Together for the 1 in 6:
Technical Report for My Neuro Survey
June 2022

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1. Introduction

The 2021/22 National Neuro Patient Experience Survey (‘My Neuro Survey’) presents a comprehensive picture of the experiences of people living with a neurological condition in the whole of the UK. It is the only survey exploring the views of people across a range of neurological conditions and those living with more than one condition. This is the fourth iteration of survey, which has been run biennially by The Neurological Alliance since 2014. This year is the first time we have included the views of children and young people living with neurological conditions. A separate paediatric survey was developed and rigorously tested – both with parents and children and young people themselves.

Through gathering data on a wide range of topics – including the impact of the Covid-19 pandemic on people living with neurological conditions, information on diagnosis and treatment, hospital care, support for mental wellbeing, access to social care, welfare and employment – the survey findings present a comprehensive picture of people’s experiences of living with a neurological condition in 2021/22. In the absence of nationally collected neurological patient outcome measures, or social care data that is segregated by condition, this approach provides much needed intelligence about how well services are performing for people with neurological conditions. In particular, it provides a benchmark of the huge impact of living through a pandemic with a neurological condition.

For 2021/22, data collection for the survey was undertaken in clinics for the second time. This was in addition to an online survey, as had been used in previous years. There were obvious challenges in delivering a survey in-clinic given the rise in remote appointments due to Covid-19. In addition, patients are encouraged to minimise their time in hospital – and were therefore not encouraged to stay in clinic completing a questionnaire. As a result, people with neurological conditions were encouraged to complete the survey at home: this had an impact on response levels. As a result, the response from clinic was lower than the previous survey (and this was expected). The methodology was again developed alongside survey experts Quality Health/IQVIA, and in partnership with a steering group of The Neurological Alliance’s member organisations and the Wales Neurological Alliance, Neurological Alliance of Scotland and the Northern Ireland Neurological Charities Alliance (niNCA). The data and free text responses it has produced brings the experiences of over 8,500 people with neurological conditions to the fore. In total there were 7,881 responses from adults and 629 responses from children. This is an overwhelming success given the challenges of gathering responses during a pandemic.

This technical report, authored by Quality Health/IQVIA on behalf of The Neurological Alliance, provides details of the background to the survey, the methodology, and data results tables. It accompanies a series of nation level policy reports and a UK summary report, which presents a thematic discussion of the results in relation to the policy context, draws conclusions, and makes recommendations for system change accordingly.

This year the results are also broken down by Integrated Care Board (ICB) as well as other UK health care footprints: Health Boards (Wales and Scotland) Health and Social Care Trusts (NI). There are also breakdowns by nation and region revealing wide geographic variation in the experience of people with neurological conditions. We also undertake analysis here of the experiences of specific groups of people affected by neurological conditions, revealing once again inequalities between and amongst different groups.

Overall, based on analysis of all the survey data, the collective call to action is as follows:

To call on the UK Government, Scottish Government, Welsh Government and Northern Ireland Executive to prioritise services for people with neurological conditions and establish a Neuro Taskforce. The Taskforce would bring together relevant Departments, health and social care bodies, professional bodies, people affected by neurological conditions and the voluntary sector to:

- Assess the current neuroscience workforce and set out plans to ensure it is fit for the future.
- Share approaches to common problems, such as addressing longstanding barriers to accessing mental, emotional and cognitive support, driving down waiting lists for elective care, improving the quality and analysis of health and care data and supporting transition between paediatric and adult neuroscience services.
- Assess the level of investment in research into the causes, impacts and possible cures of neurological conditions and set out plans to level up investment in areas that do not receive a fair share currently.

2. Background and methodology

2.1 Background

- This is the fourth iteration of the National Neuro Patient Experience Survey, gathering the views of people with neurological conditions in England. For the first time, the survey now covers the whole of the UK, thanks to the support of Wales Neurological Alliance, Neurological Alliance of Scotland and Northern Ireland Neurological Charities Alliance (niNCA). The survey was previously run in 2014, 2016, and 2018/19 in England only. The methodology was updated in 2018/19 - gathering responses in neurology clinics as well as via an online survey. This methodology was repeated in 2021/22 and included physiotherapy/rehabilitation clinics. However, in 2021/22 we have included the views of children and young people for the first time.
- The Neurological Alliance engaged survey company Quality Health/IQVIA to undertake the survey. The Neurological Alliance and Quality Health/IQVIA worked in close partnership to again develop and test the methodology and survey questions, as well as to analyse and report on the data.
- Data was collected between 25 October 2021 to 6 February 2022. The survey received 8,510 responses.

2.2 Objectives

The survey had five main objectives, to gather data about the experience of adults, children and young people with neurological conditions living in the UK in order to:

1. Enhance nationally collected data and intelligence about neurological services, by providing evidence about the experience of adults and children and young people with neurological conditions.
2. Provide the neurological community with evidence about patient experience in order to influence policy.
3. Provide condition-specific data to members of The Neurological Alliance to inform their work.
4. Provide intelligence about the experiences of people with neurological conditions to inform The Neurological Alliance's strategic priorities and longer-term work.

For 2021/22 there were three additional objectives:

5. To understand more about the experiences of children and young people with neurological conditions.
6. To achieve an even spread of responses from across the whole of the United Kingdom, and in large enough numbers in order to analyse the data at Integrated Care Board (ICB) level.
7. To specifically measure the experiences of people living with neurological conditions during a global pandemic – with a specific section on the impact of the Covid-19 pandemic in the survey.

2.3 Methodology

The methodology for this year's survey was again a dual mode of data collection: to collect feedback from respondents via an anonymous online link (predominantly promoted via members of Alliance's across the UK), and by handing out paper copies of the questionnaire in neurological clinics across the UK. It also involved collecting the views of children and young people living with neurological conditions.

This method was again chosen despite the complexities of surveying people in clinic during Covid-19. However, it was an important data collection method to ensure an even spread of responses regionally. Doing so would also offer the possibility of increasing the overall number of responses in order to improve the reliability of the data.

In addition, leaflets to take part in the survey were included in clinic appointment letters during the fieldwork period – this helped improve response rate especially from those who were having remote consultations. QR codes were developed for each clinic, these were added to the leaflet and to the invitations to take part in the survey, alongside a standard web link (URL) if individuals preferred to compete the survey online, and Quality Health/IQVIA's freephone survey helpline.

A summary of the methodology is below:

- A new iteration of the questionnaire was developed using the previous 2018/19 Neurological Alliance survey as a general guide but drew on Quality Health’s extensive experience in running other national survey programmes including the National Cancer Patient Experience Survey (CPES). At the same time a separate questionnaire was produced specifically for children and young people living with neurological conditions.
- The questionnaire was developed alongside a project steering group, comprising people affected by neurological conditions, representatives from the voluntary sector and health and care professionals. There was representation from England, Scotland, Wales and Northern Ireland on the project steering group.
- Cognitive testing was carried out with 22 people with neurological conditions to ensure that the final questionnaire could capture the information required in the most straightforward and effective way. This included adults, parents of children with neurological conditions and children themselves. Wherever possible a range of different neurological conditions were included and there was a fair representation of gender and age.
- A final questionnaire was produced in preparation for the pilot. This was produced as a paper copy for use in a pilot, which took place in one adult clinic (Poole) and a paediatric neurology clinic (Bristol).
- Based on a review of the pilot, and in discussion with the project steering group, the methodology was further refined.
- As in 2018/19, the Neurological Alliance drew up a list of neurology outpatient clinics to recruit to the full rollout, identifying at least one hospital per ICB area. This was largely driven by those who took part in 2018/19. In addition, colleagues in Wales, Scotland and Northern Ireland drew up a list of clinics. There was support from the Association of British Neurologists (ABN) and the Scottish Government which helped significantly.
- Neuroscience centres were prioritised, or neurology centres in their absence, due to the high volume of neurology patients seen in these clinics. Only where neither of these were present were district general hospitals (DGHs) chosen. DGHs were selected largely at random, though with some exceptions where it was known that such a low volume of patients would be seen at a particular DGH that respondent rates would likely be compromised.
- There was some clinic self-selection, as some clinics that were approached either never responded, or declined to participate. Similarly, a couple of requests were made by those engaged for their linked clinic(s) to become involved.
- The Neurological Alliance, together with Quality Health/IQVIA, engaged with 43 different neurological clinics (39 adult clinics and 4 paediatric clinics). Most units were sent 300 paper copies of the questionnaire to hand out to patients, with a few clinics being sent more on request part way through the rollout. Smaller clinics were sent 150 paper questionnaires. Clinics also received a comprehensive information pack ahead of roll-out, and regular follow-up to assess response rates and any further support required.
- The paper survey officially opened in clinics on 25th October 2021 and closed in line with the online survey on 6th February 2022.

2.3.1 Questionnaire design and development

The questionnaire was designed and developed between April and July 2021. This involved a detailed process of drafting, reviewing, testing and revising the questions. Quality Health/IQVIA worked closely with The Neurological Alliance on designing and agreeing the final question set. In addition, Quality Health/IQVIA worked alongside a project steering group made up of a range of The Neurological Alliance member organisations which included representatives from all major neurological conditions. The project steering group also contained representatives from all UK nations and partner alliances including Wales Neurological Alliance, Neurological Alliance of Scotland and Northern Ireland Neurological Charities Alliance (niNCA)

As a part of the process, cognitive testing was carried out with 22 volunteers with a range of neurological conditions (including both adults, parents, and children); their time and input into the process is greatly appreciated. The volunteers completed the draft questionnaire and were then invited to share their answers to the questions, and to comment on the wording, the response options, any omissions, and any comments on the layout and length of the survey. After these interviews a report was provided to The Neurological Alliance and the project steering group. A number of changes were made, and a revised questionnaire was then re-tested.

2.3.2 Pilot

As there were new challenges highlighted (most notably the impact of Covid), it was decided that a pilot was needed to test the methodology and develop and refine it if needed.

Two clinics were recruited to test the methodology directly with patients over a two-week period including both an adult and paediatric clinic.

	Pilot finding	**Change made to the methodology**
#1	Hospitals do not want patients hanging around in waiting rooms completing questionnaires due to risk of Covid transmission	All clinics that take part to be sent questionnaire packs with response envelopes so the respondent can complete at home
#2	Making contact with clinics in busy hospitals remains extremely challenging and time consuming. Often the key contact is not available	Additional time built into the project plan for partnership building. All clinics that take part to be asked for the names of three key contacts and these to be placed on a form in advance of the survey going live.
#3	Ensuring there is a lead clinician (usually a consultant neurologist) who champions the survey is a critical driver for success.	Attempting to ensure all clinics that take part have a neurologist to champion the survey.
#4	Numbers of those who access the survey via leaflets included with appointment letters is low	Continue this approach but also develop QR codes and include URLs on clinic letters

2.3.3 Sampling and data

The online survey was promoted via The Neurological Alliance's member organisations, and by Wales Neurological Alliance, Neurological Alliance of Scotland and Northern Ireland Neurological Charities Alliance (niNCA) in their respective UK nations.

There was one anonymous link which was available to all respondents. There were no invitations sent to named individuals – therefore no sampling or data requirements were needed. In addition, a number of charities representing more prevalent neurological conditions (and who were Alliance members) were sent a unique link that they were able to send to their members. Unique links were developed for each clinic who took part.

Whilst specific links were developed for the above conditions, responses from all conditions were tracked by reporting on question 2 in the survey, which asked respondents to select which neurological condition(s) they were living with. The analysis was carried out on their primary condition. This was to aid clarity and ensure consistency across responses.

The paper (in-clinic) survey was handed out to patients as they arrived in neurology clinics across the UK. They were not handed to specific named patients – and no surveys were distributed via post. There was therefore no data requirement and no sample needed preparing in advance of the survey going live.

