



NHS Patient Survey Programme

2019 Community mental health survey Statistical release

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Independent data analysis

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Summary of findings

According to [NHS England](#), one in four adults experience at least one mental health condition in any given year, with Mind stating mental health problems are common human experiences.^{1,2} Some people experience one-off episodes, requiring short-term contact with mental health services, while others may experience multiple episodes over longer periods, requiring long-term contact. However, mental health conditions often go untreated and, historically, treatment options for mental health conditions are less effective than for physical conditions.

The 2019 community mental health survey received feedback from 12,551 people who received treatment for a mental health condition between 1 September 2018 and 30 November 2018.

This report shows that people's experiences of mental health remain poor across most areas. Many of those areas, such as accessing and planning care, identified as in need of improvement in 2018 have declined further in 2019, continuing the negative trend of results consistently declining over the 2014 to 2019 period. Fifty per cent of questions with comparable data available for this time period fall below the expected limits of variation for a second consecutive year.

Survey results were also analysed to show how experience varied between different groups of people who use services. Consistent with 2018 results, findings this year showed that younger people in the 18 to 35 age group, and those diagnosed with 'non-psychotic chaotic and challenging disorders' (care cluster code 8), reported worse than average experiences. Once again, those in older age groups and those who have been in contact with NHS mental health services for less than a year, all reported better than average experiences. Similarly, people diagnosed with 'first episode psychosis' (cluster code 10), those assigned to care cluster code 11 (ongoing recurrent psychosis - low symptoms) and care cluster code 12 (ongoing or recurrent psychosis – high disability) also reported better than average experiences.

Positive results

The positive results in this survey, where the majority of people have given positive feedback, are few. However, all positive results are found within the organising care theme.

Most respondents (96%) who were told who is organising their care, knew how to contact the person in charge of their care if they had a concern. This is unchanged from 2018. Ninety per cent of people reported that this person organised their care either 'very well' (57%) or 'quite well' (33%). This is also consistent with results from 2018, showing no change.

Key areas for improvement

Support and wellbeing

As highlighted in previous years, only a proportion of respondents feel supported by NHS mental health services in other areas of their lives. This remains the case in 2019, with results deteriorating further this year. Results show that respondents were most likely to choose the negative response options across multiple support and wellbeing questions.

Support for physical health needs has continued to decline. After a five-percentage point decrease between 2017 and 2018 (35% to 30%), for those saying they 'definitely' received help in finding support, results this year have significantly declined by a further one percentage point to 29%. Almost two in five respondents (39%) stated they would have liked help but had not received this.

Almost half of respondents (46%) said they did not receive any help with finding support for financial advice or benefits but would have liked this. Less than three in ten people (28%) said they had 'definitely' received this, the lowest proportion in the 2014-2019 reporting period.

Furthermore, over half of respondents (53%) felt NHS mental health services had not given them sufficient information about getting support from people who had experience of the same mental health needs. Less than one in five (19%) felt they had 'definitely' received this information, falling below the expected limits of variation on service user experience for the first time.

Crisis care

Nearly a third (31%) of all respondents did not know who to contact out of office hours within the NHS if they had a crisis. Of people who did know who to contact in the NHS and had attempted to do so in the previous 12 months, most (80%) felt they at least partially received the help they needed during a crisis. One in five people (20%) reported they did not receive the help they needed during a crisis.

Accessing care

We have continued to see a decline in people's experience of accessing care in 2019, with only 42% of respondents saying that they had 'definitely' seen NHS mental health services often enough for their needs. This is one percentage point lower than the 2018 result and five percentage points lower than 2014.

Staff

People having enough time to discuss their needs and treatment with staff is an area that continues to decline. Fifty-seven per cent of respondents said that they were 'definitely' given enough time, which is a decrease of eight percentage points from a high of 65% in 2014 and one percentage point lower than 2018.

Only half (52%) of respondents said the person or people they saw were 'completely' aware of their treatment history.

Planning care

People's experiences of how well services plan their care has continued to decline in 2019. Almost a quarter of people (23%) were not involved in agreeing their care with NHS mental health services. Only 52%, of those who agreed their care, felt they were involved as much as they wanted to be in that process. This is a decrease of four percentage points since 2014. In addition, just over half (55%) said the care they receive takes their personal circumstances into account. This is a six-percentage point decrease since 2014. Experience of service users across each of these questions remains below the expected limits of variation.

Reviewing care

Almost a third of people (29%) have not had a formal meeting with anyone from NHS mental health services to discuss how their care is working in the last year, unchanged from 2018.

Feedback

Results show that there is considerable scope for improvement in relation to asking people who use mental health services for feedback. Almost eight out of 10 people (77%) said that they had not been asked to give feedback on the quality of their care in the last 12 months.

How experience varies for different groups of people

Findings from our subgroup analysis show a disparity in the experiences of those with non-psychotic disorders and those with psychotic disorders. Those with non-psychotic disorders reported worse than average experiences across multiple themes. In particular, respondents assigned to care cluster code 8 (non-psychotic chaotic and challenging disorders, such as antisocial personality disorder and self-harm) reported worse than average experiences across 12 themes:

- overall experience
- access
- communication
- crisis care (care)
- respect and dignity
- involvement of friends and family
- information sharing (medicines)
- information sharing (peer support)
- involvement
- support and wellbeing
- treatment history
- respect for person-centred values.

In contrast, respondents diagnosed with psychotic disorders reported better than average experiences across multiple themes. The most prevalent being those assigned to cluster code 10 (first episode of psychosis), who reported better than average experiences across 14 themes. These include all 12 themes mentioned above, as well as crisis care (access) and organisation of care.

In 2018 we highlighted that experience varied depending on age, with younger respondents reporting poorer than average experiences. Those who had been in contact with NHS mental health services for less than one year and those who were on a new Care Programme Approach (CPA) reported better than average experiences. These experiences are still evident in the 2019 results.

Introduction

Mental health care has been high on the national agenda for a number of years. The government has set out its ambitions for improving mental health services in publications including the [Next Steps on the Five Year Forward View](#) (2017), the [NHS Long Term Plan](#) (2019) and the Green paper 'Prevention is better than cure' (2019). Specifically, these plans highlight the importance of community-based care.^{3,4,5}

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. 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.⁶

According to [NHS England](#), one in four adults experience at least one mental health condition in any given year. The six most prevalent mental health conditions as defined by the [National Institute for Health and Care Excellence \(NICE\)](#) are: depression, generalised anxiety disorder, panic disorder, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD), and social phobia/social anxiety disorder.⁷

Across mental health services, there are demographic inequalities as to who is receiving treatment.^a People who are White British, female, or in mid-life (35 to 54) are more likely to receive treatment, while some groups are more likely to experience a mental health condition.⁸ These include: people from Black, Asian and minority ethnic (BAME) groups, refugees, asylum-seeking or stateless people, people with disabilities (both learning and physical), lesbian, gay, bisexual, transgender (LGBTQ+) people, 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).⁹

Everybody has a different experience of a mental health condition. Some people may have a 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

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

of varying severity throughout their lives, which may involve either ongoing 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 untreated¹⁰ and, historically, treatment options for mental health conditions are less effective than for physical conditions.^{11,12} Across mental health services, there is evidence of demographic inequalities in who is receiving treatment. The [Adult Psychiatric Morbidity Survey](#) found that 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.

The community mental health survey

The survey of people who use community mental health services has been conducted annually since 2004.^b In total, 56 providers of NHS mental health services in England participated in the 2019 survey. This includes combined mental health and social care trusts, foundation trusts and community healthcare social enterprises that provide mental health services.

People aged 18 and above were eligible to take part if they were receiving specialist care or treatment for a mental health condition between 1 September 2018 and 30 November 2018. Fieldwork took place between February 2019 and June 2019. In total, we sent a questionnaire to 47,600 people. We received responses from 12,551 people, a response rate of 27%.^c

The survey collected basic demographic information from all people who took part, and this anonymised data is available in the 'About you' section in the [Open data published on CQC's website](#). The basic demographic characteristics of respondents in 2019 remain similar to previous surveys for age, gender and ethnicity.

Wherever possible, the questions remain the same over time to measure change. However, questions are amended, added or removed to reflect changes in policy or survey best practice. We also seek guidance from an external advisory group to make sure the questions remain relevant.^d

This survey is part of a wider programme of NHS surveys, which covers a range of services including adult inpatient, children's inpatient and day-cases, urgent and emergency care services and maternity. 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 importance of collecting service user experience data

Research shows that good experience of using services has many benefits at both service user and organisational level.¹³ For service users, good experiences are linked to better health outcomes. For an organisation, good service user experience can lead to good organisational reputation and lower costs of care.

According to [NHS Improvement](#), ensuring people who use mental health services have a positive experience of care is vital to providing excellent health and social

b. In 2009, a mental health inpatient survey was conducted 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.

d. For this survey iteration, members included representatives from CQC, the Department of Health and Social Care, NHS England and NHS Improvement, NHS mental health trusts, Mind and people who use mental health services.

care services.¹⁴ The 2012 [NHS Patient Experience Framework](#) outlines a number of elements that are important to people's experiences of NHS services.¹⁵ These include:

- respect for patient-centred values, preferences and expressed needs, such as cultural issues and shared decision-making
- welcoming the involvement of friends and family
- emotional support
- access to care, with attention given to waiting times.

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.¹⁶ 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 [NHS outcomes framework](#) (Domain 4) and the Department of Health and Social Care's [NHS Mandate for 2018/19](#) also recognise the importance of patient experience in relation to a high quality of service.^{17,18} The latter, in particular, places a high degree of importance on good care, by including 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.

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.¹⁹

Mental health policy

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

In February 2016, NHS England's Mental Health Taskforce published the [Five Year Forward View for Mental Health](#).²⁰ This set out recommendations for the reform of mental health care, highlighting the importance of community services in this. NHS England then published an [implementation plan](#) in July 2016, which set out the actions needed to deliver the recommendations of the taskforce.²¹ In March 2017, the taskforce published a '[one year on](#)' report. This outlined the progress made within all key areas and included additional recommendations on how to build on the changes already made.²²

More recently, the [NHS Long Term Plan](#) has set out the key priorities for the NHS over the next 10 years. The plan discusses increased funding for both primary and community mental health services, as well as improved service provision, especially for those seeking help in crisis and redesigning core community mental health services by 2023/24. The plan also covers prevention and health inequalities, encouraging the NHS to influence behaviour change. This in turn has resulted in the green paper, [Prevention is better than cure](#). The paper encourages the NHS and local authorities to put prevention at the heart of everything they do, tackling the root causes of ill health. Specifically, the paper highlights the value of community care services in offering early support and helping people to live healthy and independent lives for longer.

Care and treatment

One of the overall aims of the NHS, as set out in the [NHS Objectives for 2020](#), is to deliver the safest, highest quality of health and care possible through continuously reviewing and improving services.²³

As a result of findings from CQC's community mental health survey in 2018, the National Institute for Health and Care Excellence (NICE) has updated its quality standard on service user experience in NHS adult mental health services.²⁴ The update sets out the importance of ensuring people who require mental health support are provided with access to high-quality care in a timely and effective manner. In particular, the statements in the standard that have been updated concentrate on ensuring people who use mental health services are treated with dignity, respect and sensitivity, in order to encourage the use of services ([statement 1](#))²⁵; supporting service users to be at the centre of decisions about their care and treatment ([statement 2](#))²⁶; timely access to mental health services, including crisis care, which should be available 24 hours a day, seven days a week ([statement 5](#))²⁷; and ensuring individuals are involved in agreeing their care plan, identifying the support required to help them live an independent life and achieve their goals ([statement 6](#)).²⁸

Crisis and acute care

In its [Five Year Forward View Implementation Plan](#), NHS England aspires to deliver a 24 hours a day, seven days a week community-based crisis response service, as well as an intensive home treatment service as an alternative to acute inpatient admissions by 2020/21. This is also highlighted in the [NHS Long Term Plan](#) as an important area to be addressed; raising the issue of long waiting times, with the Clinical Review of Standards recommending that urgent and emergency mental health is included in waiting time standards. The intention of this is to ensure timely care is delivered to people when they need it.

The [NHS Long Term Plan](#) further highlights the supportive role played by ambulance services, with one NHS ambulance trust reporting that 10 to 15% of all calls are related to mental health. One aim of the plan is to provide specialist education and training to ambulance staff, enabling them to respond effectively to those in crisis. Another aim is the introduction of mental health nurses to ambulance control rooms to improve triage and overall response to mental health calls.

Mental health liaison

Mental health liaison services deliver specialist mental health care in settings providing physical health care. Services support the work of clinicians, 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.

The [NHS Long Term Plan](#) aims for all urgent and emergency care departments and inpatient wards to have a mental health liaison service for all ages by 2020/21. In addition, the plan sets out a commitment to provide a single point of access and timely, universal mental health crisis care for everyone within the next 10 years, specifically discussing the NHS 111 telephone service as a point of access to support in the community. By 2023/24, NHS England plan for 70% of these services to meet the Core 24 service standard as a minimum. This service standard encourages the provision of mental health liaison cover 24 hours per day.

Early intervention

As well as helping people to recover and regain a good quality of life, evidence shows that early intervention in mental ill health can reduce the risk of relapse, risk of suicide and number of hospital admissions. The Mental Health Taskforce introduced a [national access and waiting time standard](#) for Early Intervention in Psychosis (EIP) services in April 2016.²⁹ 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. This is reiterated in the [NHS Long Term Plan](#) as still being a main priority for both community and acute mental health services.

Physical health interventions

[Academic research](#) connects mental health disorders to an increased risk of diseases, as well as contributing to physical ill-health.³⁰ Similarly, the [World Health Organisation \(WHO\)](#) estimates those with severe mental health illness die 10 to 25 years earlier than the general population.³¹ The [NHS Long Term Plan](#) recognises the health inequalities faced by people with a severe mental illness. In response, the plan sets out a commitment to provide physical health checks to 280,000 people by 2020/21 and 390,000 people by 2023/24, ensuring physical health needs are met.

Finding and keeping work

Many people find stable employment to be an important factor in maintaining good mental health. In particular, research finds that for people with severe mental illness, work can provide social support, independence and improved wellbeing.³²

The [Five Year Forward View for Mental Health](#) recognises this and highlights the importance of helping people with severe mental health illness to find and keep work. In response, NHS England has pledged to double access to Individual Placement and Support (IPS) services by 2020/21.³³ IPS is a vocational rehabilitation intervention for people with severe mental disabilities.³⁴

The [NHS Long Term Plan](#) also addresses the need to improve access to mental health services for those already in employment, emphasising poor mental health as a significant reason for sickness absence. The plan discusses new integrated models of community mental health care, which include employment support and improved digital support services to fit around work.

Access to therapies for serious mental health illness

In 2006, the NHS introduced the Improving Access to Psychological Therapies (IAPT) programme.³⁵ This offers talking therapies to people of working age who have anxiety and depression. The programme was expanded in 2011 to include different types of mental health conditions, including psychotic disorders, bipolar disorder and personality disorders.

In 2016, the [Five Year Forward View for Mental Health](#) outlined plans to expand IAPT services so at least 1.5 million people are able to access care each year by 2020/21. The [NHS Long Term Plan](#) continues to support this with plans to expand IAPT for adults and older people with common mental health conditions, focussing on those with long-term conditions.

Equality between physical and mental health services

In 2011, [No Health Without Mental Health](#) set out the government's ambitions to ensure that mental health services and physical health services were given equal priority, or 'parity of esteem'.³⁶ This was then enshrined in law in 2012 through the Health and Social Care Act.

[Five Year Forward View for Mental Health](#) highlights the government's continued commitment to parity of esteem between mental and physical health care. For

example, this recommended that the Department of Health and Social Care (DHSC) should carry out a review of the Health and Social Care Act in order to identify disparities in the provisions for both physical and mental health.

Funding

Mental health services have historically suffered from underfunding.³⁷ In 2018, the [Royal College of Psychiatrists](#) reported that 34 out of 55 NHS mental health trusts (62%) in England had a lower income in real-terms at the end of 2016/17 than they did in 2011/12.³⁸

As part of its 10-year long-term plan, DHSC announced in 2018 that the NHS would receive a real-term increase of 3.4% per year over five years, increasing funding to £20.5 billion per year.

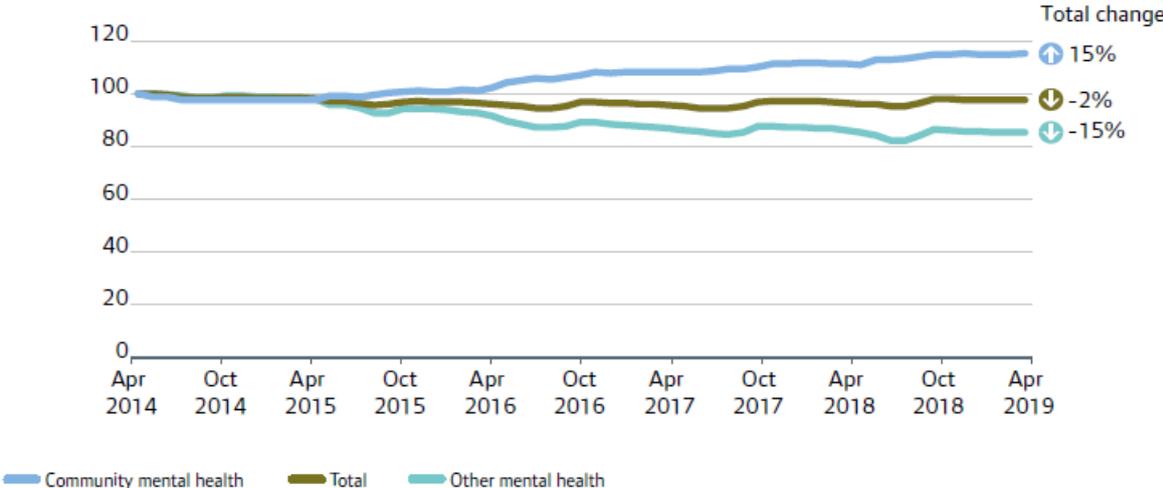
Most recently, the NHS Long Term Plan has highlighted the importance of spending NHS funding wisely. This is reinforced by the green paper, *Prevention is better than cure*. This sets out the government’s intention to put a bigger share of new funding towards those geographical areas with greater health inequalities.

Staffing

In [Implementing the Five Year Forward View](#), there is a distinct emphasis on strengthening community-based mental health services as a means of reducing the demand on the acute sector and inpatient beds. To cope with this shift, NHS England acknowledges the need to expand the workforce, and the skills of the existing workforce, in key areas such as crisis care and mental health liaison.

According to [NHS Digital workforce statistics](#), there has been a decline in the total number of mental health nursing staff between April 2014 and April 2019 of 2%, as shown in figure 1.

NHS full-time equivalent mental health nurses, 2014 to 2019



Source: CQC, The state of health and adult social care in England 2018/2019

CQC discussed staff shortages in the report, [The state of health care and adult social care in England 2018/19](#), specifically raising concerns that community mental health provision is not compensating for the reduction in inpatient beds.³⁹ In contrast to the NHS Digital workforce statistics that show an overall increase in the number of community mental health nurses between April 2014 and April 2019, feedback from CQC inspection staff suggests community services are still encountering staff shortages. This report follows the CQC's [The state of care in mental health services 2014 to 2017](#)⁴⁰ and [The state of health care and social care in England 2017/18](#)⁴¹ reports, both of which highlight concerns around poor staff levels and lack of specialist skills.

Prevention

In terms of prevention, in 2017 the government introduced the [Prevention Concordat for Better Mental Health](#). The concordat promotes cross-sector action to reduce mental health problems, through the adoption of evidence-based planning and commissioning. As part of this, [Public Health England](#) have developed a set of key resources, including guidance and toolkits, which are aimed at helping stakeholders to promote better mental health.

In 2019, the DHSC green paper, [Prevention is better than cure](#) set out the government's vision for change to prevent health problems. The paper acknowledges the need for better integration between hospital-based and community-based health services, as well as the need to recruit and retain more community-based staff. The paper also places a large emphasis on improving technology and data collection to enable staff to be more effective in their roles and allow for a more strategic and targeted approach to providing services that are focused on preventing health issues from arising.

The Care Programme Approach (CPA)

The [Care Programme Approach](#) (CPA) is a package of care, used by secondary NHS mental health services to help those who are most vulnerable and/or have complex needs. The framework is used to co-ordinate the care for those who require support from multi-disciplinary teams, by assessing individual needs to identify the appropriate level of care and monitoring that care on an ongoing basis. Each person under CPA will receive a care plan specific to their needs, as well as a care co-ordinator who will review the care plan regularly to ensure the service user's needs are unchanged⁴².

As the CPA is almost 30 years old, some academics and health professionals have been calling for the approach towards the delivery of community mental health care to be radically changed.⁴³ They also believe it has become increasingly outdated when considered alongside the change in mental health policies over the last decade.

Findings from previous iterations of this survey found stark variations in the proportion of service users on the CPA between NHS mental health trusts, this is once again evident within the 2019 data. This implies CPA policy is not interpreted or implemented consistently.

