meaningful change unless the results exceed expected limits.<sup>41</sup> This method is useful as it allows comparisons between a number of years of data, rather than only for statistical significance between just two time points. Seeing trends in survey results over multiple years gives us greater confidence when interpreting patterns in the data.

When changes between survey results fall outside of expected limits, it suggests there is an underlying phenomenon behind this change, or that there has been a real change in behaviour; one that is greater than the standard variation or fluctuation you might expect to see between years. Where results remain in the 'expected limits', this indicates there is no underlying pattern in the results.

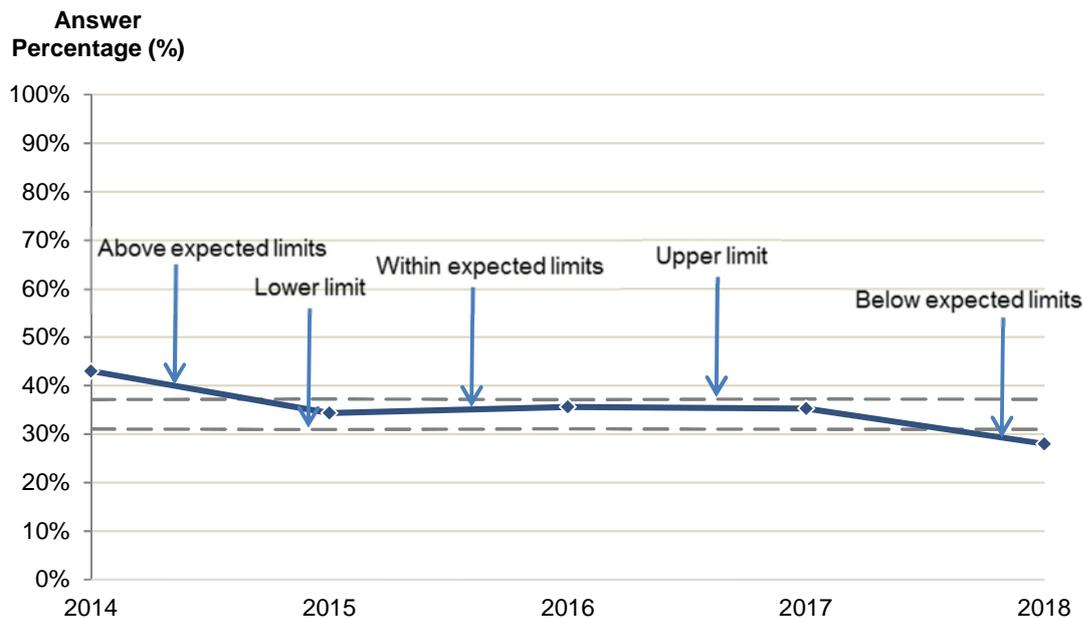
Due to the relatively large number of respondents in each time period, the control limits can be very small. It is important to consider the magnitude of change when survey results fall outside of expected limits, as they could fall outside of expected limits with only a small change.

Where p-chart results are not reported, this is because results did not fall outside of expected limits or it was not possible to compare questions over time. The following example shows a p-chart that fluctuates from above expected limits in 2014 to below expected limits in 2018; suggesting a real deterioration in results.

d. Responses to questions such as "don't know/could not remember" are not shown and excluded from percentage calculations. The wording for these responses is designed for when a respondent cannot remember, or does not have an opinion.

e. Five per cent or less probability that the result could have been observed when there has been no underlying change.

## Example of a p-chart



All charts are available in the open data source files on CQC's website.

Survey results are organised under the following key themes:

1. Care and treatment
2. Health and social care workers
3. Organising care
4. Planning care
5. Reviewing care
6. Changes in who you see
7. Crisis care
8. Medicines
9. NHS Therapies
10. Support and wellbeing
11. Overall

We also include analysis that compares how different subgroups of people rated their experience. The analysis modelled the mean scores<sup>f</sup> of different subgroups according to characteristics such as age, gender, religion, sexual orientation, ethnicity, CPA status, diagnosis (care cluster codes), length of contact, long-term conditions and 'proxy response' (whether the questionnaire was completed entirely by or with the support of someone other than the person who uses the services) for a set of composite questions based on the [NHS Patient Experience Framework](#). See [Appendix G](#) for more information and charts.

These findings are presented throughout the report; there is more detail and a full summary of results in [Subgroup analysis summary: how experience varies for different groups of respondents](#) section.

f. The sum of question scores divided by the number of questions in the composite.

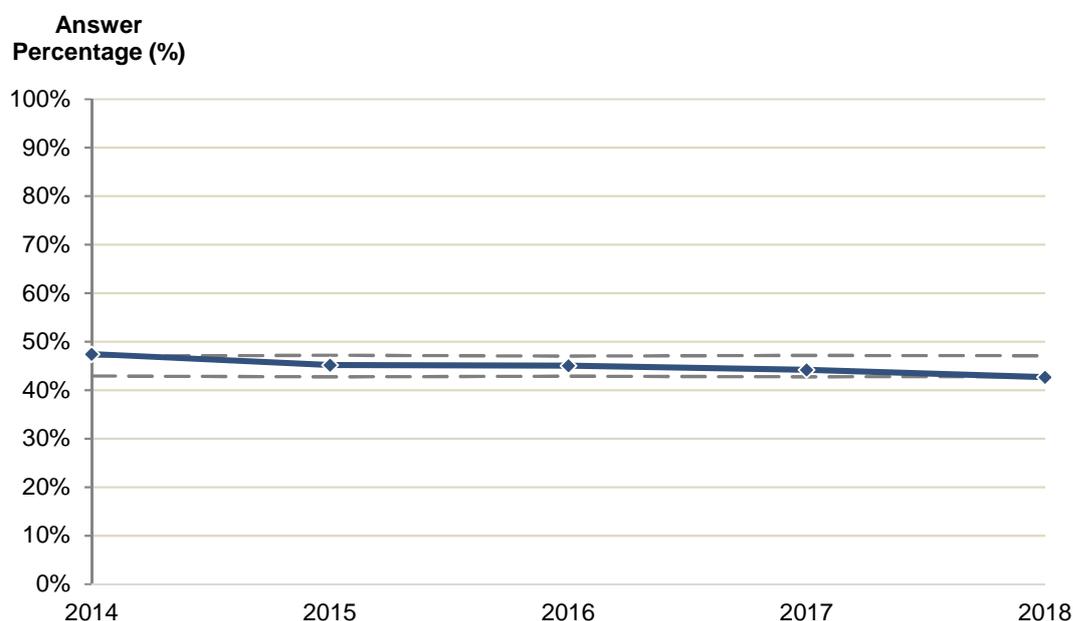
# 1. Care and treatment

The right to access effective mental health care has been set out in various government policy documents over the years. Policy publications such as [Closing the Gap, Achieving better access to mental health services by 2020](#) and the [Five Year Forward View for Mental Health](#) have committed to improving access to mental health services.

[NICE quality statement 6](#) includes a recommendation that people should be able to access mental health services when they need them.

Forty-three per cent of respondents felt that they had ‘definitely’ seen NHS mental health services enough for their needs in the last 12 months. This year’s result is the lowest since 2014. It represents a gradual deterioration in the proportion of people feeling they can definitely access the right levels of care, with the result now below ‘expected limits’ for the first time (meaning performance has deteriorated beyond what was seen previously). Twenty-five per cent of respondents said they had not seen NHS mental health services enough for their needs in the last 12 months, unchanged from 2017.

## Q3. In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs? (Answer: ‘Yes, definitely’)



Answered by all

Number of respondents: 2014 (13,061), 2015 (11,072), 2016 (12,587), 2017 (11,474) and 2018 (12,179)

**Note:** those who answered 'Don't know' were excluded from the analysis.

Subgroup analysis of Q3 '*In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs?*' has shown a large number of significant variations in experience when comparing by age, religion, CPA status, care cluster code and length of contact. Focusing specifically on care cluster codes, those reporting significantly worse than average experiences in this area were:

- Care Cluster 3 – Non-Psychotic (Moderate Severity)
- Care Cluster 4 – Non-Psychotic (Severe)
- Care Cluster 6 – Non-Psychotic Disorder of Over-Valued Ideas
- Care Cluster 7 – Enduring Non-Psychotic Disorders (High Disability)
- Care Cluster 8 – Non-Psychotic Chaotic and Challenging Disorders

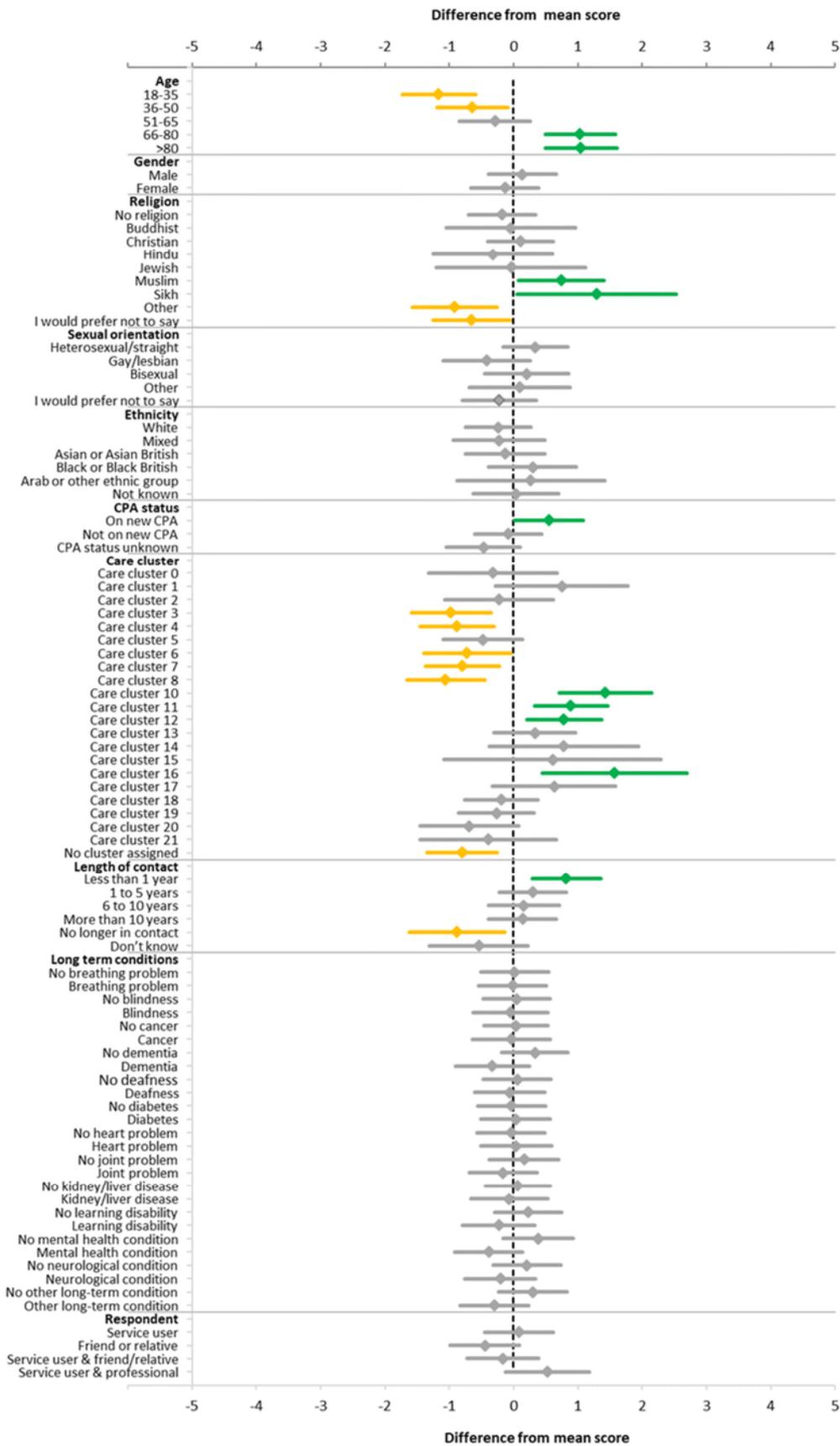
Whereas better than average experiences were reported by those assigned to the following care cluster codes:

- Care Cluster 10 – First Episode Psychosis
- Care Cluster 11 – Ongoing Recurrent Psychosis (Low Symptoms)
- Care Cluster 12 – Ongoing or Recurrent Psychosis (High Disability)
- Care Cluster 16 – Dual Diagnosis

Full results of the subgroup analysis for this question are displayed in the figure on the next page. Results are represented in the following way:

-  Worse than average experience
-  Average experience
-  Better than average experience

Access theme: difference from mean score by subgroup with 95% confidence interval



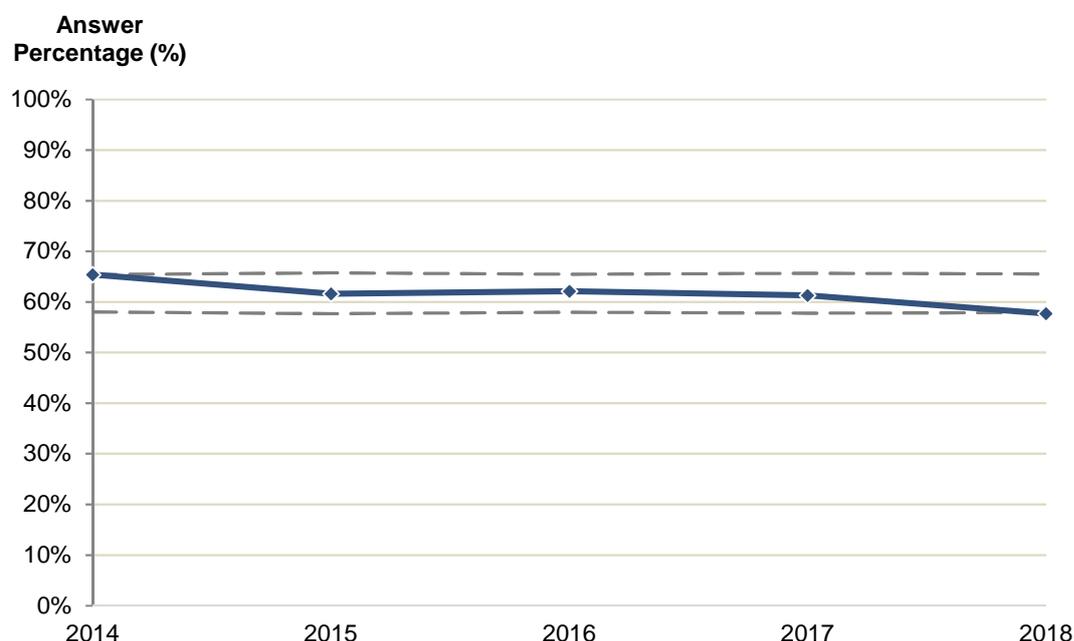
## 2: Health and social care workers

[NICE quality statement 3](#) states that service providers should ensure that there are systems to involve people in shared decision-making and to support self-management.

Questions in this section asked respondents about the health and social care workers they saw for their most recent appointment. People's experiences are influenced by their interactions with the staff providing their care, and it is expected that a good relationship with staff will be important. Research suggests that a positive relationship between people who use services and mental health staff can improve outcomes.<sup>42</sup>

Fifty-eight per cent of respondents said they were 'definitely' given enough time to discuss their needs and treatment, a significant decrease from 61% in 2017. This significant decrease also means the proportion of respondents answering 'Yes, definitely' falls below the expected limits for the first time in 2018. Starting from 65% in 2014 (which was above the expected limits), results have decreased by 7.7 percentage points in total.

### Q4: Were you given enough time to discuss your needs and treatment? (Answer: 'Yes, definitely')



Answered by all

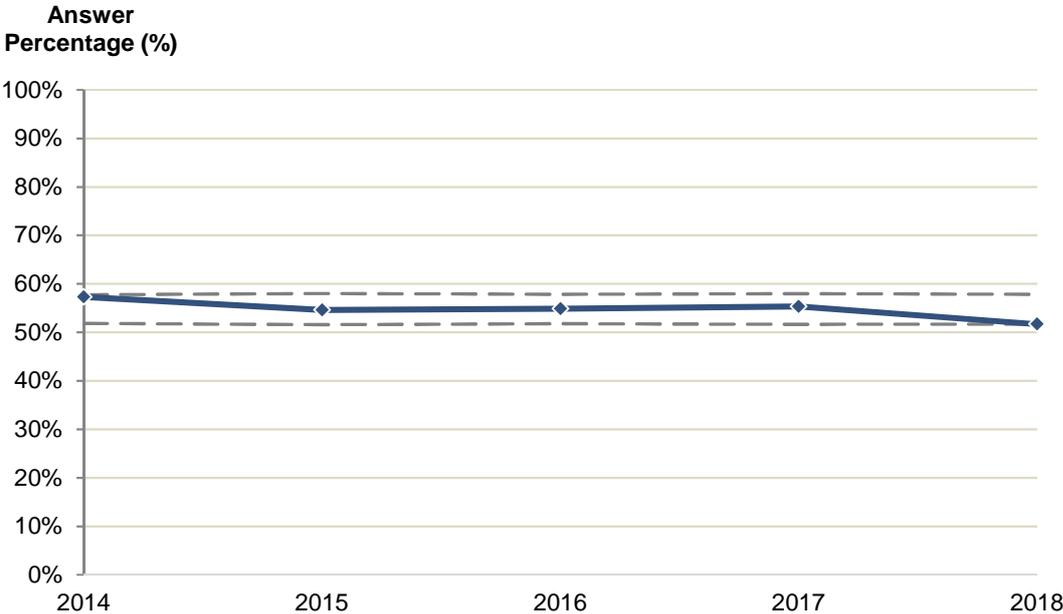
Number of respondents: 2014 (13,085), 2015 (10,925), 2016 (12,507), 2017 (11,454) and 2018 (12,149)

**Note:** those who answered 'Don't know'/'Can't remember' were excluded from the analysis.

When comparing how experiences of communicating with staff differed by sub group, respondents aged between 18 and 50 and those diagnosed with Severe Non-Psychotic or Non-Psychotic Chaotic and Challenging disorders (care clusters codes 4 and 8 respectively), reported worse than average experiences.

Fifty-two per cent of respondents said that the person or people they saw 'definitely' understood how their mental health needs affect other areas of their life. This is a statistically significant decrease from 2017 (55%) and is the first time results have fallen below the expected limit. Fifteen per cent of respondents reported that the person or people they saw did not understand how their mental health needs affected other areas of their life.

**Q5: Did the person or people you saw understand how your mental health needs affect other areas of your life? (Answer: 'Yes, definitely')**



Answered by all  
 Number of respondents: 2014 (12,777), 2015 (10,799), 2016 (12,312), 2017 (11,102) and 2018 (11,937)  
**Note:** those who answered 'Don't know/' 'Can't remember' were excluded from the analysis.

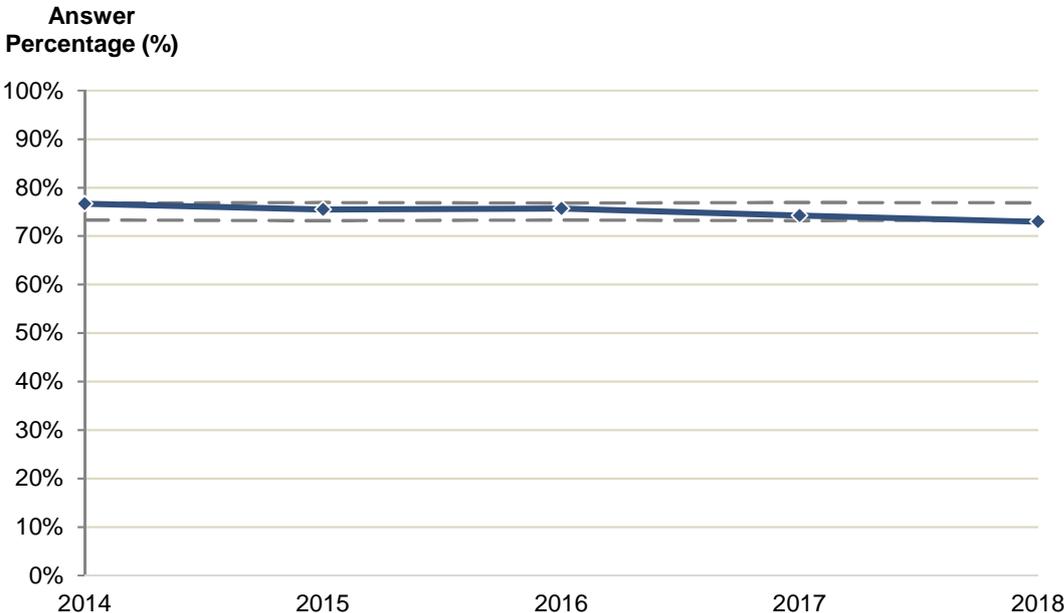
### 3: Organising care

As the care coordinator will oversee people's care and keep in contact with them, it is important that people using services know who this person is, and that the person does their job effectively. According to the Royal College of Psychiatrists, a care coordinator should get to know the person they are working with, learn about their difficulties, find out how they see their problems, know about their strengths, discuss their plans with them, give counselling, provide information and advice, make sure that everybody is working together, and make sure they have a clear care plan about how they are going to be helped.<sup>43</sup>

NICE quality statement 4 also recommends that people using community mental health services are supported by staff from a single multi-disciplinary community team that is familiar to them, and with whom they have a continuous relationship.