2.4 Timescales and fieldwork

The timescales were as follows:

- **Development of question set:**
    - Steering group meetings and development of questions: Feb – June 2021
    - Cognitive testing of questionnaire: June – July 2021
    - Further refinements to questionnaire: July – August 2021
    - Questionnaire ready for first pilot: August 2021
- **Pilot to develop and refine methodology:**
    - Pilot: August - September 2021 carried out in one adult clinic (Poole) and a paediatric neurology clinic (Bristol).
- **Full rollout:**
    - Online: 25th October 2021 – 6th February 2022
    - Paper (in-clinic): 25th October 2021 – 6th February 2022

2.5 Response rates

2.5.1 Adult Survey

Online
7,325

Paper
556

TOTAL
7,881

2.5.2 Paediatric Survey

Online
625

Paper
4

TOTAL
629

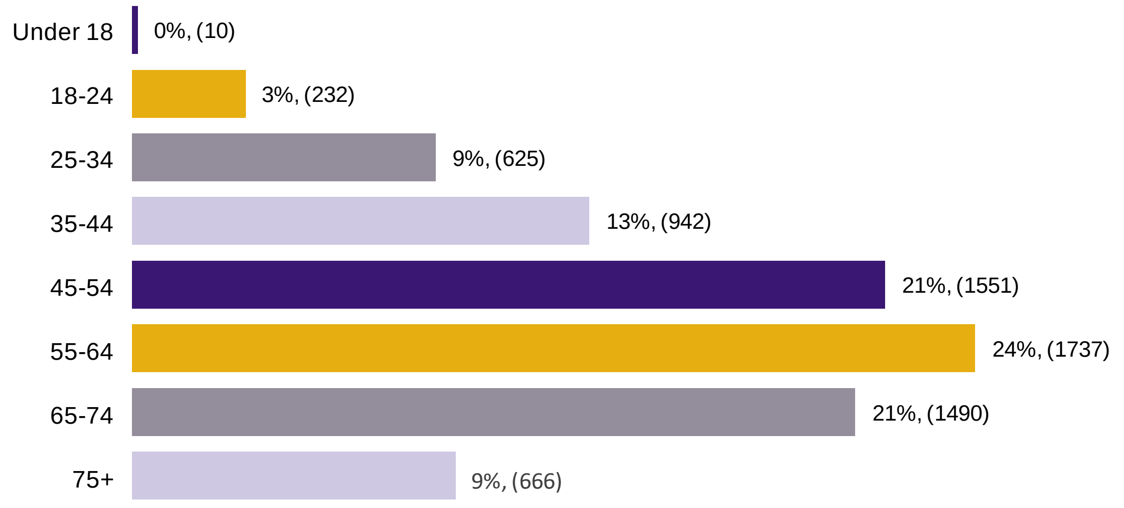
3. Results of the Adult questionnaire

3.1 Respondent characteristics

3.1.1 Age

Over three quarters of respondents (79%) were aged between 35 and 74. 12% of respondents were aged between 18 and 34. 9% were aged over 75. 10 people who were under 18 responded to the adult survey

Q47. Age Band (derived from "What is your year of birth?")



Based on 7253 responses.

Fig 1. Age range of adult respondents

3.1.2 Ethnicity

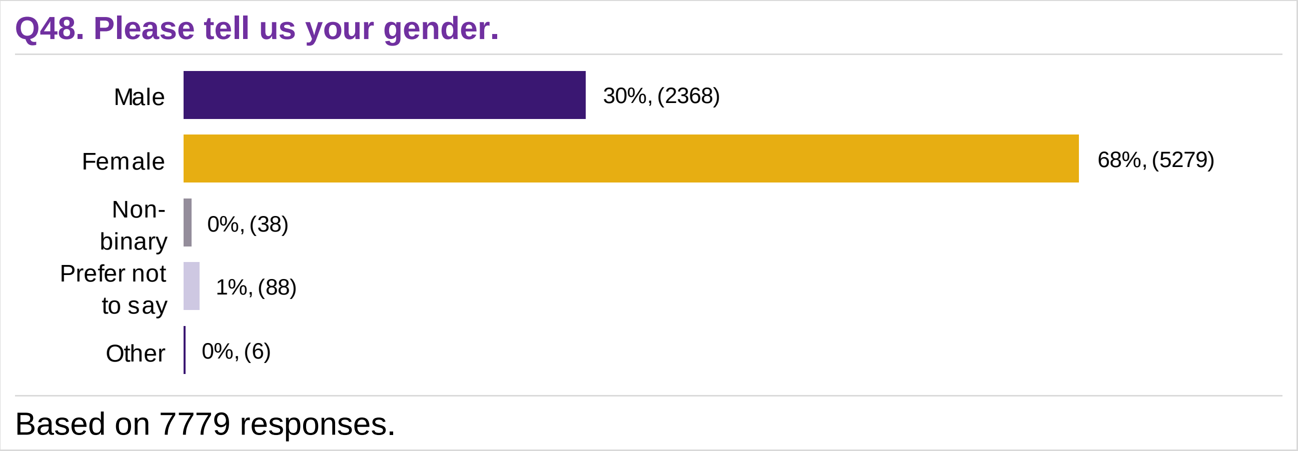
As in the previous survey, the majority of respondents (97% n=7448) identified themselves as ‘White’ - either English / Welsh / Scottish / Northern Irish / British – or Irish / other White background.

The numbers of those identifying themselves as Black (including African, Caribbean and other Black background), Asian (including Bangladeshi, Indian, Chinese and other Asian background), Mixed Heritage (including White & Asian, White & Black African, White & Black Caribbean and other Mixed background), Arab or any other ethnicity except White, is very low (just 3% n=292).

141 respondents did not answer this question.

3.1.3 Gender

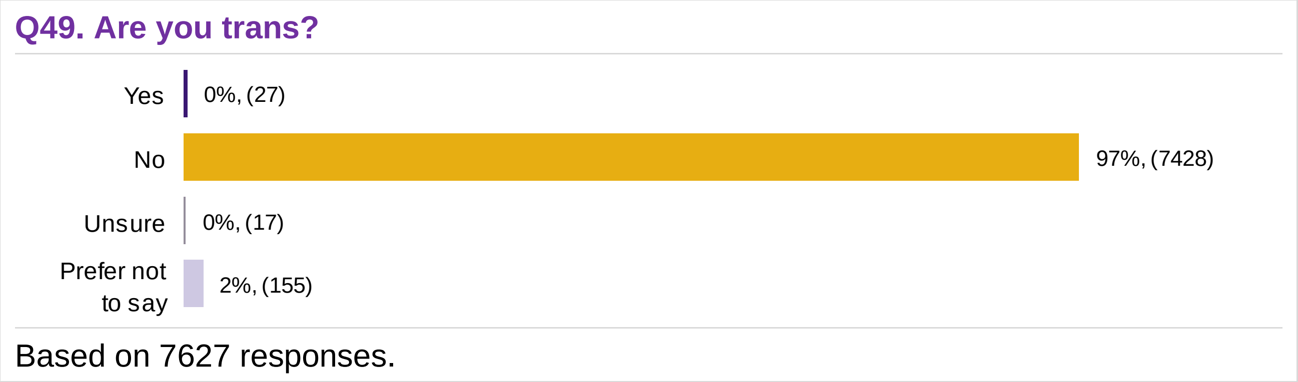
5279 respondents (68% overall) identified themselves as female. Around a third (30% n=2368) identified themselves as male. 38 respondents describe themselves as non-binary and 6 individual respondents preferred to use their own term to describe their gender.


Q48. Please tell us your gender.

Based on 7779 responses.

Fig 2. Gender breakdown of adult respondents

Only 27 respondents identified themselves as trans, 2% (n=155) preferred to not say.

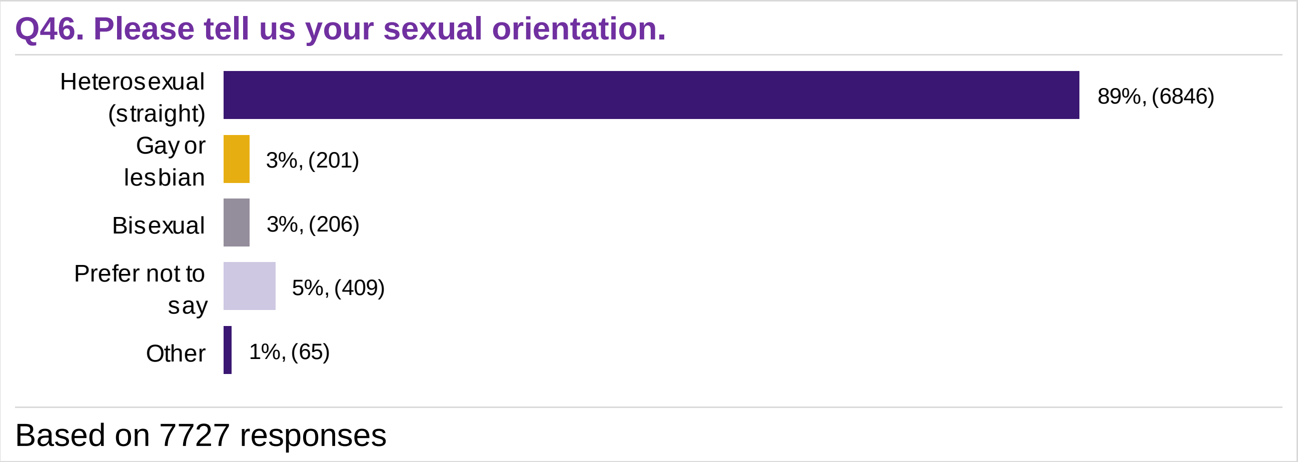

Q49. Are you trans?

Based on 7627 responses.

Fig 3. Transgender breakdown of adult respondents

3.1.4 Sexual orientation

Of those taking part to this survey,89% (n=6846) identified themselves as heterosexual, 3% (n=201) as gay or lesbian, a further 3% as bisexual (n=206) and 5%(n=409) preferred to not disclose.


Q46. Please tell us your sexual orientation.

Based on 7727 responses

Fig 4. Sexual orientation of adult respondents

3.1.5 Co-morbidities

More than half of the respondents with neurological conditions (59%, n=4509) live with other conditions.


Q45. Apart from your neurological conditions, do you live with any other conditions?

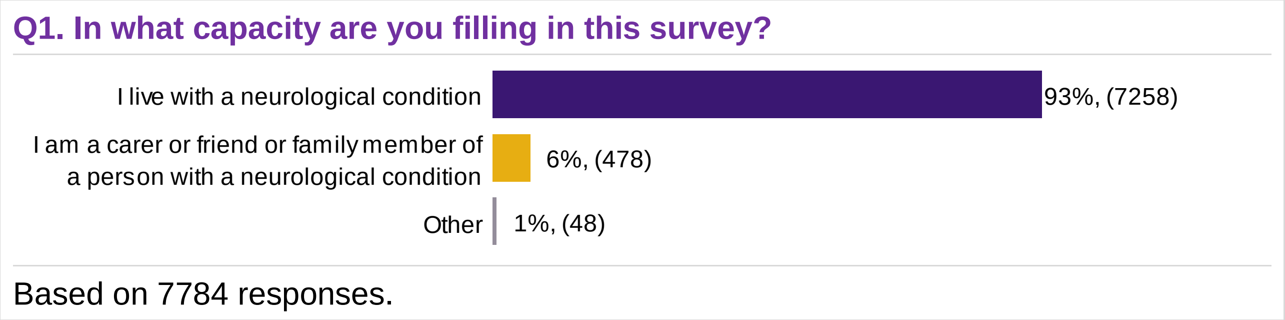
Based on 7634 responses

Fig 5. Co-morbidities of adult respondents

3.2 Introductory questions

3.2.1 Completing the questionnaire

The majority of respondents (93%) filled in the survey themselves, as the person with a neurological condition (or conditions). 6% were responses from a carer, friend or family member filling it in on behalf of the person with a neurological condition. Just 1% completed the survey by another means.


Q1. In what capacity are you filling in this survey?

Based on 7784 responses.

Fig 6. Method of survey completion for adult respondents

3.2.2 Conditions

Respondents were asked to report what neurological condition(s) they have, from a list of 58 conditions. [1]

7702 respondents reported at least one condition, 250 said they are awaiting a diagnosis (of which 91 do not have a diagnosis of any other neurological condition) and 88 did not answer.

Of those respondents who were able to report having a condition, 5407 (70%) reported living with one condition while 2295 (30%) reported living with more than one condition.

The five conditions with the highest number of adult respondents were:

Multiple sclerosis (MS)	1245
Epilepsy	1006
Migraine	851
Functional neurological disorder (FND)	849
Dystonia	753

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[1] Respondents were able to select multiple responses to this question