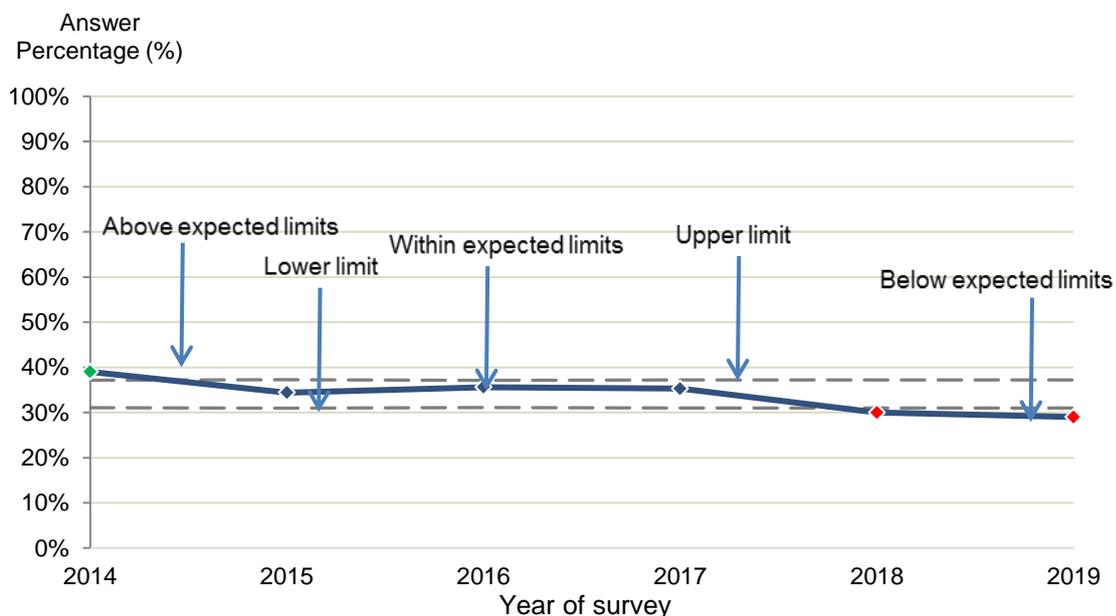
Results from the survey

This section presents key results for the 2019 community mental health survey.^e Statistically significant differences between results from the most recent survey (2019) and from the previous 2018 survey are also highlighted where they appear.^f

We also present the results that have changed noticeably over time and identify long-term trends where appropriate through 'p-charts'. The p-charts in this report plot the percentage of the most positive responses to questions and show the expected limits of variation in survey results. We make the assumption that there has been no 'real' or meaningful change unless the results go outside of expected limits.⁴⁴ Using p-charts allows comparisons between data points covering a number of years, as opposed to observing statistical significance between just two time points. Viewing trends in survey results over a number of years allows for greater confidence in interpreting relationships within the data. Following the re-development of the survey in 2014, this type of analysis can only be used from 2014 onwards.

Where results do not fall outside of expected limits or it is not possible to compare questions over time, no p-chart results are reported. The following example shows a p-chart that fluctuates from above expected limits in 2014, to below expected limits in 2018 and 2019; suggesting a deterioration in results.

Example of a p-chart



e. Responses to questions such as “don't know/can't 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.

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

All charts are available in the open data source files on the [CQC website](#).

Survey results are presented 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. Crisis care
7. Medicines
8. NHS Therapies
9. Feedback
10. Support and wellbeing
11. Overall

Within the results, we have included subgroup analysis which compares the experiences of different groups of people. Using a set of composite themes based on the [National Patient Experience Framework](#), the analysis models the mean scores of subgroups according to characteristic indicators. These indicators are^g:

- age
- gender
- religion
- sexual orientation
- ethnicity
- CPA status
- diagnosis (care cluster codes)
- length of contact
- long-term conditions
- 'proxy response' (whether the questionnaire was completed entirely by or with the support of someone other than the person who used the services).

See [appendix G](#) for more information and charts. A full summary of results can be found in the [Subgroup analysis summary: how experience varies for different groups of respondents](#) section.

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

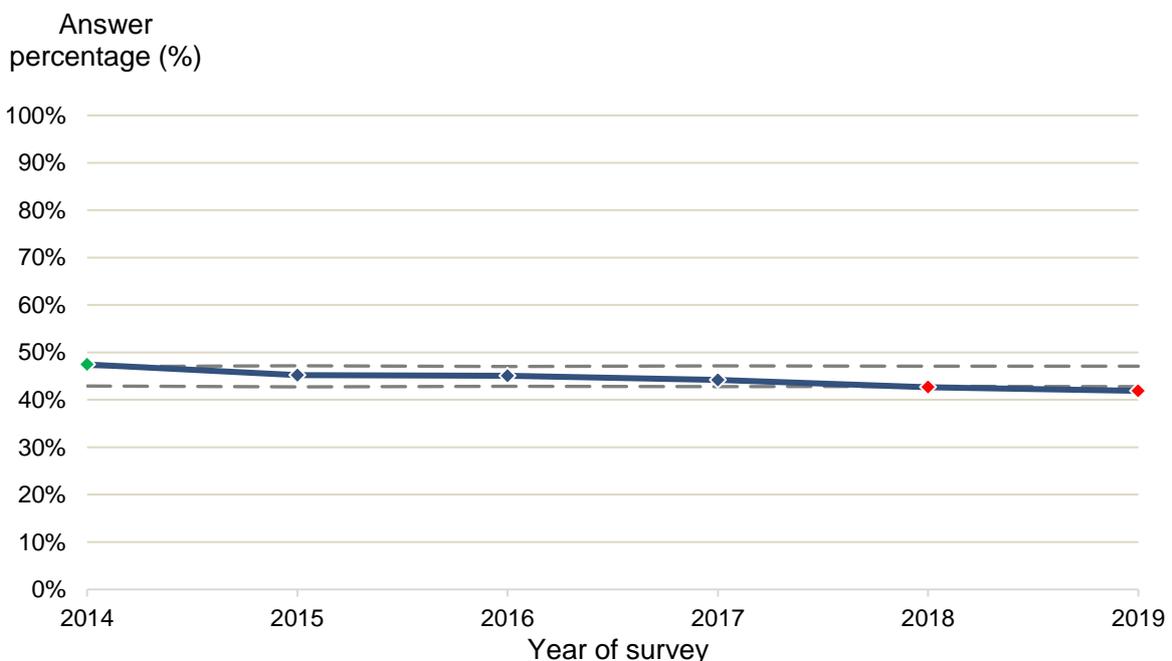
1. Care and treatment

The importance of ensuring people have access to a high standard of mental health care has been discussed in a number of national government policies in recent years. Most recently, the [NHS Long Term Plan](#) commits to ring-fence funding for mental health services to allow for service expansion. The plan highlights one outcome of this funding as being faster access to community and crisis mental health services.

[NICE quality statement 5: Access to services](#) highlights the importance of ensuring people have timely access to high-quality mental health services when they need them. In addition to this, the national access and waiting time standard for early intervention in psychosis services requires at least 50% of people with a first episode of psychosis to start treatment with a NICE recommended package of care within two weeks of referral.

Forty-two per cent of respondents said they had 'definitely' seen NHS mental health services often enough for their needs, with the result dropping below the expected limits of variation for the second year in a row. This is one percentage point lower than last year and five percentage points lower than 2014, showing a gradual and sustained decline in the proportion of people feeling they can access services often enough.

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.

Respondents who stated that they didn't know have been excluded.

Number of respondents: 2014 (13,061), 2015 (11,072), 2016 (12,587), 2017 (11,474), 2018 (12,179) and 2019 (11,883).

When comparing experience across subgroups, 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 significant variation in experience.

People in the younger age groups reported worse than average experiences, while those in the older age groups reported better than average experiences. Likewise, people who had shorter lengths of contact with NHS mental health services reported better than average experiences compared to those who had been in contact longer. However, the greatest levels of variation can be seen when comparing care cluster codes. Those reporting significantly worse than average experiences in this area were found in the non-psychotic and cognitive impairment and dementia care clusters:

- Care Cluster 2 - Common mental health problems (low severity with greater need)
- Care Cluster 3 - Non-Psychotic (Moderate Severity)
- Care Cluster 4 - Non-Psychotic (Severe)
- Care Cluster 5 - Non-Psychotic Disorders (Very 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
- Care Cluster 20 - Cognitive impairment or dementia complicated (high need)

Those reporting significantly better than average experiences in this area were assigned to the psychotic care clusters:

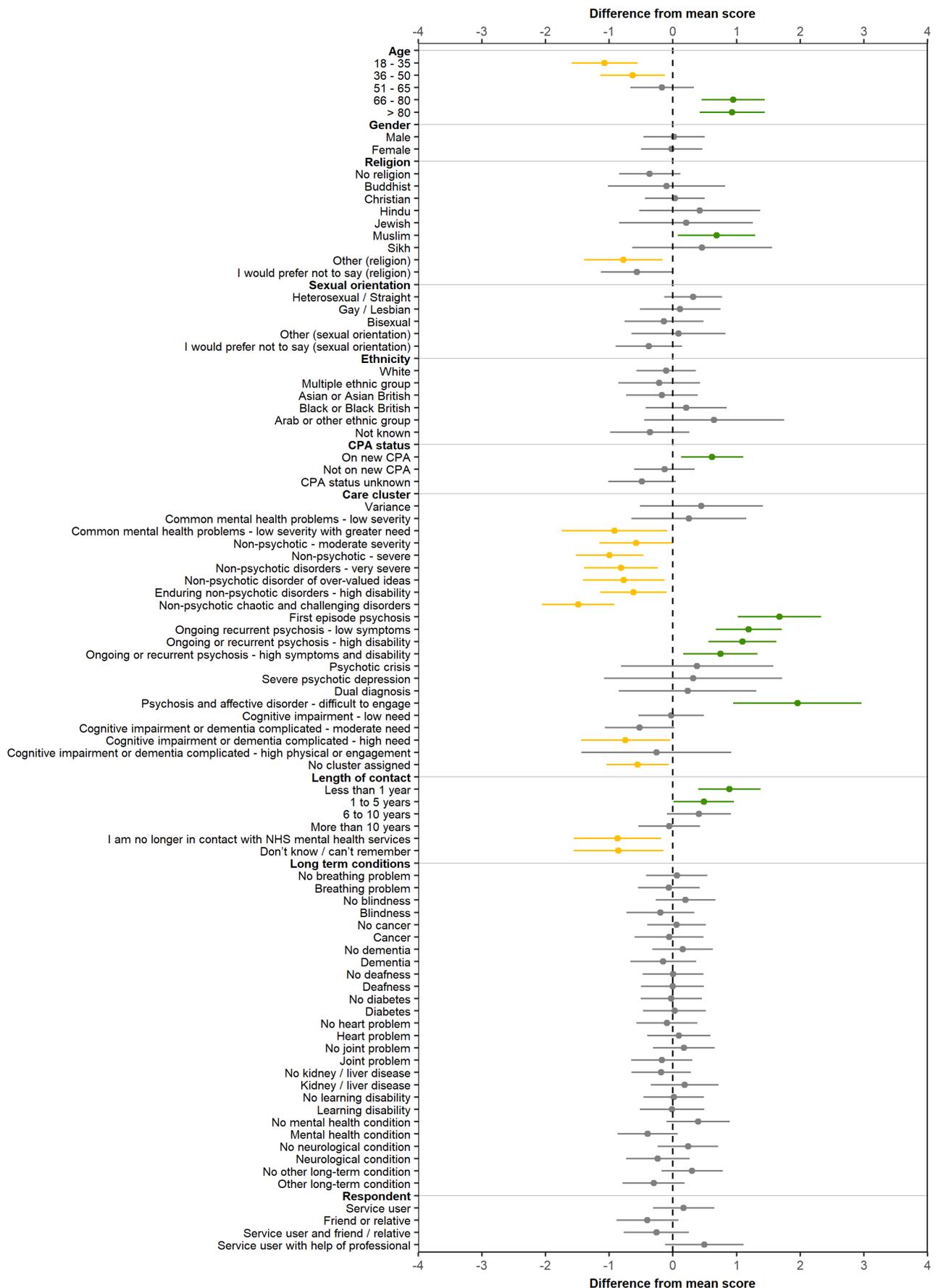
- Care Cluster 10 - First Episode Psychosis
- Care Cluster 11 - Ongoing Recurrent Psychosis (Low Symptoms)
- Care Cluster 12 - Ongoing or Recurrent Psychosis (High Disability)
- Care Cluster 13 - Ongoing or Recurrent Psychosis (High Symptoms and Disability)
- Care Cluster 17 - Psychosis and Affective Disorder (Difficult to Engage)

For more information about care cluster codes, please see [appendix H](#).

The following chart displays full subgroup analysis for this question. 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

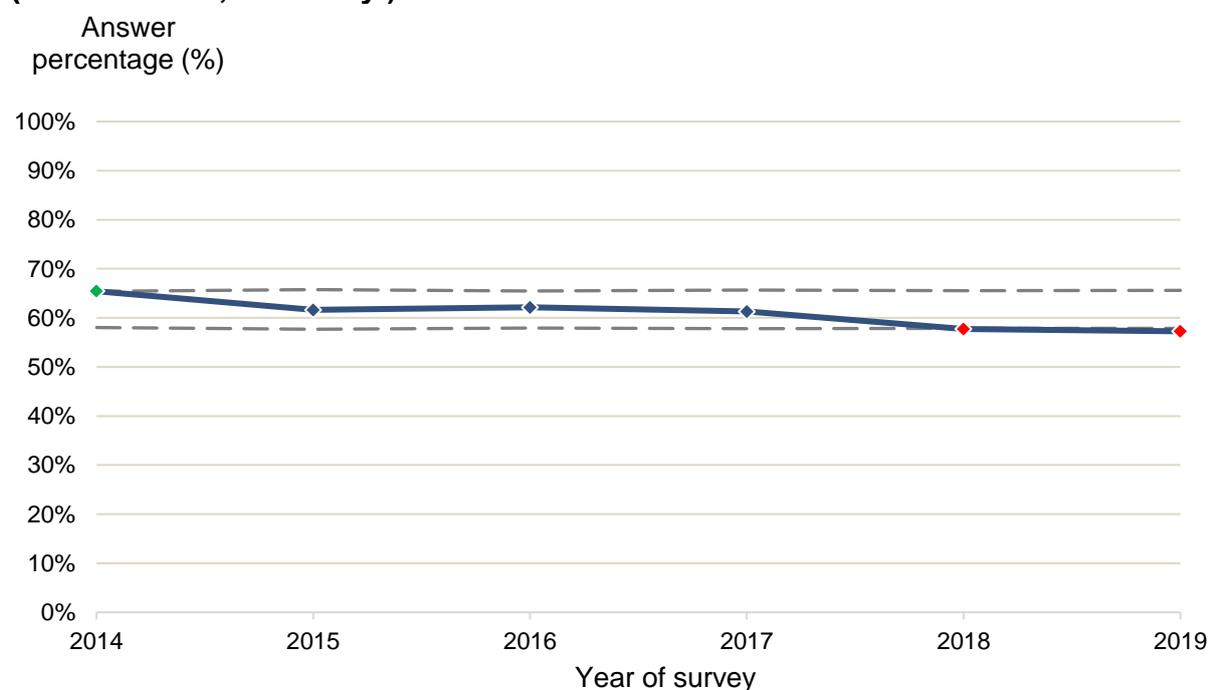
Research has found that positive interactions between people who use services and mental health staff can improve overall outcomes.⁴⁵ Therefore, respectful relationships which allow for two-way communication are important.

[NICE quality statement 3: Involvement to improve services](#) reiterates this by stating that service providers should promote self-management and ensure that people who use services are involved in decision-making processes.⁴⁶ Furthermore, the [Five Year Forward View for Mental Health](#) sets out plans to train staff across the NHS that allows them to understand mental health conditions.

Questions in this section look at whether staff provide people who use services with the opportunity to discuss their individual circumstances, as well as recognise the impact their mental health has on other areas of their lives.

Fifty-seven per cent of respondents said they were 'definitely' given enough time to discuss their needs and treatment, which for the second year running, remains below expected levels of variation. This is a decrease of eight percentage points from 2014, in which 65% of people felt they had 'definitely' been given enough time.

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



Answered by all.

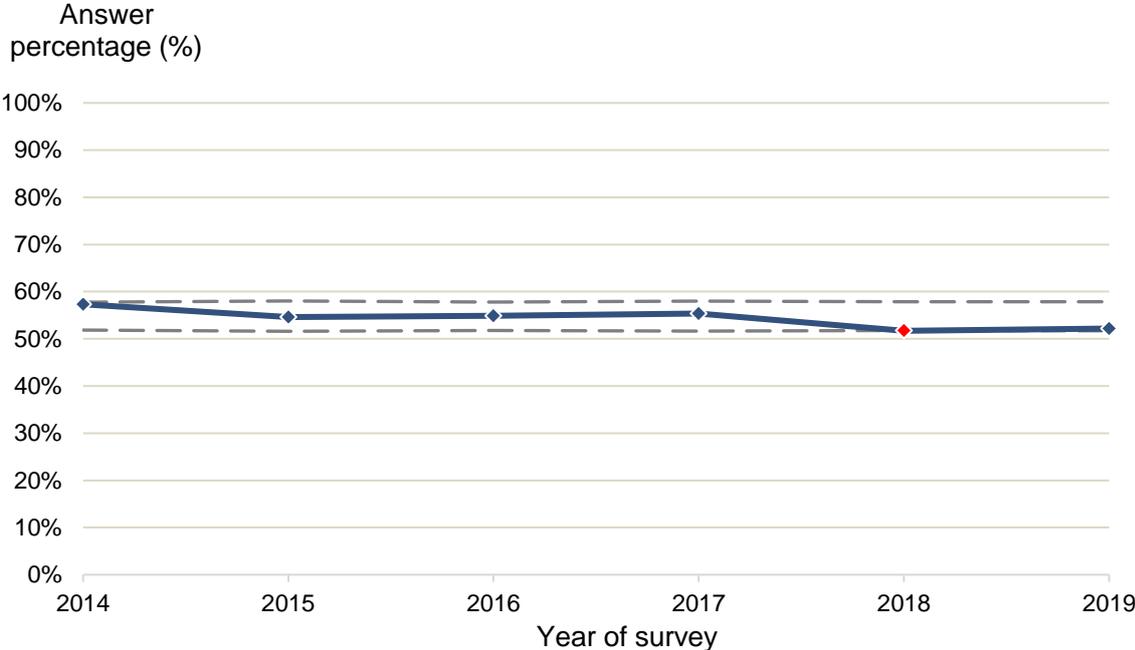
Respondents who stated they didn't know/couldn't remember have been excluded.

Number of respondents: 2014 (13,085), 2015 (10,925), 2016 (12,507), 2017 (11,454), 2018 (12,149) and 2019 (11,860).

Analysis of subgroups shows that people in the older age groups, 66 to 80 and over 80, and those who had been in contact with NHS mental health services for 10 years or less, had better than average experiences. People assigned to care cluster code 10 (first episode of psychosis) and care cluster code 11 (Ongoing recurrent psychosis – low symptoms) also reported better than average experiences. In comparison, people aged between 18 and 35 reported worse than average experience, as did people allocated to non-psychotic care cluster codes.

When asked if the person or people the respondent saw understood how their mental health affected other areas of their lives, 52% responded ‘yes, definitely’. This is within the expected limits this year, having fallen below them last year. However, this is five percentage points lower than the 2014 result of 57%.

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.

Respondents who stated that they didn't know/couldn't remember have been excluded.

Number of respondents: 2014 (12,777), 2015 (10,799), 2016 (12,312), 2017 (11,102), 2018 (11,937) and 2019 (11,738).

When discussing what service experience should look like, the [Five Year Forward View for Mental Health](#) states that each person should be able to say that they see the same person or team, building relationships of familiarity and trust. Meeting with people who are unfamiliar or appear unaware of a person’s treatment history affects people’s ability to build trusting relationships. They may have to repeat their history to multiple people, which can be frustrating and lead to a poor experience.

Respondents were asked, for the first time this year, if the person or people they saw appeared to be aware of their treatment history. Fifty-two per cent responded ‘yes, completely’, with 13% people responding ‘no’. In addition,

analysis of subgroups found that worse than average experiences were reported by the following groups;

- those aged 18 to 35
- those within the 'Common mental health problems – low severity with greater need', 'Non-psychotic chaotic and challenging disorders' and 'Cognitive impairment or dementia complicated – high need' care cluster codes.

3: Organising care

It is important that people using mental health services are aware of who is in charge of their care and that this person or people carry out their role effectively. This allows people to feel fully supported, enabling treatment to be more successful.⁴⁷ The Royal College of Psychiatrists add to this by stating that a care co-ordinator should:

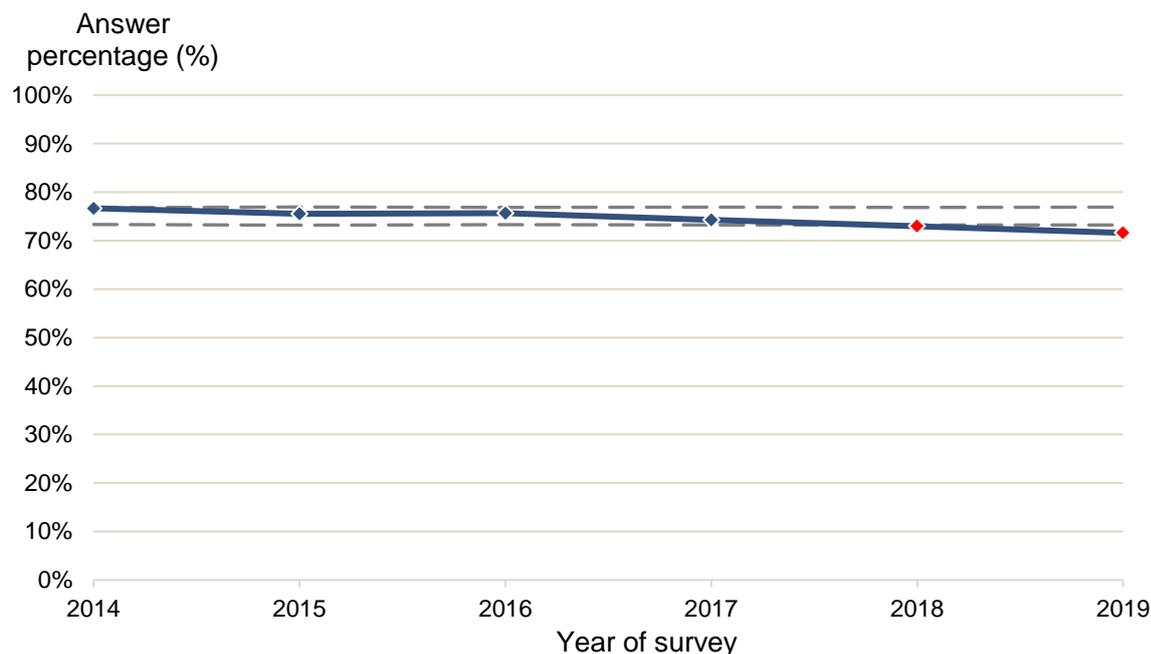
- get to know the person they are working with
- find out how the service user sees their problems
- identify the service user's strengths
- discuss care plans with them
- provide counselling, information and advice
- ensure everyone involved in care and treatment are working collaboratively
- make sure the care plan is very clear about how the service user will be helped.⁴⁸

[NICE quality statement 4: Contacts for ongoing care](#) recommends that people who use community mental health services are supported by staff from a single multidisciplinary team.⁴⁹ In providing continuous care, the team will build a relationship of familiarity with individuals. This encourages a person to manage their mental health more effectively and the impact it has on their life.