Seventy-three per cent of all respondents said they had been told who was in charge of organising their care and services, a statistically significant decrease from 2017 (74%). For the first time this year, the proportion of respondents answering ‘Yes’ has fallen below the expected limit, having been in the expected range of change between 2014 and 2017. Twenty-seven per cent of respondents said they had not been told this information (23% in 2014).

**Q6. 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”.) (Answer: ‘Yes’)**



Answered by all  
 Number of respondents: 2014 (11,314), 2015 (9,589), 2016 (10,838), 2017 (9,863) and 2018 (10,358)  
**Note:** respondents who stated that they were not sure have been excluded.

Respondents who knew who the main person in charge of organising their care was were asked two supplementary questions.<sup>g</sup>

The vast majority of these respondents knew how to contact the main person in charge of organising their care if they had a concern (96%). Furthermore, more than half said that the person who organised their care and services did this ‘very well’ (57%), with a further 33% saying they did this ‘quite well’.

g. Respondents who told us (at Q7 in the questionnaire) that their GP is in charge of organising their care and services have been removed from the analysis for these questions. This is because results will not be attributable to the mental health trust.

We analysed results for questions related to ‘organisation of care’ as a composite indicator of Q6 and Q9. When looking at variation in the experiences of respondents by subgroup for this theme, those who reported better than average experiences included people aged 66 and over, those on new CPA and those with care cluster codes 10 (First Episode Psychosis), 11 (Ongoing Recurrent Psychosis, – Low Symptoms) and 14 (Psychotic Crisis).

## 4: Planning care

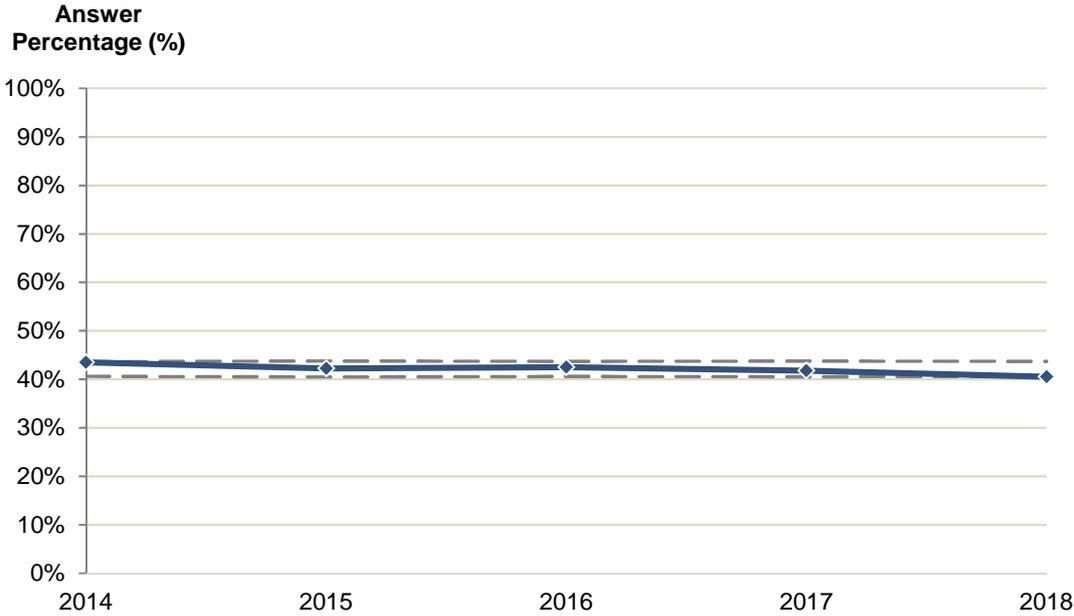
[Guidance on the care plan approach](#) from the Department of Health and Social Care recommends that everyone receiving care from specialist mental health services should agree what care they will receive. This may be known as a ‘care plan’ or a ‘recovery plan’ and should have been developed jointly with mental health and social care professionals. This plan should set out their individual mental health needs, plans and goals for their care and treatment.

A collaborative approach to agreeing care plans is also emphasised in [NICE quality statement 8](#), which recommends that people using mental health services jointly develop a care plan with mental health and social care professionals, and that a copy of the plan is given to people with an agreed date to review it.

Research in 2011 suggests that the majority of people with mental illness prefer to go through the stages of the decision-making process together with their provider and be involved in agreeing a treatment.<sup>44</sup>

Respondents were asked whether they had agreed with someone from NHS mental health services what care they will receive. Forty-one per cent of respondents said they ‘definitely’ had in 2018. Although this decrease compared with 2017 was not significant, it was large enough to fall below the expected limits of change for the first time.

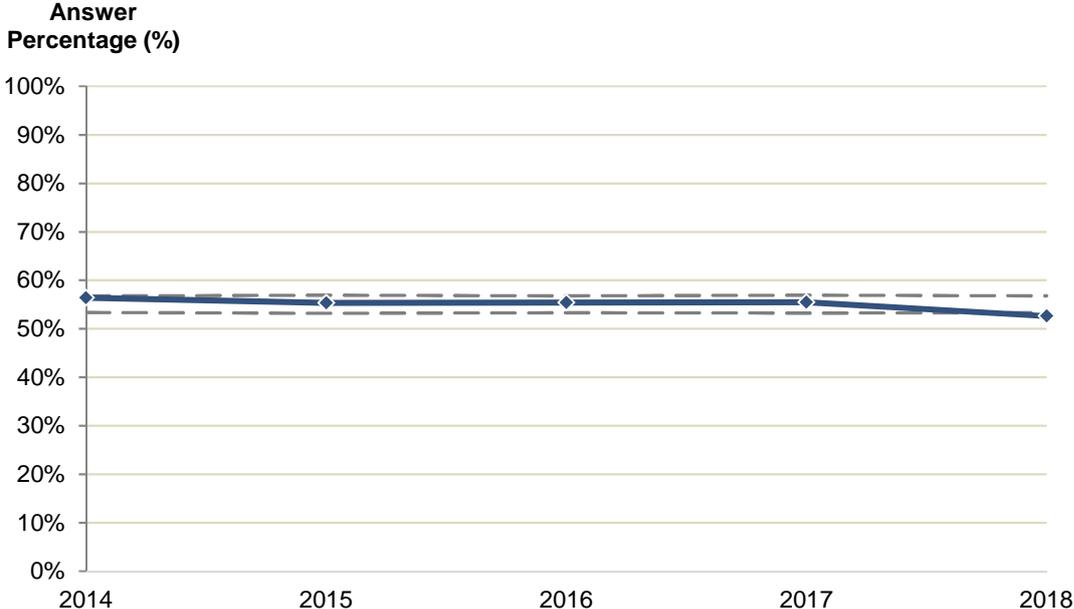
**Q10: Have you agreed with someone from NHS mental health services what care you will receive? (Answer: 'Yes, definitely')**



Answered by all  
 Number of respondents: 2014 (13,223), 2015 (11,178), 2016 (12,728), 2017 (11,569) and 2018 (12,342)

Those respondents who agreed their care with someone from NHS mental health services were then asked how involved they were in this process. Fifty-three per cent stated they were 'definitely' involved as much as they wanted to be, a statistically significant decrease of three percentage points compared with 2017. The 2018 result has fallen below the expected limits for the first time, having fluctuated in the expected range between 2014 and 2017. The proportion of respondents who answered 'no, but I wanted to be' is unchanged from 2017 at 8%.

**Q11: Were you involved as much as you wanted to be in agreeing what care you will receive? (Answer: ‘Yes, definitely’)**

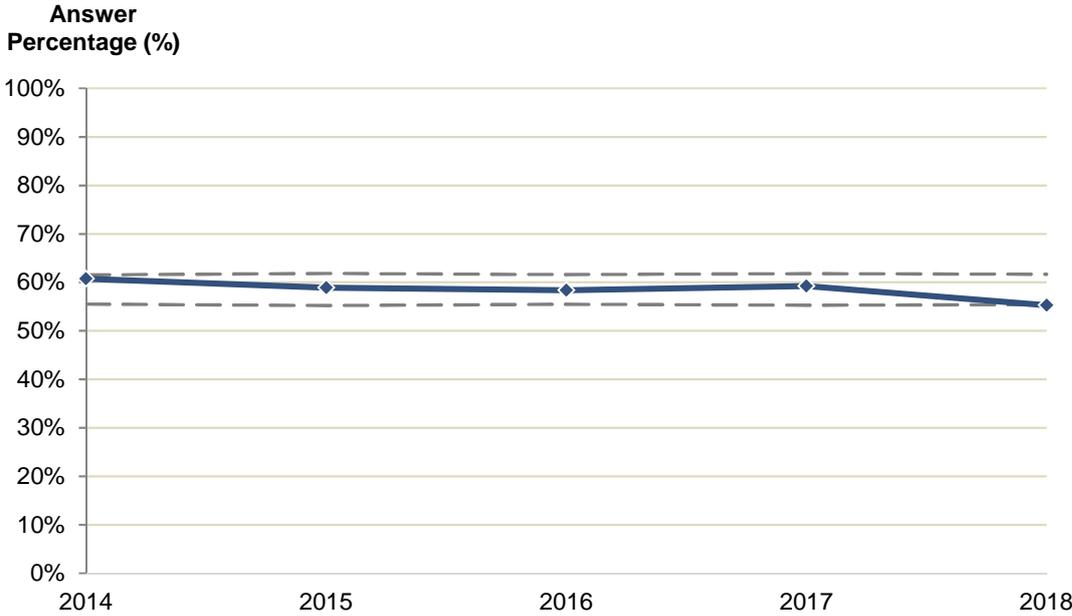


Answered by all who had agreed with NHS mental health services what care they would receive.  
 Number of respondents: 2014 (9,821), 2015 (8,242), 2016 (9,412), 2017 (8,395) and 2018 (9,208)  
**Note:** respondents who stated that they did not know/can't remember and those who did not want to be involved have been excluded.

We analysed results for questions related to ‘involvement’ as a composite indicator of Q11, Q14, Q21 and Q28. When comparing how people’s experiences varied for this theme, those who reported worse than average experiences included people aged 18-35, and those diagnosed as under Non-Psychotic, Moderate Severity (care cluster 3) or Non-Psychotic Chaotic and Challenging disorders (care cluster 8).

The same respondents who had agreed their care with someone from NHS mental health services were also asked whether their personal circumstances were taken into account during this process. Fifty-five per cent said ‘Yes, definitely’, a significant decrease from 59% (2017) and a total of six percentage points lower compared with 2014. The p-chart analysis shows that results fluctuated in the expected range between 2014 and 2017, falling below the expected limit for the first time in 2018.

**Q12: Does this agreement on what care you will receive take your personal circumstances into account? (Answer: ‘Yes, definitely’)**



Answered by all who had agreed with NHS mental health services what care they would receive.  
 Number of respondents: 2014 (9,718), 2015 (8,070), 2016 (9,342), 2017 (8,228) and 2018 (9,058)  
**Note:** respondents who stated that they did not know/can't remember have been excluded.

We analysed by subgroup in relation to person-centred values by combining Q5 (*Did the person or people you saw understand how your mental health needs affect other areas of your life?*) and Q12 (*Does this agreement on what care you will receive take your personal circumstances into account?*). This has shown worse than average experiences for people in the following subgroups: those aged 18-35 or Non-Psychotic Chaotic and Challenging Disorders (care cluster 8).

## 5: Reviewing care

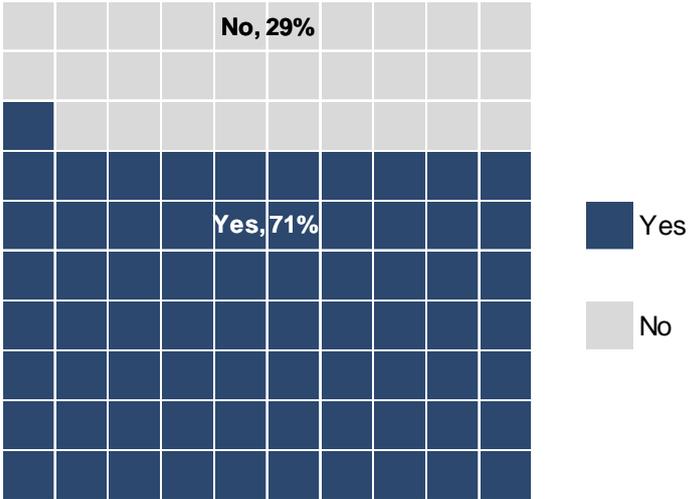
Involving people in their own care is important, as research suggests it can lead to more effective decision-making and better health outcomes. This is also reflected in [NICE quality statement 3](#), which emphasises a collaborative approach to decision-making.

According to [Mind](#), it is important to review care regularly (12 months from when it was first set up, and every 12 months after that) as people's needs may change over time. The purpose of reviewing care is to: monitor progress and changes; consider how the care and support plan is meeting needs, allowing people to achieve their personal outcomes; keep the plan up to date; and determine what, if any, services might be needed in the future.<sup>45</sup>

All respondents were asked if they had a formal meeting with someone from NHS mental health services to discuss how their care was working in the previous 12 months. Seventy-one per cent answered 'Yes', which has not fluctuated beyond the expected range since 2014.

Respondents who had a formal meeting in the previous 12 months were then asked whether decisions were made together between themselves and the person they saw, with 59% saying they 'definitely' were.

**Q13. 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?**



Answered by all

Number of respondents: 2014 (10,255), 2015 (8,798), 2016 (9,735), 2017 (8,963) and 2018 (9,485)

**Note:** those who answered 'Don't know / can't remember' and those who had been in contact with NHS mental health services for less than a year were excluded from the analysis.

## 6: Changes in the staff who people see

There is evidence that continuity positively affects people's experiences of care and that breaks in continuity have been linked to negative outcomes. Mental health professionals have an important role to play in supporting people to navigate complex systems and in creating the continuity of services, relationships and care contacts that people feel they need.<sup>46,47</sup>

[NICE quality statement 4](#) recommends that people using community mental health services are supported by staff from a single, multi-disciplinary community team, that is familiar to them and with whom they have a continuous relationship.

All respondents were therefore asked whether the people they see for their care and services had changed in the previous 12 months. Forty-two per cent said 'Yes' it had changed for reasons other than them requesting the change

personally or moving home. Forty-eight per cent of respondents stated that the people they see had not changed in 2018, a statistically significant decrease compared with 2017 (50%).

Looking at the respondents<sup>h</sup> who had experienced a change in the people they see for their care or services in the previous 12 months:

- less than half (45%) said that the reasons for this change were ‘completely’ explained to them at the time, while almost a quarter said reasons were not explained (23%)
- 68% said that their care ‘stayed the same’ or ‘got better’ following the change, but 32% said their care ‘got worse’.

## 7: Crisis care

A mental health crisis is an emergency and it is important that people know who to contact to receive effective care. It often means that someone no longer feels able to cope or be in control of their situation. They may feel great emotional distress or anxiety, can’t cope with day-to-day life or work, think about suicide or self-harm, or experience hallucinations and hearing voices.<sup>48</sup>

The [Crisis Care Concordat](#) (a national agreement between services and agencies involved in the care and support of people in crisis) sets out the areas which organisations should focus on when working together to ensure that people get the support they need during a mental health crisis. These four areas are: (1) access to support before crisis point, (2) urgent and emergency access to crisis care, (3) quality of treatment and care when in crisis and (4) recovery and staying well.<sup>49</sup>

Recent policy has included a focus on improving services for people who experience a mental health crisis. The [Five Year Forward View for Mental Health](#) includes a priority that people facing a crisis should have access to mental health care seven days a week and 24 hours a day, in the same way that they are able to get access to urgent physical health care.

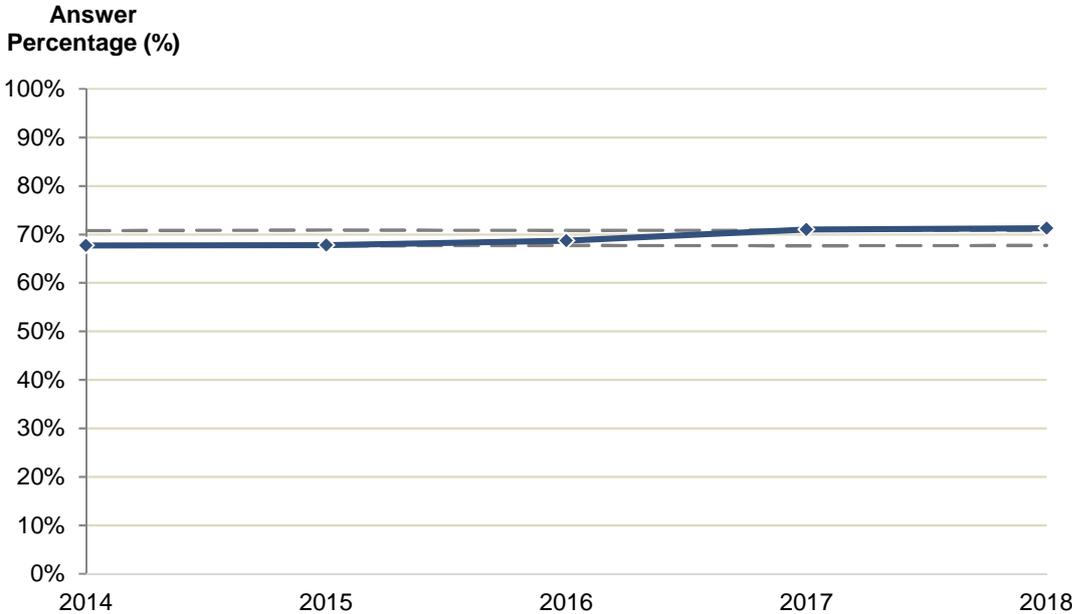
According to latest figures from NHS England’s [Mental Health Five Year Forward View Dashboard](#), only 24% of crisis resolution home treatment services were able to meet the selected ‘core functions’ in 2016/17. Core functions include an urgent and emergency community response and intensive home treatment, available 24 hours a day, seven days week.

All respondents in the survey were asked if they knew who to contact out of office hours if they had a crisis, with 71% answering ‘Yes’. Falling below the expected lower limit in 2014, there has been a gradual increase in the percentage of

<sup>h</sup>. These questions are only answered by respondents who selected the first response option ‘Yes’ at Q15.

respondents answering 'Yes' to this question over time, with results for 2017 and 2018 above the expected limits. This suggests a consistent improvement in people's experiences in this area.

**Q18 Do you know who to contact out of office hours if you have a crisis? (Answer: 'Yes')**



Answered by all  
 Number of respondents: 2014 (11,868), 2015 (10,155), 2016 (11,417), 2017 (10,469) and 2018 (11,044)  
**Note:** those who answered 'Not sure' were excluded from the analysis.

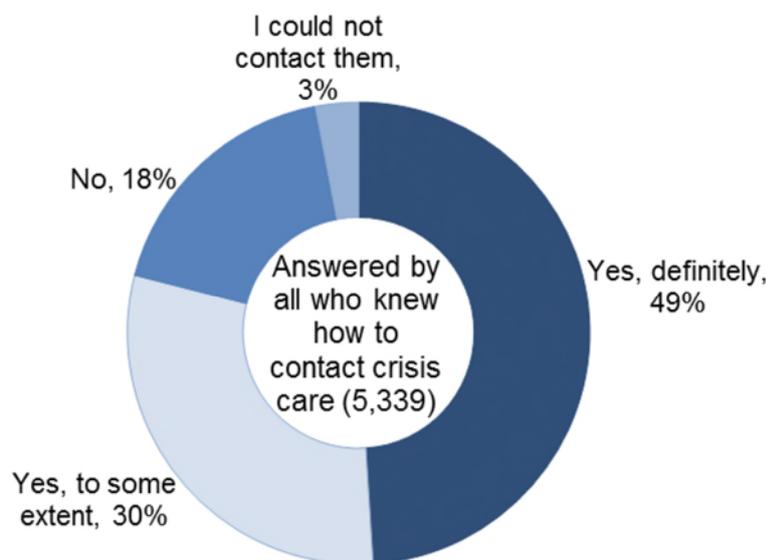
Analysis of Q18 'Do you know who to contact out of office hours if you have a crisis?' for different subgroups of respondents showed differences in experience of access to crisis care. Those that reported worse than average experiences included respondents diagnosed with: Cognitive Impairment, Low Need (care cluster codes 18), Cognitive Impairment or Dementia Complicated, Moderate Need (care cluster code 19) and Cognitive Impairment or Dementia Complicated, – High Need (care cluster code 20). This suggest that a large proportion of people with a Cognitive Impairment or Dementia do not know who to contact out of hours when they have a crisis.