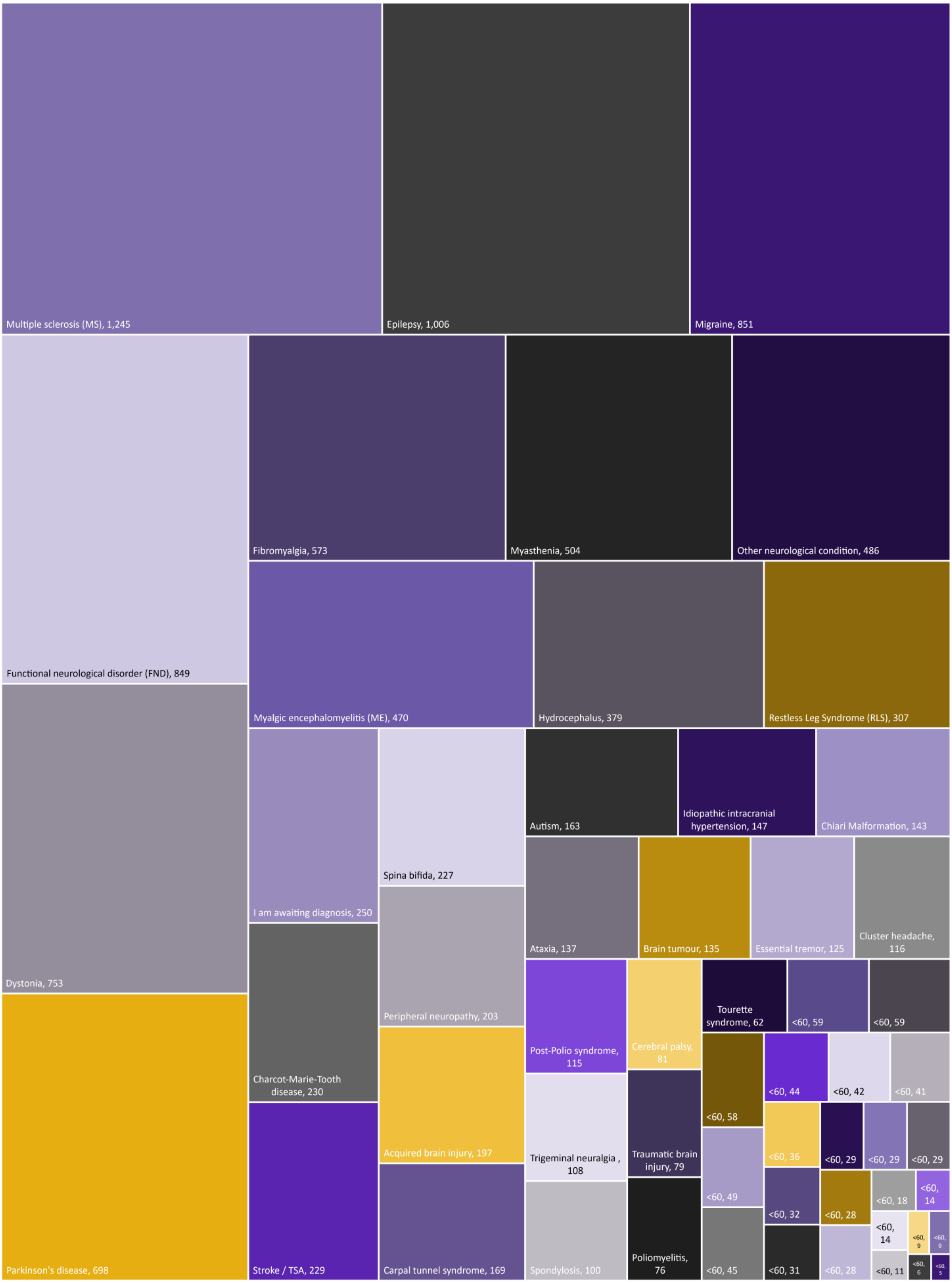


Fig 7. Condition representation for adult respondents

3.3 Care during the COVID-19 pandemic

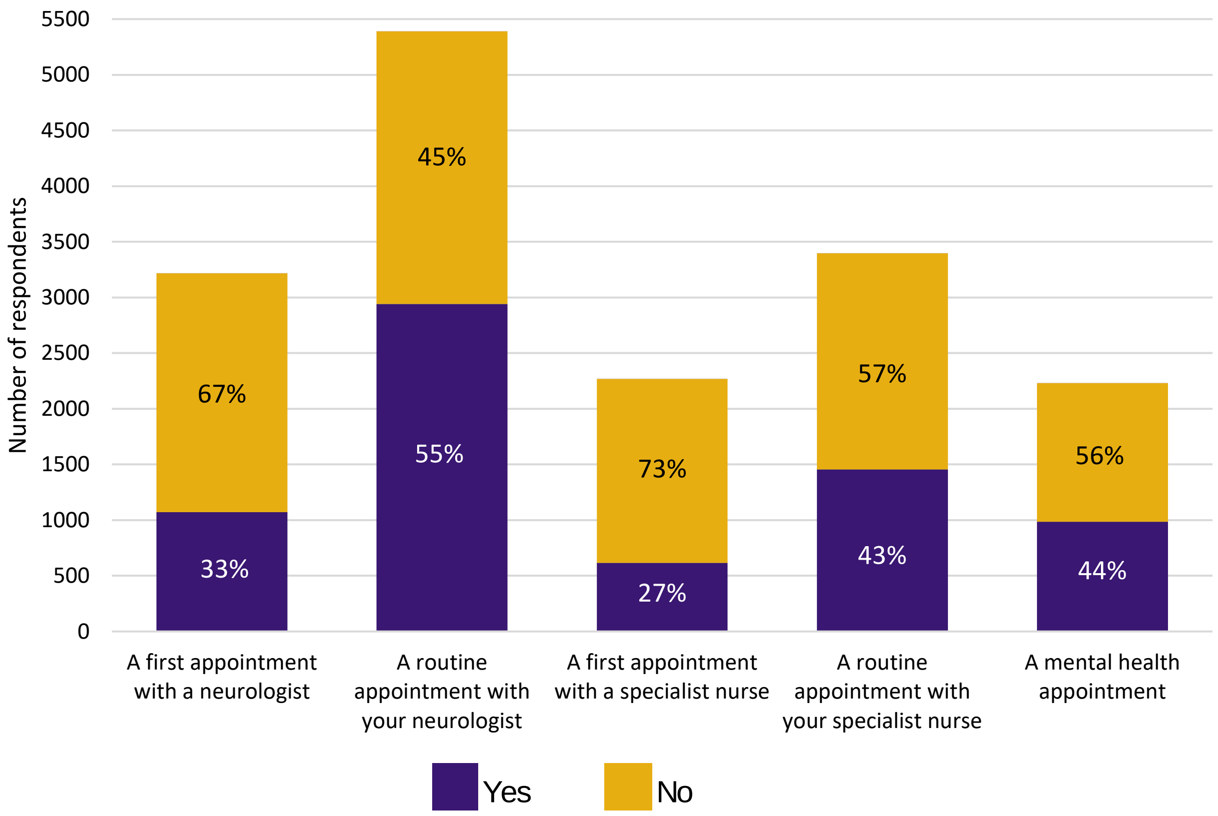
In this iteration of the survey The Neurological Alliance wanted to understand what impact the COVID-19 pandemic had on experience and access to care. Questions were asked about changes and delays to care and treatment, their mental wellbeing during the pandemic and their experiences with remote appointments.

3.3.1 Delays to care and treatment

Where it was applicable to their circumstances in the last 12 months:

- 33% (n=1071) experienced a delay with their first appointment with a neurologist
- 55% (n=2941) experienced delays at being seen by a neurologist for their routine appointment
- 27% (n=615) faced delays at being seen by a specialist nurse for the first time
- 43% (n=1456) experienced delays at seeing a specialist nurse for their routine appointments
- 44% (n=985) experienced delays with a mental health appointment

Q3. Have you experienced delays to your neurological care or treatment in the past 12 months? Appointments



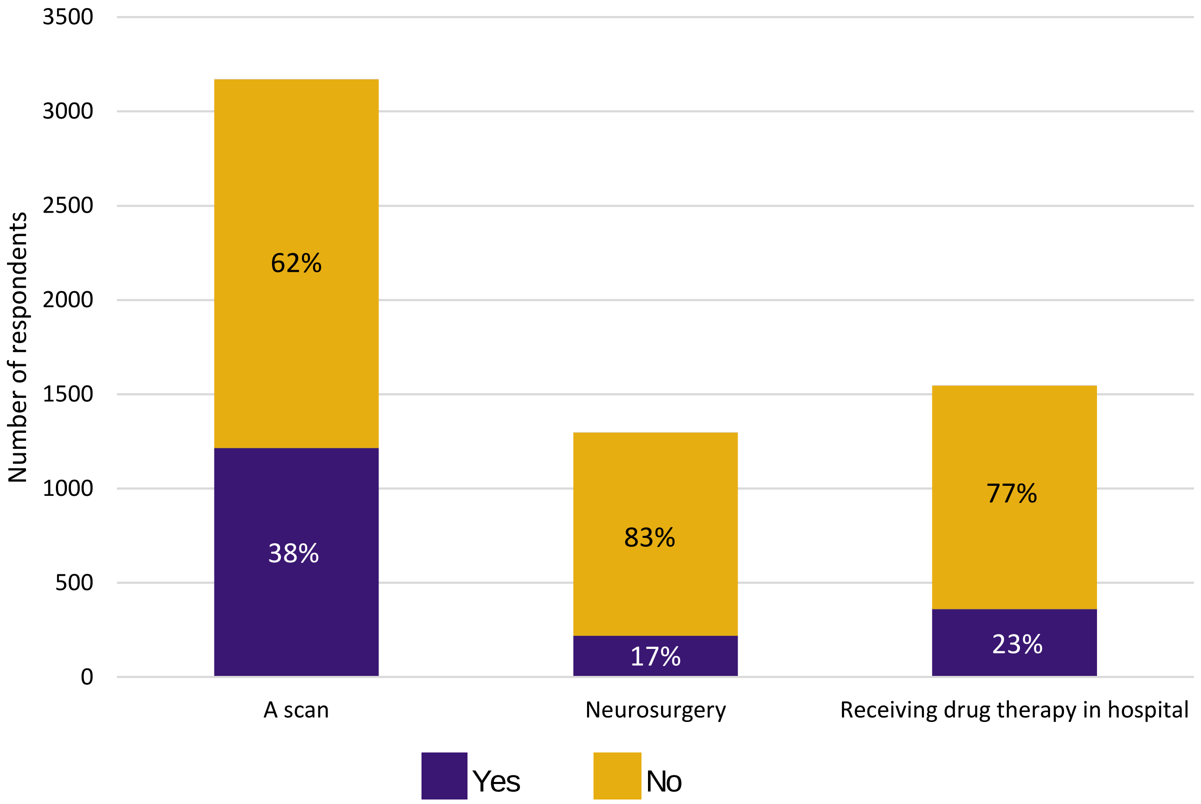
Based on responses for: A first appointment with a neurologist – 3216, A routine appointment with your neurologist – 5393, A first appointment with a specialist nurse – 2268, A routine appointment with your specialist nurse – 3398 and A mental health appointment – 2232

Fig 8. Delays to appointments – adult respondents

Where it was applicable to their circumstances in the last 12 months:

- 38% (n=1215) experienced a delay in getting a scan
- 17% (n=220) experienced delays to neurosurgery
- 23% of people (n=360) faced delays at receiving drug therapy in hospital

Q3. Have you experienced delays to your neurological care or treatment in the past 12 months? Hospital scans and treatment



Based on responses for: A scan – 3171, Neurosurgery – 1298 and Receiving drug therapy in hospital – 1547

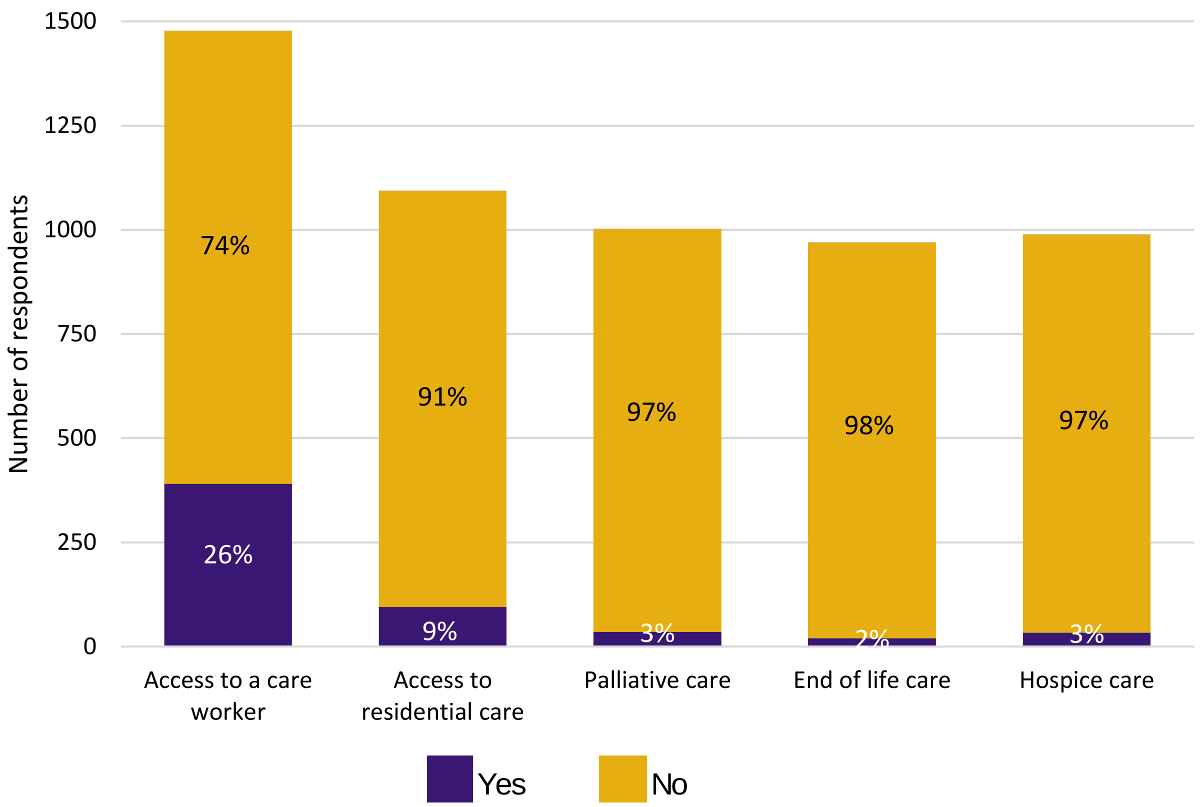
Fig 9. Delays to hospital scans and treatment – adult respondents

Where it was applicable to their circumstances in the last 12 months just over a quarter of respondents (26%, n= 390) experienced delays in accessing a care worker.