The current Care Programme Approach (CPA) adheres to this recommendation by requiring a multidisciplinary package of care in which the assigned care co-ordinator gets to know the person they are working with and maintains contact with them.⁵⁰

Respondents were asked if they had been told who was in charge of their care and services. Seventy-two per cent responded 'yes', a small but significant decrease from the result in 2018 of 73%. This deterioration continues a trend of decline over time. The 2019 result is five percentage points lower than at the highest point in 2014 (77%) and falls below the expected limits again this year. The 2018 figure was also below the expected limits

Q7. Have you been told who is in charge of organising your care and services? (Answer: 'Yes')



Answered by all.

Respondents who stated that they weren't sure have been excluded.

Number of respondents: 2014 (11,314), 2015 (9,589), 2016 (10,838), 2017 (9,863), 2018 (10,358) and 2019 (9,982).

Supplementary questions were asked of respondents who knew who was organising their care, however those stating that this person was their GP were excluded from questioning.

Ninety-six per cent responded 'yes', when asked if they knew how to contact the person in charge of their care, should they have concerns. This is unchanged from 2018. Respondents were also asked how well this person organises the care and services they need. Results were the same as those in 2018, with 57% answering 'very well' and 33% 'quite well'.

Results show that over a quarter of people do not know who is in charge of their care (28%). However, the vast majority of those who do, know how to contact that person should they need to. Guidance from NICE links the importance of familiar relationships with improved mental health outcomes.

When considering results of subgroup analysis for a composite theme of 'Have you been told who is in charge of organising your care and services?' and 'How well does this person organise the care and services you need?', those on a new CPA reported better than average experiences in the organisation of their care. This is also true for those diagnosed with psychotic disorders, particularly those diagnosed with a first episode of psychosis. In contrast, people aged between 18 and 35, as well as those in the cognitive impairment and dementia care cluster group, reported worse than average experiences within the organisation of care theme.

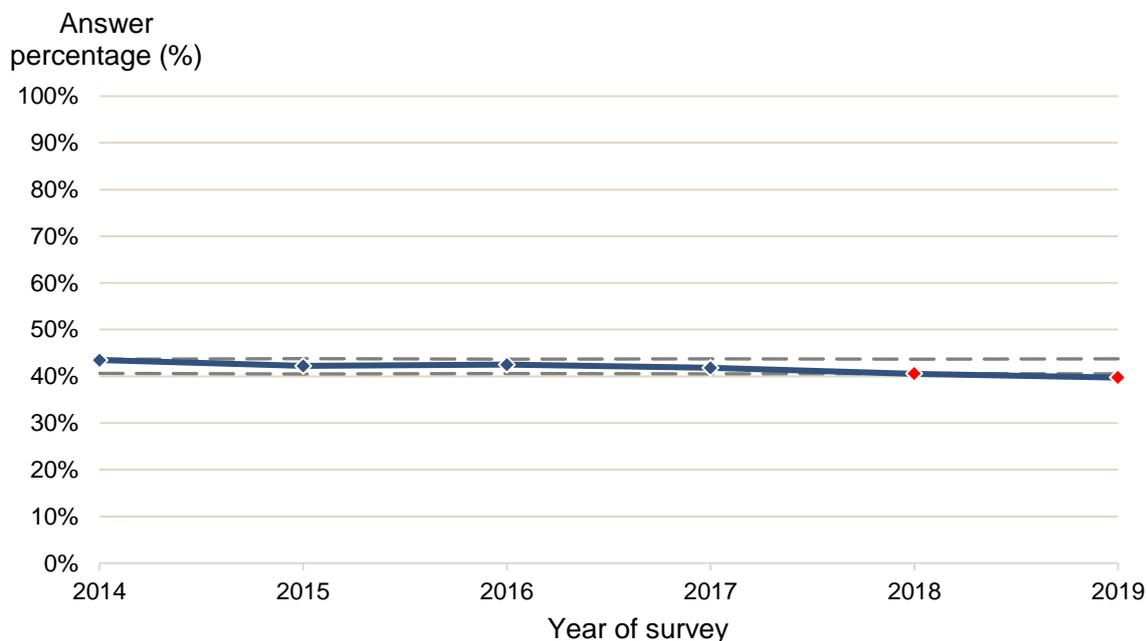
4: Planning care

NICE, in collaboration with partner organisations, have developed an action plan, aimed at embedding shared decision-making into routine practice throughout all healthcare services. This is reiterated in [NICE quality statement 6: Joint care planning](#), which recommends that people who use services should jointly plan their care with health and social care professionals.

This approach is also endorsed by [guidance produced by the Department of Health and Social Care for the CPA](#).⁵¹ This highlights the importance of actively involving people in developing their own care plan. It also recognises the need to tailor care and support to an individual's specific needs and preferences, and emphasises the role of person-centred care in improving recovery.

Forty per cent of people responded 'yes definitely' when asked if they had agreed with someone from NHS mental health services what care they will receive. This is a decrease of three percentage points from the 2014 result of 43% and falls below the expected limits of variation for the second consecutive year. Almost a quarter of people (23%) stated they had not agreed with someone from NHS mental health services what care they will receive.

Q11. Have you agreed with someone from NHS mental health services what care you will receive? (Answer: 'Yes, definitely')



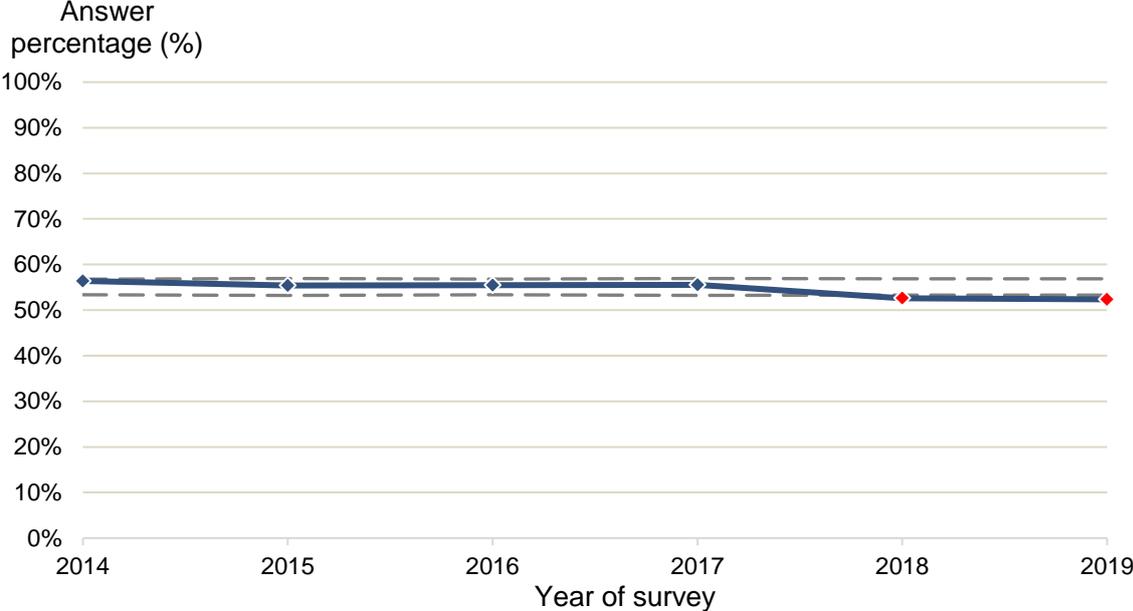
Answered by all.

Number of respondents: 2014 (13,223), 2015 (11,178), 2016 (12,728), 2017 (11,569), 2018 (12,342) and 2019 (12,035).

Respondents who indicated they had agreed what care they would receive with someone from NHS mental health services, were also asked if they were

involved as much as they wanted to be. Fifty-two per cent responded ‘yes, definitely’. This falls below the expected limits for two consecutive years (2018 had a result of 53%). Over time, we have seen a decline of four percentage points in people’s experience for this question.

Q12. Were you involved as much as you wanted to be in agreeing what care you will receive? (Answer: ‘Yes, definitely’)



Answered by those who have agreed with someone from NHS mental health services what care they will receive.

Respondents who stated that they did not know/couldn’t remember or did not want to be involved have been excluded.

Number of respondents: 2014 (9,821), 2015 (8,242), 2016 (9,412), 2017 (8,395), 2018 (9,208) and 2019 (8,832).

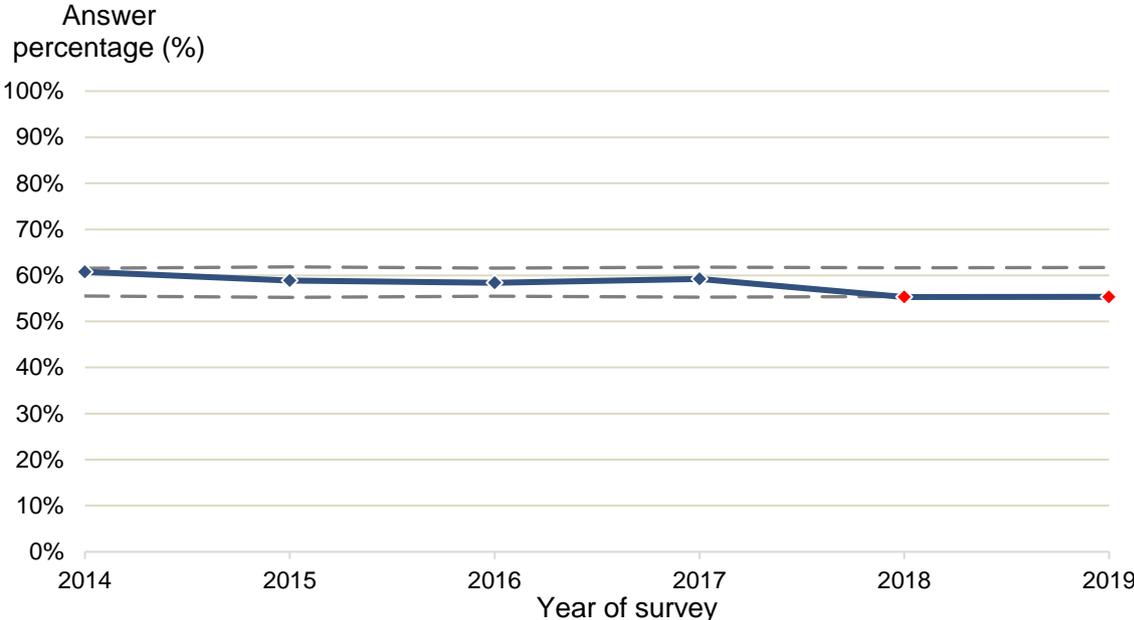
We analysed subgroup experiences for the theme of involvement using a composite of ‘*Were you involved as much as you wanted to be in agreeing what care you will receive?*’ and ‘*Did you feel that decisions were made together by you and the person you saw during this discussion?*’. As with other themes, we found that those in the 18 to 35 age group had worse than average experiences, while those in the 66 to 80 age group had better than average experiences.

Respondents who were diagnosed with ‘first episode of psychosis’ (care cluster code 10) and ‘ongoing recurrent psychosis – low symptoms’ (care cluster code 11) had better than average experiences in terms of involvement, while those diagnosed with ‘non-psychotic chaotic and challenging disorders’ (care cluster code 8) had worse than average experiences.

Fifty-five per cent of people who agreed with someone from NHS mental health services what care they will receive ‘definitely’ agreed their personal circumstances were taken into account. People’s experience in this area fell

below the expected limits for the second year in a row. Overall, results decreased by six percentage points between 2014 and 2019.

Q13. Does this agreement on what care you will receive take your personal circumstances into account? (Answer: ‘Yes, definitely’)



Answered by those who have agreed with someone from NHS mental health services what care they will receive.

Respondents who stated that they didn't know/couldn't remember have been excluded.

Number of respondents: 2014 (9,718), 2015 (8,070), 2016 (9,342), 2017 (8,228), 2018 (9,058) and 2019 (8,624).

When analysing subgroups for the theme of respect for person-centred values, we used a composite indicator, combining ‘*Did the person or people you saw understand how your mental health needs affect other areas of your life?*’ and ‘*Does this agreement on what care you will receive take your personal circumstances into account?*’. This analysis found that those in the 18 to 35 age group had worse than average experiences, while those over the age of 66 reported better than average experiences.

Respondents diagnosed with ‘non-psychotic chaotic and challenging disorders’ (care cluster code 8) had worse than average experiences, whereas those diagnosed with ‘first episode of psychosis’ (care cluster code 10) or ‘ongoing recurrent psychosis – low symptoms’ (care cluster code 11) reported better than average experiences.

Findings for this section show that almost a quarter of people have not agreed what care they will receive, and of those who have, only just over half were involved as much as they wanted to be and felt their care fully took their personal circumstances into account. [NICE quality statement 6: Joint care planning](#) and the [Department of Health and Social Care](#), both highlight the importance of collaborative care planning in improving overall recovery.

5: Reviewing care

As discussed previously, it is important to involve people in their own care and this extends to a collaborative approach when reviewing their care plan too. According to [Mind](#), care plans should be reviewed regularly to:

- monitor progress and make changes should a person's needs change
- consider how the care plan is meeting specific needs and allowing an individual to achieve personal outcomes
- keep the plan up to date
- determine which services may be required in future.⁵²

Mind recommend reviewing care plans 12 months from the initial set up, with reviews taking place every 12 months after that. However, the NHS states that care plans will receive their initial review within a few months of set up and annually after that.⁵³

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 last 12 months. Seventy-one per cent of people responded 'yes', in line with last year's result. However, this figure was 74% in 2014, showing a decrease of three percentage points overall.

In order to establish if people who use services felt involved in decisions made about their care and treatment, respondents who indicated that they had a formal meeting with NHS mental health services in the last 12 months were asked if decisions were made together by themselves and the person they saw during this meeting. Sixty per cent of people responded 'yes, definitely', with 9% stating they did not feel decisions were made together.

6: Crisis care

Some people experience mental health crises as part of their ongoing mental health conditions, whereas, for others, a mental health crisis may be a less frequent or one-off occurrence.

The [Crisis Care Concordat](#), a national agreement between different services and agencies involved in delivering care and support to people in crisis, identifies the four key areas organisations should focus on when working collaboratively in supporting individuals during a mental health crisis.⁵⁴ These areas are:

- access to support before a person reaches crisis point

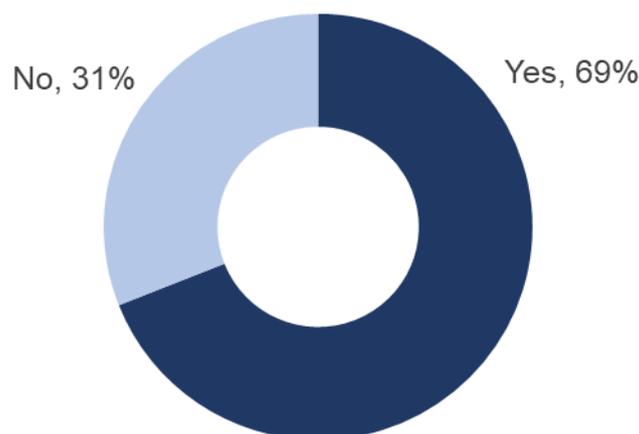
- urgent and emergency access to crisis care
- quality of care and treatment when a person is in crisis
- recovery and staying well.

In recent years, there have been a number of mental health policies that address crisis care. Most notably, the [Five Year Forward View for Mental Health](#) states that people facing a crisis should have access to good quality care 24 hours a day, seven days a week, as they would if they needed emergency physical care. The plan further recommends that NHS England move towards a service that offers 24 hours a day, seven days a week community-based mental health crisis care in all areas across England. It specifically noted intensive home treatment as an alternative to acute inpatient admissions.

This is further supported in the [NHS Long Term Plan](#) which states the NHS will provide a 24-hours a day, seven days a week community-based crisis response across England by 2020/21. One of the overall priorities is to reduce the number of suicides in the next 10 years. In addition, specific waiting time targets for emergency mental health services will be introduced for the first time and take effect from 2020.

In line with this, all respondents were asked if they knew who to contact out of office hours, within the NHS, if they had a crisis. Almost a third of respondents stated they do not know who to contact (31%), compared to 69% who do know who to contact.

Q16. Do you know who to contact out of office hours within the NHS if you have a crisis?



Answered by all.

Respondents who stated that they weren't sure have been excluded.

Number of respondents: 2019 (10,665)

People who do know who to contact out of office hours when they have a crisis were then asked if, in the last 12 months, they received the help they needed when they tried to contact this person or team. Fifty-one per cent responded 'yes,

definitely' and 29% responded 'yes, to some extent'. Therefore, although a third of people do not know who to contact for help in a crisis, the majority of those who do reach out for help, receive it. However, one in five are not getting the help needed (18% said 'no' and 2% said 'I could not contact them').

When considering experiences of crisis care for different subgroups of people, those over the age of 80 reported worse than average experiences than other age groups for accessing crisis care. However, the same age group had better than average experiences when receiving crisis care.

In addition, people's experience also varied depending on which cluster code they were assigned to. Those reporting significantly worse experiences were assigned to the following care cluster codes:

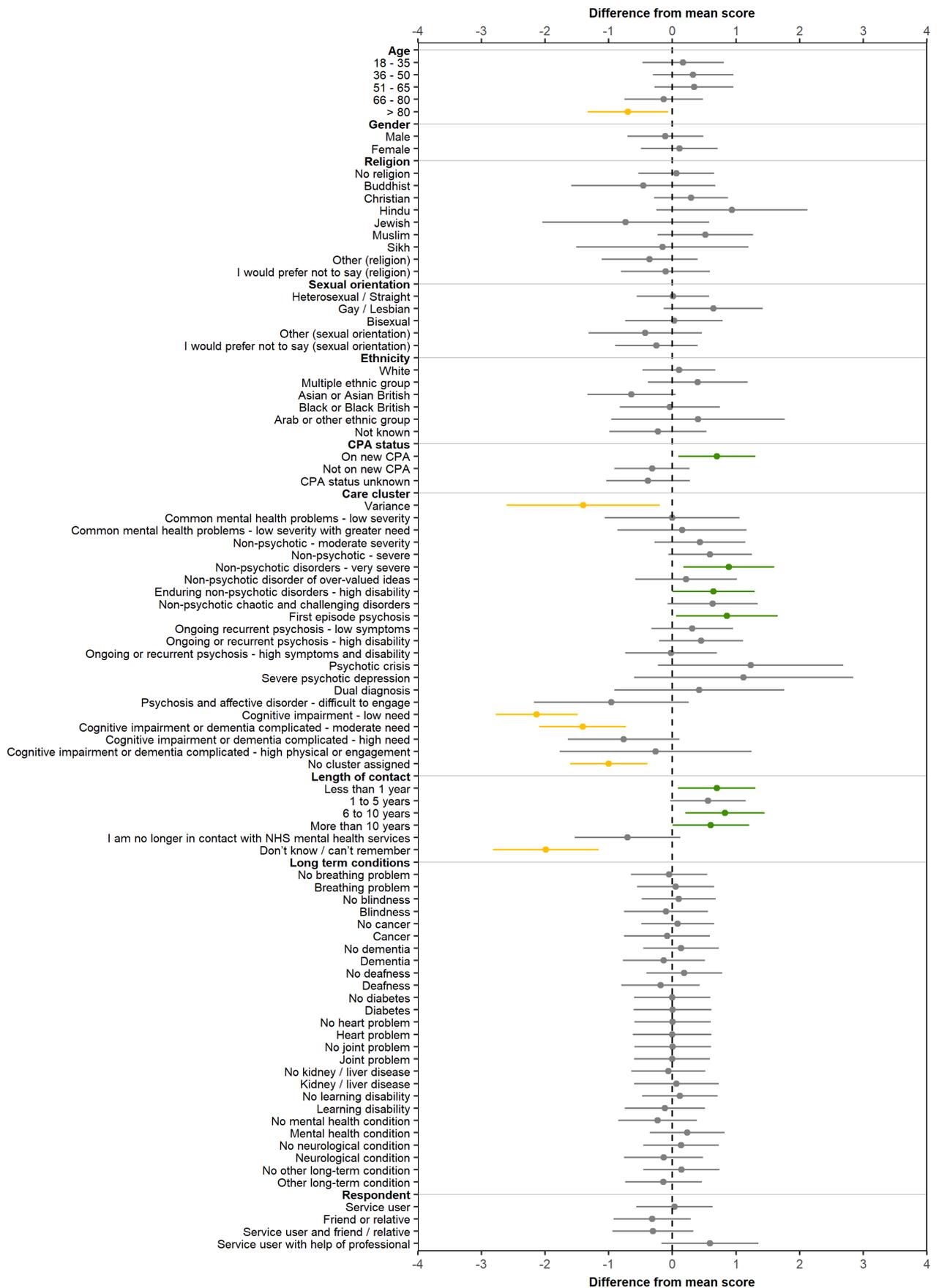
- Care Cluster 18 - Cognitive Impairment (Low Need)
- Care Cluster 19 - Cognitive Impairment or Dementia Complicated (Moderate Need)

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

- Care Cluster 5 - Non-Psychotic Disorders (Very Severe)
- Care Cluster 7 - Enduring Non-Psychotic Disorders (High Disability)
- Care Cluster 10 - First Episode Psychosis

The chart on the following page shows subgroup analysis for crisis care access in more detail.