As well as knowing how to access crisis care, it is important that people then get the help they needed.

CQC's report [Right here, right now](#) looked at people's experiences of crisis care and found many people experienced problems getting help when they needed it.<sup>50</sup> Furthermore, it found that some healthcare professionals sometimes lacked compassion and warmth when caring for people who are having a crisis.

Forty-nine per cent of respondents who knew how to get help out of hours during a crisis, and did so in the last 12 months, said they 'definitely' got the help that they needed. Just under a fifth (18%) said they did not get the help needed

**Q19: In the last 12 months, did you get the help you needed when you tried contacting this person or team?**



**Note:** respondents who had not tried in the previous 12 months to make contact and those who stated that they could not remember have been excluded.

Subgroups of respondents that reported worse than average experiences for the care they received when contacting crisis services include: those aged 18-35 and those diagnosed under Non-Psychotic Chaotic and Challenging Disorders (care cluster 8).

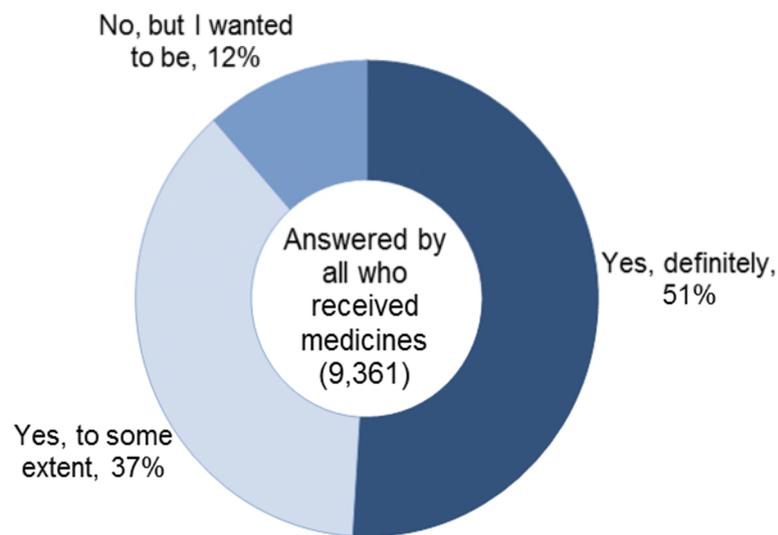
## 8: Medicines

Guidance from [NICE](#) on [adherence to medication](#) recommends involving people in decisions around which medicines to take, as this can help improve their compliance with taking medicines.<sup>51</sup>

Academic research has also found that adherence to treatment can be improved by shared decision making between mental health professionals and people using the service. Treatment adherence is often low for people being treated for mental health problems. Irregular use of medicines was found to be one of the strongest predictors of hospital use and higher costs of treatment.<sup>52 53</sup> Aside from increased and prolonged hospitalisations, poor adherence to medicines leads to an increase in relapse rates for people with schizophrenia and suicide rates are increased for people with bipolar disorder who do not routinely take their medicines.<sup>54</sup>

Of those respondents who wanted to be involved in decisions about which medicines they receive for their mental health needs, 51% said that they 'definitely' were. This figure has changed little since 2014.

**Q21: Were you involved as much as you wanted to be in decisions about which medicines you receive?**



**Note:** respondents who stated that they did not know / could not remember or who did not want to be involved have been excluded.

People who are receiving treatment (medicines or therapies) should be given information about that treatment, including any side-effects. The [NICE quality statement 7](#) says that people should be given information and explanations on their assessment, diagnosis and treatment options in a way in which they can understand. Only 53% of respondents that received medicines in the previous 12 months said that they were 'definitely' given information about them in a way they could understand. A further third were given this to 'some extent'.

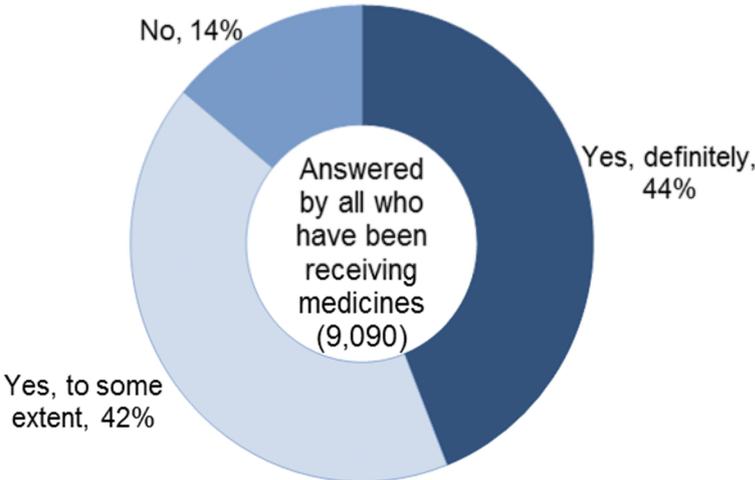
Respondents diagnosed with Non-Psychotic Chaotic and Challenging disorders (care cluster 8) reported worse than average experiences for information sharing: medicines.

The [NICE](#) guidance on [adherence to medication](#) states that people on long-term medicines should have them reviewed at regular intervals. The guidance sets out four requirements when reviewing medicines: (1) understanding service user knowledge, understand and concerns about medicines, (2) reviewing regularly, (3) enquiring about adherence and (4) being aware that people who use services may sometimes evaluate medicines using their own personal criteria.

The majority (85%) of respondents had been taking medicines for their mental health needs for 12 months or longer. Of these people, 79% said that in the last 12 months a NHS mental health worker had checked with them about how they were getting on with their medicines (77% in 2017, a significant increase from 2018).

NICE quality statement 1 says that people using mental health services should be able to feel optimistic that their care will be effective. When asked if people thought their medicines have helped their mental health, 44% said they 'definitely' had.

**Q23: Do you feel your medicines have helped your mental health?**



**Note:** respondents who stated that they were not sure have been excluded.

## 9: NHS Therapies

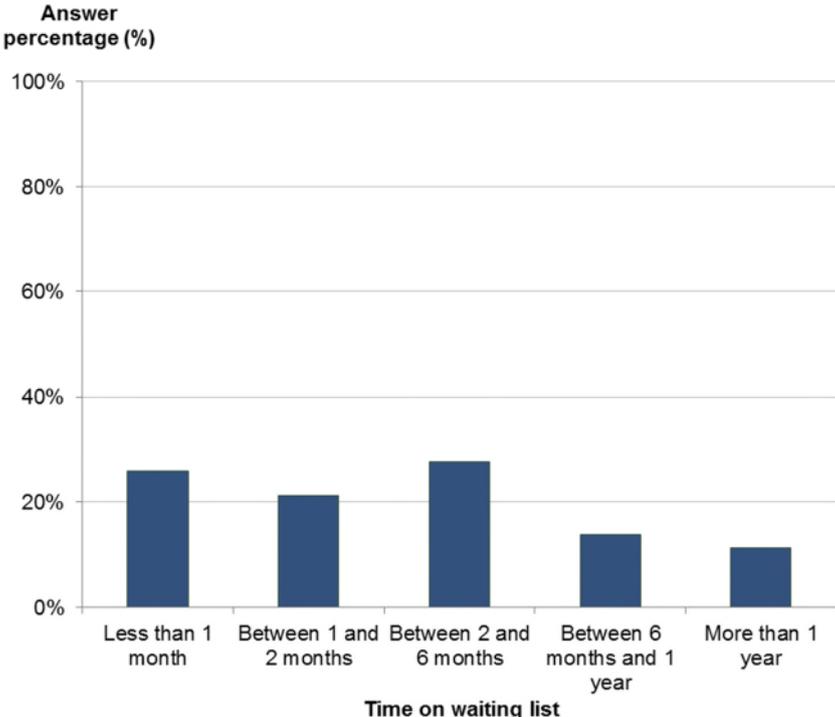
Effective care for mental health conditions may involve a range of different therapies. Those used by NHS mental health professionals vary in terms of intensity and duration, depending on the type and severity of the mental health condition or symptoms. People with depression may be treated with a wide variety of therapies, and most often cognitive behavioural therapy, psychodynamic psychotherapy and /or interpersonal therapy are used. For people with antisocial personality disorder who are treated in the community, NICE clinical guidelines recommend using group-based cognitive and behavioural interventions. For all therapies, the level of risk should be assessed, and the duration and intensity of the programme adjusted accordingly.<sup>55,56</sup>

As with medicines, NICE quality statement 1 (feeling optimistic about care) and statement 7 (information and explanations) also relate to the NHS therapies that people receive.

All respondents were asked if they had received any NHS therapies for their mental health needs that did not involve medicines in the last 12 months. Less than half (46%) said that they had. More than a quarter (28%) said 'No, but I would have liked this', leaving 27% who responded 'No, but I did not mind'.<sup>i</sup>

Of the people who received NHS therapies in the previous 12 months, nearly half (47%) reported being on a waiting list for less than two months before their therapy started. Eleven per cent were on a waiting list for more than a year.

**Q30: How long were you on the waiting list before your NHS therapy began?**



Answered by all who have been receiving NHS therapies in the previous 12 months.

Number of respondents: 2018 (3,675)

**Note:** respondents who stated that they did not know/could not remember have been excluded.

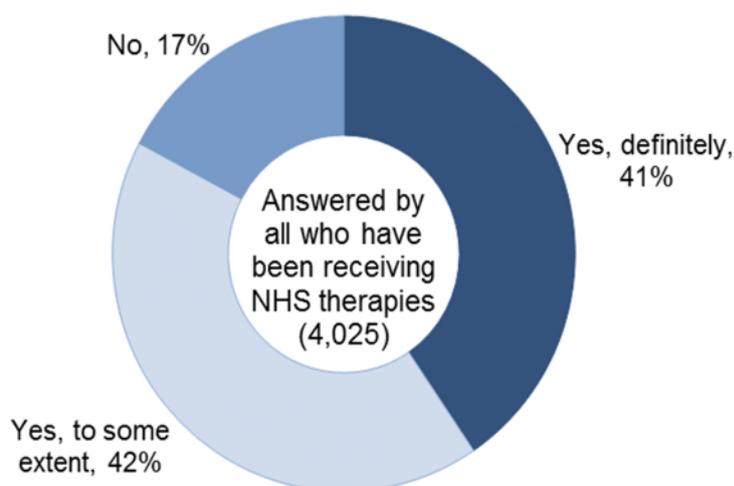
Looking at the experiences of respondents who had received NHS therapies for their mental health needs in the previous 12 months:

- 64% said that their NHS therapies were 'completely' explained to them in a way they could understand
- only 49% were 'definitely' involved as much as they wanted to be in deciding what NHS therapies to use.

When asked if they thought their NHS therapies have helped their mental health, 41% said 'Yes, definitely'.

i. Please note that those who responded 'this was not appropriate for me' were excluded from the analysis for this question.

## Q29: Do you feel your NHS therapies have helped your mental health?



**Note:** respondents who stated that they were not sure have been excluded.

## 10: Support and wellbeing

People using specialist mental health services sometimes have wider needs, such as those related to their finances, housing or employment. While NHS mental health services do not necessarily provide support for this directly, they should help people to find support from other sources, such as signposting them to other services.<sup>57</sup>

### Physical health needs

There are strong links between physical and mental health problems. [The King's Fund](#) reported that almost half of people with a mental health condition also have a long-term physical health problem.<sup>58</sup>

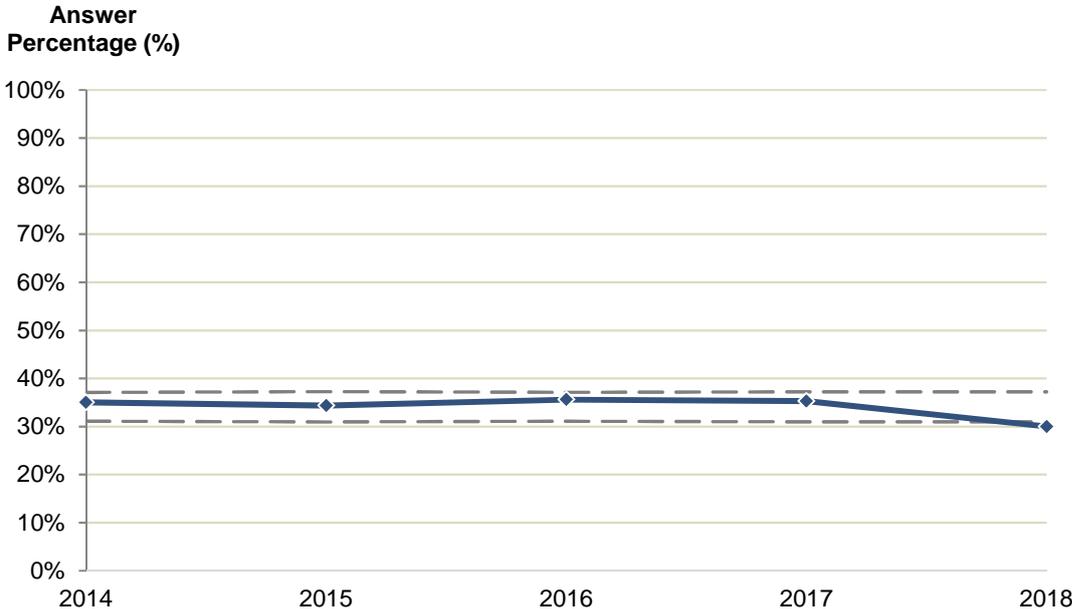
According to [Public Health England](#), people with a mental health condition have worse outcomes for their physical health, and those with physical health conditions often have mental health needs that go unrecognised. Two out of three people with serious mental health conditions will die prematurely due to treatable physical conditions such as cardiovascular, respiratory and infectious diseases. The [Department of Health and Social Care](#) aims is to achieve parity of esteem and put mental health on a par with physical health by closing the health gap between people with mental health conditions and the population as a whole.

Long-term conditions can have a life-changing effect on a person's wellbeing, functional capability and quality of life. Co-morbid long-term conditions lead to more frequent and varied use of healthcare services and raises the costs of physical health care. It is therefore important to make sure that people's mental health and physical health care needs are equally met.<sup>59</sup>

Guidance from [Public Health England](#) states that, “All healthcare professionals have a responsibility to promote the physical health and wellbeing of individuals, at risk of, or living with, mental health problems.” Over 40,000 deaths could be prevented if people with serious mental illness received the same health care as the rest of the population. As part of its [National Commissioning for Quality and Innovation \(CQUIN\)](#) goals, NHS England has committed to lower the 15 to 20 year premature mortality difference for people with psychosis.<sup>60</sup>

All respondents were asked whether, in the last 12 months, NHS mental health services had given them help or advice with finding support for physical health needs. Of those who needed or wanted this type of support, only 30% said that they ‘definitely’ received this, a significant decrease of five percentage points compared with 2017. When analysing the results over time, they were in the expected range of variation between 2014 and 2017, but in 2018 have fallen below the expected limit for the first time. Thirty-nine per cent of respondents answered ‘No, but I would have liked help or advice with finding support’ in 2018, a significant increase of three percentage points from 2017 (36%).<sup>j</sup>

**Q31. In the last 12 months, did NHS mental health services give you any help or advice with finding support for physical health needs (this might be an injury, a disability, or a condition such as diabetes, epilepsy, etc)? (Answer: ‘Yes, definitely’)**



Answered by all  
 Number of respondents: 2014 (6,530), 2015 (5,948), 2016 (6,551), 2017 (6,022) and 2018 (6,106)  
**Note:** respondents who stated that they already have support and did not need advice, or who did not need support for this, or who did not have physical health needs have been excluded.

j. We excluded respondents who said that they ‘have support in place and did not need help or advice with finding support’, or that they ‘did not need support’ or that they ‘do not have any physical health needs’.

## Financial advice or benefits and employment

According to the independent government review, [Thriving at Work: a review of mental health and employers](#), the UK faces a mental health challenge at work. The reports states that there are more people at work with mental health conditions than ever before and that 300,000 people with a long-term mental health condition lose their jobs each year. This is a much higher rate than those with physical health conditions.<sup>61</sup>

Consistent with this, the Mental Health Foundation's [Surviving or thriving: the state of the UK's mental health](#) report found that household income and economic activity are the most notable demographic difference for determining mental health conditions.<sup>62</sup>

[The Improving Access to Psychological Therapies Manual](#) produced by [The National Collaborating Centre for Mental Health](#), states that there are poorer employment outcomes for people with coexisting mental and physical health problems. There is a higher risk of unemployment, absenteeism and poorer performance compared with people who do not have a mental health condition. It has been established that the longer people are absent, or out of work, the more likely they are to experience depression and anxiety. Therefore, employment advice, delivered as a core part of a service, is integral to the success of that service.

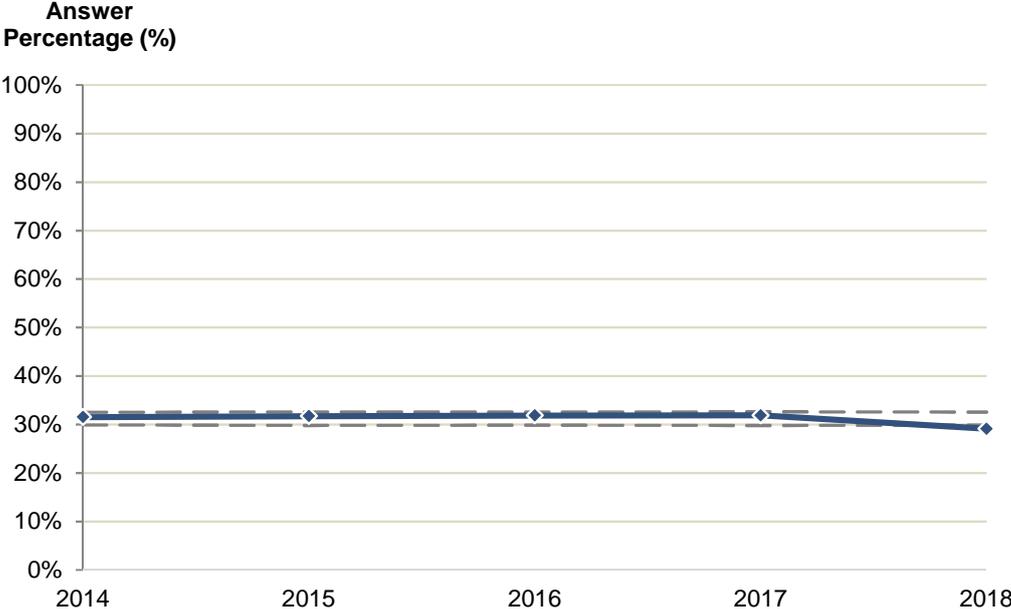
According to the Mental Health Taskforce's [Five Year Forward View for Mental Health](#), psychological therapies and Individual Placement and Support (IPS) services have proved highly effective in helping people into work – with around 30% moving into jobs through IPS – but these are not being commissioned at scale.

We asked all respondents whether, in the last 12 months, NHS mental health services gave them any help or advice with finding support for financial advice and benefits, and finding and keeping work.<sup>k</sup>

Of those respondents who wanted or needed help or advice with finding support for financial advice or benefits, 29% said that they 'definitely' received this in the last 12 months, a significant decrease since 2017 (32%). The p-chart analysis shows that for the first time, the percentage of respondents answering 'Yes, definitely' fell below the expected limits, having previously remained in the expected range of variation between 2014 and 2017. Forty-seven per cent answered 'No, but I would have liked help or advice with finding support', a significant increase compared with 2017 (45%).

k. We excluded respondents who said that they 'have support in place and did not need help or advice with finding support' or that they 'did not need support'.

**Q32: In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits? (Answer: ‘Yes, definitely’)**



Answered by all

Number of respondents: 2014 (7,315), 2015 (6,294), 2016 (7,028), 2017 (6,420) and 2018 (6,897)

**Note:** respondents who stated that they already have support and did not need advice, or who did not need support for this have been excluded.

Only 23% said that in the previous 12 months, NHS mental health services ‘definitely’ gave them help or advice with finding support for finding or keeping work, a significant decrease compared with 2017 (27%) but still in expected limits of change this year. Forty-seven per cent answered ‘No, but I would have liked help or advice with finding support’ (43% in 2017).

**Community/social activities**

Promoting the social inclusion of people with mental health conditions has been set out as a priority in the government’s [No Health Without Mental Health](#) policy. The government aims to promote social action, social inclusion and human rights, among other things, through a localised approach, reforms to health and other services, and reforms to government departments. [NICE quality statement 8](#) states that care plans should include activities that promote social inclusion such as employment, volunteering, and other aspects, such as leisure activities.