Reassuringly delays were experienced by fewer respondents across residential, palliative and end of life care where it was needed.

- 9% (n=95) faced delays accessing residential care
- 3% (n= 35) of respondents experienced problems accessing Palliative care
- 2% (n=20) experienced delays at accessing End of life care
- 3% (n=33) had delays accessing Hospice care

Q3. Have you experienced delays to your neurological care or treatment in the past 12 months? Additional care needs and end of life care



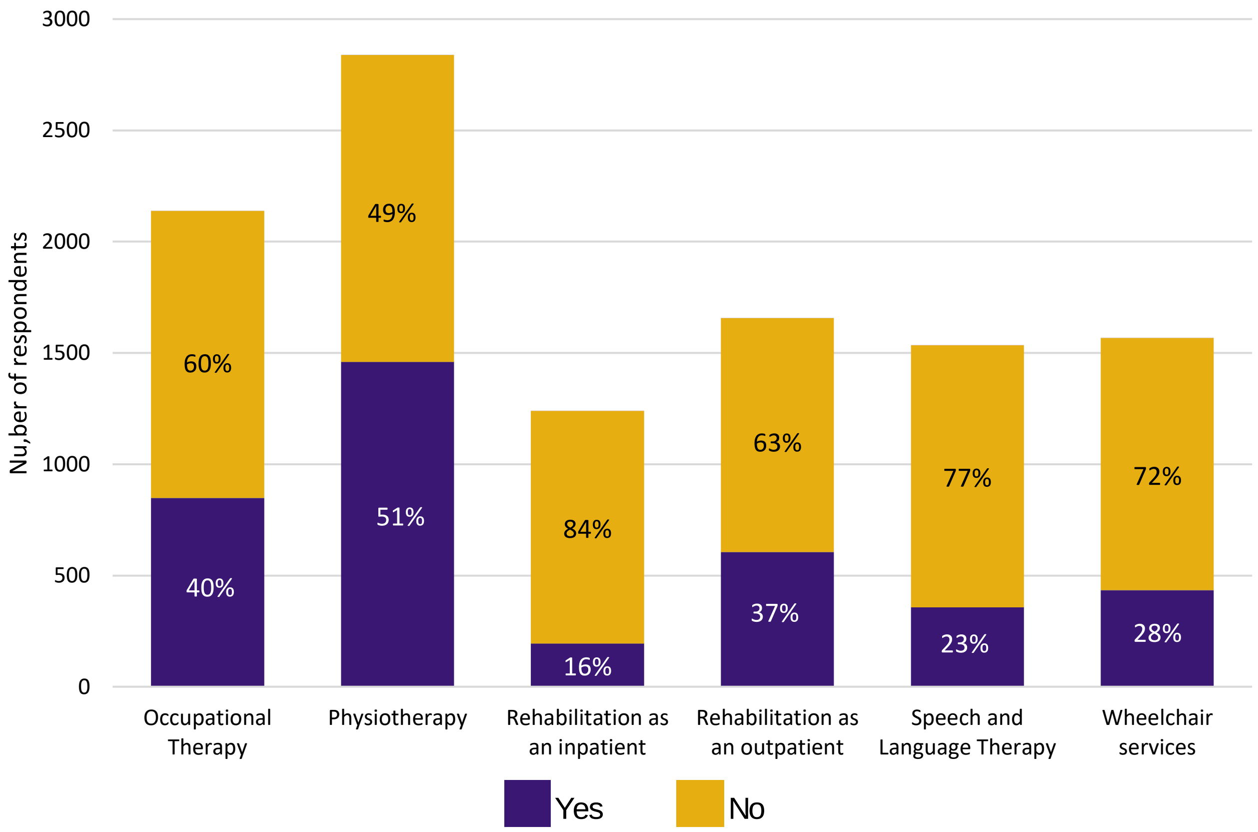
Based on responses for: Access to a care worker – 1478, Access to residential care – 1094, Palliative care– 1002, End of life care – 970 and Hospice care – 989

Fig 10. Delays to additional care needs and end of life care – adult respondents

Where it was applicable to their circumstances in the last 12 months:

- Two fifths of respondents (n=848) reported delays accessing Occupational therapy
- Just over half of respondents (51%, n=1460) experienced delays accessing Physiotherapy
- 16% (n=195) of people experienced delays to access Rehabilitation as an inpatient
- Over a third (37%, n= 605) faced delays with Rehabilitation as an outpatient
- Nearly a quarter (23%, n= 357) reported a delay with Speech and Language therapy
- Over a quarter (28%, n=434) experienced delays to access to Wheelchair services.

Q3. Have you experienced delays to your neurological care or treatment in the past 12 months? Rehabilitation and physical therapies



Based on responses for: Occupational Therapy – 2138, Physiotherapy – 2838, Rehabilitation as an inpatient – 1240, Rehabilitation as an outpatient – 1656 Speech and Language Therapy– 1535 and Wheelchair services – 1568

Fig 11. Delays to rehabilitation and physical therapies – adult respondents

3.3.2 Remote appointments

Respondents were asked for their views on remote appointments and their preferences for how appointments are carried out.

The majority of people, 43% (n= 3354) said that their preference would depend on the reason for the appointment, a further 43% of people (n=3317) preferred to have an appointment in person. Only 7% (n=541) would prefer a video appointment, and 6% of people (n=456) would prefer a phone appointment. 1% (n=107) were not sure.

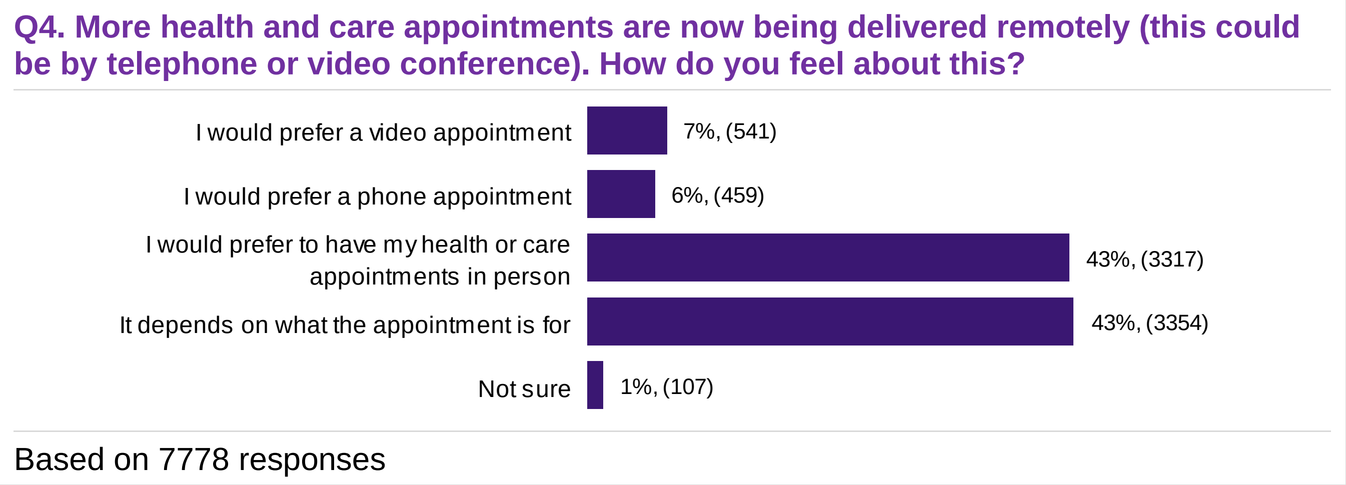


Fig 12. Preferences for remote appointments – adult respondents

45% (n=2816) of respondents agreed that their remote appointments were useful, followed by 34% of people (n =2112) neither agreeing nor disagreeing. 21% (n=1346) disagreed that their remote appointments were useful.

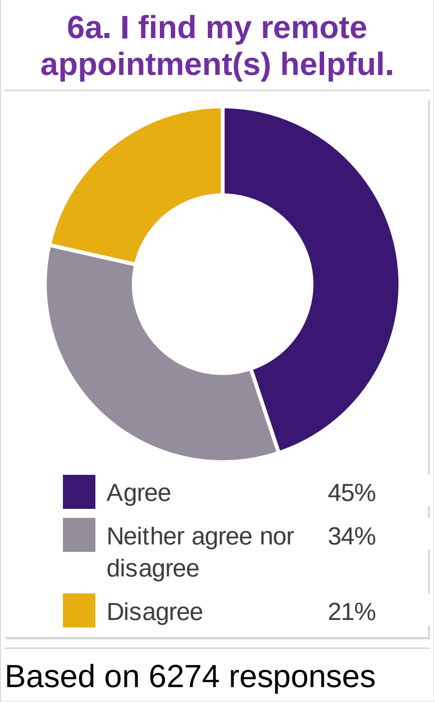


Fig 13. Helpfulness of remote appointments – adult respondents

Only 10% of respondents (n=383) reported not having a remote appointment because they couldn't access the right technology. 68% (n=2508) indicated that this was not the case and 21% (n =772) gave a neutral response.

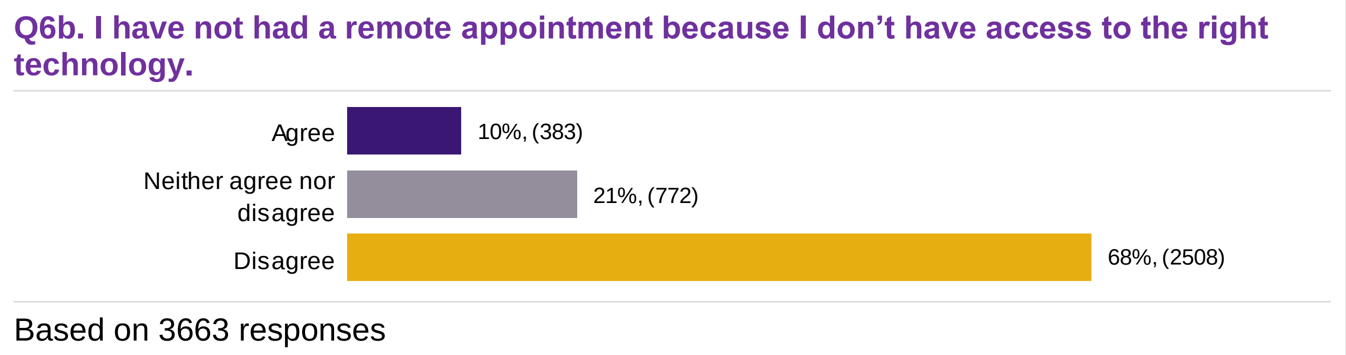


Fig 14. Access to technology for remote appointments – adult respondents

69% of the respondents (n=4701) feel confident in using the technology followed by 17% of people (n=1141) that neither agree nor disagree and 14% (n=926) that are not feeling confident in using technology.

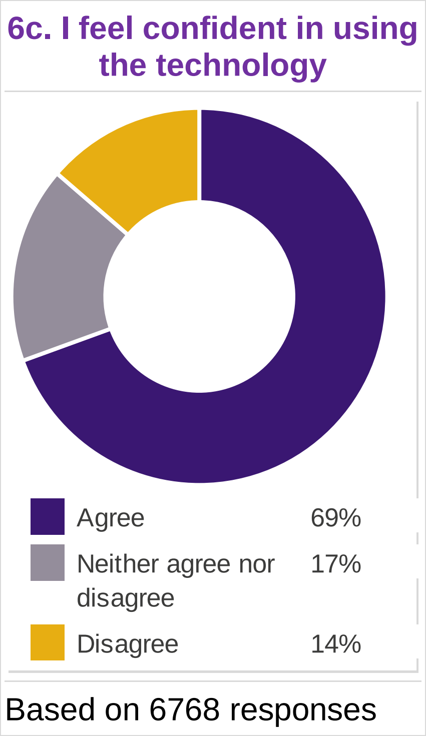


Fig 15. Confidence in using technology – adult respondents

The majority of respondents (80%, n=5161) agreed that they have access to a private space for remote appointments. 10% (n=673) indicated that this was not the case followed by 9% (n=595) neither agreeing nor disagreeing.

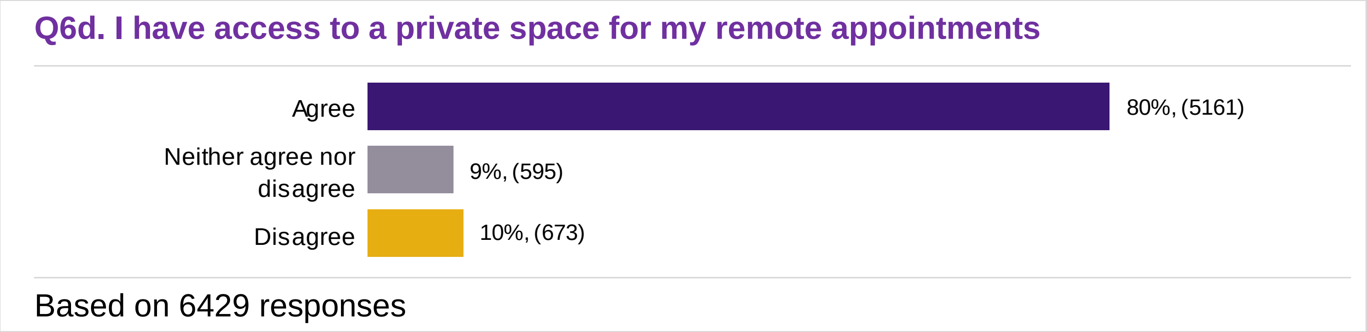


Fig 16. Access to privacy for remote appointments – adult respondents

There was some ambivalence around the effectiveness of remote appointments as 42% of respondents (n =2690) gave a neutral response to the statement ‘Remote appointments are ineffective’. 36% (n=2323) disagreed and just over a fifth 22% (n=1427) agreed with the statement.