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



7: Medicines

Research has found that the irregular use of medicines was one of the strongest predictors of whether people would use general health services, and is linked to higher costs of treatment.^{55,56} Adherence to treatment is often low for people with mental ill health.⁵⁷ As well as prolonged hospitalisation, suicide rates for people with bipolar disorder increase and relapse rates increase for individuals with schizophrenia when medicines are not routinely taken.⁵⁸

Guidance produced by [NICE on medicine adherence](#), recommends including people in discussions and informed decision-making about their prescribed medicines.⁵⁹ This can help professionals to understand an individual's motivations for taking or not taking medicines and help increase overall compliance.

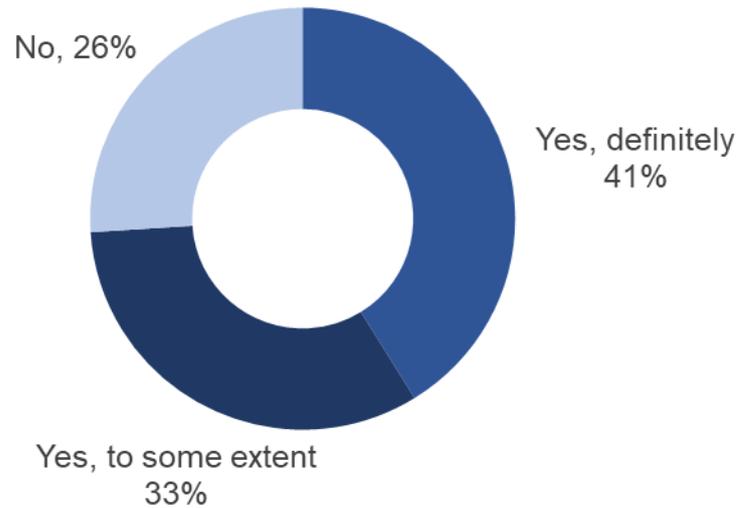
The questions in this section were asked of those who were receiving medicines in the last 12 months for their mental health needs.

Respondents were asked if they were involved as much as they wanted to be in decisions about which medicines they received. Fifty-one per cent of people responded 'yes, definitely', while a further 38% responded 'yes, to some extent' and 12% responded 'no'. Comparing results over time, there has been almost no change over the period of 2014 to 2019.

Respondents were also asked, for the first time this year, if the purpose of their medicines had been discussed with them. Fifty-seven per cent responded 'yes, definitely' and almost one in 10 (9%) answered 'no'.

When asked if the possible side effects of their medicines had been discussed with them, over a quarter of people (26%) responded 'no', compared to 41% who responded 'yes, definitely'.

Q21. Have the possible side effects of your medicines ever been discussed with you?



Answered by those who have been receiving any medicines in the last 12 months for their mental health needs.

Respondents who stated they didn't know/couldn't remember were excluded.

Number of respondents: 2019 (9,492)

When comparing subgroup experiences for the information sharing (medicines) theme, we found that those reporting worse than average experiences were diagnosed with:

- non-psychotic chaotic and challenging disorders (care cluster code 8)
- cognitive impairment or dementia complicated – high need (care cluster code 20)
- cognitive impairment or dementia complicated – high physical or engagement (care cluster code 21).

However, those diagnosed with 'first episode of psychosis' (care cluster code 10) had better than average experiences. Respondents who had been in contact with NHS mental health services for less than one year also reported better than average experiences for this theme.

Respondents who indicated they have been receiving medicines for 12 months or longer were asked if an NHS mental health worker had checked with them about how they were getting on with their medicines during this time. Seventy-eight per cent of people responded 'yes', compared to 22% who responded 'no'. Results have remained stable between 2014 and 2019.

8: NHS therapies

Often, effective and timely care for mental health conditions involves a wide variety of therapies. These vary in intensity and duration depending on the severity of the mental health condition or symptoms. For example, people with depression may be treated using a number of therapies; most often cognitive behavioural therapy (CBT) and/or interpersonal therapy. All therapies delivered should be assessed for the level of risk posed, with intensity and duration adjusted accordingly to meet the needs of the individual.⁶⁰

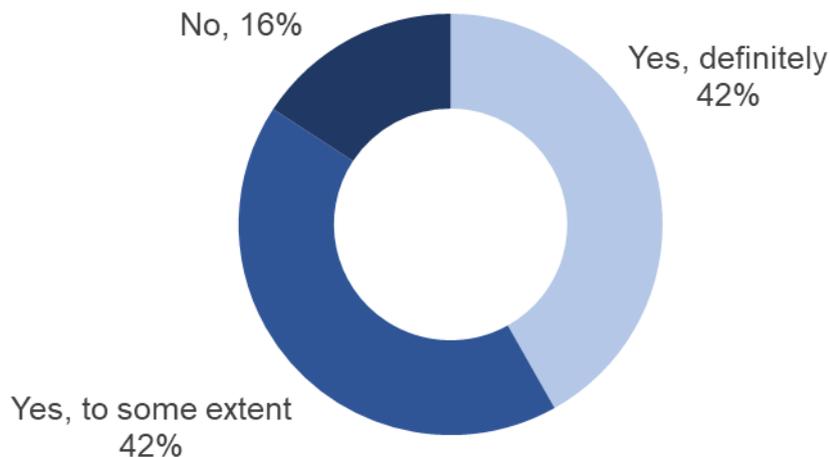
The [NHS Long Term Plan](#) sets out intentions to increase support for people to manage their own health. Part of this will be to offer online therapies for common mental health conditions. The plan also discusses the development of apps and online resources to support good mental health and enable recovery.

The questions in this section were asked to people who had received any NHS therapies in the last 12 months for their mental health needs that do not include medicines.

Respondents were asked if the NHS therapies were explained to them in a way they could understand. Sixty-four per cent of people responded 'yes, completely' with a further 32% responding 'yes, to some extent' and 4% 'no'. This is the same as 2018.

The same respondents were asked if they were involved as much as they wanted to be in deciding which NHS therapies to use. Half of people (50%) stated 'yes, definitely', with results this year almost unchanged from 2018. In addition, respondents were asked if they felt their NHS therapies had helped their mental health. Sixteen per cent of people responded 'no', compared to 42% who responded 'yes, definitely'.

Q28. Do you feel your NHS therapies have helped your mental health?



Answered by those who have received NHS therapies in the last 12 months for their mental health needs.

Respondents who stated that they weren't sure have been excluded.

Number of respondents: 2019 (3,920)

9: Feedback

The [NHS Constitution](#) commits the NHS to encouraging people to give feedback about their experiences. The overall intention is to use this information for service improvement. Providing people with a good experience also has other benefits. As highlighted by [NHS England](#), these include:

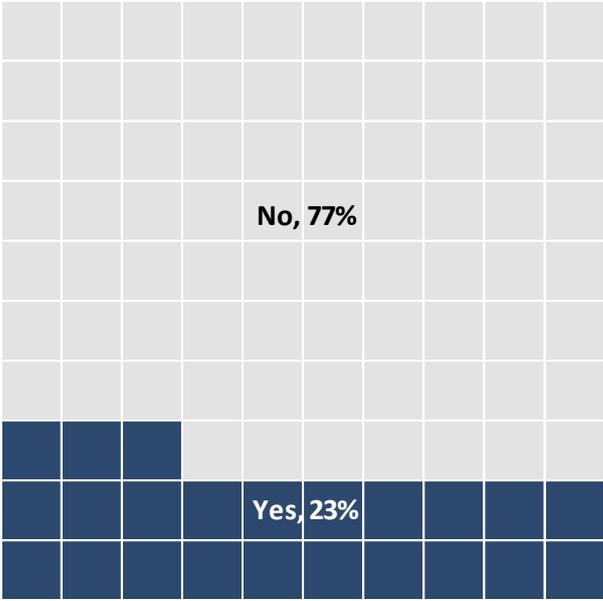
- better health outcomes for people who use services
- good organisational reputation
- positive impact on staff
- lower care costs.

The [NHS Patient Experience Framework](#) describes a good experience as including respect for patient-centred values, coordination and integration of care, timely access to care and good relationships between people and health professionals.

Respectful relationships that allow for two-way interaction between people who use services and providers are important as they allow people to feel in control of their care, improving outcomes overall. This is further discussed in [NICE quality statement 3: Involvement to improve services](#), which encourages involving people, and self-management of care and treatment. Furthermore, the [Five Year Forward View for Mental Health](#) says that people should experience care that is flexible to their changing needs and is based on a collaborative and open relationship.

All respondents were asked if, in the last 12 months, they were asked by NHS mental health services to give views on the quality of their care. Almost eight out of 10 people (77%) responded 'no'.

Q37: Aside from in this questionnaire, in the last 12 months, have you been asked by NHS mental health services to give your views on the quality of your care?



Answered by all.

Respondents who stated that they weren't sure have been excluded.

Number of respondents: 2019 (10,357)

10: Support and wellbeing

Many people who use specialist mental health services often have wider needs in other areas of their lives that can impact recovery. These needs can include housing, financial support and employment. According to [Mind](#), while NHS services do not provide support for these needs directly, they should offer signposting to other services that can help.⁶¹

Respondents were asked a series of questions about the support provided by the NHS for their wider needs. Those who responded that they already have active support and did not need help or advice to find it or did not need support for a particular need, were excluded from results.

Physical health needs

As identified in the [Five Year Forward View for Mental Health](#), physical and mental health are closely linked. People experiencing mental ill health have worse outcomes for their physical health, and those with physical health issues

often have underlying mental health needs that go unrecognised.⁶² People with severe and prolonged mental illness are at risk of dying on average 15 to 25 years earlier than other people, with two thirds of these deaths resulting from avoidable physical illness.

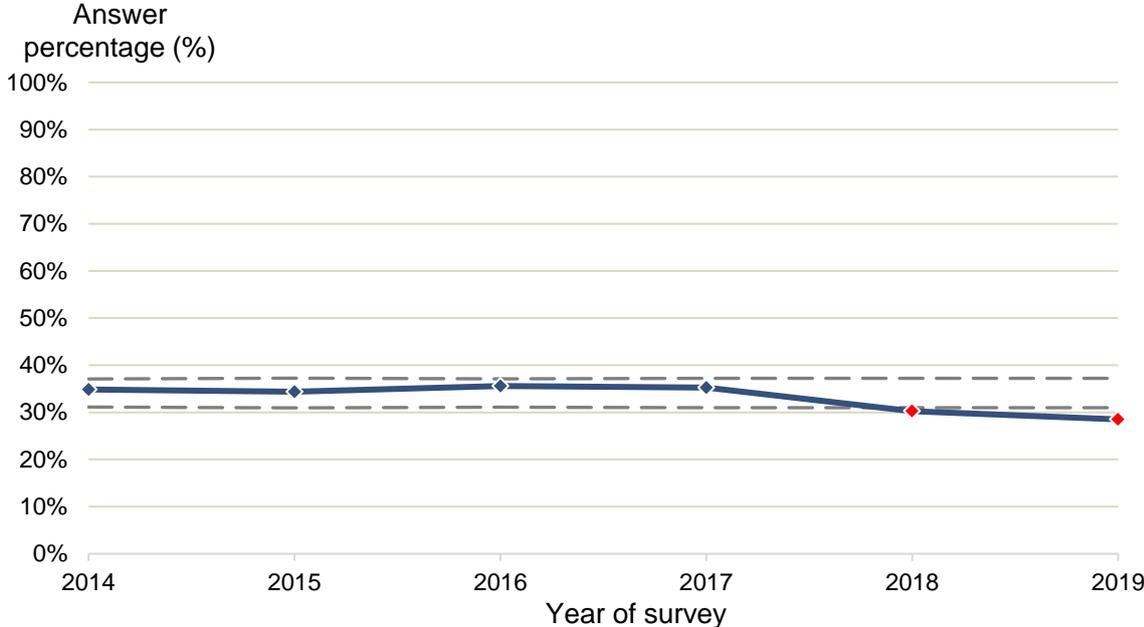
The National Commissioning for Quality and Innovation estimates that 40,000 early deaths could be prevented if this issue is addressed.⁶³ Long-term conditions can have a detrimental and life-changing impact on a person's wellbeing, functional capability and quality of life. When a person has both physical and mental health conditions, they will access a range of services, which raises the overall cost of care. As set out in [the Improving Access to Psychological Therapies Manual](#), it is important to address both mental and physical health equally.⁶⁴

Several policies recognise the need to achieve parity of esteem between mental and physical health, closing the health gap between people with mental ill health and the population as a whole. The [Department of Health and Social Care](#) identify the 2020s as the decade for working towards parity of esteem in how conditions are treated and also prevented.⁶⁵

All respondents were asked if, in the last 12 months, NHS mental health services gave them any help or advice with finding support for physical health needs. Thirty-nine per cent of people responded 'no, but I would have liked help or advice with finding support', compared to 29% of people who responded 'yes, definitely'. When comparing experience's for people with different long-term health conditions, the proportion of people answering 'yes, definitely' was highest amongst those who self-reported as having Diabetes (33%). Where as only 26% of those who reported having a joint problem, such as arthritis 'definitely' felt they received this support.

As shown in the chart below, the percentage of those responding 'yes, definitely' falls below the expected limits in 2018 and 2019. Since 2014, the score has declined by six percentage points when 35% of people responded 'yes, definitely'.

Q29. In the last 12 months, did NHS mental health services give you any help or advice with finding support for physical health needs? (Answer: 'Yes, definitely')



Answered by all.

Respondents who stated that they have active support and did not need help/advice to find it, do not need support for this, or do not have physical health needs have been excluded.

Number of respondents: 2014 (6,530), 2015 (5,948), 2016 (6,551), 2017 (6,022), 2018 (6,106) and 2019 (6,174).

Financial advice, benefits and employment

A key factor in maintaining good mental health is stable employment and financial security. However, mental health conditions are one of the main reasons for sickness absence. *Thriving at work: a review of mental health and employers* has found that 15% of people at work have symptoms of an existing mental health condition, with 300,000 people with a long-term mental health condition losing their jobs each year.⁶⁶ This is a much higher number than those with physical health conditions.

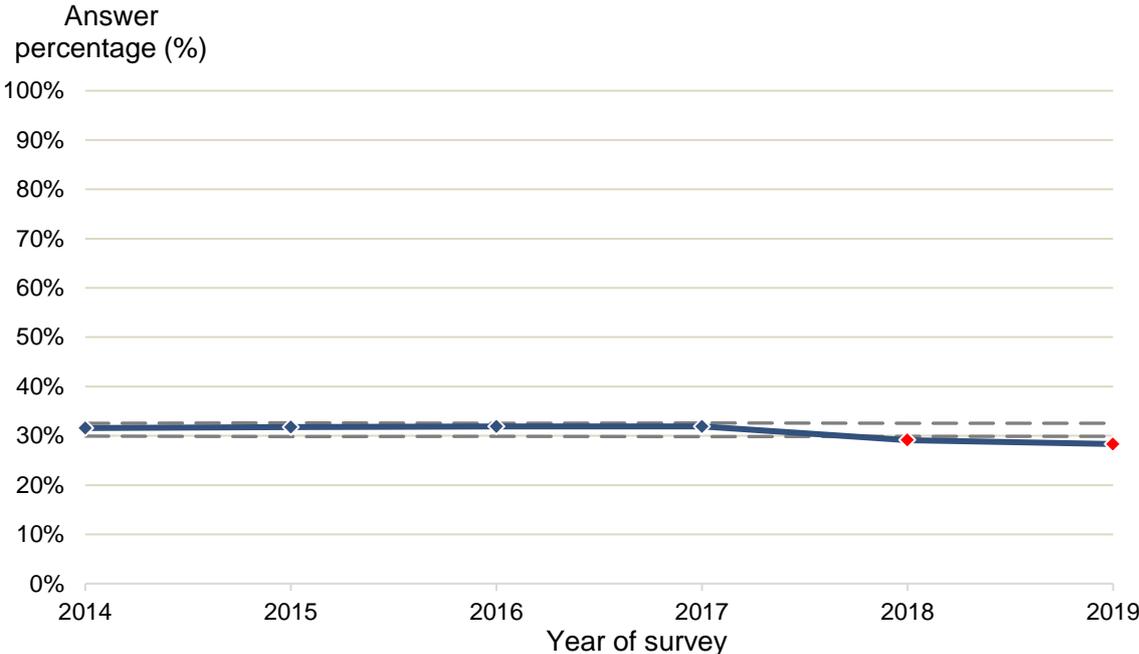
The *Five Year Forward View for Mental Health* highlights that 60 to 70% of people with common mental health conditions are in employment, yet very few of these people have access to specialist occupational health services. In addition, the report found that people with mental health conditions are often over-represented in low-paying, high-turnover, temporary roles. The *NHS Long Term Plan* addresses this issue, emphasising the importance of ensuring fast and convenient access to mental health services is available for those in employment.

Respondents were asked if, in the last 12 months, NHS mental health services gave them help or advice with finding support for financial advice or benefits.

Forty-six per cent of people responded ‘no, but I would have liked help or advice with finding support’.

Only 28% of people responded ‘yes, definitely’, a decrease of four percentage points compared to 2014. The proportion of respondents answering ‘yes, definitely’ fell further below the expected limits for the second year in a row.

Q30. In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits? (Answer: ‘Yes, definitely’)



Answered by all.

Respondents who stated that they have active support and did not need help/advice to find it, or do not need support for this have been excluded.

Number of respondents: 2014 (7,315), 2015 (6,294), 2016 (7,028), 2017 (6,420), 2018 (6,897) and 2019 (7,049).

Additionally, respondents were asked if, in the last 12 months, NHS mental health services gave them any help or advice with finding support for finding or keeping work. Almost half of the respondents (47%) stated ‘no, but I would have liked help or advice with finding support’. This is unchanged from 2018 but is an increase of four percentage points when compared with 2016 and 2017. Twenty-four per cent of people responded ‘yes, definitely’ to the same question. This is an increase of one percentage point since 2018 and remains within expected limits of variation.

Community/social activities

The government report *No Health Without Mental Health* recognises the importance of social activity in improving mental health outcomes. *Mind* also advocate for social inclusion as a buffer against poor mental health, highlighting

the importance of social support in promoting wellbeing.⁶⁷ [The Improving Access to Psychological Therapies Manual](#) highlights the importance for mental health service providers to work as part of a wider system to facilitate links between people and those providing sources of support in the community.

[NICE quality statement 6: Joint care planning](#) states that care plans should include activities that promote social inclusion through activity. These activities include education, employment, volunteering, leisure and caring for dependents.

Respondents were asked if, in the last 12 months, someone from NHS mental health services supported them in joining a group or taking part in an activity. Thirty-eight per cent of people responded 'no, but I would have liked this', unchanged from 2018.

Differences in experience related to support and wellbeing were analysed using a composite of the following questions:

- 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.)?
- In the last 12 months, did NHS mental health services give you any help or advice with finding support for financial advice or benefits?
- In the last 12 months, did NHS mental health services give you any help or advice with finding support for finding or keeping work?
- In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?

Those found to have reported worse than average experiences included those assigned to care cluster code 8 (Non-psychotic chaotic and challenging disorders) and care cluster code 20 (cognitive impairment or dementia complicated – high need).

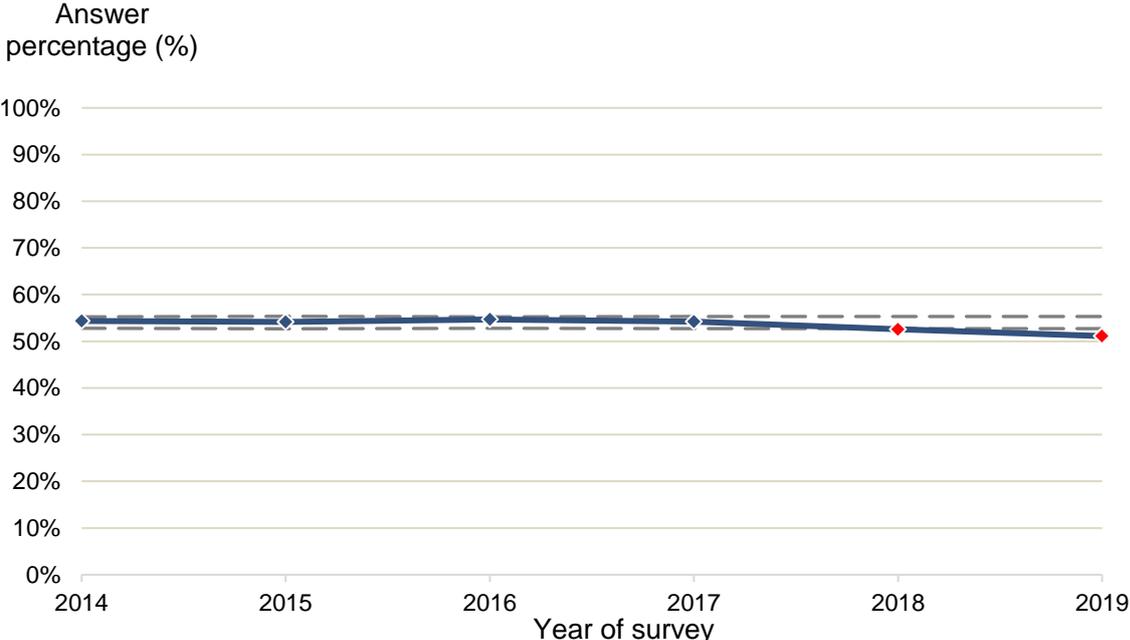
Whereas those reporting better than average experiences were: on new CPA, in contact with NHS mental health services for less than one year or assigned to care cluster codes 10 'First Episode Psychosis', 11 'Ongoing Recurrent Psychosis (Low Symptoms)', 12 'Ongoing or Recurrent Psychosis (High Disability)' or 13 'Ongoing or Recurrent Psychosis (High Symptoms and Disability)'.