The World Health Organisation describes these services as ‘informal community mental health services’ and states that “these services can play an important supportive role in improving outcomes for persons with mental disorders. They are important for maintaining integration in communities and providing support networks that minimise the risk of relapse.”<sup>63</sup>

According to [The Improving Access to Psychological Therapies Manual](#), it is important that providers work as part of the wider system and facilitate a link for people with non-medical sources of support in the community. These actions are termed social prescribing, the objectives of which support the principles set out in NHS policy documents, including the [Five Year Forward View](#), which encourages a focus on prevention and wellbeing, patient-centred care, and better integration of services, as well as highlighting the role of the third sector in delivering services that promote wellbeing.<sup>64</sup>

Respondents were asked whether someone from NHS mental health services supported them in joining a group or taking part in activities in the last 12 months. Of those respondents who needed or wanted it, only 32% answered 'Yes, definitely', 30% answered 'Yes, to some extent' and 38% answered 'No, but I would have liked it'.

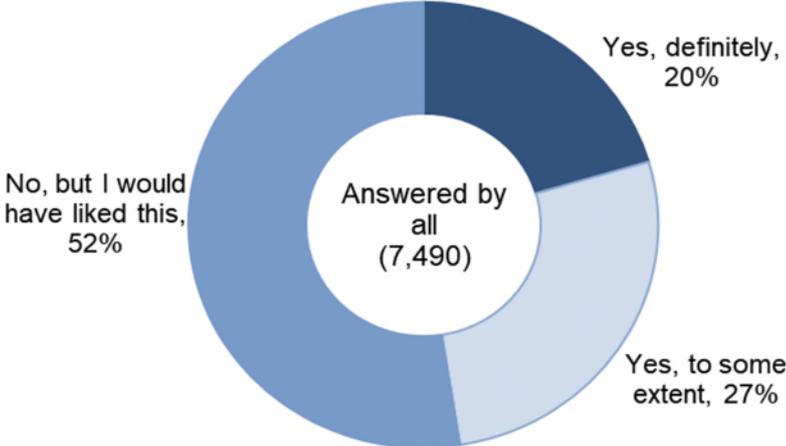
### Peer support

[NICE guidance](#) includes a number of statements relating to people's wider lives, including that people using services should be informed of appropriate local user-led support organisations or options for peer support.

Research conducted by [Repper and Carter](#) (2011) highlighted the benefits of peer support for improving mental health. This study found that peer support promotes hope and belief in the possibility of recovery, empowerment and increased self-esteem, self-efficacy and self-management of difficulties, social inclusion and engagement, and increased social networks.<sup>65</sup>

Respondents were asked whether they had been given information by NHS mental health services about getting support from people who have experience of the same mental health needs as them. Of the respondents who wanted this, there was a significant decrease in the respondents that answered 'Yes, definitely', from 2017 (23%) to 2018 (20%) but this difference is still in an expected range of change when taking account of the trend from 2014. More than half (52%) responded 'No, but I would have liked this', a significant increase compared with 2017 (49%).

### Q36. 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?

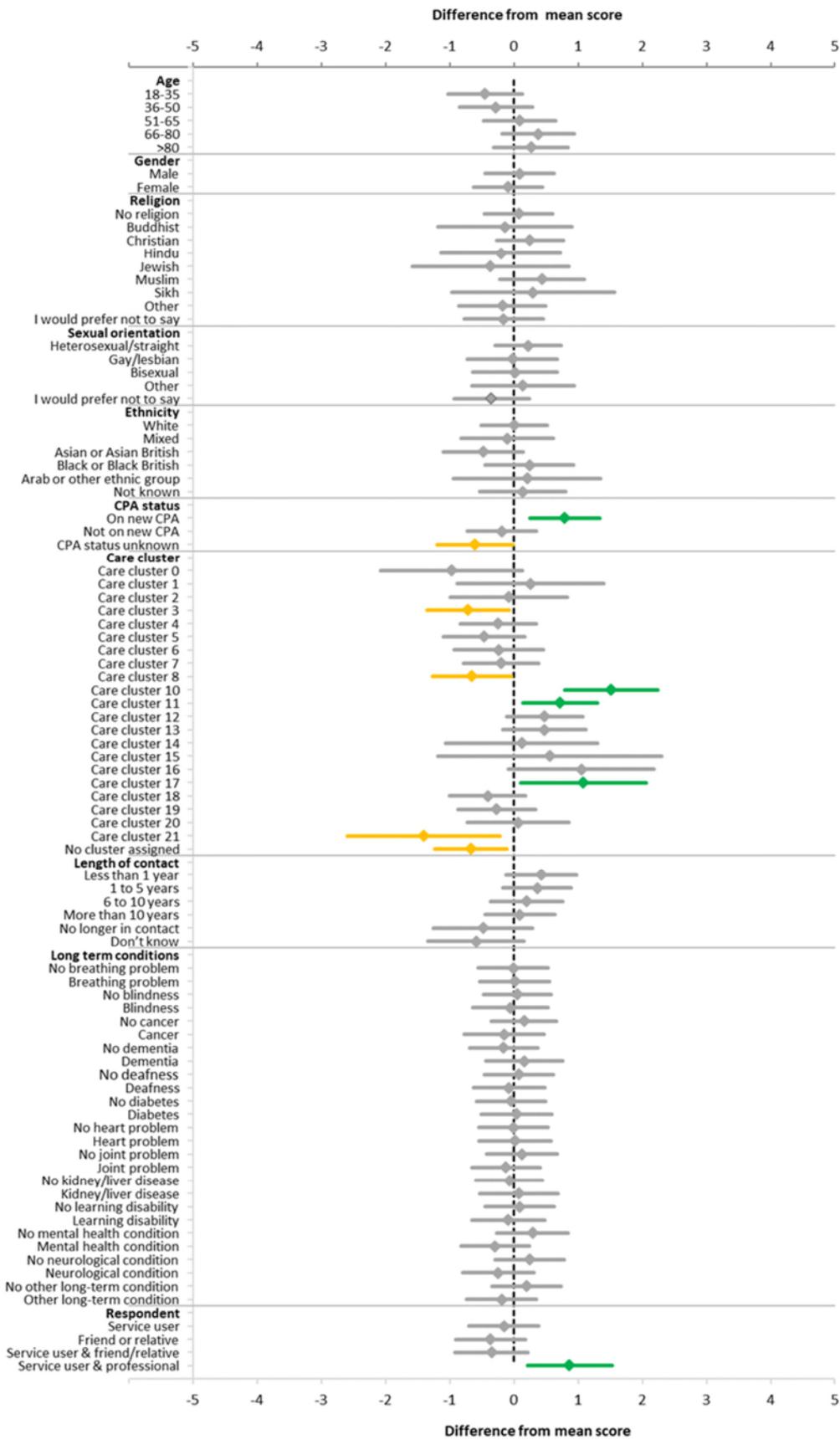


Note: those who answered 'I did not want this' were excluded from the analysis.

When looking at the experiences of the different subgroups about peer support information sharing, those that reported worse than average experiences were people aged 18-35 and people diagnosed as having a non-psychotic (moderate severity) disorder.

Looking at the overall support and wellbeing experience, the following groups of people using services reported worse than average experiences: people with an unknown CPA status, people diagnosed as having a non-psychotic disorder, moderate severity (care cluster 3), non-psychotic chaotic and challenging disorders (care cluster 8), and cognitive impairment or dementia complicated, high physical or engagement (care cluster 21).

Support and wellbeing theme: difference from mean score by subgroup with 95% confidence interval



## Involving family or friends

The involvement of a person's family (or someone else close to them), when wanted, is an essential part of providing good care. The King's Fund report [People in control of their own health and care: The state of involvement](#) suggests this can increase people's knowledge, confidence and understanding in dealing with health issues.

[NICE guidance](#) states that NHS mental health services should welcome the involvement of friends or family in the care of those using services, if this is what they want. This is also a theme in the [Patient Experience Framework](#), which states that family and friends' involvement should be welcomed in decision making.

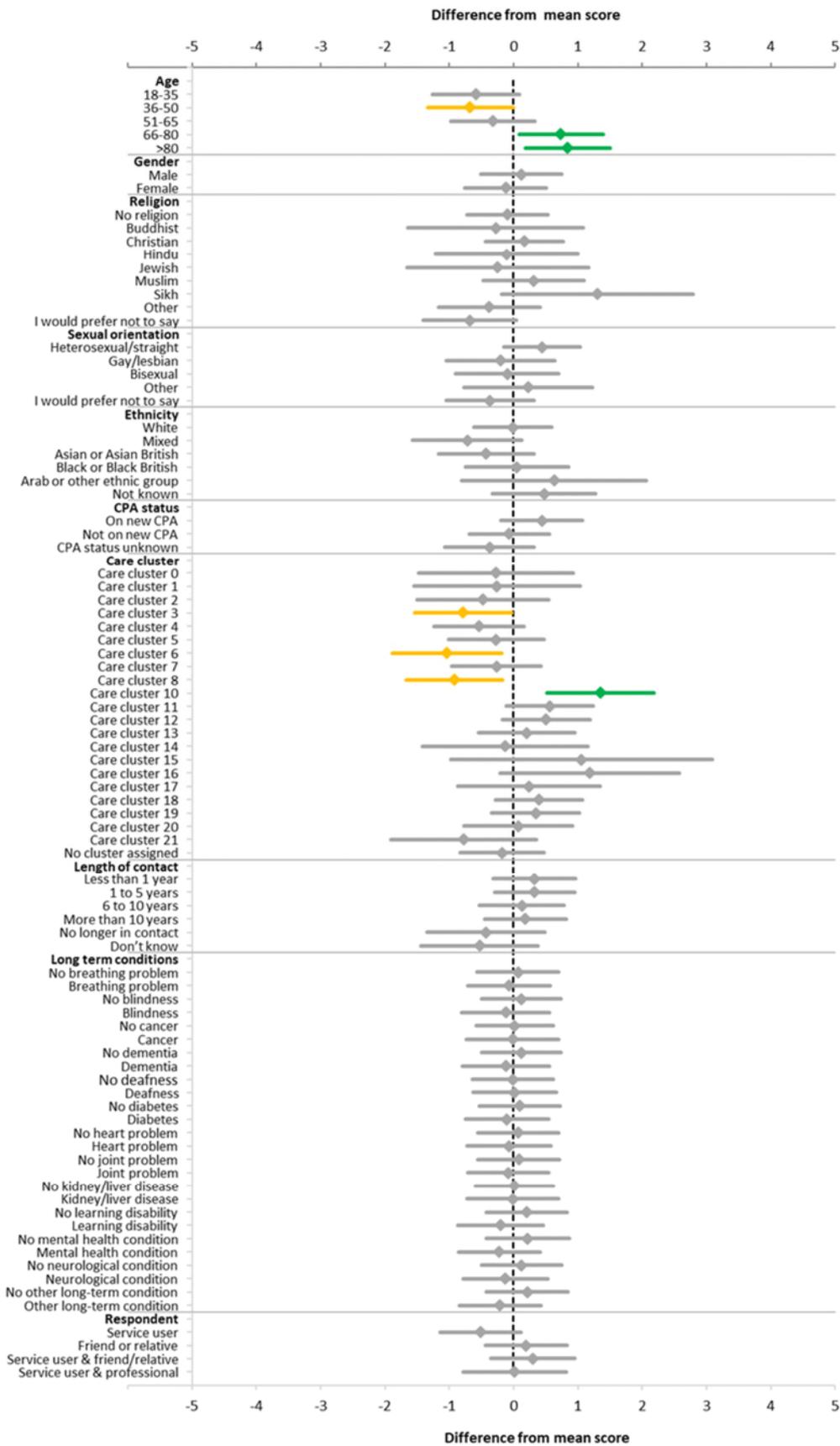
The [Joint review of partnerships and investment in voluntary, community and social enterprise organisations in the health and care sector](#) produced in partnership by representatives of the voluntary, community and social enterprise sector, Department of Health and Social Care, NHS England and Public Health England recommends that there should be greater co-production with people who use services and their families at every level of the health and care system.<sup>66</sup>

We asked respondents whether NHS mental health services involved a member of their family or someone else close to them as much as they would have liked them to. Of those who wanted friends or family involved, only 53% said that a member of their family or someone else close to them had 'definitely' been included as much as they would have liked them to be.<sup>1</sup>

The following chart shows our analysis of subgroups of respondents, which revealed that the following groups of people had worse than average experiences relating to involvement of family and friends: people diagnosed as having a non-psychotic, moderate severity (care cluster 3), non-psychotic disorder of over-valued ideas (care cluster 6), and non-psychotic chaotic and challenging disorders (care cluster 8).

1. We excluded people who said that 'my friends or family did not want to be involved', that they 'did not want my friends or family to be involved' or that 'this does not apply to me'.

**Involvement of family and friends theme: difference from mean score by subgroup with 95% confidence interval**

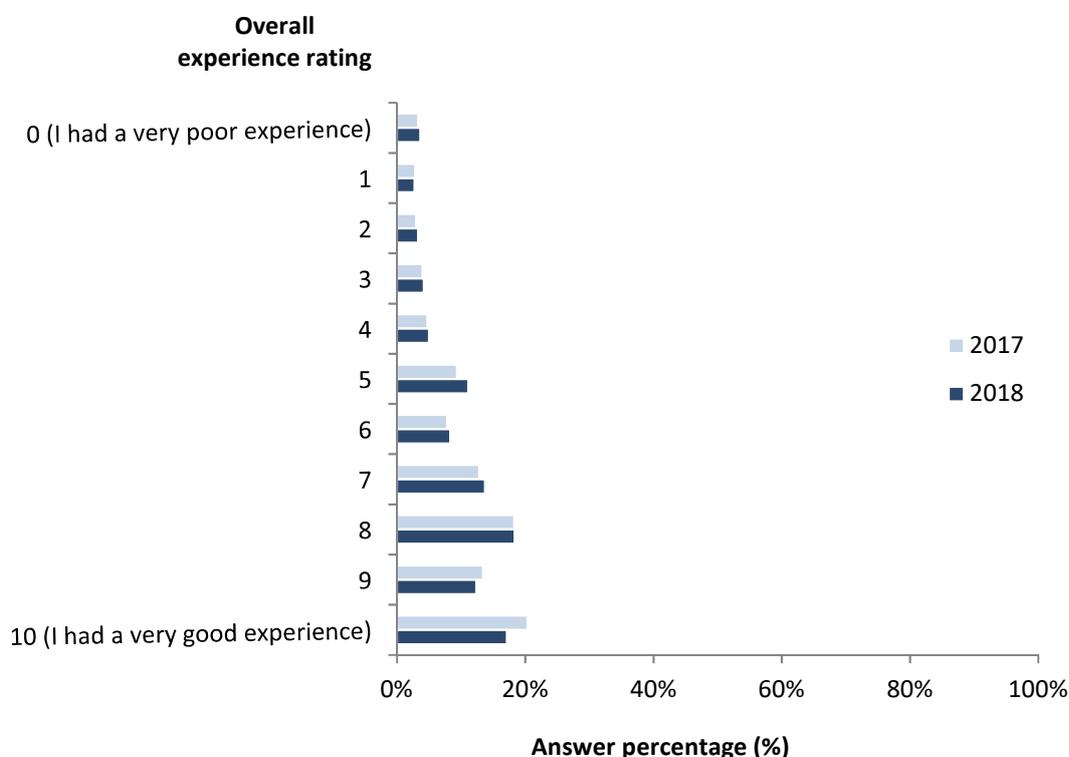


# 11. Overall

## Overall experience

We asked all respondents to evaluate their overall experience on a scale of 0 to 10 (where 0 is 'I had a very poor experience' and 10 is 'I had a very good experience'). Thirty per cent rated their overall experience with a score of nine or above out of 10 in 2018 (34% in 2017).<sup>m</sup> This four-percentage point decline is still in the expected limits of change, despite being a significant decrease.

### Q37. Overall.....



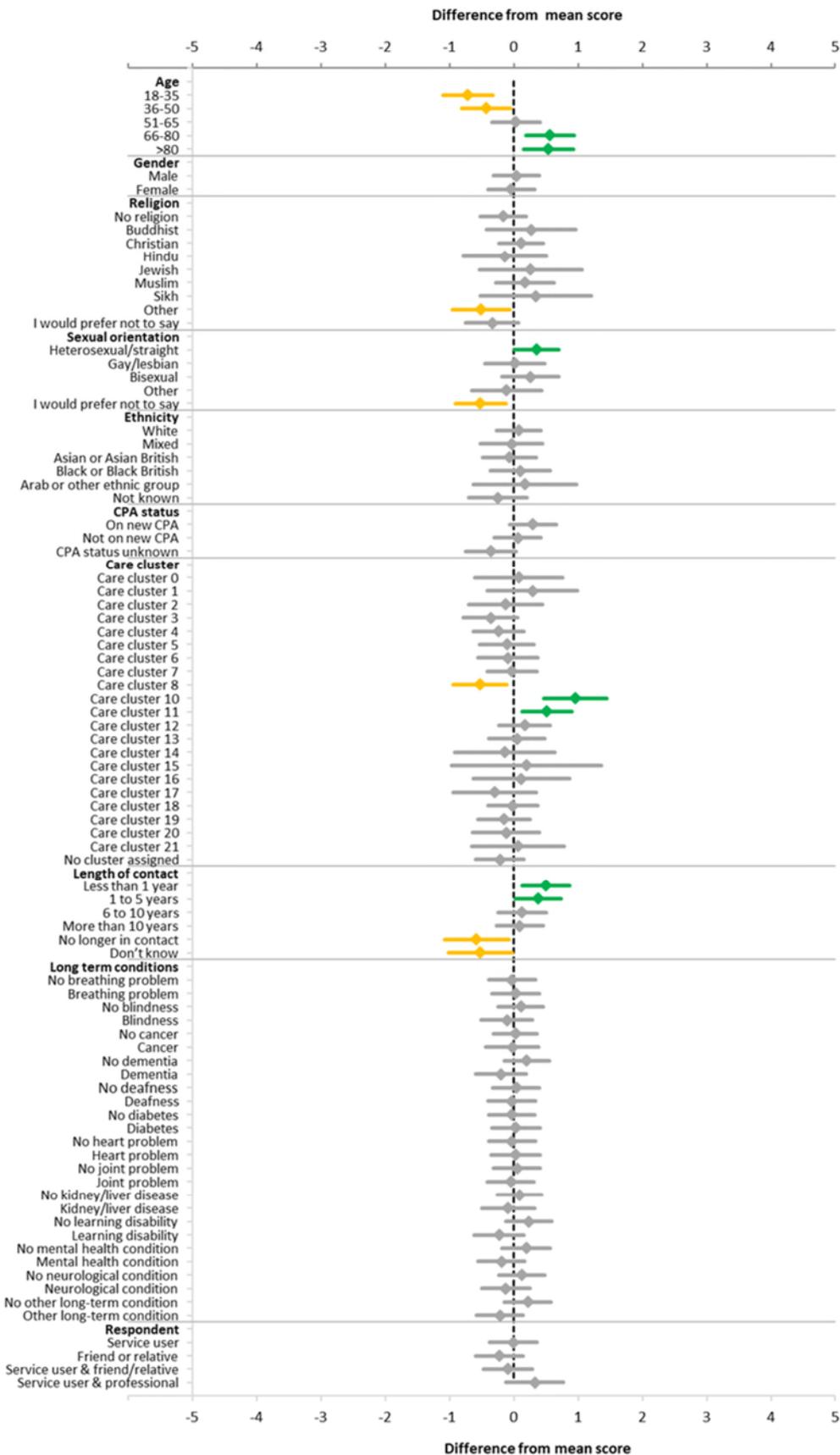
Answered by all

Number of respondents: 2017 (11,202) and 2018 (11,738)

As the figure on the next page shows, our subgroup analysis highlighted that people aged 18-50 and those diagnosed as having a Non-Psychotic Chaotic and Challenging disorder (care cluster 8) had a worse than average overall experience. Whereas people aged 66 and older, heterosexual/straight people, people diagnosed as having a first episode of psychosis (care cluster 10) and ongoing recurrent psychosis, low symptoms (care cluster 11), and people in contact with mental health services for five years or less reported a better than average overall experience.

m. Calculated using rounded numbers

Overall theme: difference from mean score by subgroup with 95% confidence interval



## Respect and dignity

The [NHS Constitution](#) states that patients have the right to be treated with respect and dignity. This is also reflected in [NICE quality statement 2](#), which states that people using mental health services, and their families or carers, should feel they are treated with empathy, dignity and respect.

Seventy-one per cent of respondents said that, overall in the last 12 months, they felt that they were 'always' treated with respect and dignity by NHS mental health services. The figure has remained broadly static since 2014.

Analysis of the subgroups showed that the following groups of respondents reported a worse than average experience when asked if they were treated with respect and dignity: people aged 18-50, people diagnosed as having a non-psychotic chaotic and challenging disorder (care cluster 8) and psychosis and affective disorder, difficult to engage (care cluster 17).