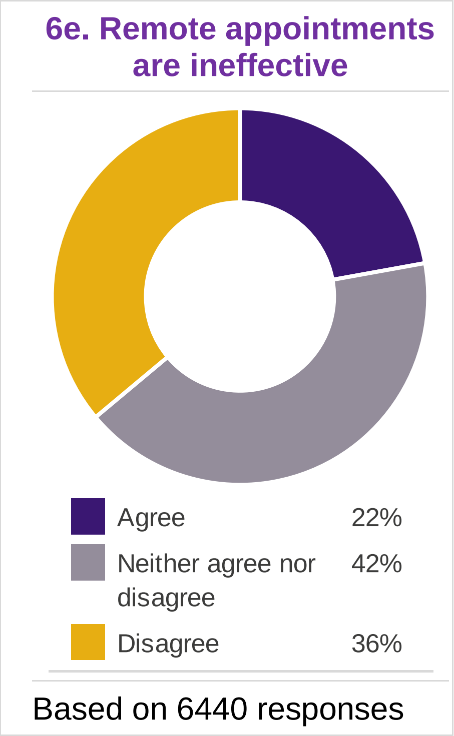
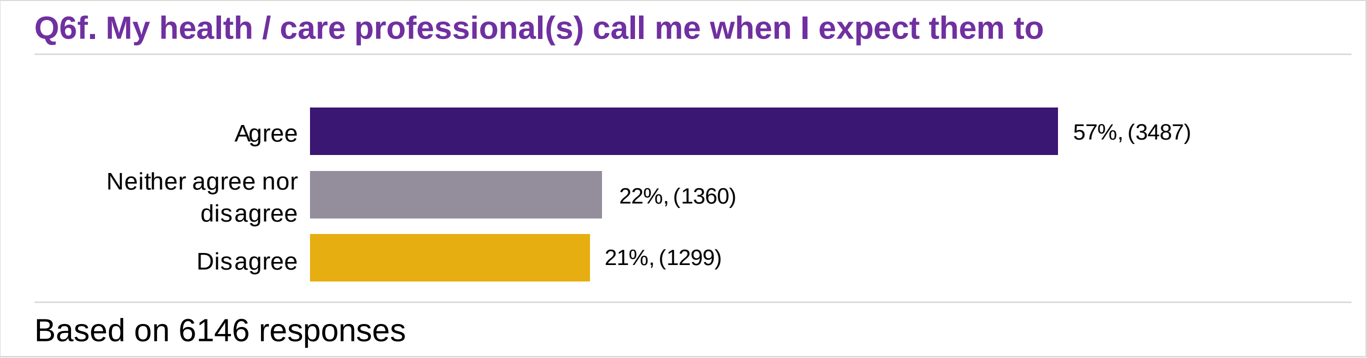


Fig 17. Remote appointments are ineffective – adult respondents

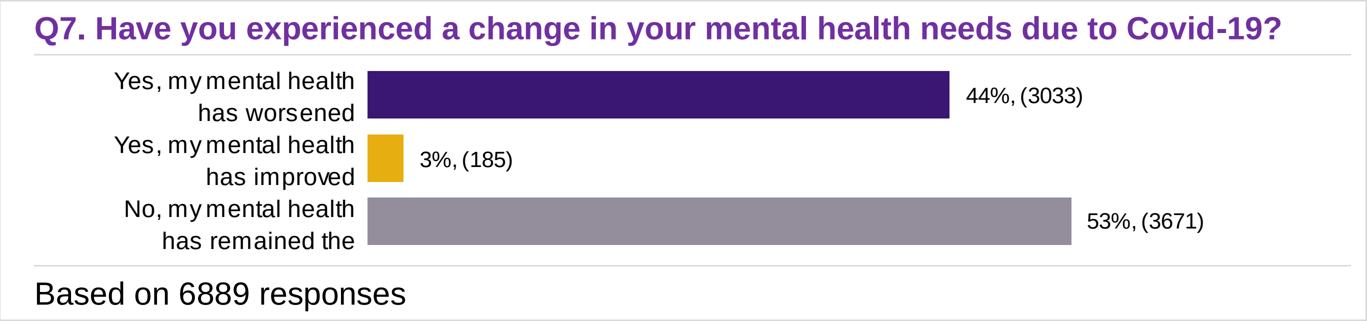
While over a half of respondents 57% (n=3487) agreed that their health / care professional(s) call them when they expect them to, just over a fifth (21%, n=1299) disagreed that this happens. 22% of people (n =1360) neither agreed nor disagreed.

Fig 18. Healthcare professionals calling when expected– adult respondents


Q6f. My health / care professional(s) call me when I expect them to

Based on 6146 responses

Just over half of the respondents 53% (n= 3671) do not feel that their mental health has been affected by Covid-19. However, 44% (n=3033) reported that their mental health has worsened due to the pandemic, leaving only 3% (n=185) of the respondents that said it had actually improved.


Q7. Have you experienced a change in your mental health needs due to Covid-19?

Based on 6889 responses

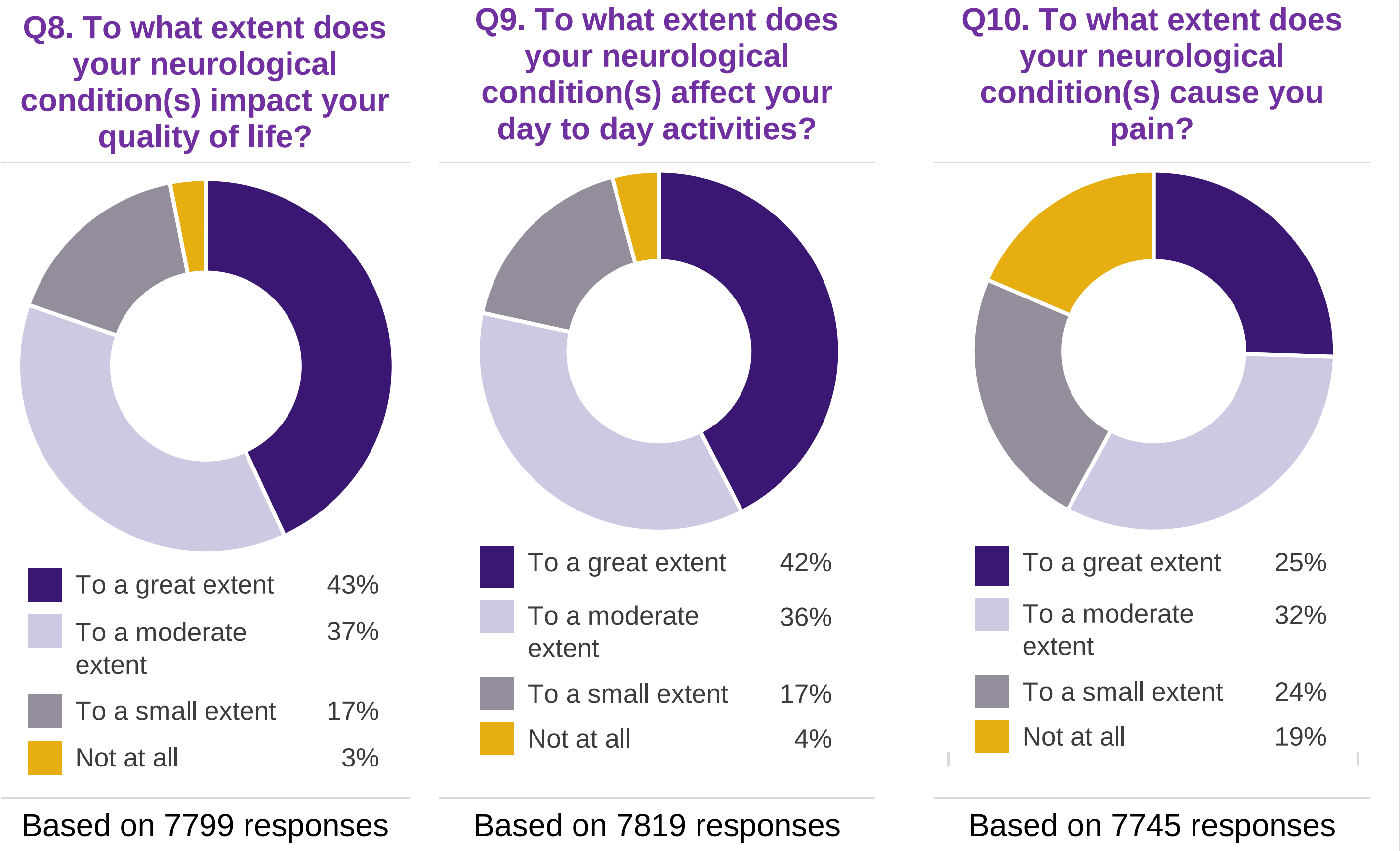
Fig 19. Change to mental health needs due to Covid-19 – adult respondents

3.4 Overall impact of neurological conditions

43% (n=3363) of respondents reported that their neurological condition affected their quality of life to a great extent (the most severe response option). A further 37% (n=2900) reported that their neurological condition affected their quality of life to a moderate extent followed by a 17% (n=1296) that were affected to a small extent. Just 3% (n=240) of respondents reported that their neurological condition did not affect their quality of life at all.

78% (n=6132) of respondents reported that their neurological condition affected their day to day activities to a moderate or great extent.

In terms of pain or discomfort caused by neurological conditions, nearly three-fifths of respondents (57%, n=4483) reported that their condition caused pain or discomfort to a moderate or great extent.


Q8. To what extent does your neurological condition(s) impact your quality of life?

Q9. To what extent does your neurological condition(s) affect your day to day activities?

Q10. To what extent does your neurological condition(s) cause you pain?

Based on 7799 responses

Based on 7819 responses

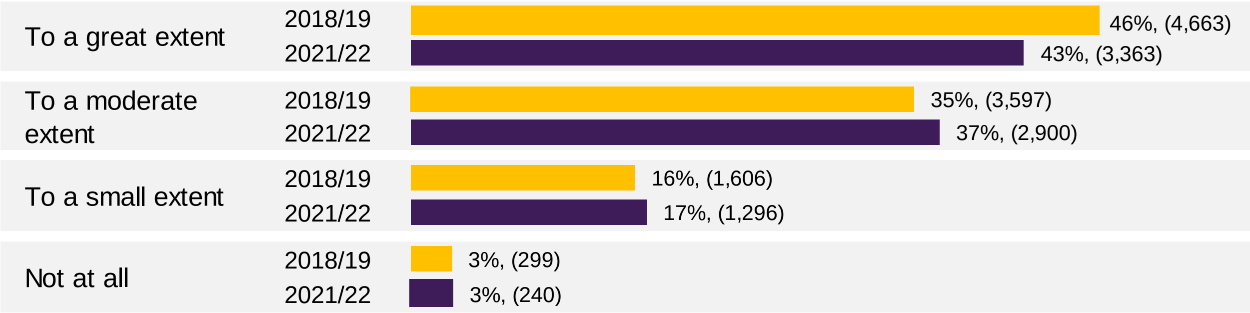
Based on 7745 responses

Fig 20. Overall impact of neurological conditions – adult respondents

Comparison was possible between the 2018/19 and 2021/22 results for the questions relating to quality of life, day to day activities and pain.

Respondents in 2021 report slightly more positively around quality of life with a smaller proportion saying their neurological condition affects them to a great extent.

Q8. To what extent does your neurological condition(s) impact your quality of life?

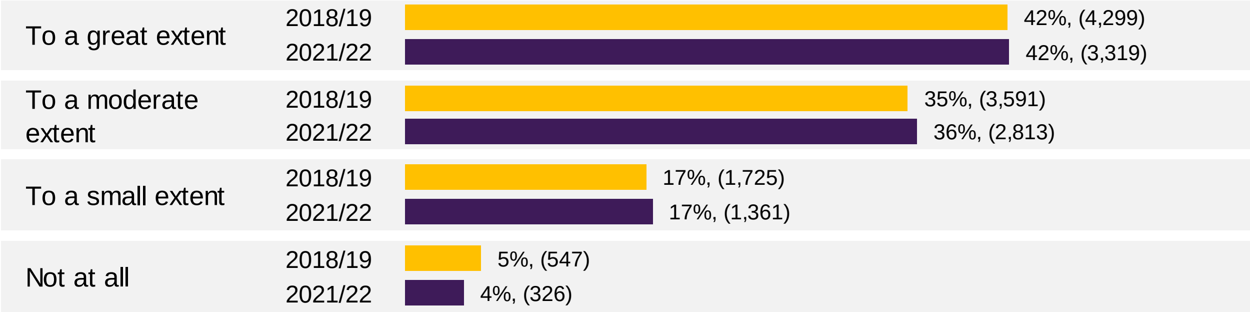


2018/19 based on 10165 responses. 2021/22 based on 7799 responses.