Involving family or friends

The King's Fund report, [People in control of their own health and care: The state of involvement](#), suggests that involving a person's family or people close to them can be an integral part of providing good care.⁶⁸ A person is more likely to feel confident in their understanding and their ability to deal with mental health conditions if they have this support. [NICE guidance](#) encourages mental health providers to actively involve family and carers of service users, should the person receiving care want this.⁶⁹

Respondents were asked if NHS mental health services involved a member of their family or someone close to them as much as they liked. Fifty-one percent of people responded 'yes, definitely'. This is a decline of three percentage points since 2014 and is below the expected limits in 2018 and 2019. A fifth of people (20%) stated NHS mental health services did not include a family member or someone close to them enough. This is a significant increase from 18% in 2018.

Q33. Have NHS mental health services involved a member of your family or someone else close to you as much as you would like? (Answer: 'Yes, definitely')



Answered by all.

Respondents who stated that their friends or family did not want to be involved, did not want their friends or family to be involved, or that this does not apply to them have been excluded.

Number of respondents: 2014 (8,870), 2015 (7,448), 2016 (8,718), 2017 (7,978), 2018 (8,231) and 2019 (8,284).

When comparing the experiences of different subgroups for involving family and friends, people aged 18 to 50 had worse than average experiences, while those aged 66 and over had better than average experiences.

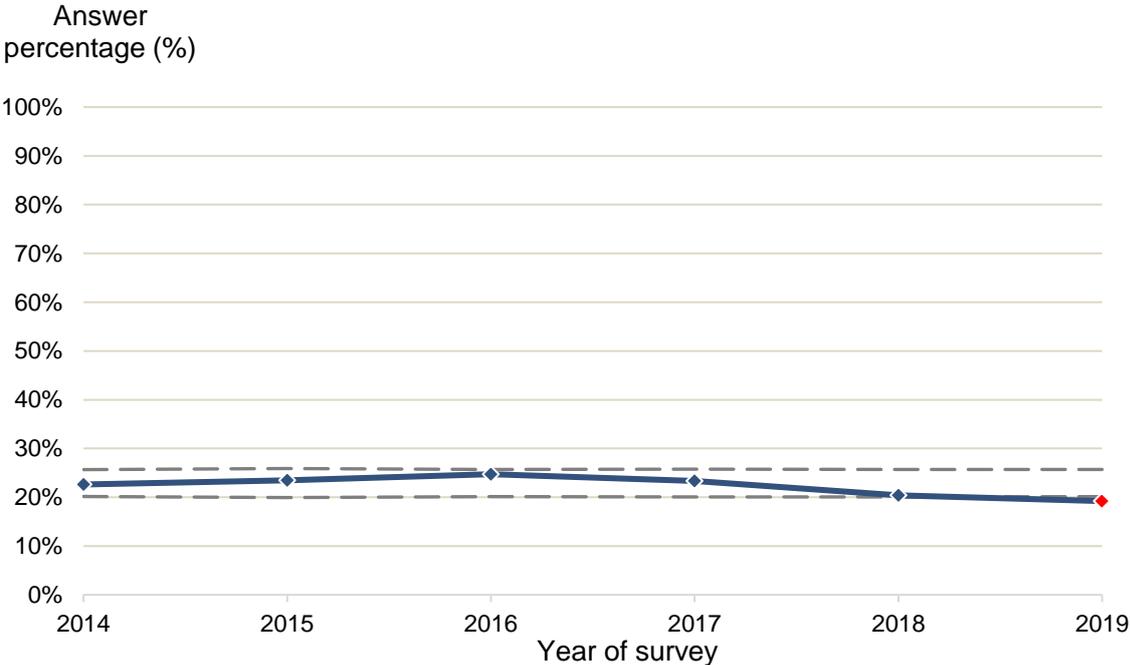
Peer support

Research has found numerous benefits of peer support for improving mental health, including promoting hope and belief in the possibility of recovery, empowerment, increased self-esteem, self-management of difficulties, social inclusion and engagement, and increased social networks.⁷⁰

NICE guidance also recognises the importance of peer support in recovery and has included numerous statements relating to people’s wider lives, recommending that people who use services should be informed of appropriate user-led support organisations.

All respondents were asked if they had received information from NHS mental health services about getting support from people who have experience of the same mental health needs as them. More than half (53%) of people did not receive this information, responding 'no, but I would have liked this'. Nineteen per cent of people responded 'yes, definitely'. This is a decrease of four percentage points compared to 2014 and falls below expected limits for the first time in 2019.

Q34. 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? (Answer: 'Yes, definitely')



Answered by all.

Respondents who stated that they did not want this have been excluded.

Number of respondents: 2014 (7,842), 2015 (6,699), 2016 (7,804), 2017 (7,259), 2018 (7,490) and 2019 (7,557).

11: Overall

Dignity and respect

Research has found that stigma, or perceived stigma, relating to mental ill health, including that within the healthcare system, can act as a barrier to people seeking help.⁷¹ Providers should adopt an approach that is sensitive, respectful and empathetic, in order to ensure people feel able to access the help they need. [NICE quality statement 1: Empathy, dignity and respect](#) links good experience to being treated with empathy, dignity and respect. NICE recognises that this is fundamental to building good relationships between those providing mental health services and those receiving care and treatment. As discussed in earlier

sections, good experiences between mental health staff and people who use services can result in improved outcomes and more effective treatment.

The [NHS constitution](#) states that people who use services should be treated with dignity and respect as a basic human right. It further adds that providers have the responsibility to treat every individual with compassion, dignity and respect, as patient safety, experience and outcomes are all improved as a result.

Respondents were asked if overall, in the last 12 months, they felt they were treated with respect and dignity by NHS mental health services. Seventy-one per cent of people responded 'yes, always'. This is a decrease of three percentage points since 2014 but unchanged from 2018.

When comparing experiences of being treated with respect and dignity by subgroup, we found that younger age groups reported worse than average experiences while older age groups reported better than average experiences. Respondents identifying as heterosexual or straight also reported better than average experiences, as did those who had been in contact with NHS mental health services for less than five years. Analysis also found that those diagnosed with non-psychotic chaotic and challenging disorders (care cluster code 8) reported worse than average experiences, whereas those diagnosed with a first episode of psychosis (care cluster code 10) and ongoing recurrent psychosis – low symptoms (care cluster code 11) reported better than average experiences.

In addition, all respondents were asked to rate their overall experience, with a score of 0 representing 'a very poor experience' and 10 representing 'a very good experience'. Thirty per cent of people rated their experience very positively, giving it a score of nine or 10. This remains within the expected limits and is unchanged from 2018. When comparing this to overall experiences reported in other national patient surveys, 48% of respondents to the recently published 2018 adult inpatient survey scored their experience as a nine or 10. Although this service is very different to community mental health services in many aspects, we can see a notable difference of 18 percentage points between the two services.

When comparing overall experience by subgroups, we found, as with multiple other themes, those in the 18 to 35 age group reported worse than average experiences. In comparison, those aged 66 and over reported better than average overall experiences. Worse than average experiences were once again most prevalent in the non-psychotic chaotic and challenging disorders diagnosis group (care cluster code 8). Better than average experiences were seen within the psychotic diagnosis groups, most notable being the group for those experiencing a first episode of psychosis (care cluster code 10).

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

Subgroup analysis has modelled the mean scores of different groups of people using community mental health services, based on their age, gender, religion, ethnicity, sexual orientation, CPA status, diagnosis (care cluster codes), length of contact, long-term conditions and proxy response ('Q41. *Who was the main person or people that filled in this questionnaire?*').

The composites are:

- Overall (Q35)
- Access (Q3)
- Communication (Q4)
- Crisis care (access) (Q16)
- Crisis care (care) (Q17)
- Involvement of family and friends (Q33)
- Information sharing (medicines) (Q20 and Q21)
- Information sharing (peer support) (Q34)
- Information sharing (therapies) (Q26)
- Involvement (Q12 and Q15)
- Organisation of care (Q7 and Q10)
- Respect and dignity (Q36)
- Respect for person-centred values (Q5 and Q13)
- Support and wellbeing (Q29, Q30, Q31 and Q32)
- Treatment history (Q6)

[Appendix G](#) contains more information about the questions used, as well as the charts. The [survey methodology](#) section provides further information about how the analysis was undertaken 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 consistently reported less-positive experiences than older people, with the exception of access to crisis care in which those over 80 years old reported worse than average experiences.

People in the 18 to 35 age group reported worse than average experiences in almost all themes. These were:

- overall experience
- access
- communication
- crisis care (care)
- involvement of friends and family
- information sharing (peer support)
- involvement
- organisation of care
- respect and dignity
- respect for person-centred values
- treatment history.

Those in the 66 to 80 age group reported better than average experiences in ten areas. These were:

- overall experience
- access
- communication
- crisis care (care)
- respect and dignity
- involvement of friends and family
- involvement
- organisation of care
- respect for person-centred values
- treatment history.

Religion

Analysis shows Muslim respondents reported better than average experiences in three themes. These are access, involvement and respect for person-centred values. Additionally, respondents who self-designate their religion as 'other' reported worse than average experiences in four themes. These are respect and dignity, involvement of family and friends, access; and information sharing (medicines).

Sexual orientation

Those respondents who identify as heterosexual or straight reported better than average experiences for the respect and dignity theme, while those who preferred not to disclose their sexual orientation reported worse than average experiences in the respect for person-centred values theme.

Ethnicity

Asian or Asian British respondents reported worse than average experiences for the support and wellbeing theme, with people from all other ethnic groups reporting average experiences across remaining themes.

CPA status

Respondents on a new CPA reported better experiences across four themes. These were: access, crisis care access, organisation of care and support and wellbeing.

Diagnosis/care cluster codes

Generally, across multiple themes, those diagnosed with non-psychotic disorders and those diagnosed with cognitive impairments and dementia reported worse than average experiences than those with psychotic disorders. This is in line with findings in the CQC's [The state of health care and adult social care in England 2018/19](#) report. Feedback provided by organisations representing people who use services, highlighted an increase in availability of early intervention services, such as talking therapies and support with education, employment and physical health. However, they raised concerns that this was having a negative impact on those with more challenging mental health issues, as it appeared that funding was being diverted away from some community mental health services.

Non-psychotic disorders

Those diagnosed with non-psychotic chaotic and challenging disorders (care cluster code 8), such as personality disorder, reported worse than average experiences across 12 of 15 themes. These themes were:

- overall experience
- access
- communication
- crisis care (care)
- involvement of friends and family
- information sharing (medicines)
- information sharing (peer support)
- involvement
- respect and dignity

- respect for person-centred values
- support and wellbeing
- treatment history.

Psychotic disorders

In contrast, those diagnosed with a first episode of psychosis (care cluster code 10) reported better than average experiences across 14 themes. These were:

- overall experience
- access
- communication
- crisis care (access)
- crisis care (care)
- involvement of friends and family
- information sharing (medicines)
- information sharing (peer support)
- involvement
- organisation of care
- respect and dignity
- respect for person-centred values
- support and wellbeing
- treatment history.

Similarly, those assigned to care cluster code 11 (ongoing recurrent psychosis - low symptoms) and care cluster code 12 (ongoing or recurrent psychosis – high disability) both reported better than average experiences across multiple themes.

Cognitive impairments and dementia

Respondents assigned to cognitive impairment and dementia care codes generally experienced worse than average experiences. Respondents diagnosed with cognitive impairment or dementia complicated (high need) (care cluster code 20) reported worse than average experiences in the following themes: access, information sharing (medicines), support and wellbeing and treatment history.

Length of contact

Largely, those with a shorter length of contact with NHS mental health services reported better than average experiences in multiple themes. For instance, those who have been in contact with services for less than one year reported better

than average outcomes across 14 themes, whereas those who have been in contact with services for longer than 10 years reported better than average experiences in only one theme.

Those who were no longer in contact with NHS mental health services reported worse than average experiences for seven themes.

Long-term conditions

All long-term conditions groups, across all themes, reported average experiences.

Proxy response (response to 'Q41. Who was the main person or people that filled in this questionnaire?')

Those respondents who completed the survey with the help of a professional, reported better than average outcomes in three themes. These were information sharing (peer support); support and wellbeing; and respect for person-centred values.

See [Appendix G](#): Subgroup analysis for charts and [Appendix H](#): Care cluster codes for the definition of each code.

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.

Sample members received their first survey pack containing a questionnaire, covering letter and a leaflet offering guidance on multi-language options for completing the questionnaire. This was followed by a reminder letter, then a final survey pack containing a questionnaire, reminder letter and multi-language sheet.

This iteration of the survey saw the introduction of the 'faster first reminder', with the first reminder being mailed five working days after the first mailing. The second reminder maintained the standard interval of two to 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 2018 and 30 November 2018. 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 sampling instructions 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 with services 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 2019.

For more detailed information on the inclusion and exclusion criteria, please see the [sampling instructions](#) for the survey.

The age profile of respondents has not changed meaningfully between the 2014 and 2019 surveys.

Respondent age profile for 2014 to 2019

	18-35	36-50	51-65	66+
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%
2019	15%	19%	25%	40%

In comparison to the sample profile, we have a lower proportion of younger service users and a higher proportion of older service users within our respondent profile. To account for this, we apply weights to our data which are discussed below in the analysis methodology section.

Further information about the sample profile can be found in the [quality and methodology report](#) on the CQC website.

Questionnaire design

Wherever possible, the questions remain the same over time to measure change. However, questions are amended, added or removed to reflect changes in policy or survey best practice. We also seek guidance from an external advisory group to make sure the questions remain relevant. For this survey iteration, 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.

For this 2019 survey, new questions were added around medicines and treatment history. Additionally, Q16 was amended to improve clarity, which had an impact on the comparability of Q17.

For more detailed information please see the [Community mental health 2019 survey development report](#) and the [final questionnaire for the 2019 survey](#).

Analysis methodology

Weighting

The data presented in this report has been weighted with two weights:

1. A 'trust weight', which aims to weight responses from each trust to ensure that each trust has an equal influence on England results. As some trusts have a higher response rate than others, they have a larger share of respondents in the

total respondent's population for England. Without weighting, the views of respondents from these trusts would be over-represented in the England-level results. The weighting is therefore designed so that each trust that participated contributes equally to the overall results for England, regardless of differences in response rates.

2. A 'population weight', which aims to weight responses for each individual to make sure it is representative of the trust's own population (based on the initial eligible sample). This involves weighting based on variables that are related to how people respond: age group and sex.

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. The demographic 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 2019 compared with the last time the survey was conducted in 2018.

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.

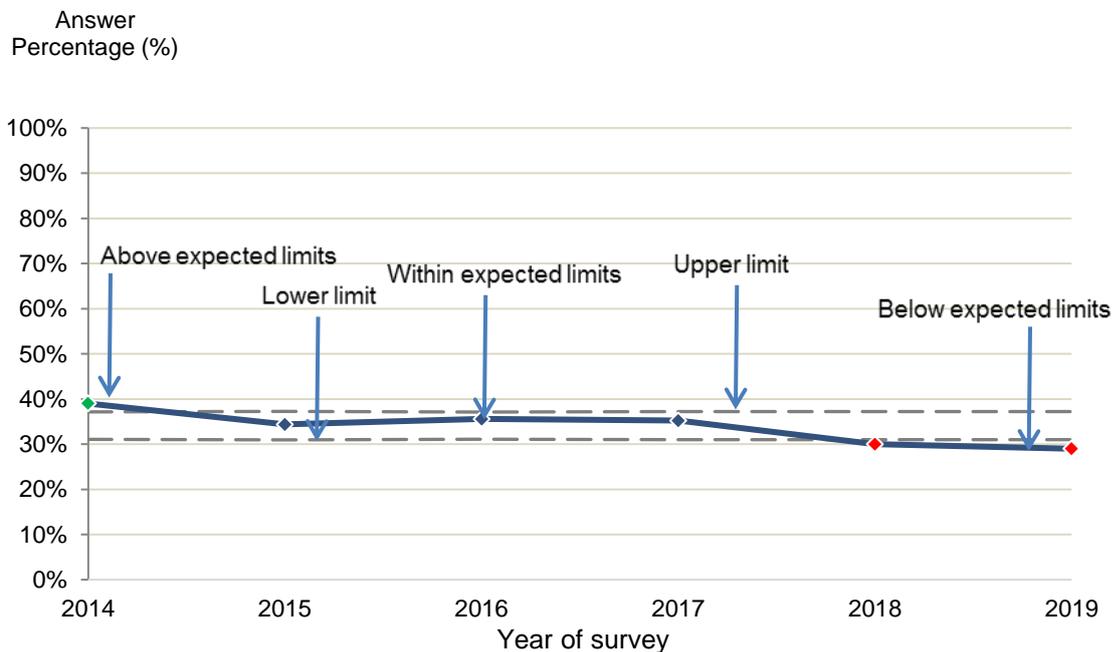
Long-term trends

Results that have changed noticeably over time and identify long-term trends where appropriate are presented using 'p-charts'. We plot the percentage of the most positive responses to questions and show the expected limits of variation in survey results.

An assumption is made that there has been no 'real' or meaningful change unless the results go outside of expected limits.⁷² Viewing long-term trends in survey results allows for greater confidence in interpreting relationships within the data. Where results do not fall outside of expected limits or it is not possible to compare questions over time, no p-chart results are reported.

The following example shows a p-chart that fluctuates from above expected limits in 2014, to below expected limits in 2018 and 2019; suggesting a deterioration in results.

Example of a p-chart



Within our analysis we have retained the control limits for the 2014-2018 period as our baseline. This means the upper and lower control limits for each question will now remain the same for each future survey iteration. Adopting this approach avoids a scenario whereby results identified as being outside control limits in previous reports, fall within limits when we update the time series with the 2019 results.

As the volume of respondents in each time period is relatively large, the control limits can be very small. Therefore, it is important to consider the extent of change when results exceed the expected limits, as this could be the result of a small change.

Notes on specific questions

Analysis/cleaning applied to particular questions

Question	Analysis/cleaning applied
<p>Q8:^h 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 Open data available on CQC's website.</p>
<p>Q9 and Q10: Q9 Do you know how to contact this person if you have a concern about your care? Q10 How well does this person organise the care and services you need?</p>	<p>Respondents who stated at Q8 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>Q14: 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)ⁱ 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>Q15: 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 Q15 to be consistent with that applied to Q14.</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 Q15 (as well as for Q14) because we cannot be certain that they were referring to a care review.</p>

h. 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.

i. 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 Q14 and Q15 as reported in this section.

Comparability with previous years

The results for most questions from the 2019 survey are comparable with the 2014 - 2018 surveys. The following questions are **not comparable** for the reasons outlined below:

Comparability with previous years

Question	Reason for not being comparable
Q6. Did the person or people you saw appear to be aware of your treatment history?	This is a new question for 2019.
Q8. Is the main person in charge of organising your care and services...	This question's response options were reduced in 2018 to help avoid the selection of multiple response options. Only 2018 and 2019 are comparable.
Q9. Do you know how to contact this person if you have a concern about your care?	The change in Q8 influenced the way respondents answered this question, therefore only 2018 and 2019 are comparable.
Q10. How well does this person organise the care and services you need?	The change in Q8 influenced the way respondents answered this question, therefore only 2018 and 2019 are comparable.
Q16. Do you know who to contact out of office hours within the NHS if you have a crisis?	This question was amended in 2019 by adding the text 'within the NHS' to ensure respondents think about NHS services only. Therefore, this question is not comparable with any previous years.
Q17. In the last 12 months, did you get the help you needed when you tried contacting this person or team?	This is a filter question for Q16. As a result of changes, this question is not comparable with any other years.
Q20. Has the purpose of your medicines ever been discussed with you?	This question is new for 2019.
Q21. Have the possible side effects of your medicine ever been discussed with you?	This question is new for 2019.
Q22. Do you feel your medicines have helped your mental health?	This was a new question for 2018 and therefore is not comparable with 2014-2017.
Q25. In the last 12 months, have you received any NHS therapies for your mental health needs that do not involve medicines?	These questions were 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. Therefore, these questions are only comparable between 2018 and 2019.
Q26. Were these NHS therapies explained to you in a way you could understand?	
Q27. Were you involved as much as you wanted to be in deciding what NHS therapies to use?	
Q28. Do you feel your NHS therapies have helped your mental health?	This was a new question for 2018 and is only comparable with 2019.
Q32. In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?	Question was changed in 2018 as the existing wording used in 2017 was found to be confusing during cognitive testing. Therefore, this question is only comparable with 2018.