## Subgroup analysis summary: how experience varies for different groups of respondents

The analysis modelled the mean scores of different subgroups: age, gender, religion, ethnicity, sexual orientation, CPA status, diagnosis (care cluster codes), length of contact, long-term conditions and proxy response (response to Q42. Who was the main person or people that filled in this questionnaire?).

The composites are:

**Overall question (Q37)**

**Respect and dignity (Q38)**

**Organisation of care (Q6 and Q9)**

**Involvement (Q11, Q14, Q21 and Q28)**

**Involvement of family and friends (Q35)**

**Respect for person-centred values (Q5 and Q12)**

**Access (Q3)**

**Crisis care (access) (Q18)**

**Crisis care (care) (Q19)**

**Communication (Q4)**

**Information sharing (Medicines) (Q22)**

**Information sharing (Therapies) (Q27)**

**Information sharing (Peer support) (Q36)**

**Support and wellbeing (Q31, Q32, Q33 and Q34)**

[Appendix G](#) provides more information about the questions used and the charts. The [Survey methodology](#) section provides more information about how the analysis was completed and the methodology of the subgroup analysis.

In this report, differences that are equivalent to at least **0.1** standard deviations from the overall mean of the target variable are treated as being noteworthy, provided that the confidence interval does not overlap the mean line.

## Age

Younger people aged 18-35 reported worse than average experiences for the themes:

- respect and dignity
- access
- communication
- organisation
- respect for patient-centred values
- involvement
- crisis care
- peer support
- overall experience

Respondents aged 36-50 also reported worse than average experiences across multiple themes. While those aged over 66 tended to report more positive experiences.

## Religion

Muslims reported better than average experiences for the 'respect and dignity', 'involvement' and 'access' composites. Sikh respondents reported better than average experiences for 'access' and 'communication'.

## CPA status

Respondents on a new CPA reported better than average experience for the 'organisation of care', 'access', 'crisis care access' and 'support and wellbeing' themes.

## Diagnosis/care clusters

### Non-psychotic disorders

In general, respondents with non-psychotic disorders had worse than average experiences across most composites. People diagnosed under the Non-Psychotic Chaotic and Challenging disorders care cluster code 8 reported worse than average experiences for 10 out of the 14 composites:

- respect and dignity
- access
- communication
- respect for patient-centred values
- involvement
- support and wellbeing
- crisis care
- information sharing: medicines
- involvement of family and friends
- overall experience.

### **Psychotic disorders**

Better than average experiences were identified for respondents with psychotic disorders across many of the composites. People diagnosed under the First episode in Psychosis care cluster code 10 reported better than average experiences for 11 out of the 14 composites:

- respect and dignity
- access
- organisation of care
- respect for patient-centred values
- involvement
- support and wellbeing
- crisis care
- involvement of family and friends
- communication
- information sharing: peer support
- overall experience.

### **Cognitive impairments and dementia**

Respondents with cognitive impairments or dementia (Moderate Need, care cluster 19; High Need, care cluster 20; and High Physical or Engagement, care cluster 21) reported worse than average experiences for the 'access to crisis care' composite.

### **Length of contact**

Those respondents who had been in contact with NHS mental health services for less than a year reported better than average experiences for: respect and dignity, access, communication, respect for patient-centred values, involvement and overall experience.

## Proxy response (response to Q42. Who was the main person or people that filled in this questionnaire?)

Respondents who received help from a mental health professional to fill in their questionnaire reported a better than average experience for the following composites: 'involvement', 'respect for person-centred values', 'communication' and 'support and wellbeing'.

See [Appendix G: Subgroup analysis](#) for detailed charts and [Appendix H: Care cluster codes](#) for more information.

# Appendix A: Survey methodology

## Survey method

As with most surveys in the NHS Patient Survey Programme, the community mental health survey used a postal methodology.

The sample member received their first survey pack containing a questionnaire, covering letter, leaflet offering guidance on multi-language options for completing the questionnaire, and a flyer outlining the value of the data to CQC. This was followed by a reminder, then a final reminder containing another survey pack. The average time between each mailing was three weeks, allowing time to remove those who had since died or had opted-out from mailings.

People aged 18 and over were eligible for the survey if they received specialist care or treatment for a mental health condition and had been seen by an NHS trust between 1 September and 30 November 2017. Trusts drew a random sample from their records of 850 people who had been seen at the trust during the sampling period. The sample size is sufficient to allow analysis of results at individual trust level. Full details of the sampling are available in the instruction manual for the survey (see links in [Appendix F](#)).

All NHS providers of community mental health services were eligible to take part in the survey.

Certain groups of people were excluded from the survey before providers drew their samples, including:

- anyone who was a current mental health inpatient
- anyone seen only once for an assessment
- anyone seen for assessment only through a liaison service
- anyone primarily receiving the following services: drug and alcohol, learning disability, forensic, psychological treatments from Improving Access to Psychological Therapies (IAPT), chronic fatigue/ME, psychosexual medicine (sexual dysfunction) and gender identity
- people who have only been in contact by telephone or email, and have not been seen in person at all.

Fieldwork for the survey (the time during which questionnaires were sent out and returned) took place between February and June 2018.

For more detailed information on the sampling instructions, and inclusion and exclusion criteria, please see the [instruction manual](#) for the survey.<sup>67</sup>

The age profile of the respondents has not changed meaningfully between the 2014 and 2018 surveys.

## Respondent age profile for 2014 to 2018

	18-35	36-50	51-65	65+
2014	14%	23%	25%	38%
2015	14%	23%	25%	39%
2016	14%	22%	25%	39%
2017	14%	21%	25%	40%
2018	15%	20%	25%	39%

Answered by all

Number of respondents: 2014 (13,787), 2015 (11,695), 2016 (13,254), 2017 (12,139) and 2018 (12,795)

**Note:** taken from sample data if missing.

## Questionnaire design

An external advisory group ensured that a wide range of stakeholders had the opportunity to contribute to the development of this survey. Members included representatives from CQC, the Department of Health and Social Care, NHS England, NHS mental health trusts, Mind and people who use mental health services.

The same questions are included to enable year-on-year comparisons where possible, which means that most questions included in the 2018 questionnaire can be compared with results from the 2014, 2015, 2016 and 2017 surveys. However, questions are reviewed before each survey to determine whether any new questions are needed, to ensure that the questionnaire is up to date and in line with current policy and practice. The ongoing work to develop the questionnaire has shown that all survey questions are important to people who use services and to other stakeholders who use the survey data in their work. There is more information on survey stakeholders and how they use the data in [Appendix D](#).

For this 2018 survey, the 'Treatments' section was divided into 'Medicines' and 'NHS Therapies', and new questions were added to both these sections. New questions were also added about long-term conditions (LTC). LTC questions are used consistently across the NHS Patient Survey Programme.

For more detailed information please see the [Development report for the Community Mental Health Survey 2018](#) and the [Final questionnaire for the 2018 survey](#).

## Analysis methodology

### Weighting

Some trusts have a higher response rate than others and would therefore have a greater influence over the England average if a simple mean was calculated across all respondents. To avoid this, weights are applied to the data. By applying these weights, the responses from each trust have an equal influence over the England average, regardless of differences in response rates between trusts.

Trust weights are useful for calculating the figures for England because they describe the results of the hypothetical 'average trust' for a given year. As they are intended to produce a single estimate, they do not take into account any of the individual level variables that are related to how people respond – such as age and gender. Further weighting this year compensates for such non-response. This method minimises changes to historical analysis as this weight will not change in future. Both sets of weights are then multiplied together to produce a single combined weight for the data tables that underpin the analysis.

This weighting has been applied to all questions except for demographic questions. These questions are presented without weights applied, as it is more appropriate to present the real percentages to describe the profile of respondents, rather than adjust figures.

## **Rounding**

The results present percentage figures rounded to the nearest whole number, so the values given for any question will not always add up to 100%. Please note that rounding up or down may make differences between survey years appear bigger or smaller than they actually are.

## **Statistical significance**

Statistical tests were carried out on the data to determine whether there had been any statistically significant changes in the results for 2018 compared with the last time the survey was conducted in 2017.

A 'z-test' set to 95% significance was used to compare data between survey years. A statistically significant difference means that there is a less than 5% chance that we would have obtained this result if there was no real difference.

However, due to the relatively large number of respondents, small changes in results may show to be statistically significant. Such small changes do not necessarily indicate a longer-term trend. The use of 'p-charts' for this analysis shows whether change is in 'expected limits of variation'. Results outside these expected limits would suggest underlying behavioural or real change.

However, in other cases there may be a visible change in the results between survey years that is not significant. There are a number of reasons for this, such as:

- Rounding figures up or down makes a difference appear larger than it actually is.
- Generally speaking, the larger the sample size, the more likely that findings will be statistically significant, and we can be more confident in the result. In contrast, the fewer people that answer a question, the greater the difference has to be for it to be statistically significant.
- The amount of variation also affects whether the difference is significant. 'Variation' means the differences in the way people respond to the question. If there is a lot of variance then differences are less likely to be statistically significant.

## Notes on specific questions

**Table A1: analysis/cleaning applied to particular questions**

Question	Analysis/cleaning applied
<p><b>Q7:<sup>n</sup></b> Is the main person in charge of organising your care and services...?</p>	<p>Some respondents are not sure who is in charge of their care and therefore may have ticked more than one option to this question. Results are presented as percentages for each option, out of all those eligible to answer that question, because some respondents will have selected more than one category. This means that the results may add up to over 100%. Though this question is not included in this report, you can find the results to this question in the <a href="#">Open data</a> available on CQC's website.</p>
<p><b>Q8 and Q9:</b> Q8 Do you know how to contact this person if you have a concern about your care?  Q9 How well does this person organise the care and services you need?</p>	<p>Respondents who stated at Q7 that their GP is in charge of organising their care and services have been removed from the analysis for these questions. This is because results will not be attributable to the mental health trust.</p>
<p><b>Q13:</b> 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?</p>	<p>As the question specifies a time period of 'the last 12 months' we have removed people who said they have been in contact with mental health services for less than a year (based on their responses to Q2)<sup>o</sup> from the data set, and they are therefore not included in the analysis for this question. This is because they have not been in contact with services long enough to reasonably expect them to have had a care review.</p>
<p><b>Q14:</b> Q14 Did you feel that decisions were made together by you and the person you saw during this discussion?</p>	<p>We have revised the analysis rules for Q14 to be consistent with that applied to Q13.</p> <p>This approach removes respondents from the dataset who stated at Q2 they had been in contact with mental health services for less than a year, and they are therefore not included in the results for Q14 (as well as for Q13) because we cannot be certain that they were referring to a care review.</p> <p>The results from the 2015 survey for these questions have been re-run to match the revised approach.</p>

## Comparability with previous years

The results for most questions from the 2018 survey are comparable with the 2014, 2015, 2016 and 2017 surveys. The following questions are **not comparable** for the reasons outlined below:

n. The questionnaire did not instruct respondents to 'tick all that apply'. However, as a large number of respondents did this, data has been treated as multiple response.

o. Respondents who selected option one (*'less than a year'*) at Q2 (*Overall, how long have you been in touch with NHS mental health services?*) were removed from the analysis of Q13 and Q14 as reported in this section.

**Table A2: comparability with previous years**

Question	Reason for not being comparable
<b>Q7.</b> Is the main person in charge of organising your care and services...	This question's response options have been reduced to help avoid the selection of multiple response options.
<b>Q8.</b> Do you know how to contact this person if you have a concern about your care?	The change in Q7 influenced the way respondents answered this question and made it incomparable with previous years.
<b>Q9.</b> How well does this person organise the care and services you need?	The change in Q7 influenced the way respondents answered this question and made it incomparable with previous years.
<b>Q15.</b> In the last 12 months, have the people you see for your care or services changed?	A new response option ( <i>Yes, but this was because I requested this change</i> ) was added to this question in 2016. It is therefore not possible to compare the results for this question with 2014 or 2015.
<b>Q16.</b> Were the reasons for this change explained to you at the time?	This was a new question for 2016, and it is therefore not possible to compare the result for this question with 2014 or 2015.
<b>Q17.</b> What impact has this had on the care you receive?	This was a new question for 2016, and it is therefore not possible to compare the result for this question with 2014 or 2015.
<b>Q19.</b> In the last 12 months, did you get the help you needed when you tried contacting this person or team?	This question was changed in 2018 by adding 'In the last 12 months' to make respondents think about a recent contact with mental health crisis services.
<b>Q22.</b> Were you given information about your medicines in a way that you were able to understand?	This question was changed in 2018 by removing 'The last time you had a new medicine prescribed for your mental health needs,' to make respondents think about all medicines and not just new medicines.
<b>Q23.</b> Do you feel your medicines have helped your mental health?	This was a new question for 2018.
<b>Q26.</b> In the last 12 months, have you received any NHS therapies for your mental health needs that do not involve medicines?	This question was changed in 2018 by adding 'NHS' and removing 'treatments or' to make respondents think about therapies they received from the NHS rather than other organisations. The 'Treatment' section was split up into distinct 'Medicines' and 'NHS Therapies' sections.
<b>Q27.</b> Were these NHS therapies explained to you in a way you could understand?	This question was changed in 2018 by adding 'NHS' and removing 'treatments or' to make respondents think about therapies they received from the NHS rather than other organisations. The 'Treatment' section was split up into two distinct 'Medicines' and 'NHS Therapies' sections.
<b>Q28.</b> Were you involved as much as you wanted to be in deciding what NHS therapies to use?	This question was changed in 2018 by adding 'NHS' and removing 'treatments or' to make respondents think about therapies they received from the NHS rather than other organisations. The 'Treatment' section was split up into two distinct 'Medicines' and 'NHS Therapies' sections.
<b>Q29.</b> Do you feel your NHS therapies have helped your mental health?	This was a new question for 2018.

<b>Q30.</b> How long were you on the waiting list before your NHS therapy began?	This was a new question for 2018.
<b>Q34.</b> In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?	Question was changed in 2018 as the existing wording used in 2017 was found to be confusing during cognitive testing.
<b>Q39.</b> Do you have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last for 12 months or more?	This was a new question for 2018.
<b>Q40.</b> Do you have any of the following? (List of long-term conditions)	This was a new question for 2018.
<b>Q41.</b> Do any of these reduce your ability to carry out day-to-day activities?	This was a new question for 2018.

Over time, there have been a number of changes to the survey, including revisions to the eligible age range and major developments to revise the methodology and the questionnaire content, which affect historical comparability.

The 2004 and 2005 surveys included people aged 16-65 years. In 2006, the age range for the survey was extended to include people aged over 65. In 2012 the minimum age for inclusion was changed to 18. This means that to compare results with earlier surveys, younger and older respondents must be excluded from the analyses.

The survey had two major redevelopments ahead of the 2010 and 2014 surveys to reflect changes in policy, best practice and patterns of service. This means that surveys carried out between 2010 and 2013 are comparable with each other, but not with any previous surveys, because of the re-development in 2010. The 2018 survey is comparable with surveys run between 2014 to 2017, but not with any surveys before then.

## Subgroup analysis

Results for each demographic subgroup were generated as adjusted means (also known as estimated marginal means or population marginal means) using a linear mixed effects model. These means were compared on composites of questions, illustrated in the charts. This kind of model takes into account trust clustering, as trusts are likely to have a big effect on reported experience at a national level.

To assess whether experience differs by demographic factors, we carried out statistical significance tests. F tests were performed on each factor (fixed effect) as a predictor of the target variable. P-values were also generated, which showed how likely it is that the differences between groups observed in the results could have arisen from a population where there were no actual

differences. They relate to the demographic factor as a whole rather than to compare between specific categories in the factor. Variables were also checked for multicollinearity to ensure that coefficient estimates were not being influenced by additional factors (these would be chance associations in the sample that wouldn't be reproduced in another sample).

Differences that are equivalent to at least 0.1 standard deviations from the overall mean of the target variable are treated as being noteworthy in this report, provided that the confidence interval does not overlap the mean line. See [Appendix G](#) for the charts.

## Appendix B: Other sources of information related to survey results

This section summarises other sources of data related to mental health services in England. Please note that, as they do not measure experience of those using services, they are not directly comparable with the findings presented in this report.

### Statistics on the use of mental health services

The [Mental Health Services Data Set \(MHSDS\)](#) contains record-level data about the care of children, young people and adults who are in contact with mental health, learning disabilities or autism spectrum disorder services.

The latest publication (June/July 2018) provided the following data:

Between 1 April and 30 June, 3,424 referrals with suspected first episode psychosis started treatment, of which 2,192 (64.0%) waited two weeks or less. 75.9% of people in contact with adult mental health services at the end of June who had been treated under the Care Programme Approach for 12 months received a review during that time.<sup>68</sup>

The [Mental Health and Learning Disabilities Data Set \(MHLDS\)](#) is released monthly and contains record-level data about the care of people using secondary mental health services, including people with a learning disability. It includes data on the topics included in this survey. The latest publication (Nov/Dec 2015) provided the following data:

964,892 people were in contact with mental health or learning disabilities services. Of these, 923,747 people were in contact with mental health services and 53,920 people were in contact with learning disabilities services.<sup>69</sup>

Please note, this data set is **not directly comparable** with our survey results because:

- It is a different type of data: the survey data is about people's experiences of services, whereas the MHSDS data set contains data submitted from trusts' records.
- This survey covers only community mental health services, whereas MHLDS also cover other mental health services.
- The sample for this survey has certain exclusions, for example, we exclude people with a learning disability, certain specialities such as forensic services, and people under the age of 18. For full details of the survey inclusion and exclusion criteria, please see the instruction manual available at:

<http://www.nhssurveys.org/surveys/1163>.

## Mental Health Five Year Forward View Dashboard

This dashboard is intended to help monitor progress against the delivery of the Five Year Forward View for Mental Health and is published quarterly. For more information, please see: <https://www.england.nhs.uk/publication/mental-health-five-year-forward-view-dashboard/>.

## Staffing

Statistics on staffing numbers are provided in NHS Digital's statistical release on NHS Workforce Statistics. Please note this data covers all trust types, such as acute and community trusts, as well as mental health providers. For more information, please see: <http://digital.nhs.uk/workforce>.

## Waiting times

The government has committed to introducing access and waiting time standards for mental health services. For more information, please see: [www.england.nhs.uk/mentalhealth/resources/access-waiting-time/](http://www.england.nhs.uk/mentalhealth/resources/access-waiting-time/).

# Appendix C: Comparisons with other surveys

There are very few surveys related to community mental health services and this is the only survey of community mental health services currently conducted in the UK. Other surveys that are carried out tend to establish prevalence of mental health issues rather than focus on experiences of care received.

## The Health Survey for England

This is a series of annual surveys designed to measure health and health-related behaviours in adults and children. It covers a wide variety of topics including mental health. The latest iteration of the survey was 2016.

The summary of key findings states that data was collected using the General Health Questionnaire (GHQ-12) for participants aged 16 years and older. The questionnaire asks about general levels of happiness, depression, anxiety, sleep disturbance and self-confidence.

According to this survey, the proportion of adults with probable mental ill health has increased from 15% in 2012 to 19%, and the increase is particularly apparent among young men aged between 16 and 34, and young women aged between 16 and 24.<sup>70</sup>

For more information, please see:

<https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/health-survey-for-england-2016>.

# Appendix D: Main users of the survey data

This appendix lists known users of data from the Community mental health survey and how they use the data.

## Care Quality Commission (CQC)

CQC will use the results from the survey in the regulation, monitoring and inspection of NHS trusts in England. Survey data is used in CQC Insight, an intelligence tool that indicates potential changes in the quality of care to support decision-making about our regulatory response. Survey data will also form a key source of evidence to support the judgements and inspection ratings published for trusts.

## NHS England

NHS England uses questions from the NHS Patient Survey Programme (specifically the Inpatient, Community mental health and Emergency department surveys) to produce a separate index measure called the [Overall Patient Experience Score](#). The score forms part of a regular statistical series, which is updated alongside the publication of each respective survey.

The scores are calculated in the same way each year, so that the experience of people who use the NHS can be compared over time. As part of the supporting documentation, NHS England also produces and publishes a [diagnostic tool](#) to help NHS managers and the public understand what feeds in to the overall scores and to see how scores vary across individual NHS provider organisations.

For more information, see: [www.england.nhs.uk/statistics/statistical-work-areas/pat-exp/](http://www.england.nhs.uk/statistics/statistical-work-areas/pat-exp/).

## NHS Improvement

NHS Improvement oversees NHS trusts and independent organisations that provide NHS-funded care. It supports providers to give patients consistently safe, high-quality, compassionate care in local health systems. NHS Improvement will use the results of this survey to inform quality and governance activities as part of its Oversight Model for NHS trusts.

For more information, see: <https://improvement.nhs.uk/>.

## NHS trusts and commissioners

NHS trusts, and those who commission services, use the results to identify where they need to improve to provide a better experience for people who use their services.

## People who use services, their supporters and representative groups

The survey data is available on CQC's website for each participating NHS trust, under the organisation search tool. The data is presented in an accessible format to enable the public to examine how services are performing, alongside the trust's inspection results. The search tool is available on CQC's website: [www.cqc.org.uk/](http://www.cqc.org.uk/).