Fig 21. Year on year comparison for impact on quality of life – adult respondents

Scores for how neurological conditions affect day to day activities show little change since 2018.

Q9. To what extent does your neurological condition(s) effect your day to day activities?

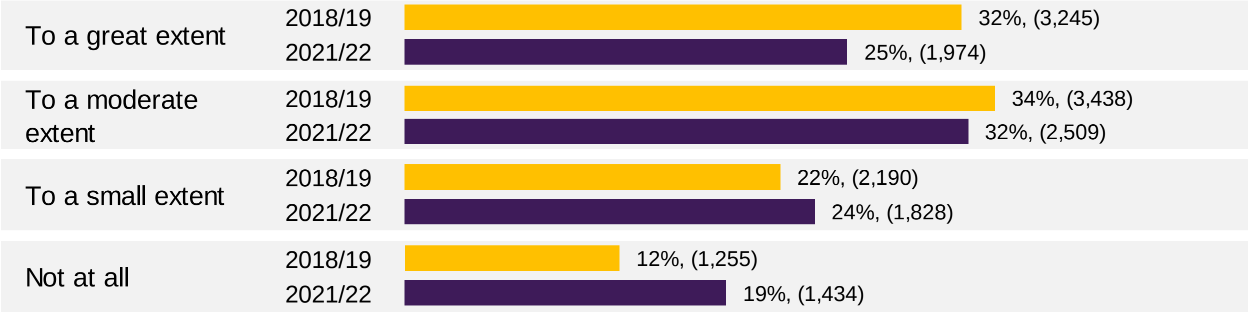


2018/19 based on 10162 responses. 2021/22 based on 7819 responses.

Fig 22. Year on year comparison for effect on day to day activities – adult respondents

Respondents in 2021 report more positively around the pain they experience with smaller proportions selecting the more severe answer options.

Q10. To what extent does your neurological condition(s) cause you pain?



2018/19 based on 10128 responses. 2021/22 based on 7745 responses

Fig 23. Year on year comparison for pain – adult respondents

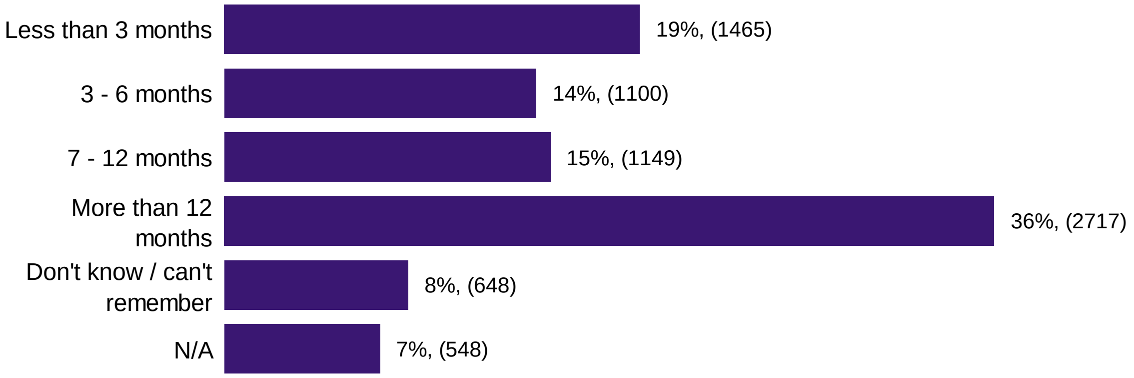
3.5 Before diagnosis

3.5.1 Waiting for a diagnosis

Respondents still face difficulties in obtaining a confirmed and accurate diagnosis for their neurological condition.

- Less than a fifth (19%, n=1465) waited less than 3 months from first experiencing symptoms to getting a diagnosis
- 14% (n=1100) received a diagnosis in 3-6 months
- 15% (n=1149) were diagnosed in 7-12 months
- Just under two fifths (36%, n=2717) waited over 12 months for a diagnosis.

Q11a. How long were you waiting between first experiencing symptoms to getting a diagnosis?



Based on 7627 responses

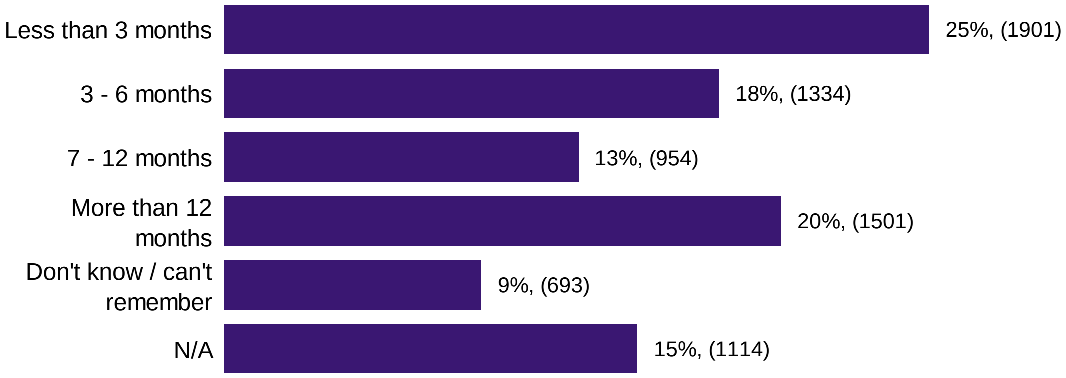
Fig 24. Waiting for a diagnosis – adult respondents

3.5.2 Waiting to see a neurologist

There continues to be some delays between people first seeing a GP and seeing a neurologist.

- A quarter waited less than 3 months (n=1901).
- 18% waited (n=1334) 3-6 months.
- 13% waited (n=954) 7-12 months.
- A fifth waited more than 12 months (n=1501).

Q11b. How long were you waiting between first seeing a GP to seeing a neurologist

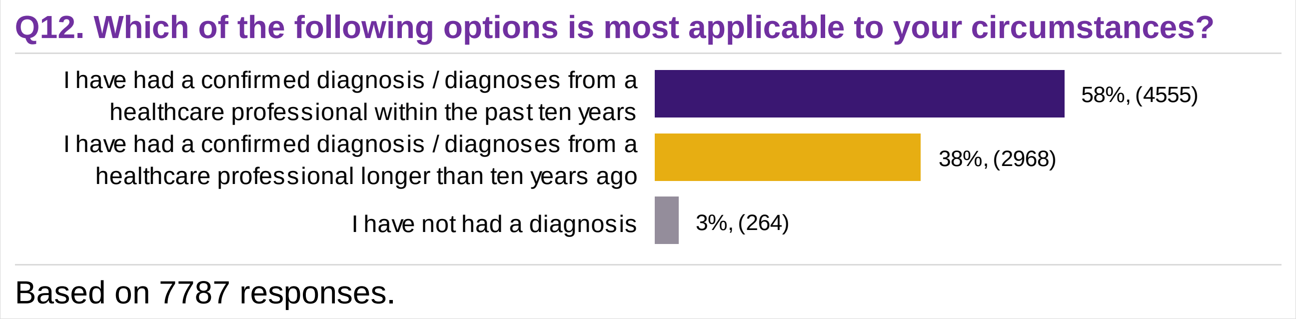


Based on 7627 responses

Fig 25. Waiting to see a neurologist – adult respondents

3.5.3 Time since diagnosis

Over half of respondents (58%, n=4555) answering the survey had their confirmed diagnosis within the last 10 years, 38% (n=2968) had their diagnosis over 10 years ago and 3% (n=264) have not have a diagnosis.


Q12. Which of the following options is most applicable to your circumstances?

Based on 7787 responses.

Fig 26. Time since diagnosis – adult respondents

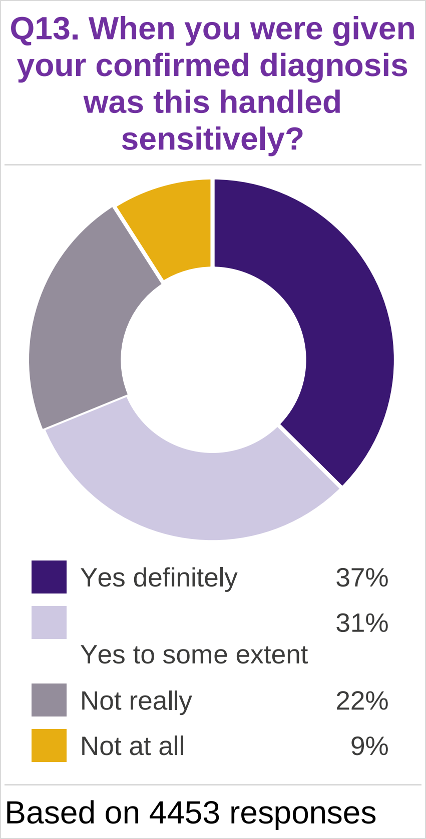
3.6 Diagnosis - Finding out about your neurological condition(s)

This section was answered by 4555 respondents who had a confirmed diagnosis within the last 10 years.

3.6.1 Sensitivity of diagnosis delivery

While nearly two-fifths (n=1669) of respondents felt their diagnosis delivery was handled sensitively there is room for improvement:

- 31% (n=1395) said yes, to some extent
- 22% (n=987) said not really
- 9% (n=402) said not at all.


Q13. When you were given your confirmed diagnosis was this handled sensitively?

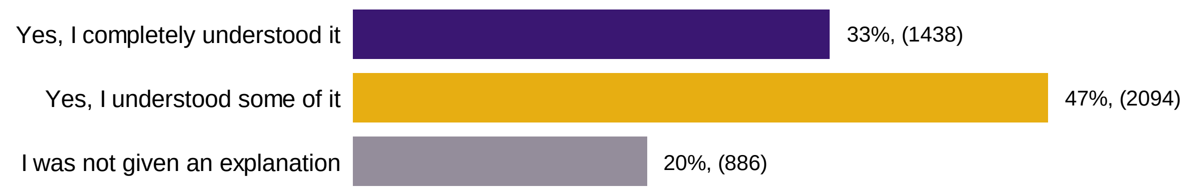
Based on 4453 responses

Fig 27. Sensitivity of diagnosis – adult respondents

3.6.2 Explanation of diagnosis

There is further work to be done around the way in which a new diagnosis of a neurological condition is explained to people.

Q14. Did you understand the explanation given to you at your diagnosis / when you were first told about your condition?



Based on 4418 responses.

Fig 28. Explanation of diagnosis – adult respondents

3.7 Information about your neurological condition(s)

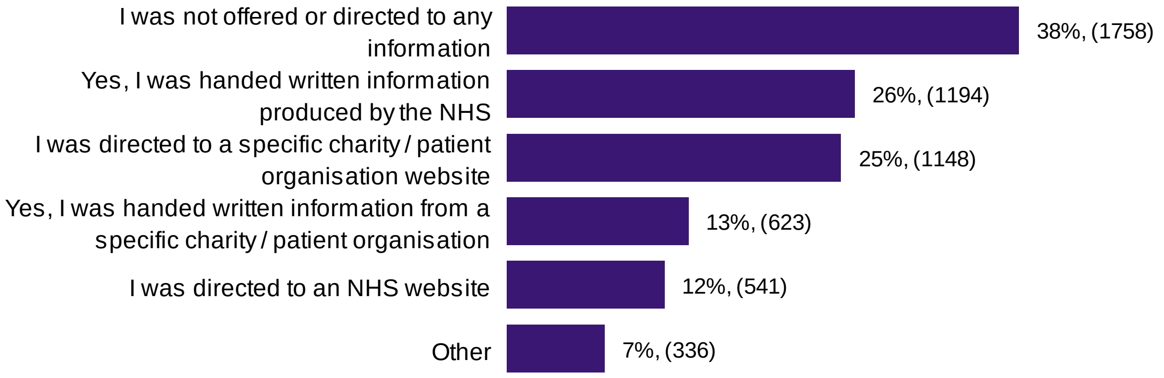
This section was answered by 4555 respondents who had a confirmed diagnosis within the last 10 years.

3.7.1 Written information

Respondents were asked to select all the kinds of written information they were given:

- More than one third of respondents (38%, n=1758) were **not** offered or directed to any form of written information.
- More than a quarter of respondents (26%, n=1194) were handed written information produced by the NHS and a further 12% (n=541) were directed to an NHS website.
- Another quarter (25%, n=1148) were directed to a specific charity/patient organisation relevant to their condition.
- 13% (n= 623) of respondents were handed written information from a specific charity/patient organisation.

Q15. When you were told you had a neurological condition, were you given written information about it?



Based on 5600 responses. **Tick all that apply question**

Fig 29. Written information – adult respondents

3.7.2 Quality of information

Just under a fifth (16% n=581) of respondents rated the quality of the information they received as Excellent, 35% (n= 1298) as Good and nearly a quarter (24%, n=874) Fair. However, a quarter of respondents (n=914) of the respondents considered the quality of the information they received to be Poor.