Question	Reason for not being comparable
Q37. Aside from in this questionnaire, in the last 12 months, have you been asked by NHS mental health services to give your views on the quality of your care?	This is a new question for 2019.
Q38. 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 and is only comparable with 2019.
Q39. Do you have any of the following? (List of long-term conditions)	This was a new question for 2018 and is only comparable with 2019.
Q40. Do any of these reduce your ability to carry out day-to-day activities?	This was a new question for 2018 and is only comparable with 2019.

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 other survey years, because of the re-development in 2010. The 2019 survey is comparable with surveys run between 2014 to 2018, 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 subgroup charts. Each question was centred by subtracting its overall mean score from the results before the questions were combined into composites. This was to remove any differences in composite scores that might potentially be caused by different patterns of response between questions.

This model takes into account trust clustering, as trusts are likely to have a big impact on reported experience at a national level. To assess whether experience differs by demographic factors, we used statistical significance tests. We performed F tests on each factor (fixed effect) as a predictor of the target variable. P-values were also generated, which showed the likelihood 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 within the factor. Variables were also checked for multicollinearity to ensure co-efficient 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 2019) provided the following data:

- at the end of June, there were 1,367,244 people in contact with services; the majority of these (1,062,437) were in adult mental health services. There were 237,349 people in contact with children and young people's mental health services and 116,267 in learning disabilities and autism services.
- 310,198 new referrals were received into services during June and 1,684,219 care contacts were attended.
- 22,247 people were subject to the Mental Health Act in June, including 15,717 people detained in hospital.⁷³

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.
- 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:

<https://nhssurveys.org/wp-content/surveys/05-community-mental-health/03-instructions-guidance/2019/Sampling%20instructions.pdf>

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/.

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 2017, however, does not cover mental health.

The Health Survey for England 2018 is scheduled to publish on 3 December 2019.

The Big Mental Health Survey

This is a relatively new annual survey carried out by Mind, the mental health charity. The survey is designed to measure people's experiences of mental health support offered by primary care and the voluntary and community sector, as well as experiences of discrimination in the community.

Data collected as part of the Big Mental Health Survey is not comparable with this survey due to differing methodologies being used. The themes covered within the questionnaire, such as information sharing, communication around medicines and support for physical health conditions, are in line with the themes adopted within our survey.

The latest survey was carried out between July and September 2017, with results being published in 2018. The survey, which was available to complete online and in paper format, was promoted using social media channels, supporter lists of leading mental health charities as well as paper forms being distributed by local Minds and Mind retail outlets.

The headline results from 2017 state that:

- survey participants reported a better overall experience of care provided by voluntary organisations than primary care services
- one in six people who were prescribed medication reported not being given enough information about their purpose
- two in five people prescribed medication were not given information about potential side effects
- one in three people who were referred to talking therapies or specialist services were not given enough information

- less than half of respondents did not feel able to discuss physical health conditions during mental health appointments.

For more information, please see:

<https://www.mind.org.uk/about-us/our-policy-work/reports-and-guides/our-research/>

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 uses the results from the survey in the regulation, monitoring and inspection of NHS trusts in England. Survey data is used in our CQC Insight monitoring tool, which provides inspectors with an assessment of how trusts are performing. The survey data will also be included in the evidence appendices to inform our inspections and as a key source of evidence to support the judgements and ratings for trusts.

NHS England and NHS Improvement

On 1 April 2019, NHS England and NHS Improvement merged, with both organisations continuing to use results from the NHS Patient Survey Programme to inform their activities.

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/.

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

CQC publishes the survey results for each participating NHS trust. This appears on the trust's profile page on our website (www.cqc.org.uk). You can find this by searching for the name of the organisation using the search function. The data is presented in an accessible format alongside inspection results to enable the public to examine how services are performing.

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.

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 service users 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.

Further information about changes to the questionnaire and overall survey development can be found in the [2019 community mental health survey development report](#), on the NHS Surveys website.⁷⁴ [Appendix A](#) provides information on the survey methodology, which covers survey development, analysis approach and overall comparability of questions with previous iterations.

Appendix F: Further information and feedback

Further information

This report, together with the trust level results, is available on the CQC 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.

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: <https://nhssurveys.org/surveys/survey/05-community-mental-health/year/2019/>

There is more information on the NHS Patient Survey Programme, including results from other surveys and a programme of current and forthcoming surveys at: <https://nhssurveys.org/surveys/>

Further questions

This summary was produced by CQC's Survey Team and reflects the findings of the 2019 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@cqc.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@cqc.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.

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^j of different subgroups: age, gender, ethnicity, religion, sexual orientation, CPA status, diagnosis (care cluster codes), length of contact, 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

Q35. Overall...

Access

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

Communication

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

Crisis care (access)

Q16. Do you know who to contact out of office hours within the NHS if you have a crisis?

Crisis care (care)

Q17. In the last 12 months, did you get the help you needed when you tried contacting this person or team?

Involvement of family and friends

Q33. Have NHS mental health services involved a member of your family or someone else close to you as much as you would like?

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

Information sharing (medicines)

Q20. Has the purpose of your medicines ever been discussed with you?

Q21. Have the possible side effects of your medicines ever been discussed with you?

Information sharing (peer support)

Q34. 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?

Information sharing (therapies)

Q26. Were these NHS therapies explained to you in a way you could understand?

Involvement

Q12. Were you involved as much as you wanted to be in agreeing what care you will receive?

Q15. Did you feel that decisions were made together by you and the person you saw during this discussion?

Organisation of care

Q7. Have you been told who is in charge of organising your care and services?

Q10. How well does this person organise the care and services you receive?

Respect and dignity

Q36. Overall, in the last 12 months, did you feel that you were treated with respect and dignity by NHS mental health services?

Support and wellbeing

Q29. In the last 12 months, did NHS mental health services give you any help or advice with finding support for physical health needs?

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

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

Q32. In the last 12 months, has someone from NHS mental health services supported you in joining a group or taking part in an activity?

Treatment history

Q6. Did the person or people you saw appear to be aware of your treatment history?

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?

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

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.

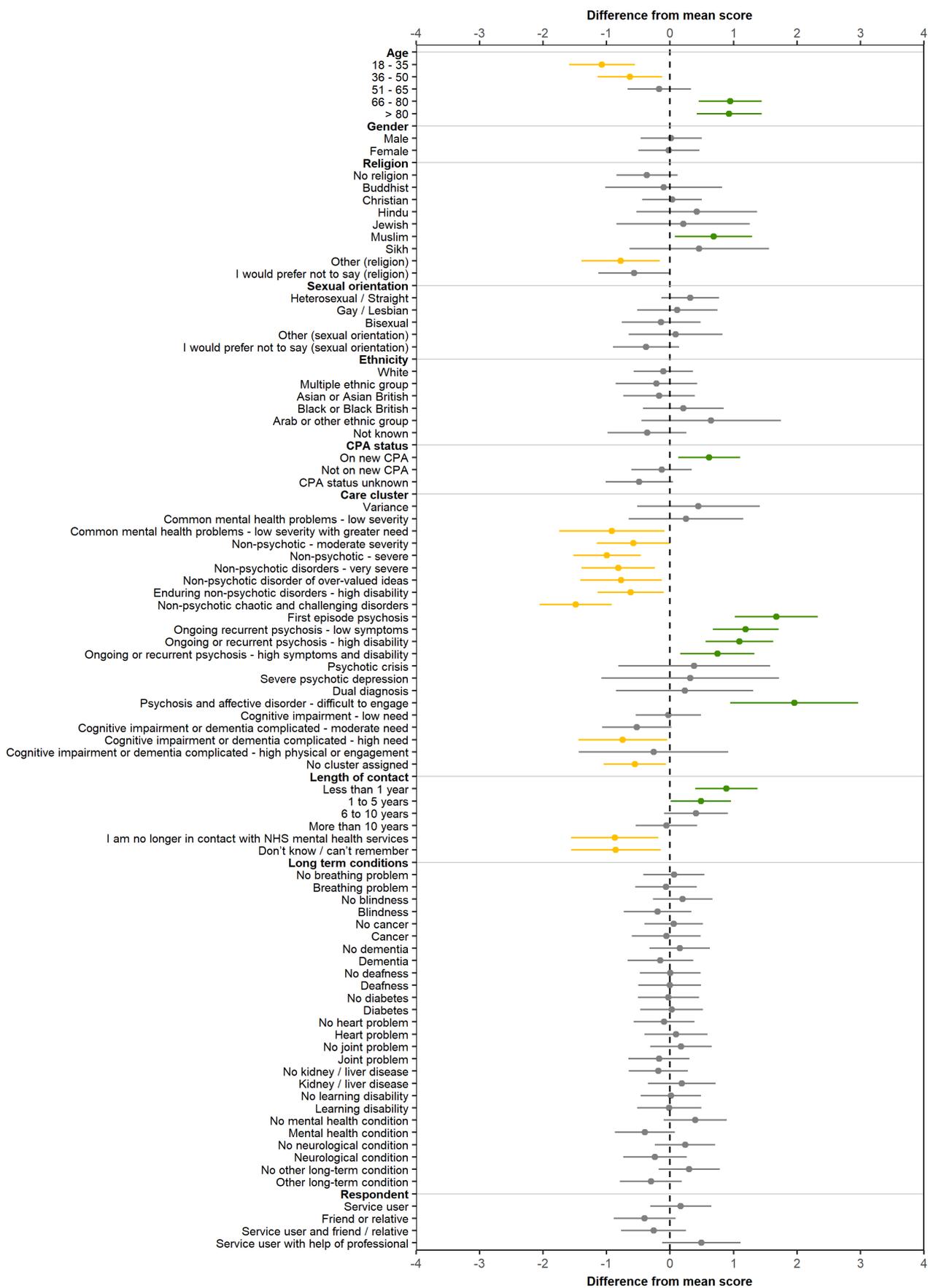
The graphs in this section highlight better than average experiences that are significant in green. Significantly worse than average experiences are highlighted in orange for all charts. The cluster code definitions are in [Appendix H](#).

 Worse than average experience

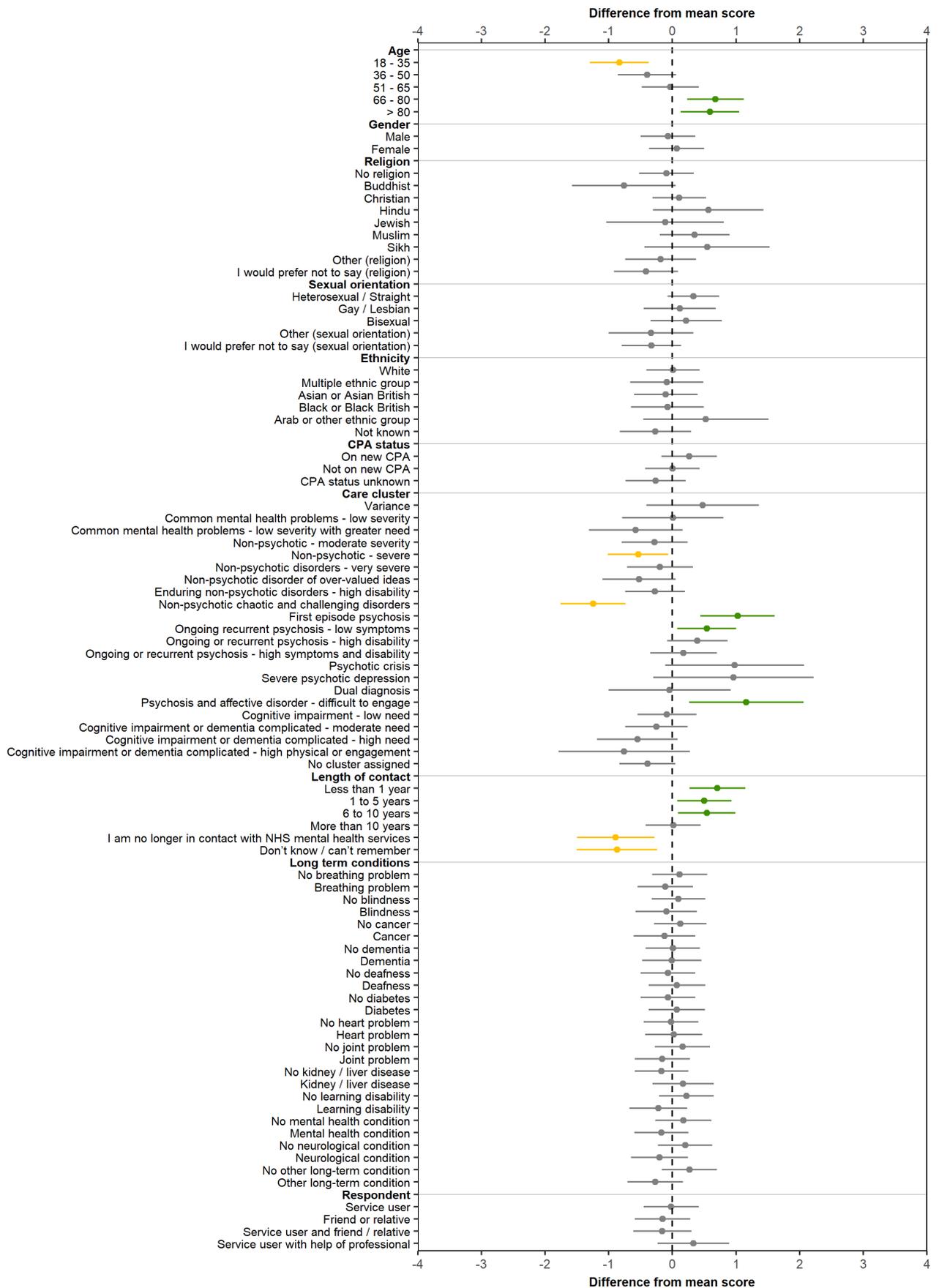
 Average experience

 Better than average experience

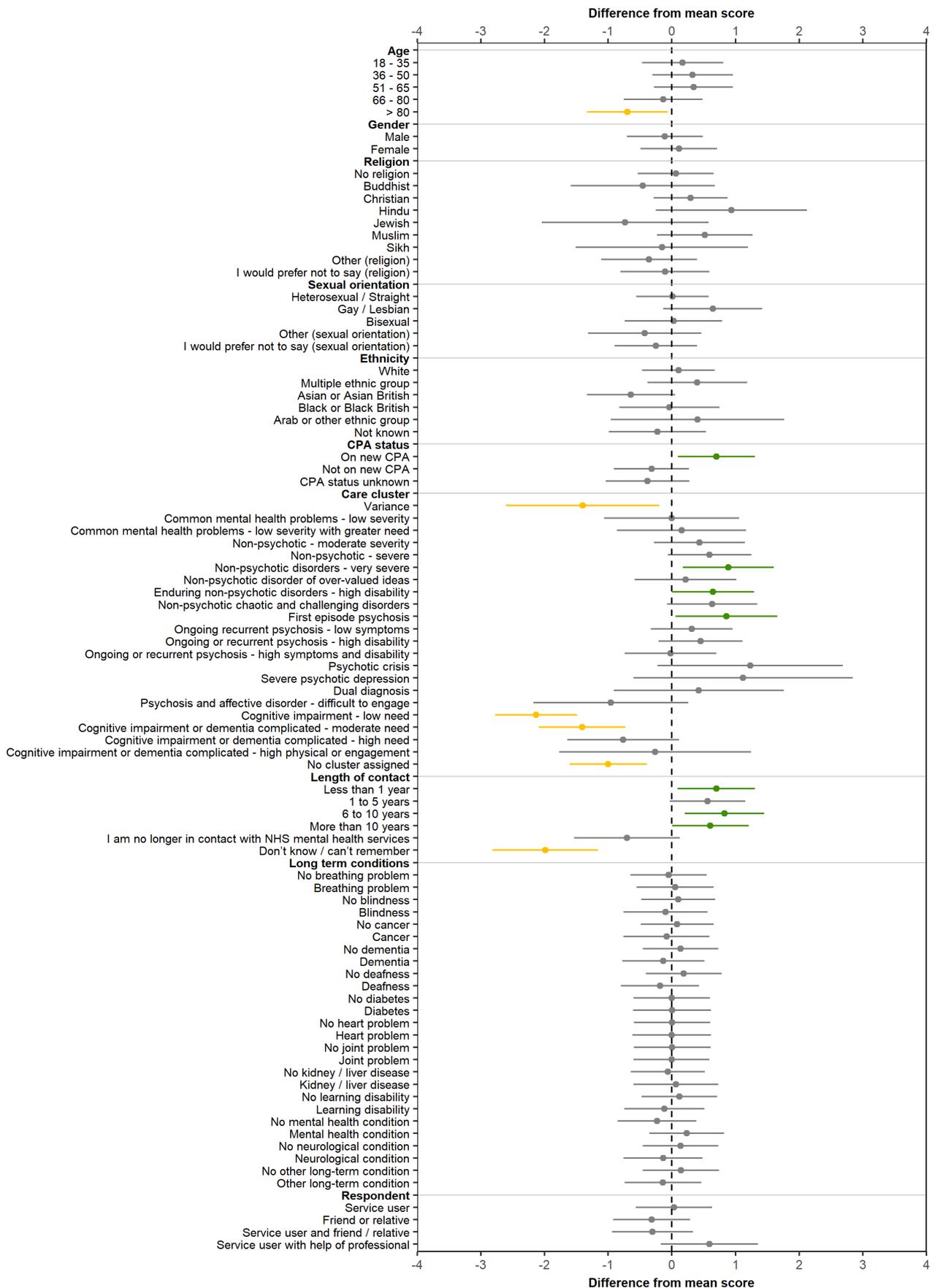
Access theme:
difference from mean score by subgroup with 95% confidence interval



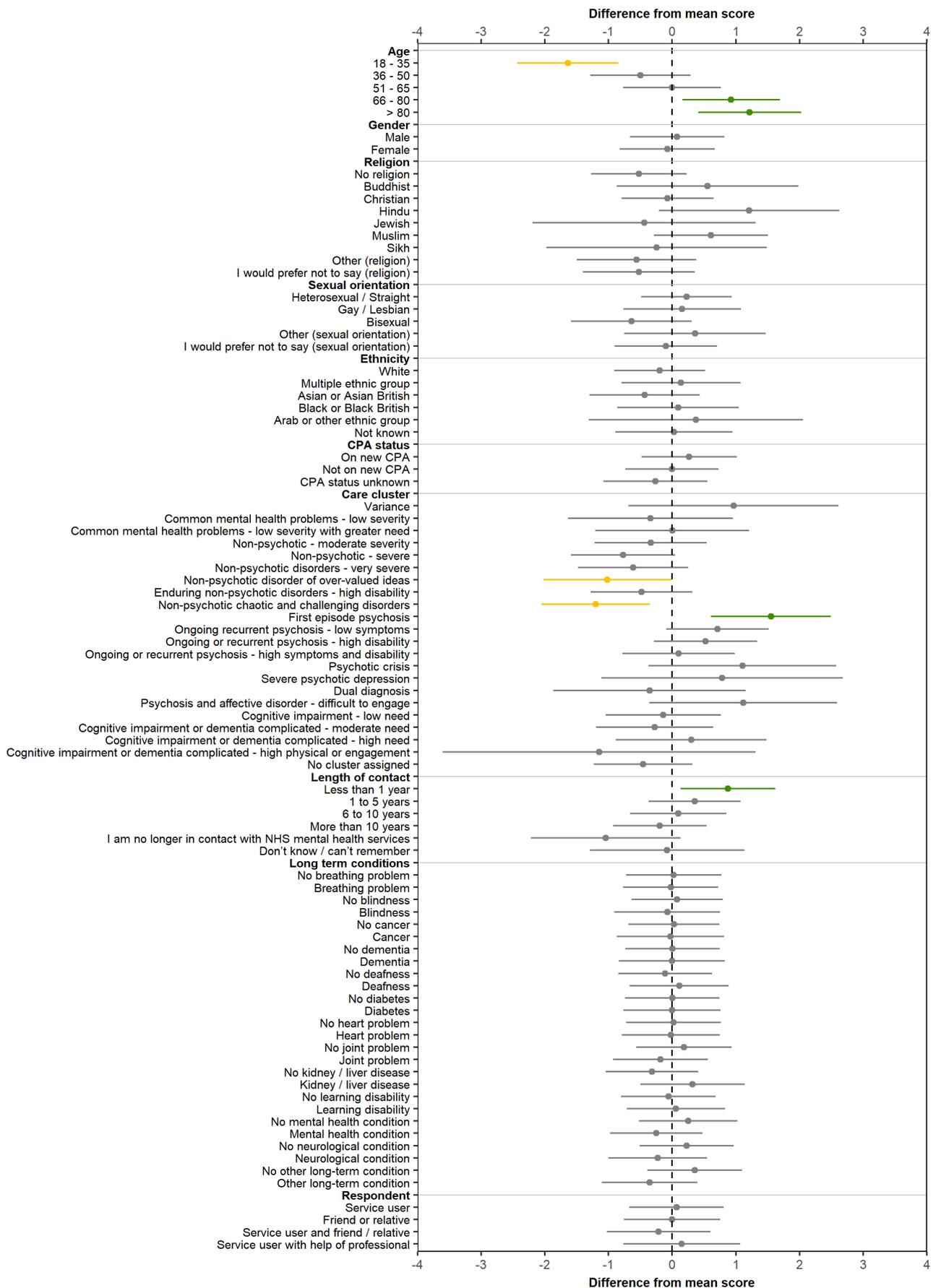
Communication theme:
 difference from mean score by subgroup with 95% confidence interval