# Appendix E: Quality and methodology

All detail on data limitations can be found in the Quality and methodology document, available at [www.cqc.org.uk/cmhsurvey](http://www.cqc.org.uk/cmhsurvey).

## Revisions and corrections

CQC publishes a [Revisions and Corrections Policy](#) relating to these statistics. The NHS Patient Survey Programme data is not subject to any scheduled revision as they capture the views of patients about their experiences of care at a specific point in time. All new survey results are therefore published on CQC's website and NHS Surveys, as appropriate, and previously published results for the same survey are not revised.

This policy sets out how CQC will respond if an error is identified in this and it becomes necessary to correct published data or reports.

# Appendix F: Further information and feedback

## Further information

This report, together with the trust level results, is available on CQC's website. You can also find a 'technical document' here, which describes the methodology for analysing trust level results, and a 'quality and methodology' document, which provides information about the survey development and methodology: [www.cqc.org.uk/cmhsurvey](http://www.cqc.org.uk/cmhsurvey).

The results from previous community mental health surveys that took place between 2004 and 2008,<sup>p</sup> and between 2010 and 2013, are available at the link below. Please note that due to redevelopment work, results from the 2018 survey are only comparable with 2014, 2015, 2016 and 2017<sup>q</sup>: [www.nhssurveys.org/surveys/290](http://www.nhssurveys.org/surveys/290).

Full details of the methodology for the survey, including questionnaires, letters sent to people who use services, instructions on how to carry out the survey and the survey development report, are available at: <http://www.nhssurveys.org/surveys/1114>.

There is more information on the NHS Patient Survey Programme, including results from other surveys and a programme of current and forthcoming surveys at: [www.cqc.org.uk/content/surveys](http://www.cqc.org.uk/content/surveys).

## Further questions

This summary was produced by CQC's Survey Team and reflects the findings of the 2018 community mental health survey. The guidance on our website should help answer any questions you have about the programme. However, if you wish to contact the Team directly, please contact Tamatha Webster, Survey Manager, at [Patient.Survey@qc.org.uk](mailto:Patient.Survey@qc.org.uk).

## Feedback

We welcome all feedback on the survey findings and the approach we have used to report the results, particularly from people using services, their representatives, and those providing services. If you have any views, comments or suggestions on how we can improve this publication, please contact Tamatha Webster, Survey Manager, at [Patient.Survey@qc.org.uk](mailto:Patient.Survey@qc.org.uk).

We will review your information and use it, as appropriate, to improve the statistics that we publish across the NHS Patient Survey Programme.

p. In 2009 there was a survey of mental health inpatient services.

q. Please note that the survey was also substantially redeveloped in 2010. This means that surveys carried out between 2010 and 2013 are comparable with each other, but not with any other surveys.

If you would like to be involved in consultations or receive updates on the NHS Patient Survey Programme, please subscribe [here](#).

## **National Statistics status**

National Statistics status means that official statistics meet the highest standards of trustworthiness, quality and public value.

All official statistics should comply with all aspects of the Code of Practice for Official Statistics. They are awarded National Statistics status following an assessment by the Authority's regulatory arm. The Authority considers whether the statistics meet the highest standards of Code compliance, including the value they add to public decisions and debate.

It is a producer's responsibility to maintain compliance with the standards expected of National Statistics, and to improve its statistics on a continuous basis. If a producer becomes concerned about whether its statistics are still meeting the appropriate standards, it should discuss its concerns with the authority promptly. National Statistics status can be removed at any point when the highest standards are not maintained, and reinstated when standards are restored.

# Appendix G: Subgroup analysis

The Equality Act 2010 requires that public bodies have due regard to eliminate discrimination, and to advance equality of opportunity by fostering good relations between people who share certain protected characteristics and those who do not. The protected characteristics are age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation, marriage, and civil partnership. The Act provides an important legal framework that should improve the experience of all people using NHS services.

We include additional analysis to compare how different groups of people using mental health services rated their experience by using a multilevel model analysis.

This subgroup analysis compares the mean scores for a subset of questions by different groups. With this model, we can more effectively explore the relationships between respondent characteristics and their experiences.

The analysis modelled the mean scores<sup>r</sup> of different subgroups: age, gender, ethnicity, religion, sexual orientation, CPA status, diagnosis (care cluster codes), length of contact long-term/short-term users, long-term conditions and 'proxy response' (whether the questionnaire was completed by someone other than the patient) – for a set of composite questions based on the [NHS Patient Experience Framework](#).

## Overall

Q37. Overall...

## Respect and dignity

Q38. Overall in the last 12 months, did you feel that you were treated with respect and dignity by NHS mental health services?

## Organisation of care

Q6. 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").

Q9. How well does this person organise the care and services you need?

## Involvement

Q11. Were you involved as much as you wanted to be in agreeing what care you will receive?

Q14. Did you feel that decisions were made together by you and the person you saw during this discussion?

Q21. Were you involved as much as you wanted to be in decisions about which medicines you receive?

r. The sum of question scores divided by the number of questions in the composite.

Q28. Were you involved as much as you wanted to be in deciding what NHS therapies to use?

### **Involvement of family and friends**

Q35. Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?

### **Respect for person-centred values**

Q5. Did the person or people you saw understand how your mental health needs affect other areas of your life?

Q12. Does this agreement on what care you will receive take your personal circumstances into account?

### **Access**

Q3. In the last 12 months, do you feel you have seen NHS mental health services often enough for your needs?

### **Crisis care (access)**

Q18. Do you know who to contact out of office hours if you have a crisis?

### **Crisis care (care)**

Q19. In the last 12 months, did you get the help you needed when you tried contacting this person or team?

### **Communication**

Q4. Were you given enough time to discuss your needs and treatment?

### **Information sharing (Medicines)**

Q22. Were you given information about your medicines in a way that you were able to understand?

### **Information sharing (Therapies)**

Q27. Were these NHS therapies explained to you in a way you could understand?

### **Information sharing (Peer support)**

Q36. 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?

### **Support and wellbeing**

Q31. In the last 12 months, did NHS mental health services give you any help or advice with finding support for physical health needs (this might be an injury, a disability, or a condition such as diabetes, epilepsy, etc)?

Q32. In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits?

Q33. In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding or keeping work?

Q34. In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?

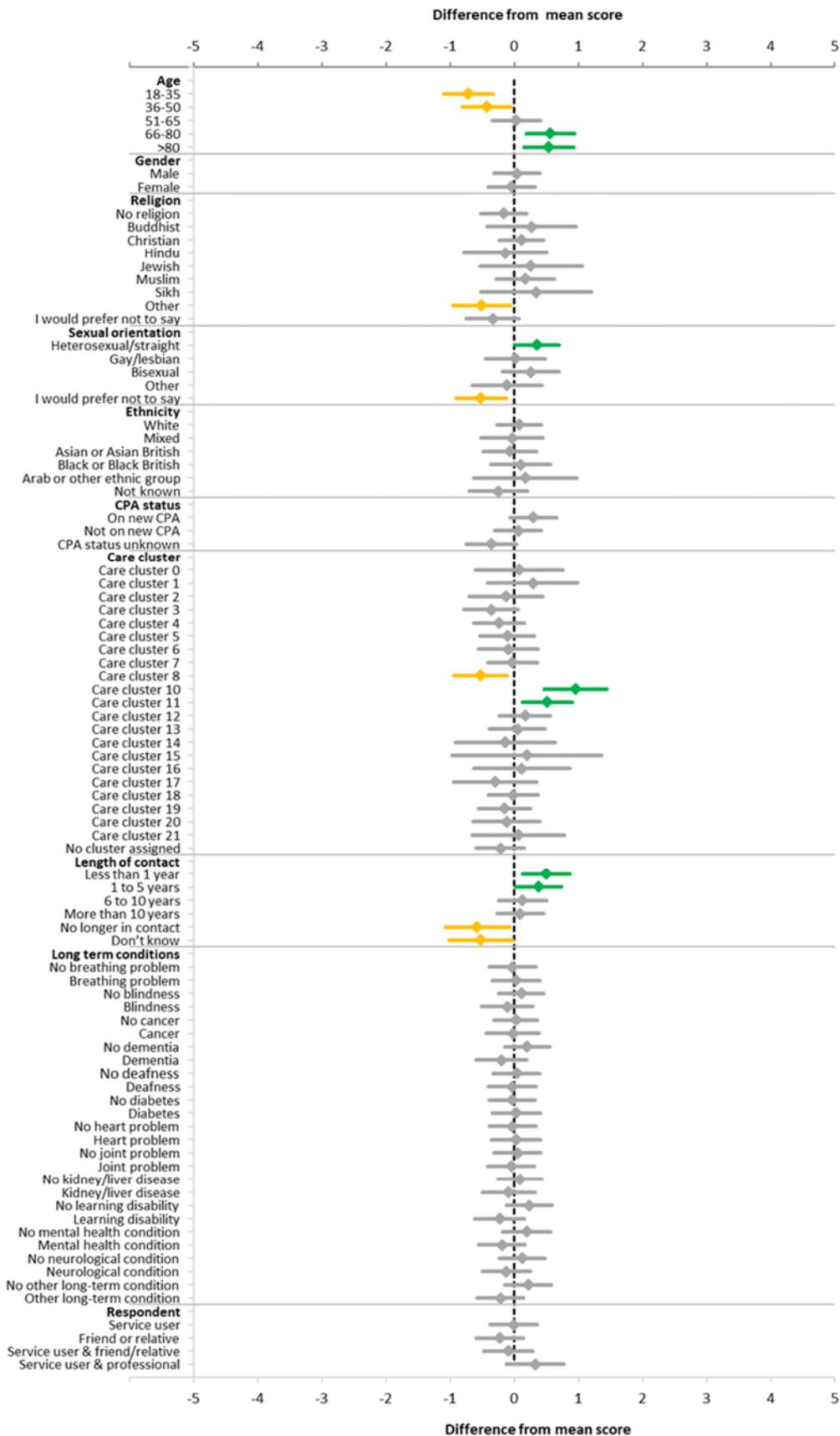
In this report, differences that are equivalent to at least **0.1** standard deviations from the overall mean of the target variable are treated as being noteworthy, provided that the confidence interval does not overlap the mean line.

For more information about how the analysis was completed or about the methodology of the subgroup analysis, see the [Survey methodology](#) section.

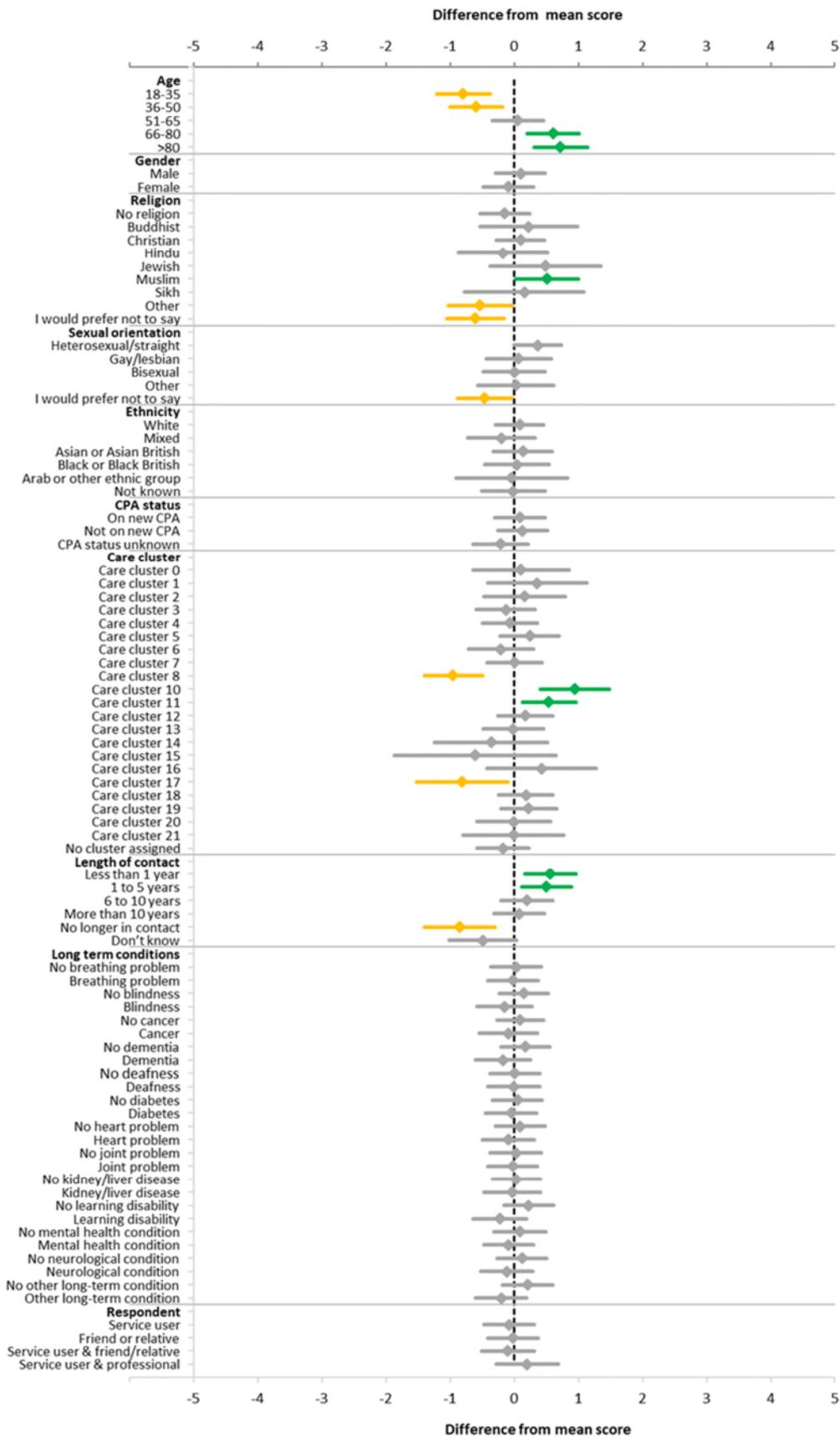
The graphs in this section highlight better than average experiences that are significant in green. Significant worse than average experiences are highlighted in orange for all charts. The cluster code definitions are in [Appendix H](#).

-  Worse than average experience
-  Average experience
-  Better than average experience

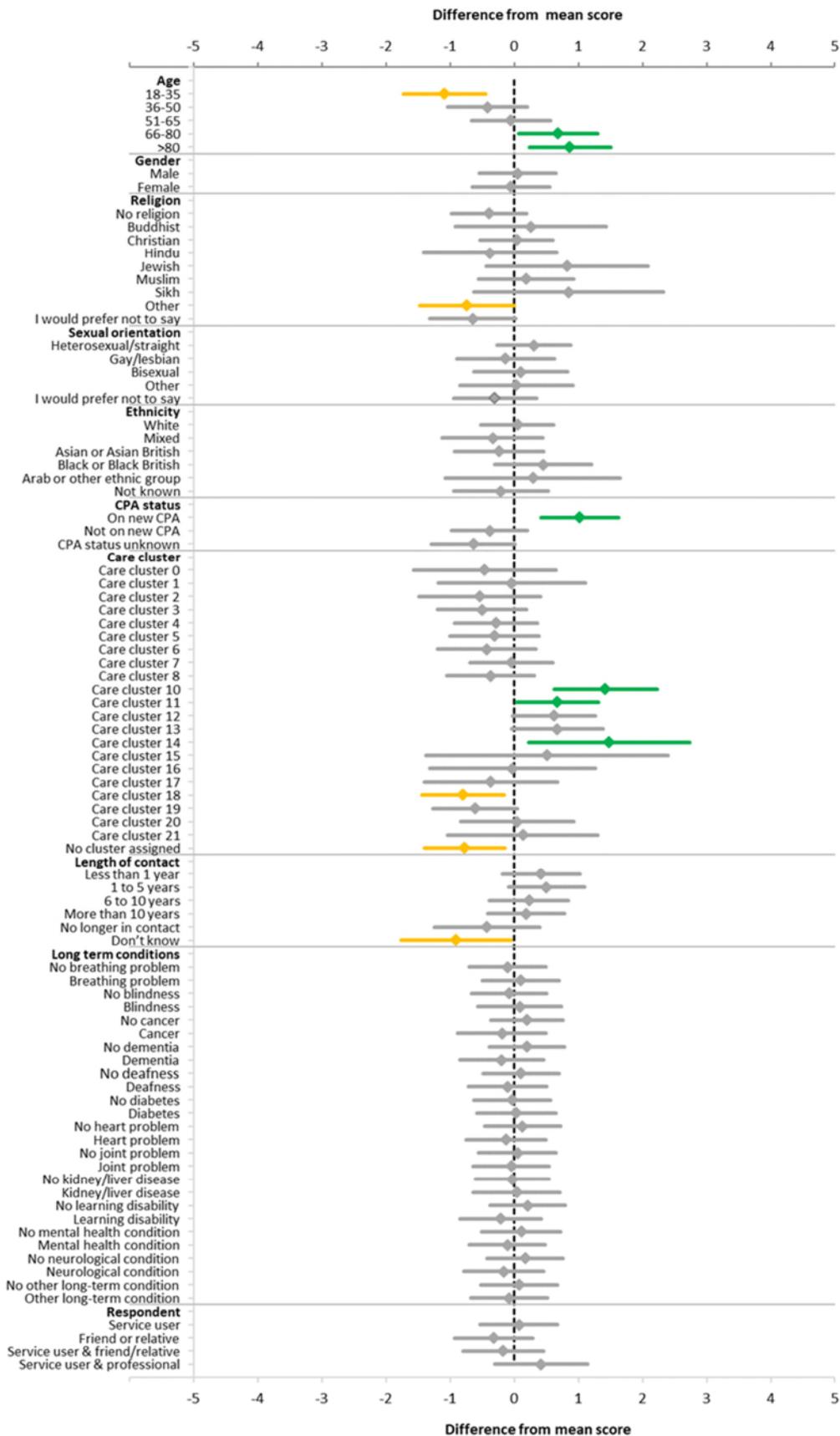
Overall theme: difference from mean score by subgroup with 95% confidence interval



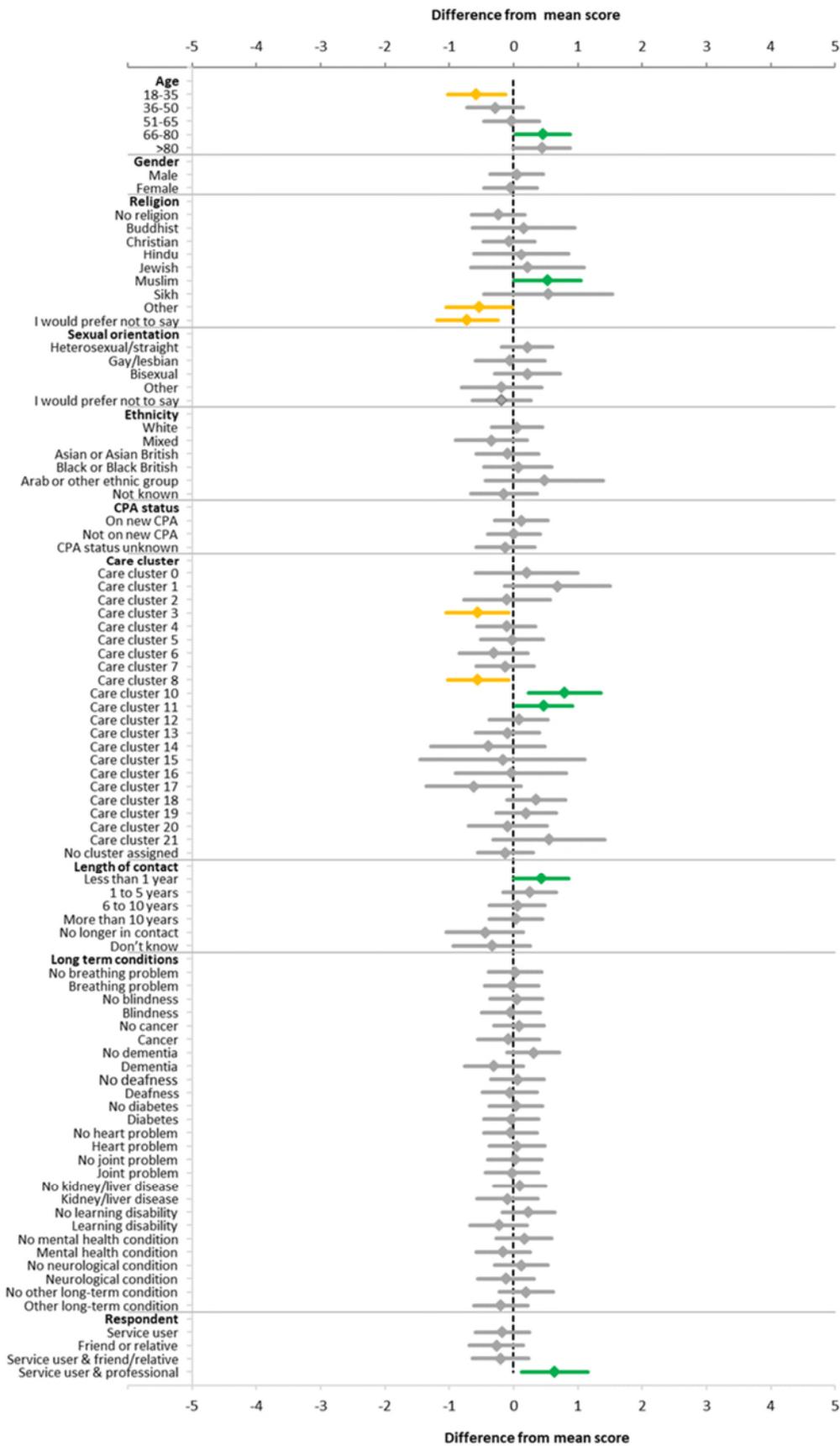
**Respect & dignity theme: difference from mean score by subgroup with 95% confidence interval**