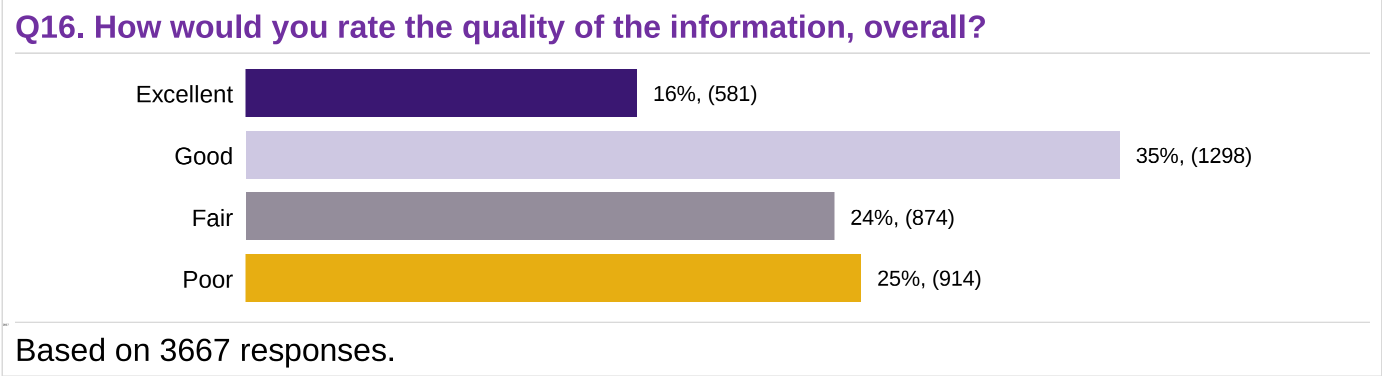


Fig 30. Quality of information – adult respondents

Respondents in 2021 reported more negatively on the overall quality of the information they received.

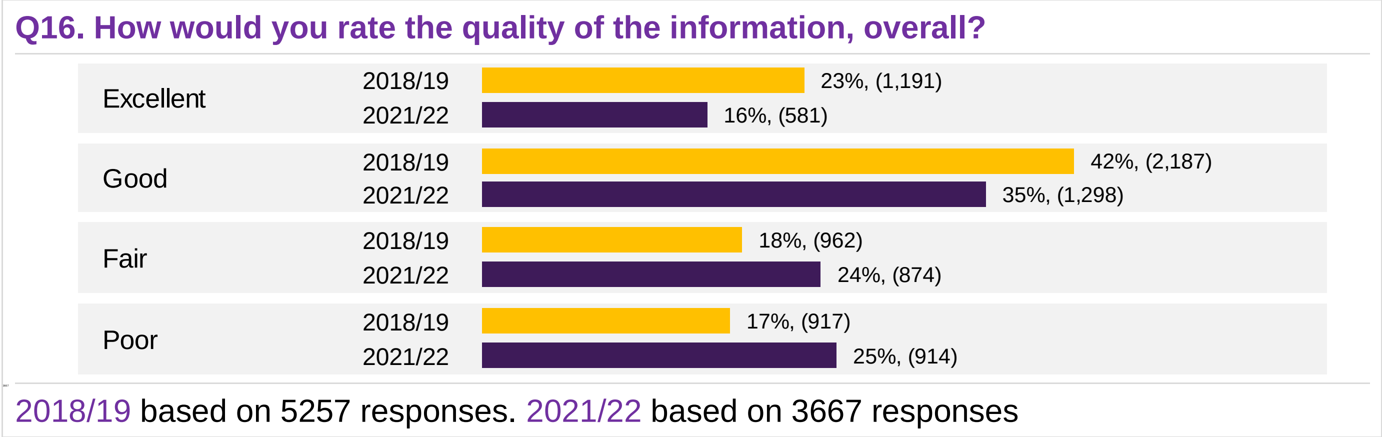


Fig 31. Year on year quality of information – adult respondents

3.8 Treatment and care

3.8.1 Prescriptions

Of those who it applied to, the majority of respondents did not have difficulty affording their prescriptions.[2]

Q17. Do you ever have difficulty affording your prescriptions?

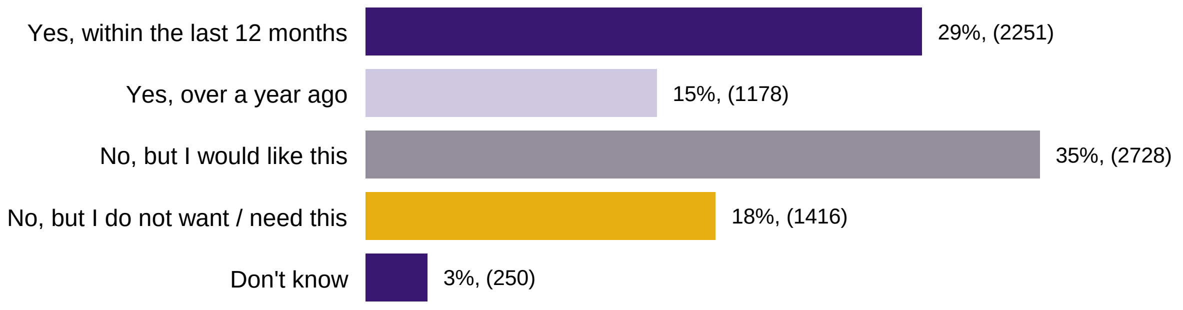
Based on 5017 responses.

Fig 32. Affording prescriptions – adult respondents

3.8.2 Specialist Nurses

In the last 12 months, 29% (n=2251) of respondents had access to a specialist nurse for their specific neurological condition, followed by a further 15% (n= 1178) that saw the specialist nurse more than one year ago. However, over a third of respondents (35%, n=2728), could not access this service even though they would like to. Around a fifth of respondents (18%, n= 1416) did not want or need to see a specialist nurse for their condition.

Q18. Have you had an appointment with a specialist nurse for your neurological condition(s)?



Based on 7823 responses.

Fig 33. Access to Specialist Nurses – adult respondents

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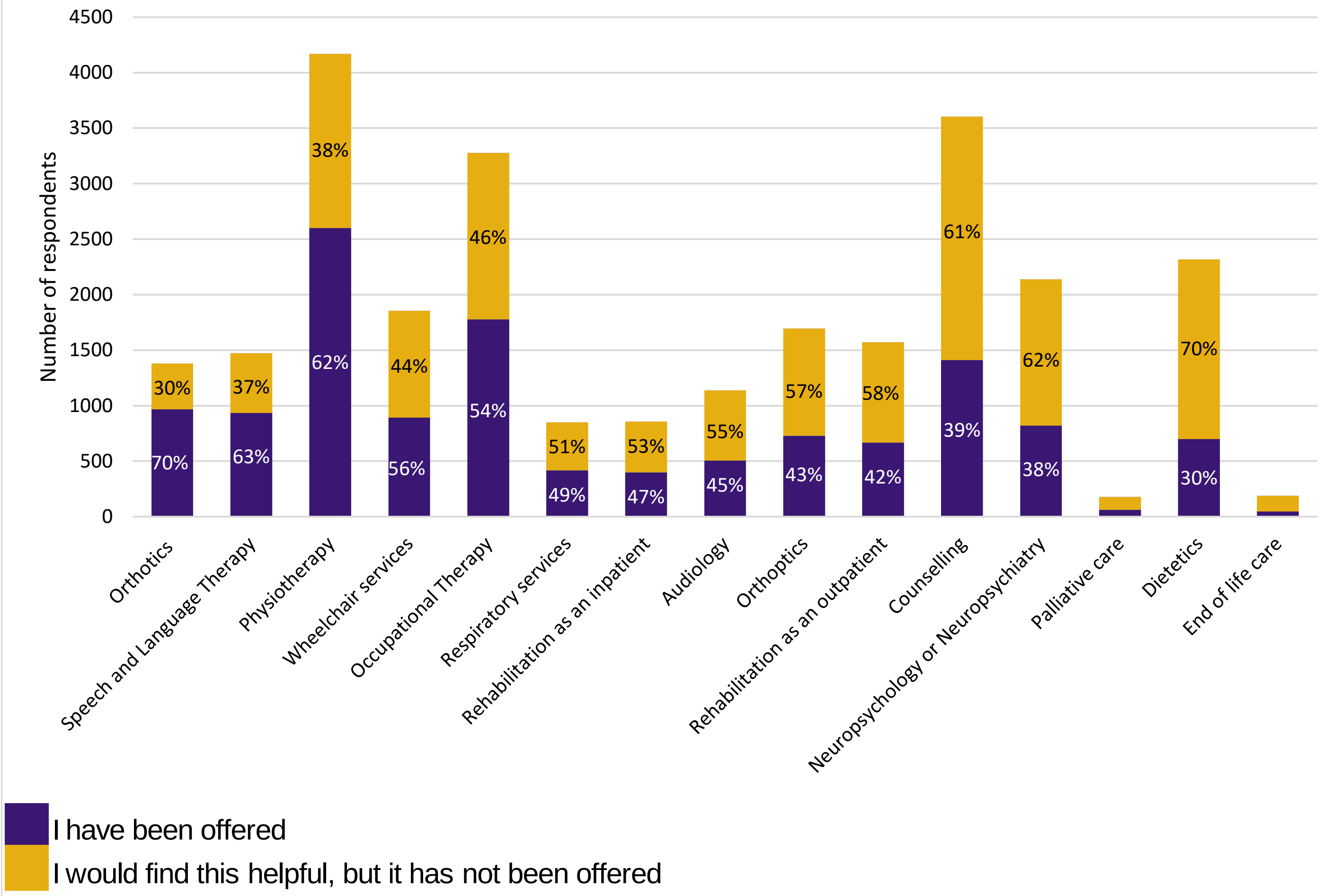
[2] It should be noted that prescriptions are free of charge in Northern Ireland, Scotland and Wales.

3.8.3 Treatments and therapies

Where it was applicable to their circumstances, Orthotics (70%, n=967), Speech and Language Therapy (63%, n=935), Physiotherapy (62%, n=2600) and Wheelchair services (56%, n=892) were offered to more than half of the respondents. Less than half of the respondents, however, had access to other services and only 26% (n=48) of them were offered access to End of life care.

Q19. Please tell us which treatments and therapies you have been offered, or you believe may help you to manage your neurological condition(s)



Based on responses for: Orthotics – 1380, Speech and Language Therapy – 1474, Physiotherapy – 4168, Wheelchair services – 1585, Occupational Therapy – 3275, Respiratory services – 850, Rehabilitation as an inpatient – 857, Audiology – 1138, Orthoptics – 1694, Rehabilitation as an outpatient – 1572, Counselling – 3605, Neuropsychology or Neuropsychiatry – 2139, Palliative care – 177, Dietetics – 2316 and End of life care – 188

Fig 34. Treatments and therapies offered – adult respondents

3.8.4 Involvement in healthcare

Reassuringly one third of the respondents (33%, n=2517) feel fully involved in their choices about their health care with a further 39% (2998) feeling involved to some extent. However, 21% (n=1586) don't feel involved as much as they would like while 8%(n=590) don't feel involved at all

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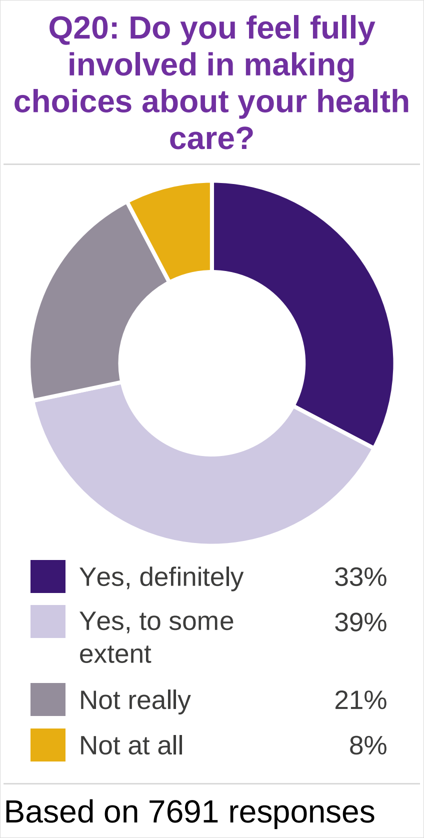


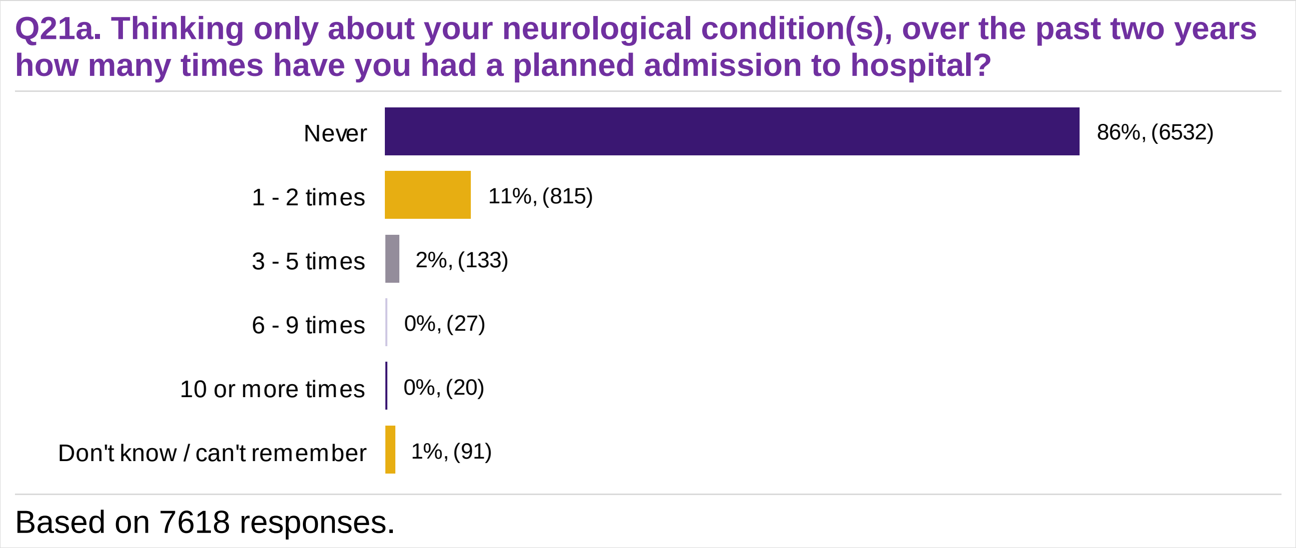
Q20: Do you feel fully involved in making choices about your health care?