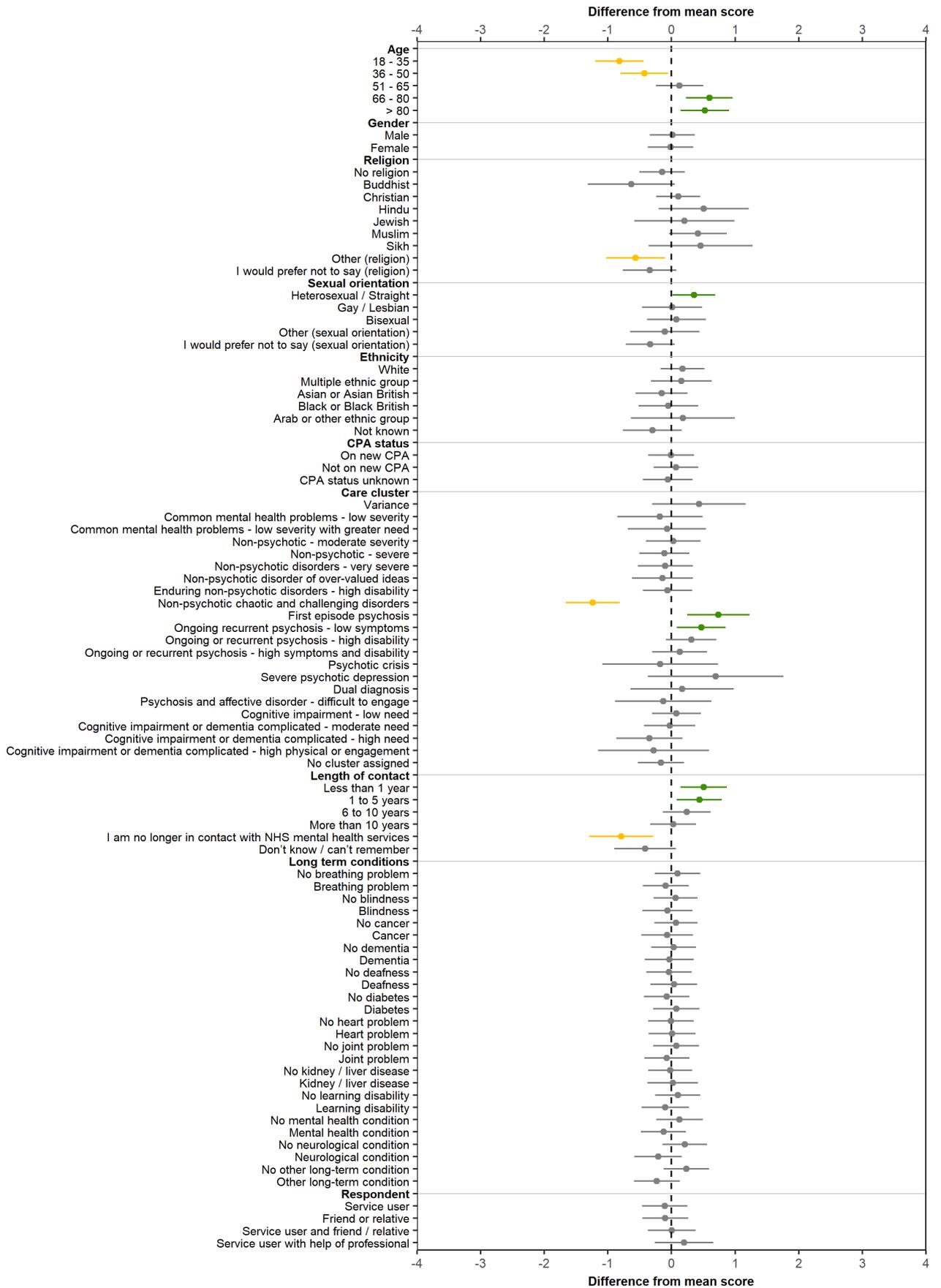
Crisis care (access) theme:
 difference from mean score by subgroup with 95% confidence interval



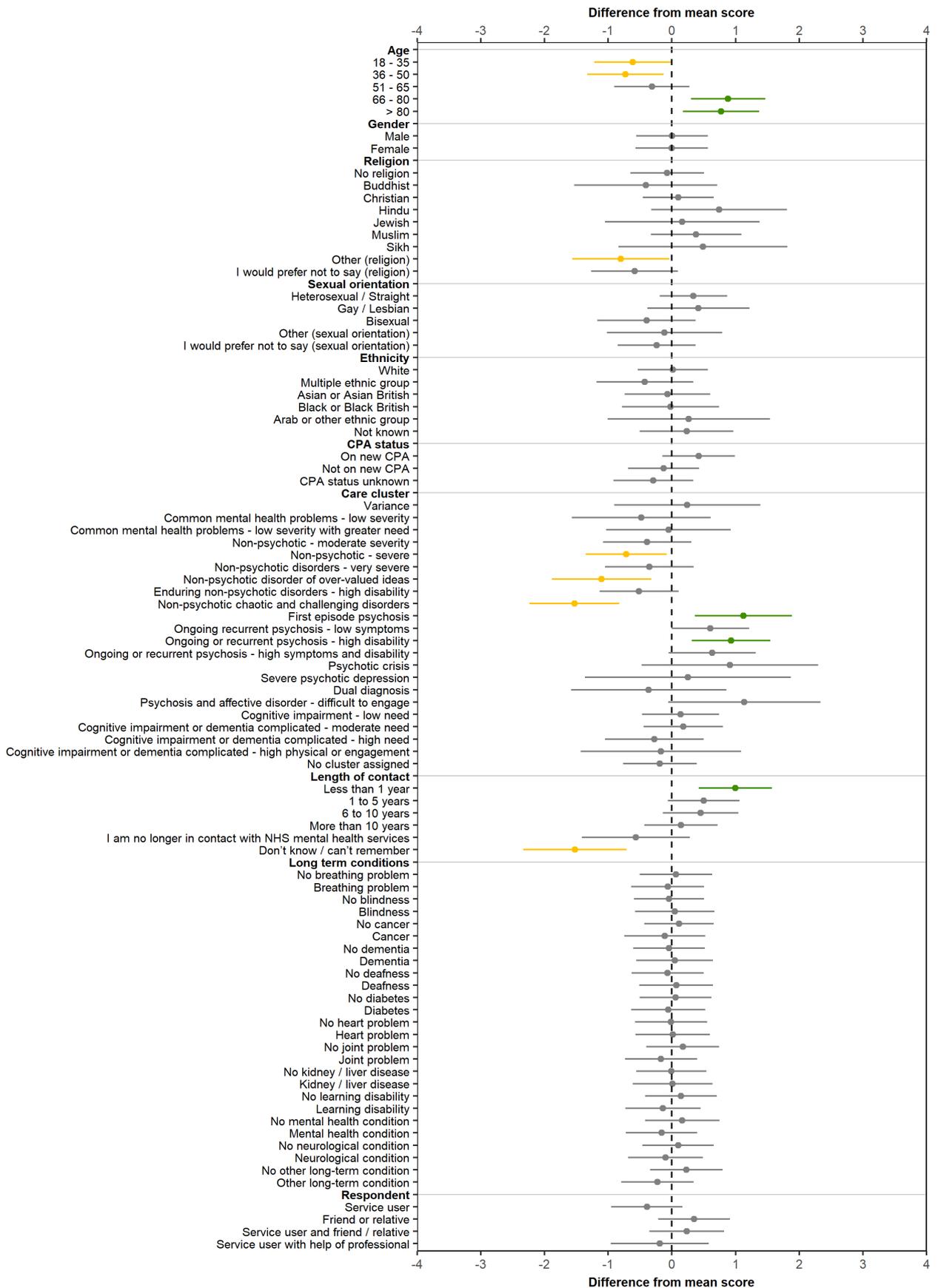
Crisis care (care) theme:
difference from mean score by subgroup with 95% confidence interval



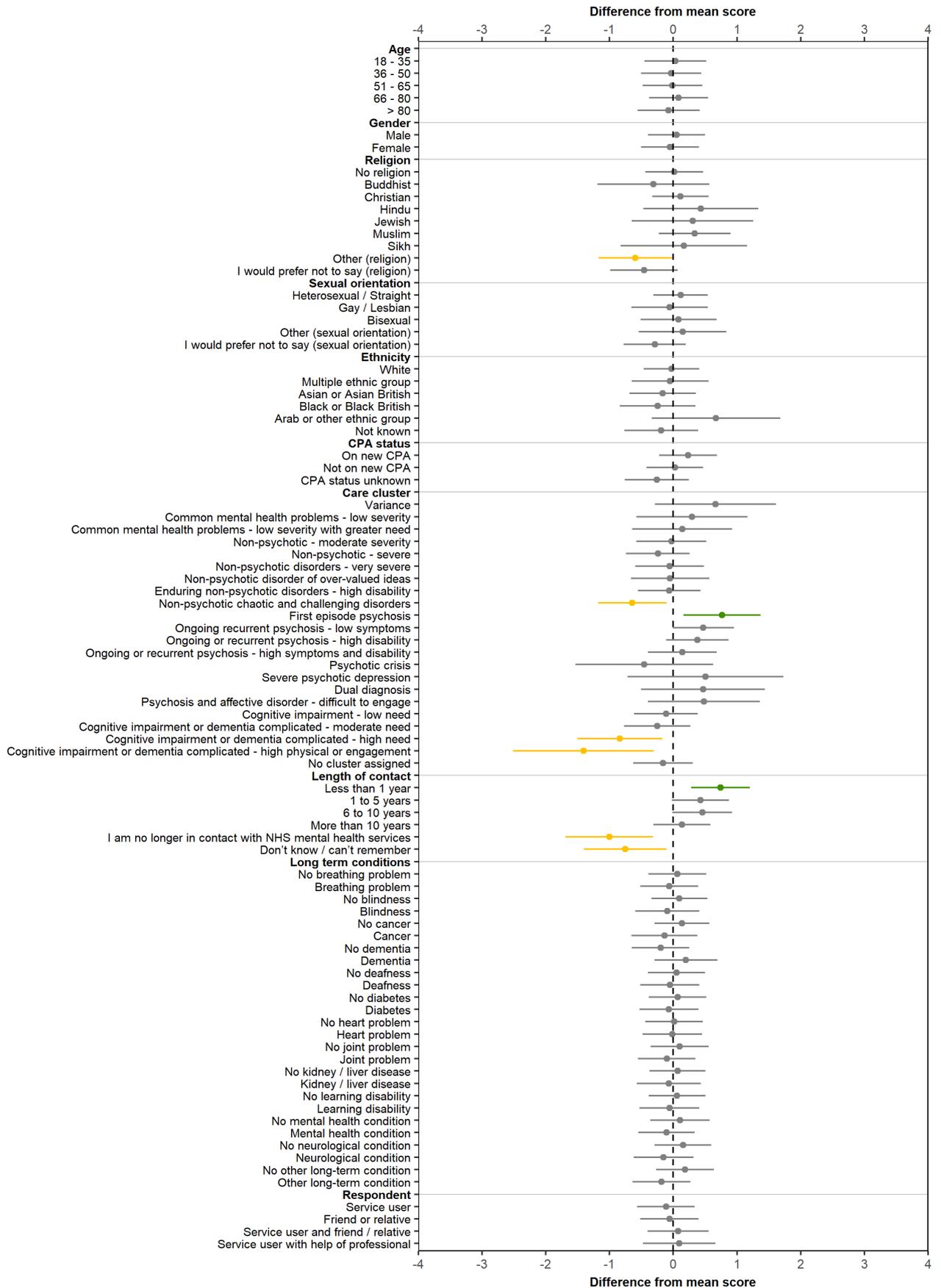
Respect and dignity theme:
difference from mean score by subgroup with 95% confidence interval



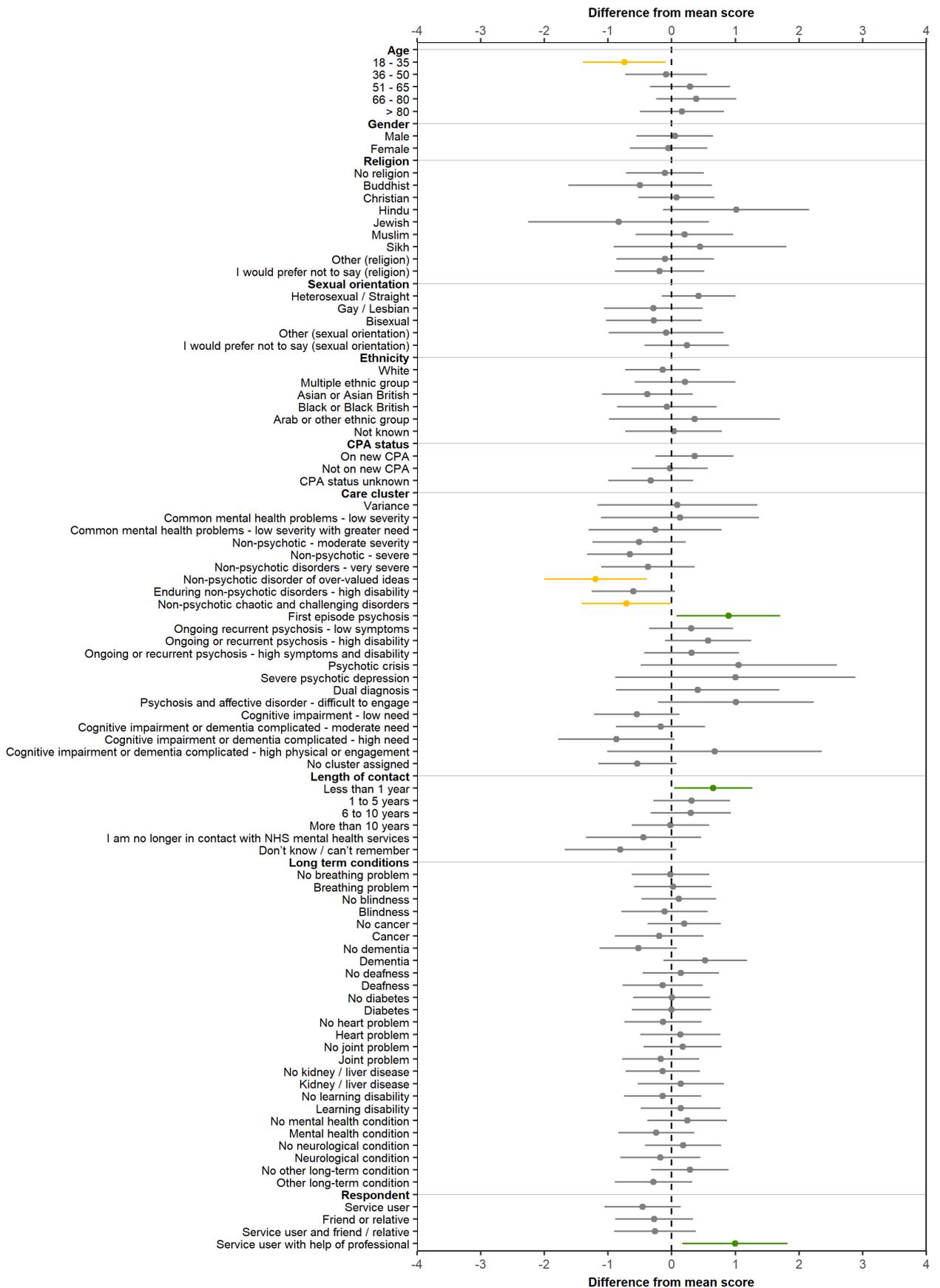
Involvement of family and friends theme:
 difference from mean score by subgroup with 95% confidence interval



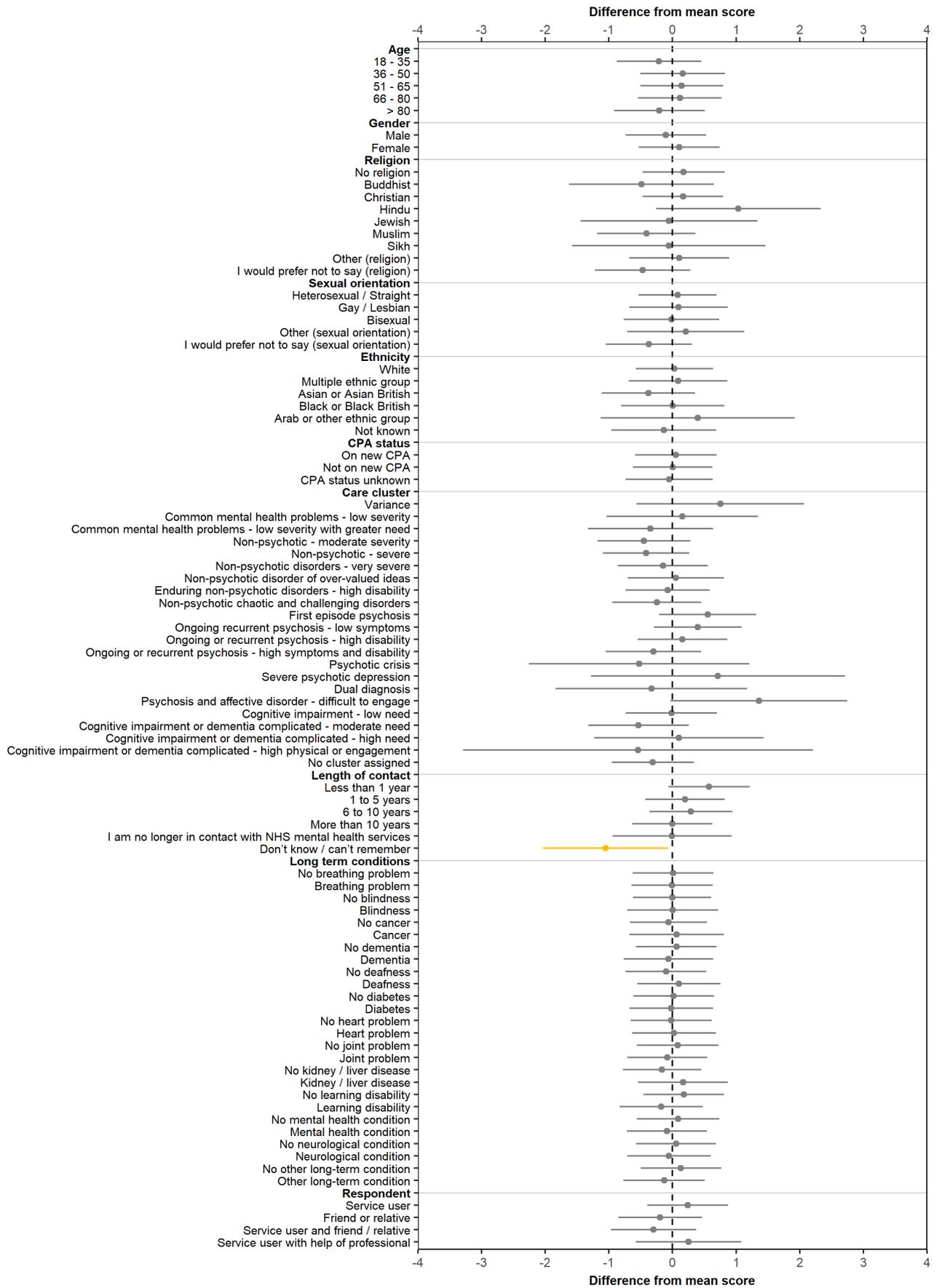
Information sharing (medicines) theme:
 difference from mean score by subgroup with 95% confidence interval



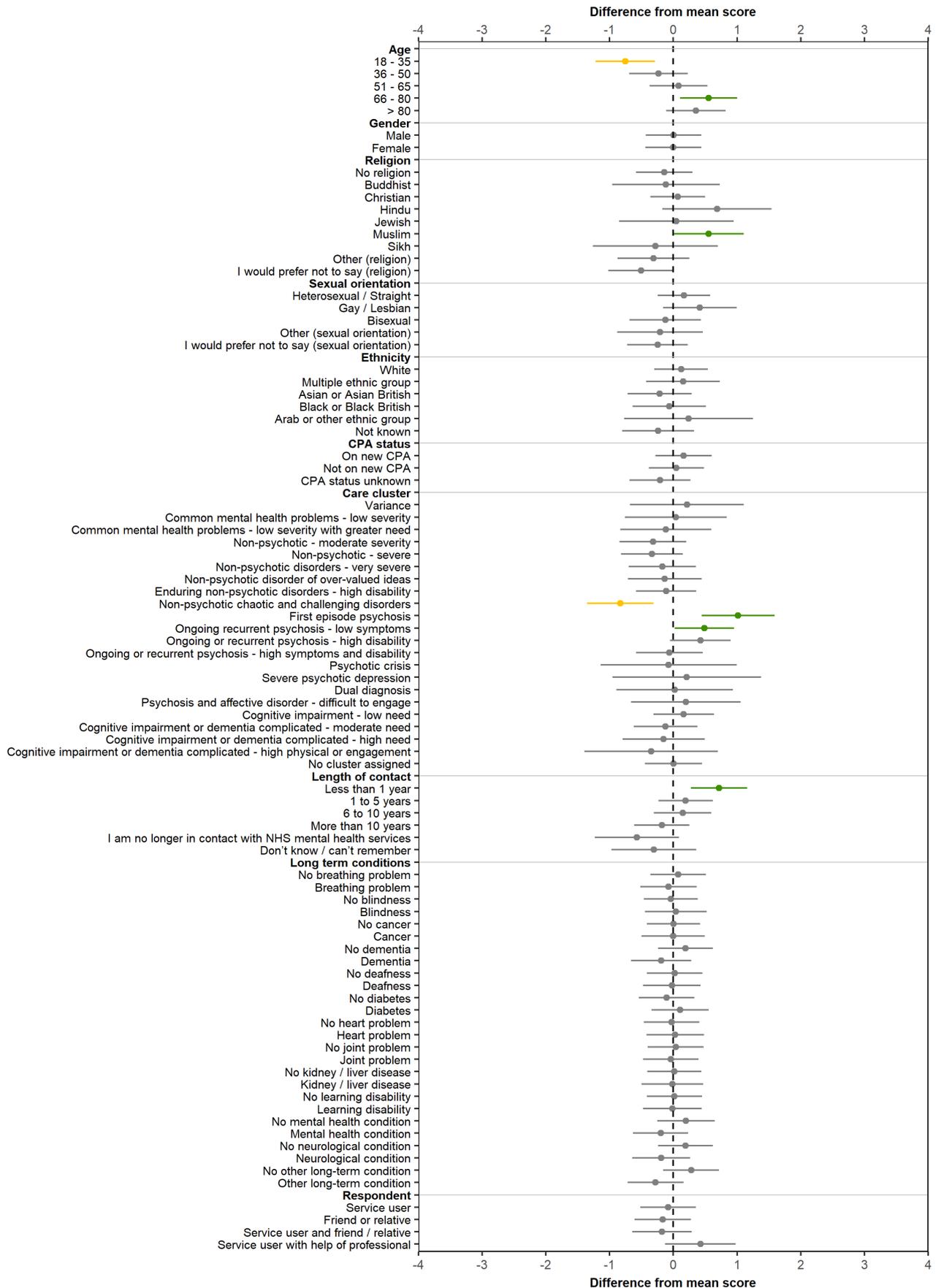
Information sharing (peer support) theme:
 difference from mean score by subgroup with 95% confidence interval