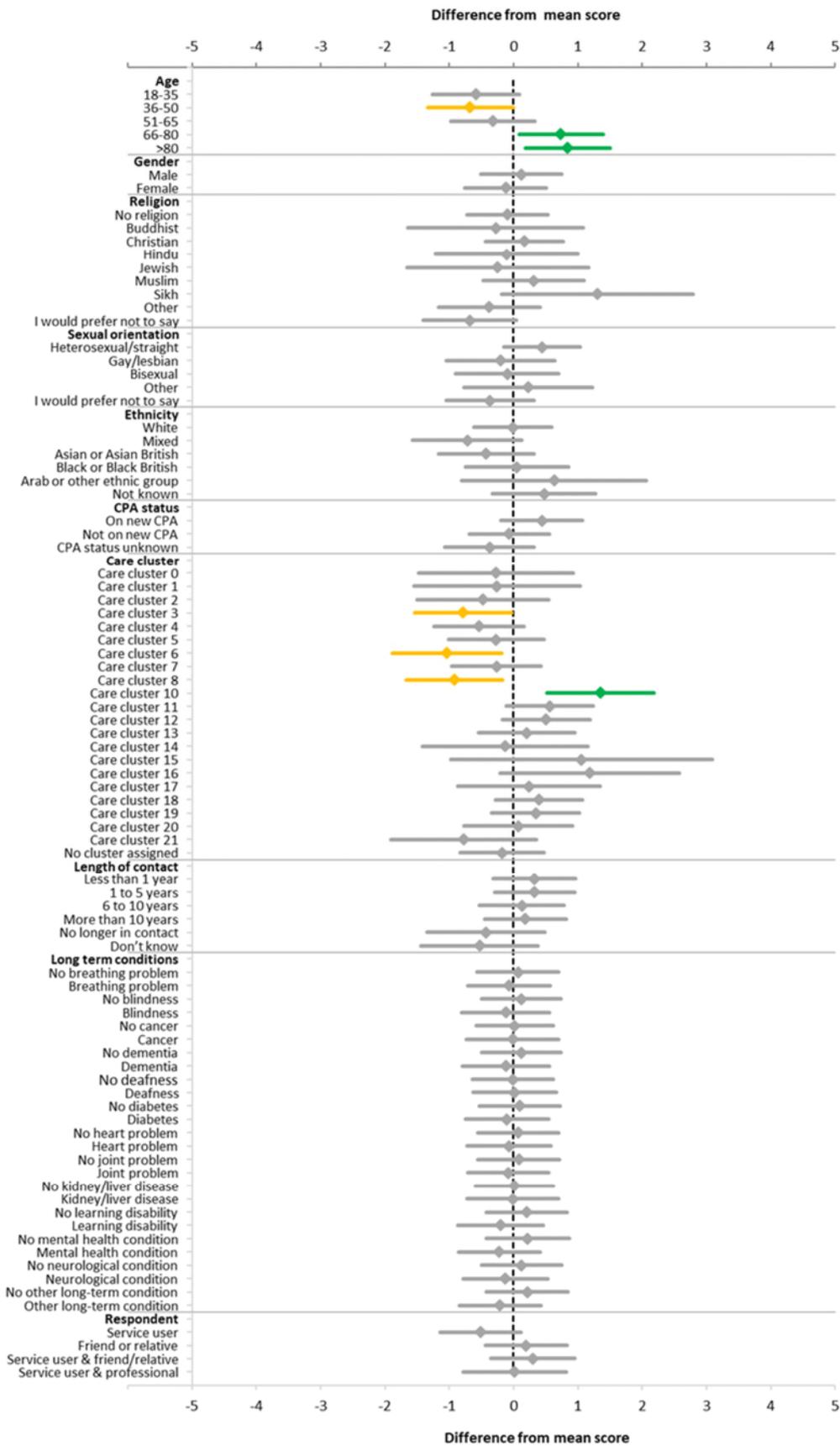
**Organisation of care theme: difference from mean score by subgroup with 95% confidence interval**



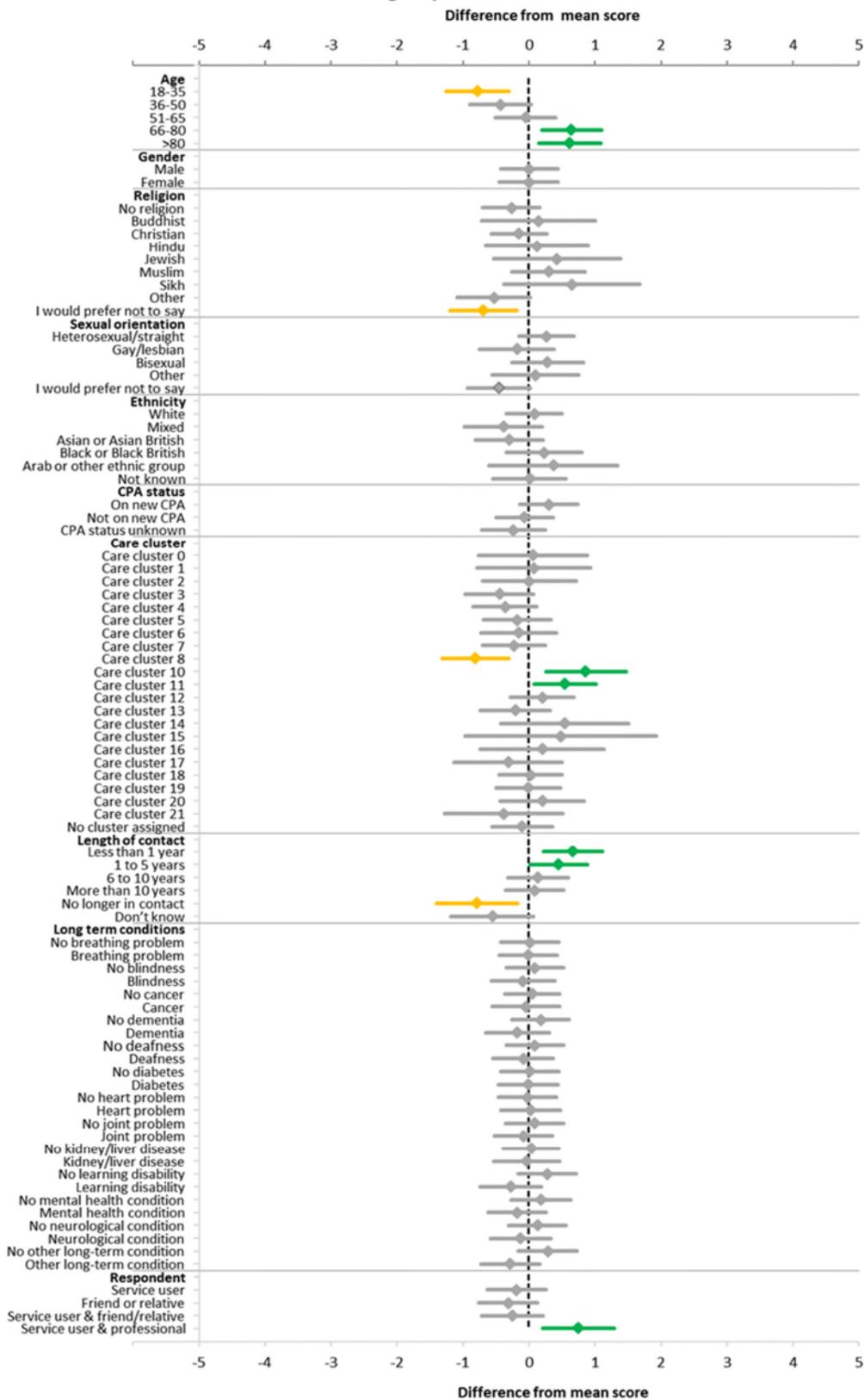
Involvement theme: difference from mean score by subgroup with 95% confidence interval



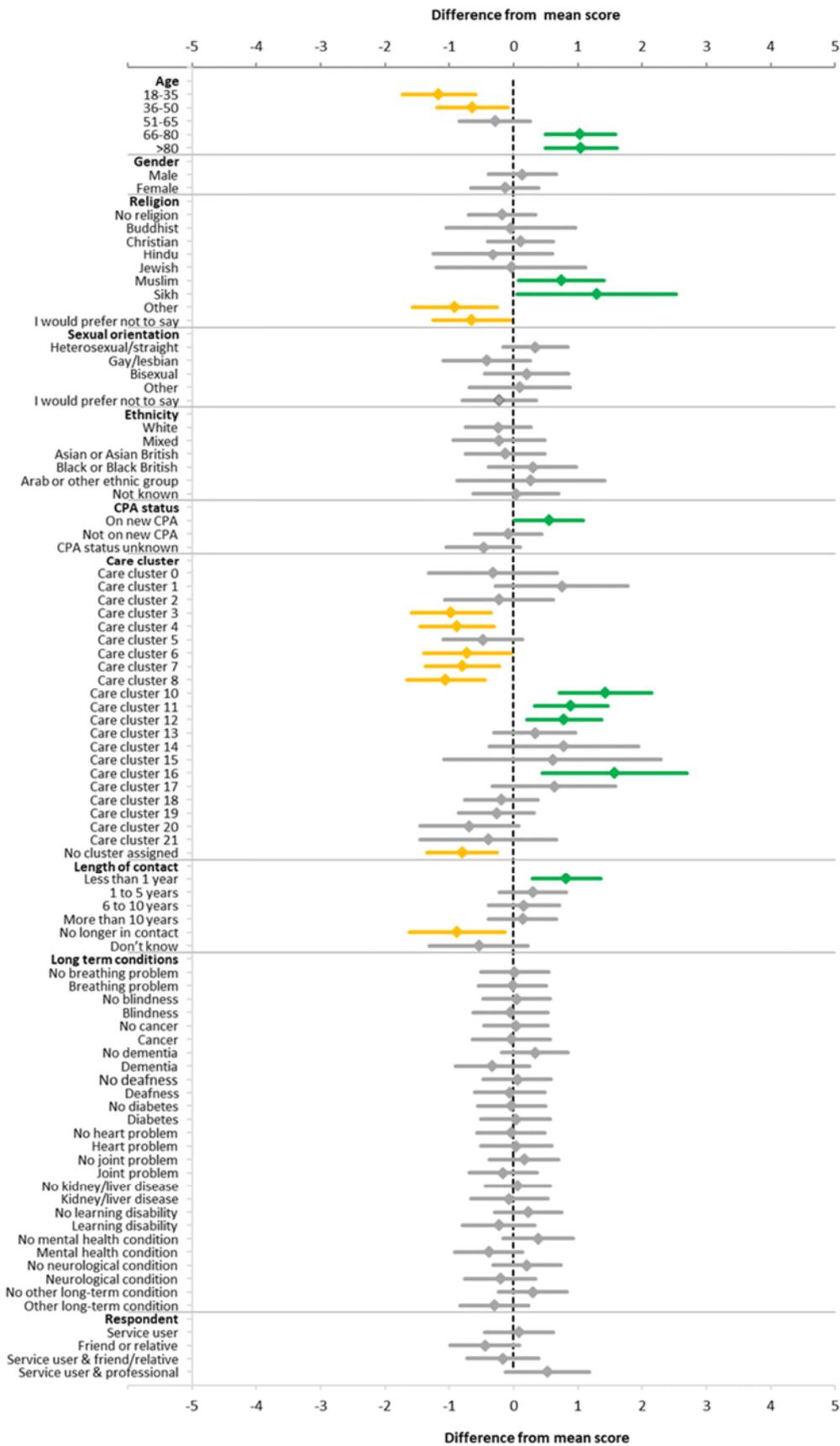
**Involvement of family and friends theme: difference from mean score by subgroup with 95% confidence interval**



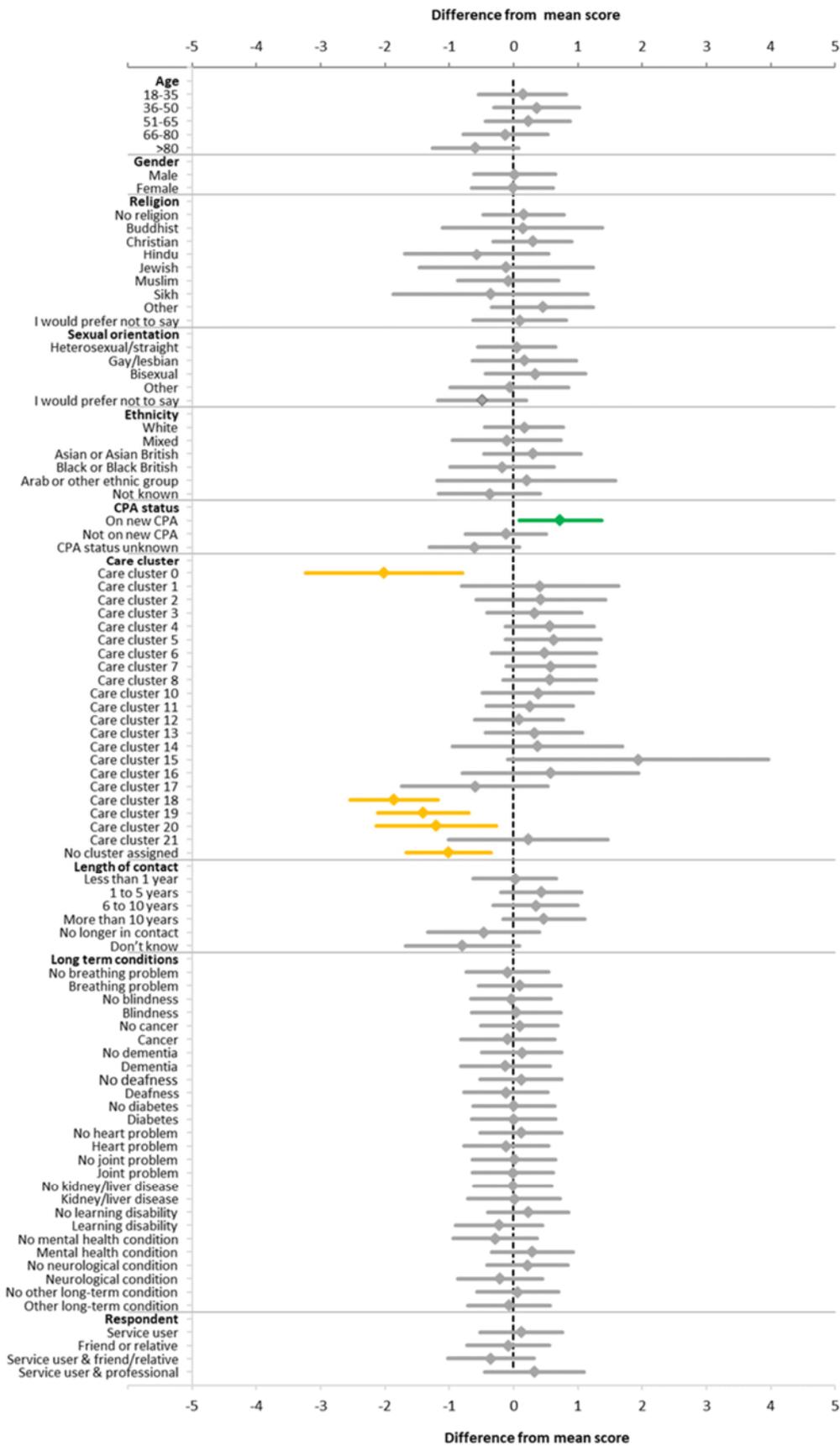
Respect for person-centred values theme: difference from mean score by subgroup with 95% confidence interval



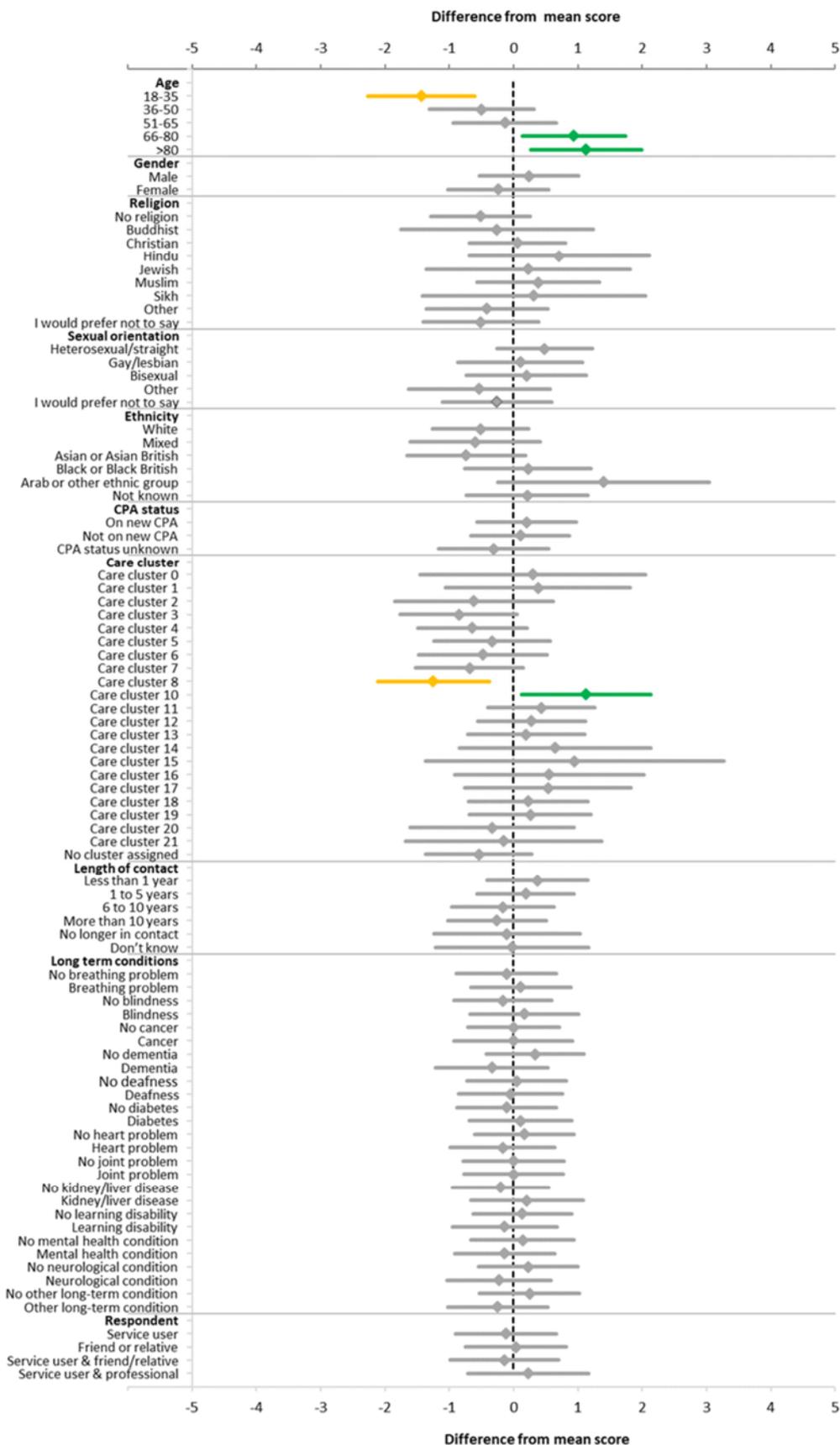
Access theme: difference from mean score by subgroup with 95% confidence interval



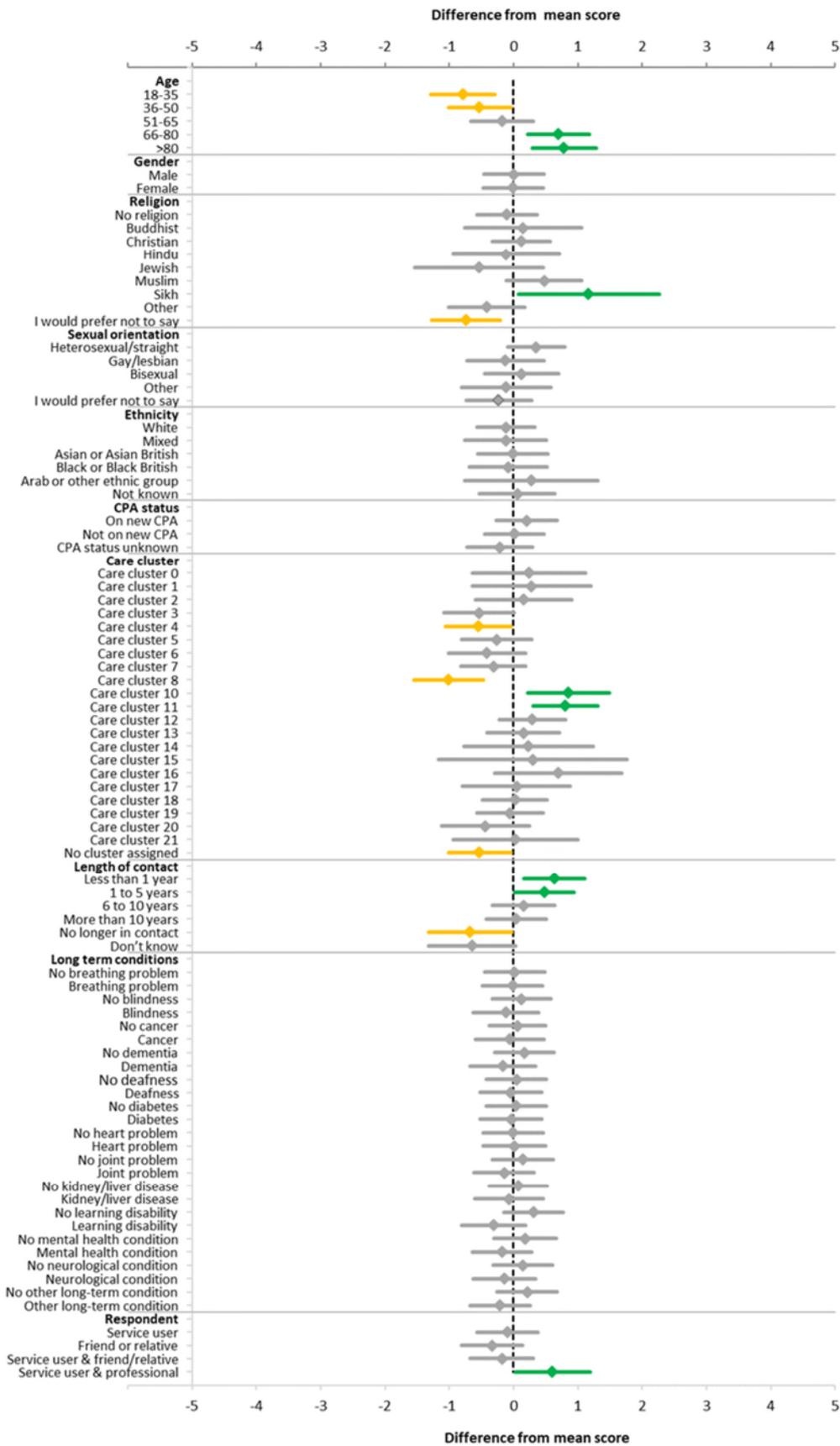
**Crisis care access theme: difference from mean score by subgroup with 95% confidence interval**



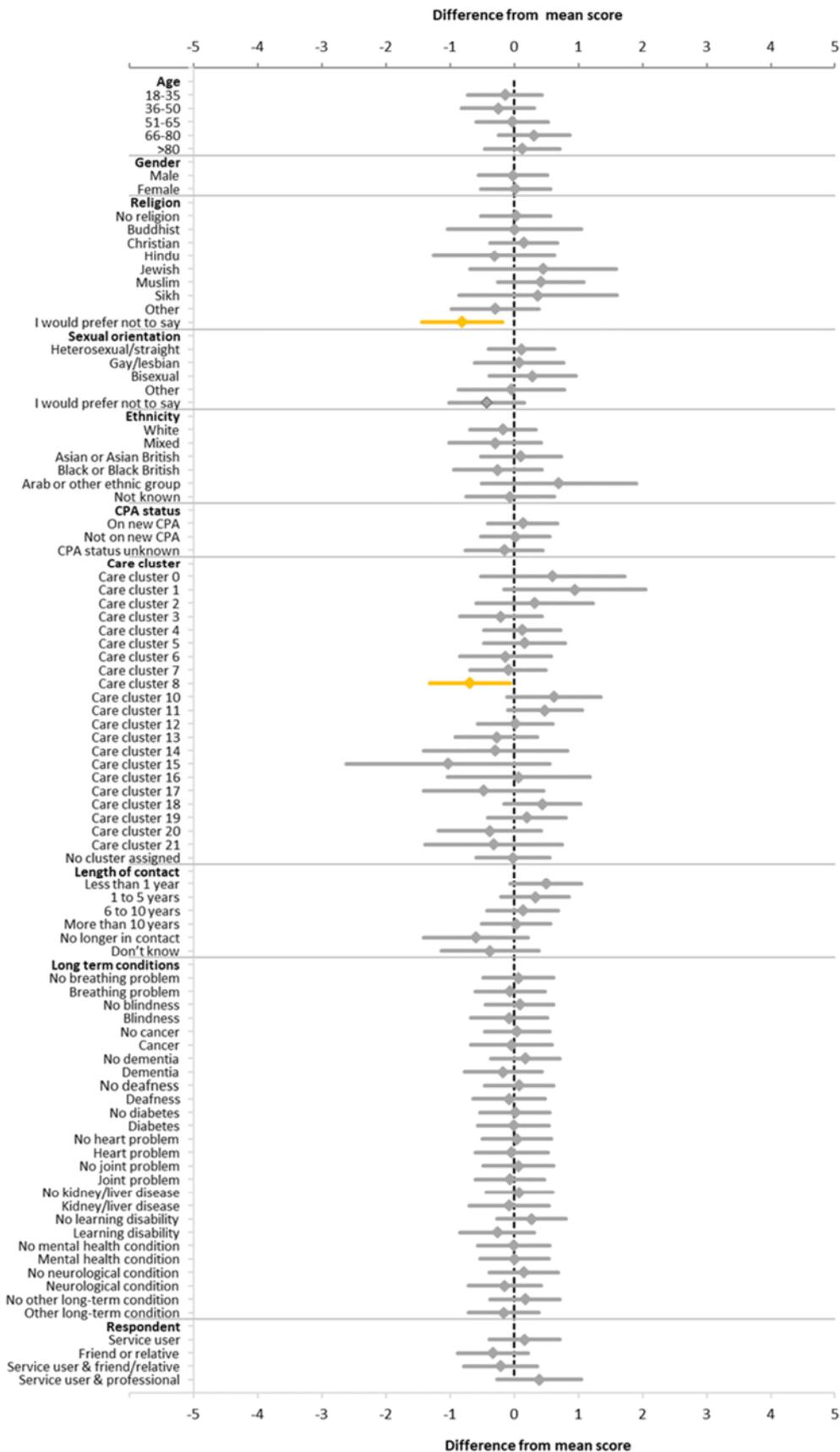
**Crisis care theme: difference from mean score by subgroup with 95% confidence interval**



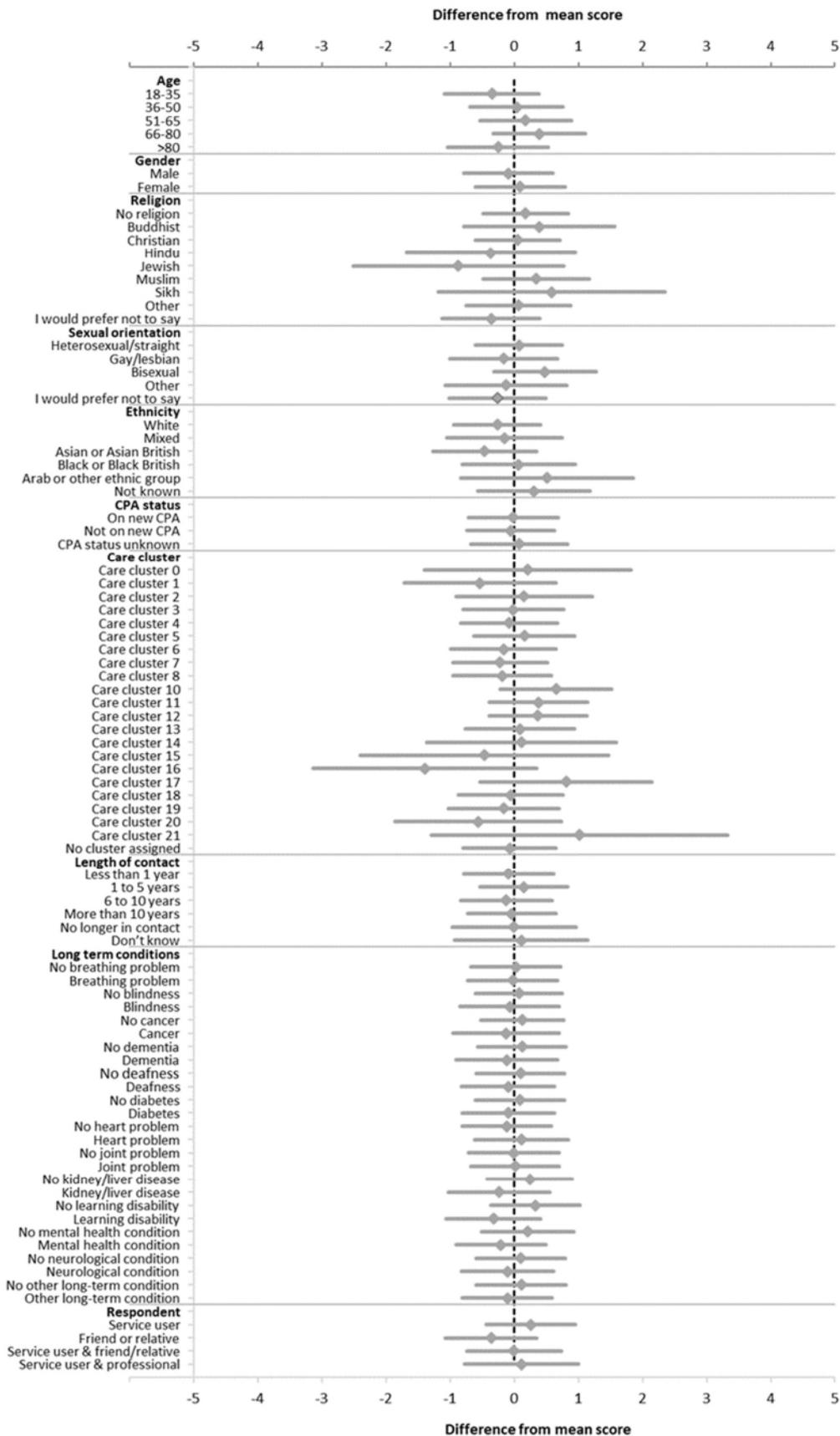
Communication theme: difference from mean score by subgroup with 95% confidence interval



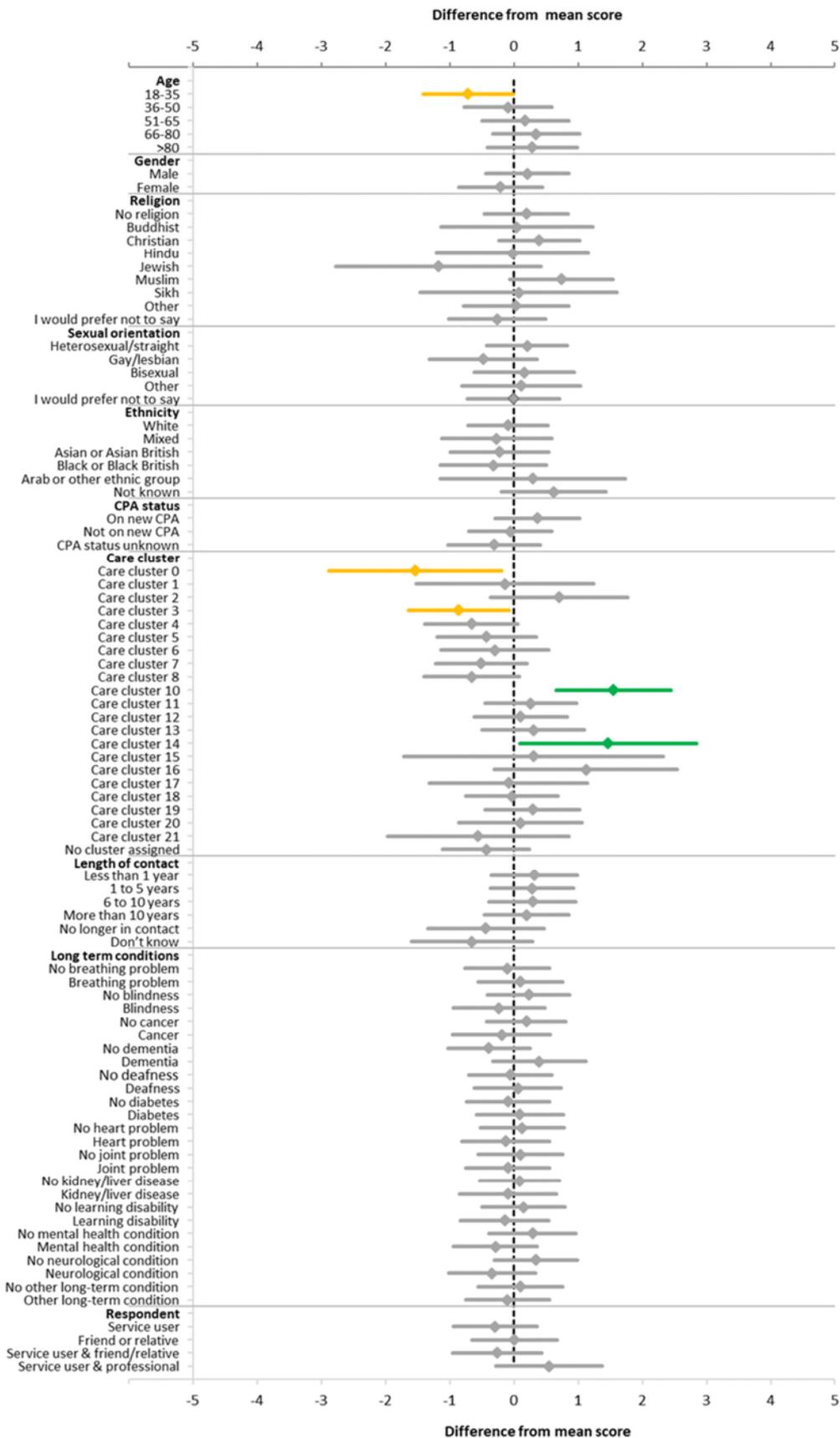
Information sharing - medicines theme: difference from mean score by subgroup with 95% confidence interval



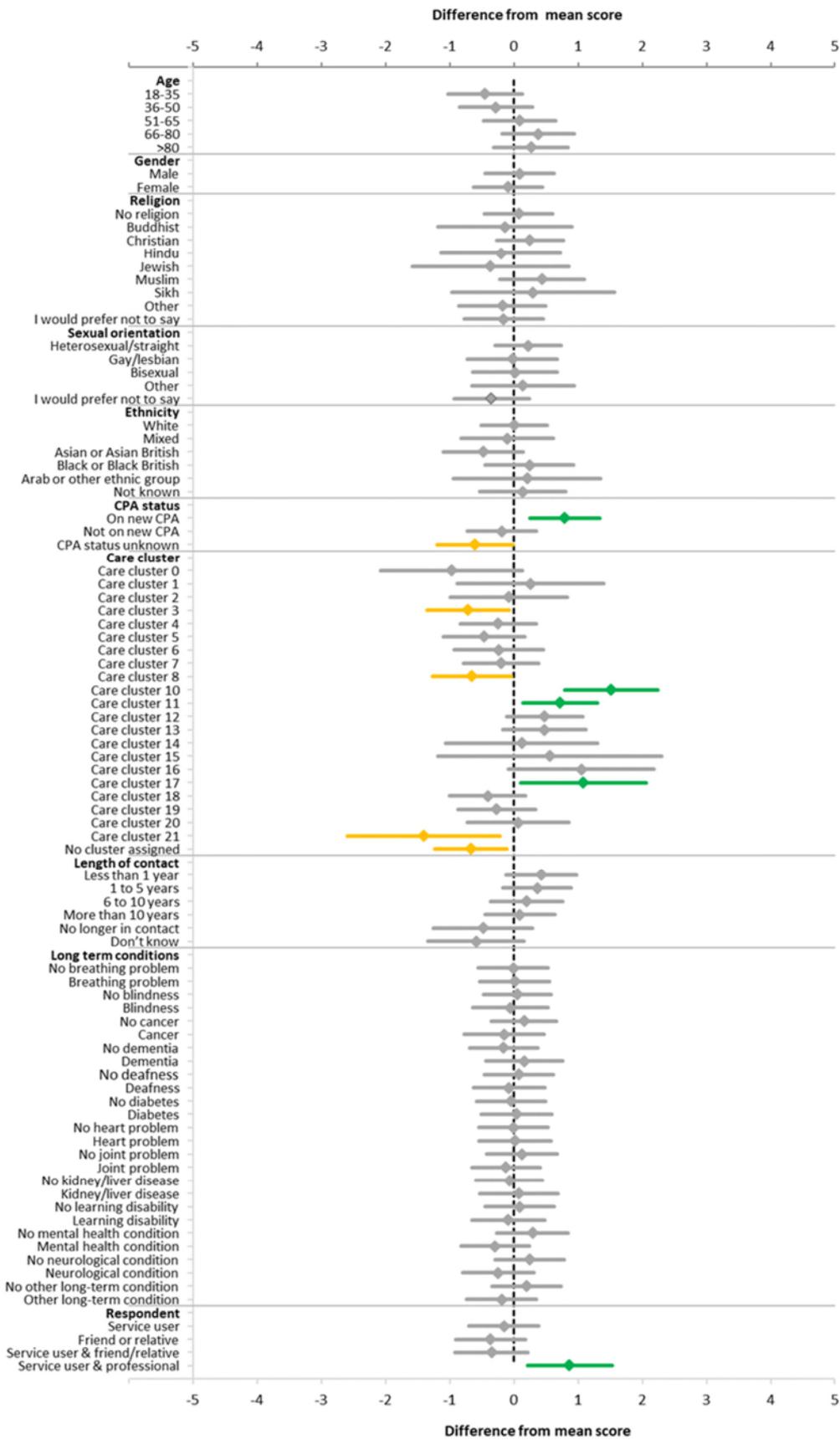
**Information sharing - therapies theme: difference from mean score by subgroup with 95% confidence interval**



**Information sharing - peer support theme: difference from mean score by subgroup with 95% confidence interval**



Support and wellbeing theme: difference from mean score by subgroup with 95% confidence interval



## Appendix H: Care cluster codes

- 00 Care Cluster 0: Variance (unable to assign [ADULT MENTAL HEALTH CARE CLUSTER CODE](#))
- 01 Care Cluster 1: Common Mental Health Problems (Low Severity)
- 02 Care Cluster 2: Common Mental Health Problems (Low Severity with Greater Need)
- 03 Care Cluster 3: Non-Psychotic (Moderate Severity)
- 04 Care Cluster 4: Non-Psychotic (Severe)
- 05 Care Cluster 5: Non-Psychotic Disorders (Very Severe)
- 06 Care Cluster 6: Non-Psychotic Disorder of Over-Valued Ideas
- 07 Care Cluster 7: Enduring Non-Psychotic Disorders (High Disability)
- 08 Care Cluster 8: Non-Psychotic Chaotic and Challenging Disorders
- 10 Care Cluster 10: First Episode Psychosis
- 11 Care Cluster 11: Ongoing Recurrent Psychosis (Low Symptoms)
- 12 Care Cluster 12: Ongoing or Recurrent Psychosis (High Disability)
- 13 Care Cluster 13: Ongoing or Recurrent Psychosis (High Symptoms and Disability)
- 14 Care Cluster 14: Psychotic Crisis
- 15 Care Cluster 15: Severe Psychotic Depression
- 16 Care Cluster 16: Dual Diagnosis
- 17 Care Cluster 17: Psychosis and Affective Disorder (Difficult to Engage)
- 18 Care Cluster 18: Cognitive Impairment (Low Need)
- 19 Care Cluster 19: Cognitive Impairment or Dementia Complicated (Moderate Need)
- 20 Care Cluster 20: Cognitive Impairment or Dementia Complicated (High Need)
- 21 Care Cluster 21: Cognitive Impairment or Dementia Complicated (High Physical or Engagement)

For more information, visit the [NHS Data model and dictionary](#).

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