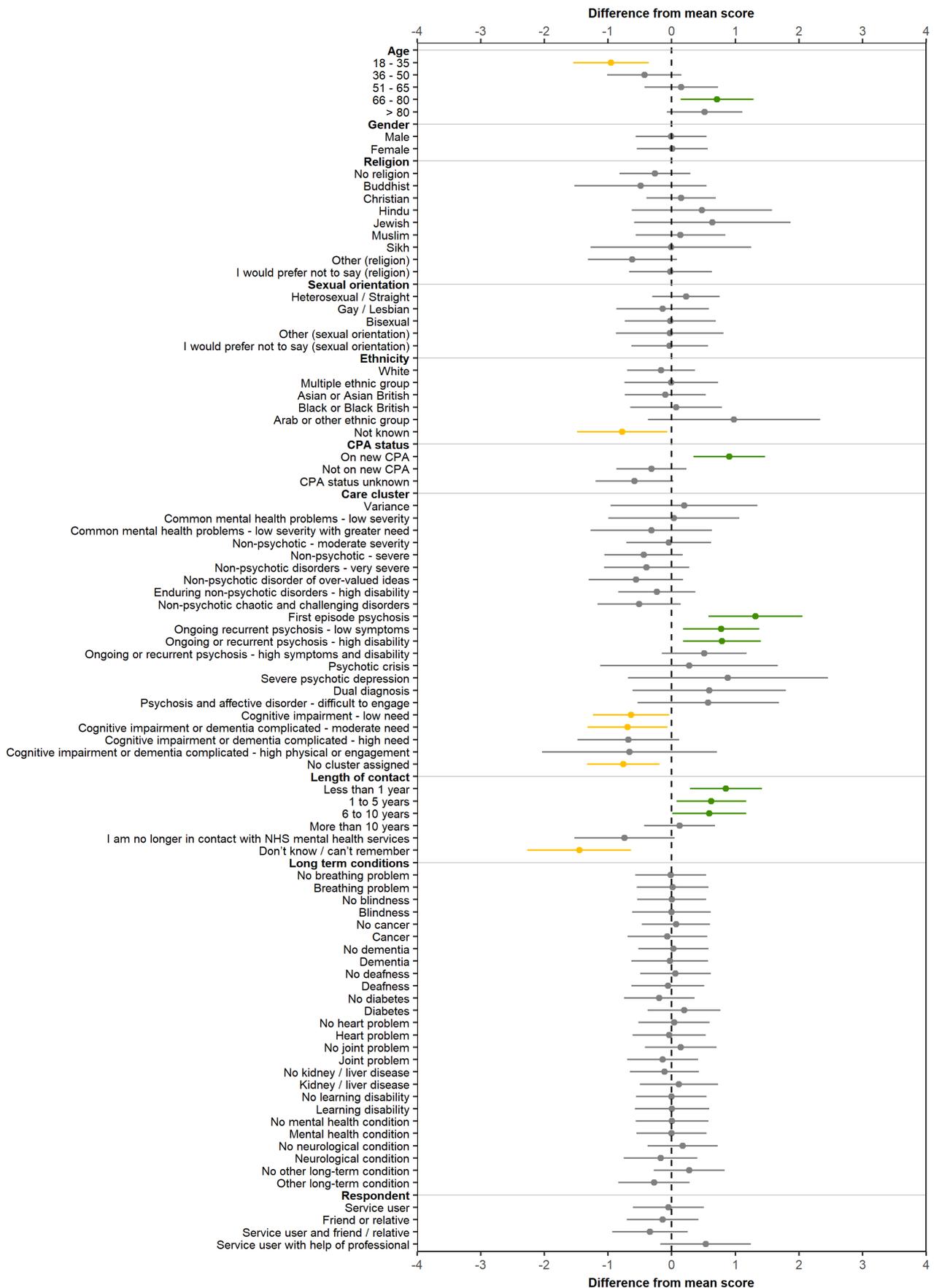
Information sharing (therapies) theme:
 difference from mean score by subgroup with 95% confidence interval



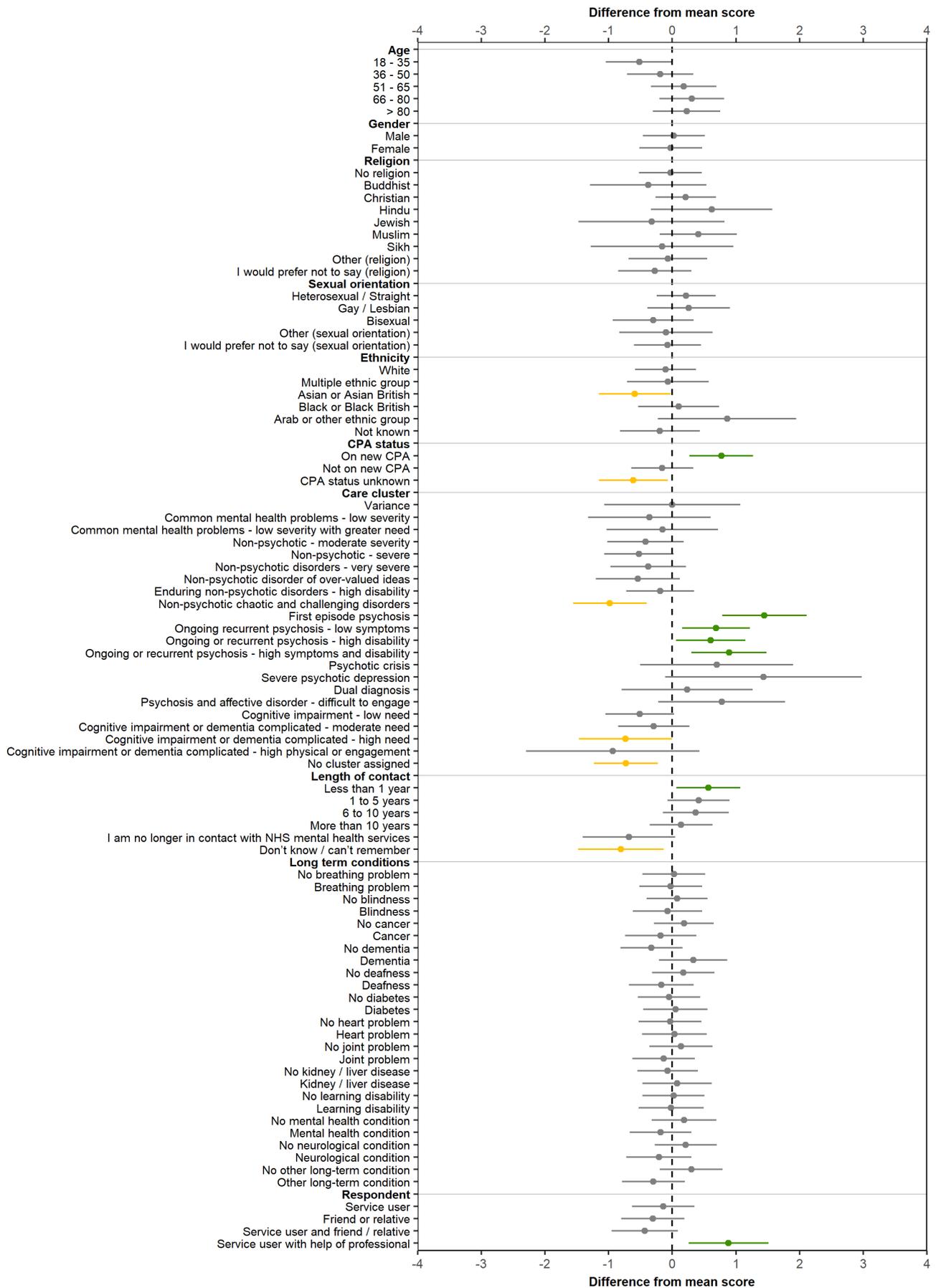
Involvement theme:
difference from mean score by subgroup with 95% confidence interval



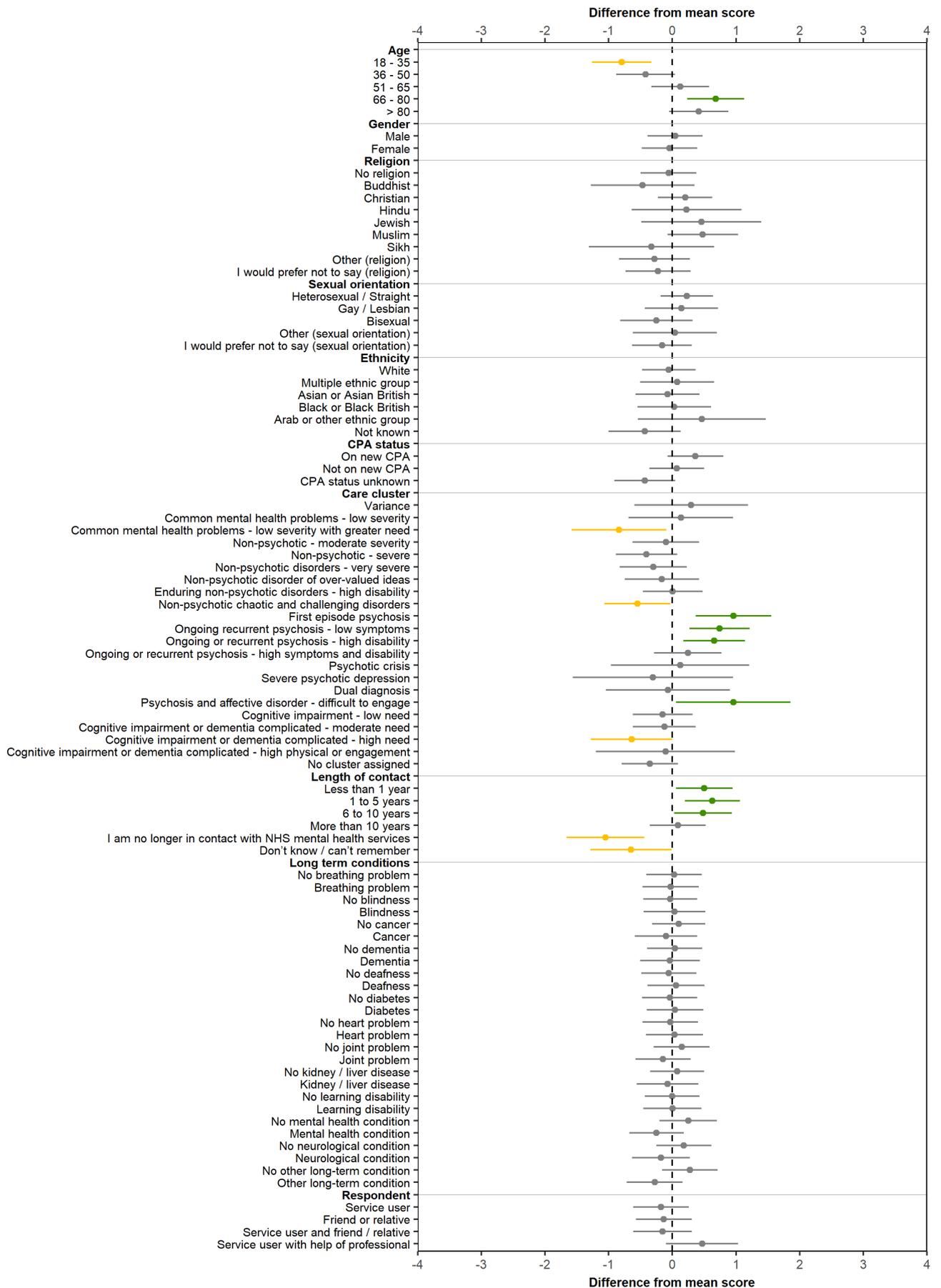
Organisation of care theme:
difference from mean score by subgroup with 95% confidence interval



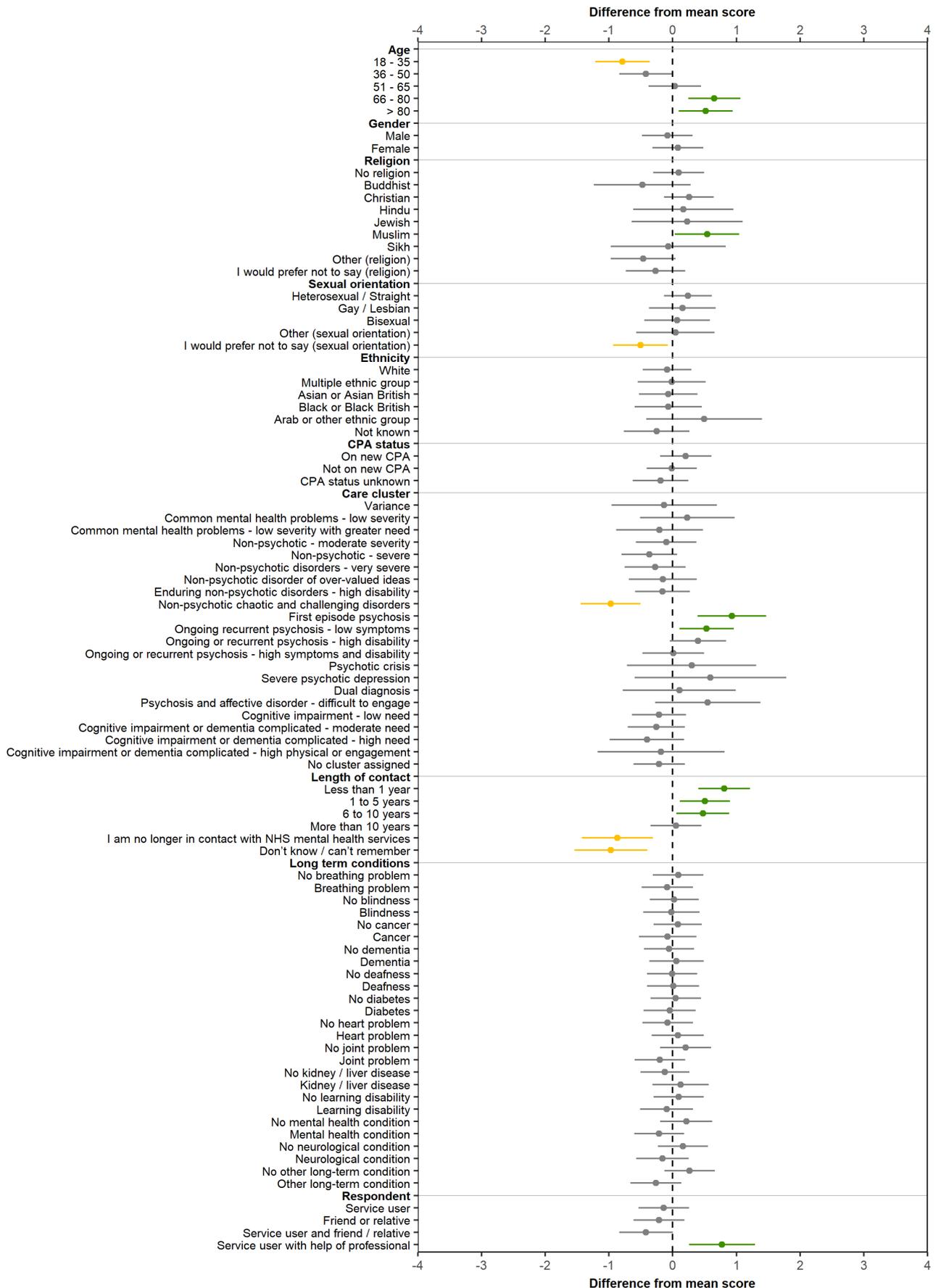
Support and well-being theme:
difference from mean score by subgroup with 95% confidence interval



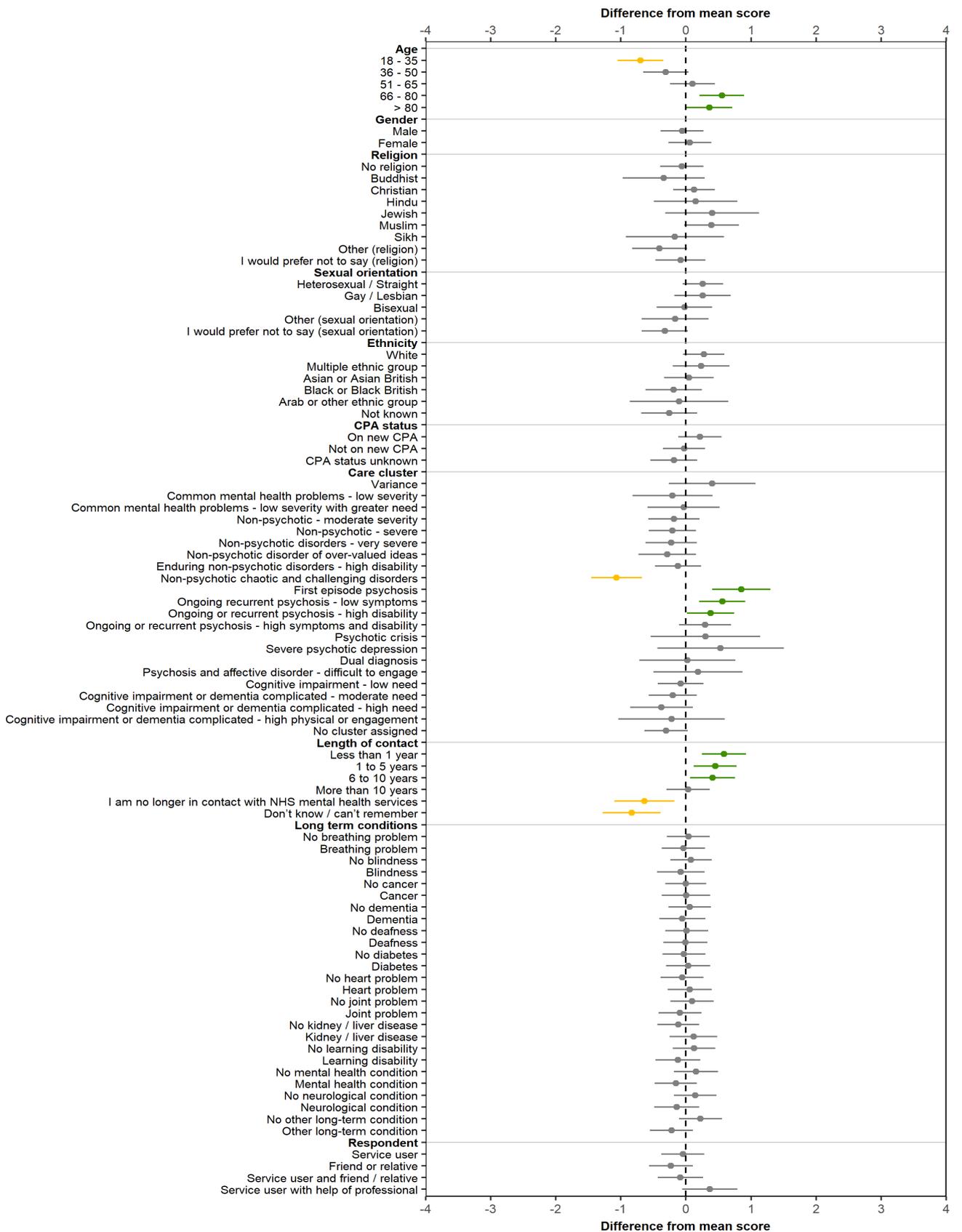
Treatment history theme:
difference from mean score by subgroup with 95% confidence interval



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



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



Appendix H: Care cluster codes

Care cluster codes enable people using mental health services to see which care and treatments are most likely to meet their needs. Created by clinicians and people who use mental health services, each care cluster considers the level of need and risk that someone has, as well as their diagnosis. There are 20 clusters in total and these fall into one of three main groups:

Non-psychotic

This group includes people diagnosed with anxiety, depression, obsessive compulsive disorder, phobic disorders and eating disorders.

Psychotic

This group includes people diagnosed with forms of psychosis, such as bi-polar disorder and schizophrenia.

Cognitive impairment and dementia

This group includes people diagnosed with dementia, including Alzheimer's disease and other types of brain injury impacting peoples' mental health.

The care cluster codes are as follows:

- 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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