Based on 7691 responses

Fig 35. Involvement in healthcare – adult respondents

3.8.5 Admissions to hospital

The majority of respondents (86%, n=6532) reported having had no planned admission to hospital in the past two years. Of the others, 11% (n=815) of respondents had had 1-2 planned admissions, 2% (n=133) had had 3-5 admissions, 27 individuals had had 6-9 admissions and a further 20 individuals had had 10 or more admissions.



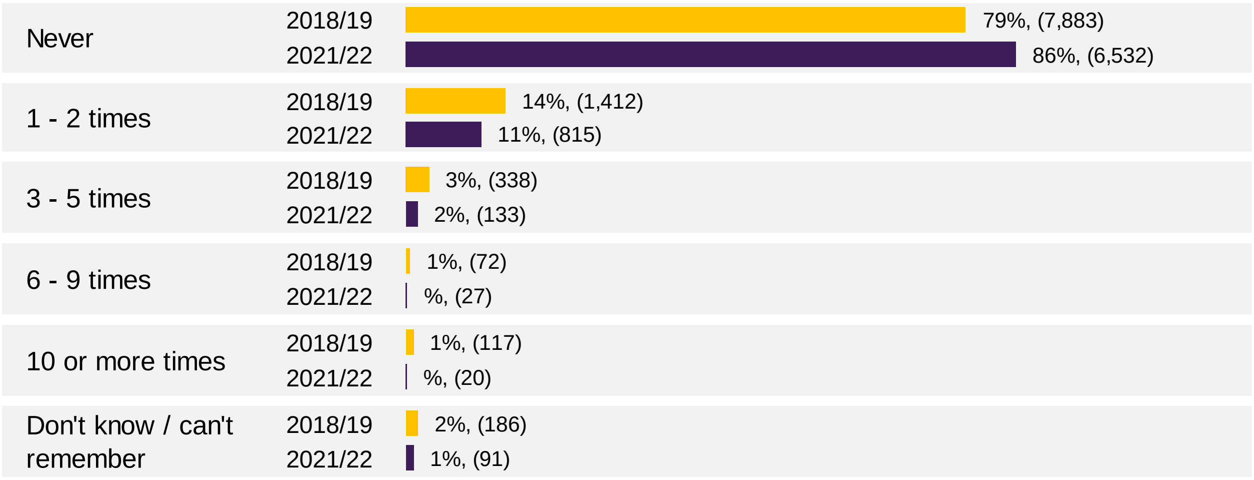
Q21a. Thinking only about your neurological condition(s), over the past two years how many times have you had a planned admission to hospital?

Based on 7618 responses.

Fig 36. Planned hospital admissions – adult respondents

Respondents in 2021 reported fewer planned hospital admissions over the past two years compared to their 2018 counterparts.

Q21a. Thinking only about your neurological condition(s), over the past two years how many times have you had a planned admission to hospital?



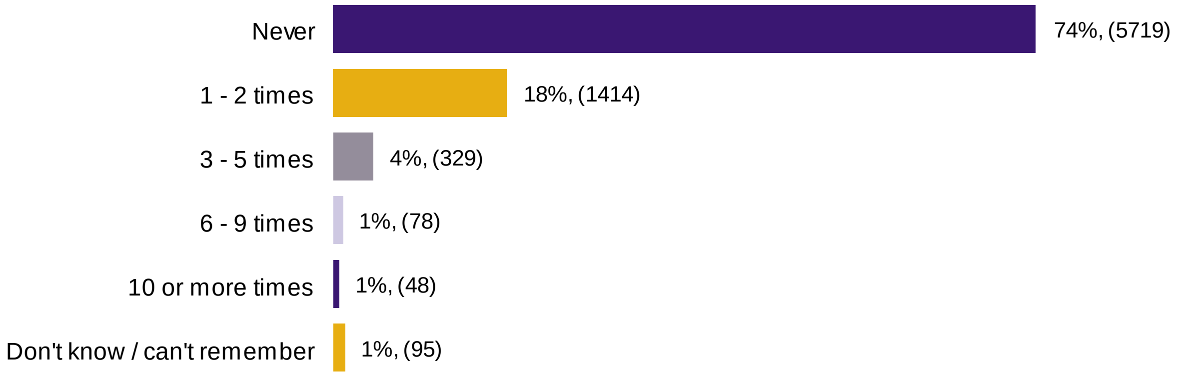
2018/19 based on 10008 responses. 2021/22 based on 7618 responses

Fig 37. Year on year planned hospital admissions – adult respondents

3.8.6 Emergency admissions

Almost three quarters of respondents (74%, n=5719) reported having had no emergency admission to hospital as a result of their neurological condition in the last two years. However, nearly a fifth (18%, n=1414) had been admitted as an emergency between 1 and 2 times, 4%(n=329) between 3-5 times, 1%(n=78) between 6-9 times and a further 1%(n=48) more than 10 times.

Q21b. Thinking only about your neurological condition(s), over the past two years how many times have you had an emergency admission?

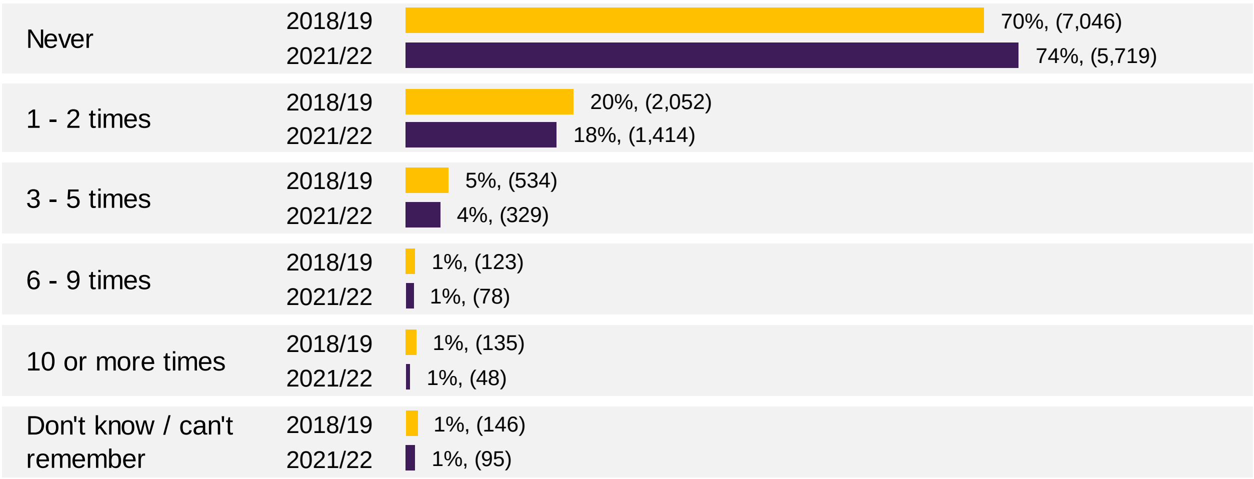


Based on 7683 responses.

Fig 38. Emergency admissions – adult respondents

Respondents in 2021 also reported fewer emergency admissions over the past two years than respondents in 2018.

Q21b. Thinking only about your neurological condition(s), over the past two years how many times have you had an emergency admission?



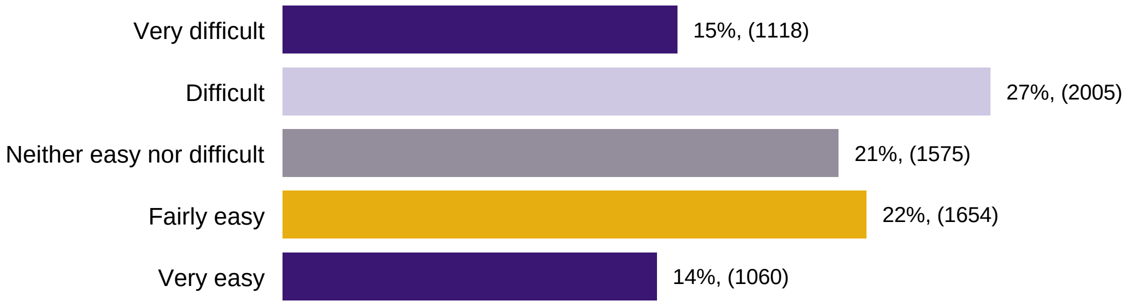
2018/19 based on 10036 responses. 2021/22 based on 7683 responses

Fig 39. Year on year emergency admissions – adult respondents

3.8.7 Travelling to appointments

More than two fifths (42%, n=3123) of respondents find it difficult or very difficult to travel to the majority of their appointments. 21% (n=1575) find it neither easy nor difficult, followed by 22% (n=1654) of respondents that find to travel to their appointment fairly easy. A further 14% (n=1060) said it is very easy.

Q22. How difficult do you find it to travel to the majority of your appointments for your neurological condition?



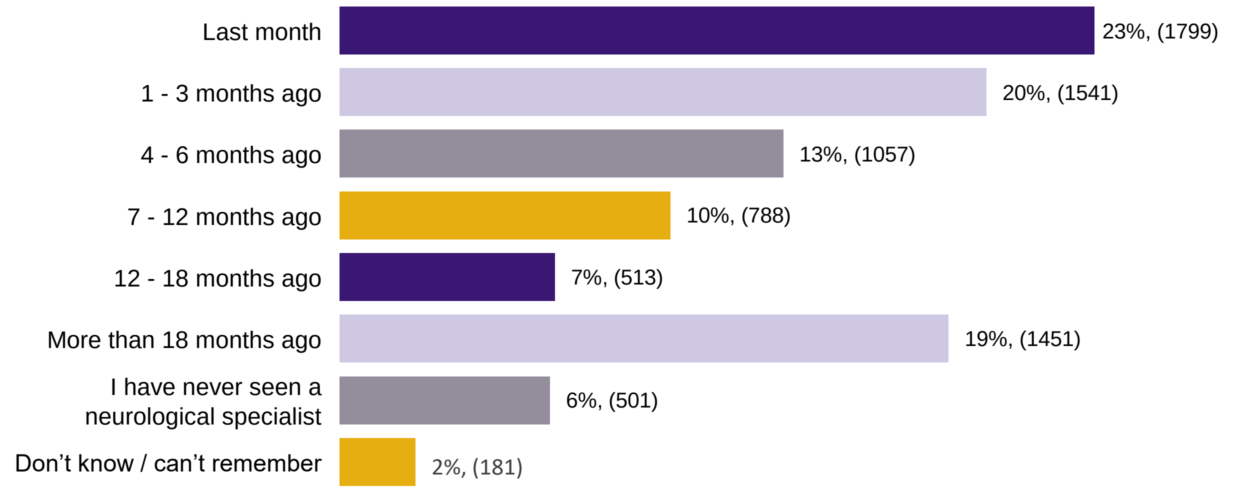
Based on 7412 responses.

Fig 40. Ease of travelling to appointments – adult respondents

3.8.8 Appointments with specialists

23% (n=1799) of the respondents saw a specialist for their neurological condition the previous month, followed by 20%(n=1541) that saw a specialist between 1 and 3 months ago. However, 19% (n=1451) saw a specialist more than 18 months ago and 6 % (n=501) reported having never seen a neurological specialist.

Q23. When did you last have an appointment with a specialist for your neurological condition?



Based on 7831 responses.

Fig 41. Appointments with specialists – adult respondents

1.2.1 Care and communication

Results show that nearly two fifths (38%, n=2692) of respondents do not think that their health and care are joined up and centred on their priorities. The same proportion also disagreed that information about their condition is effectively passed between the people that care for them (38%, n=2804). In addition, 40% (n=2880) of respondents reported that they do not find it easy to contact their specialist(s)

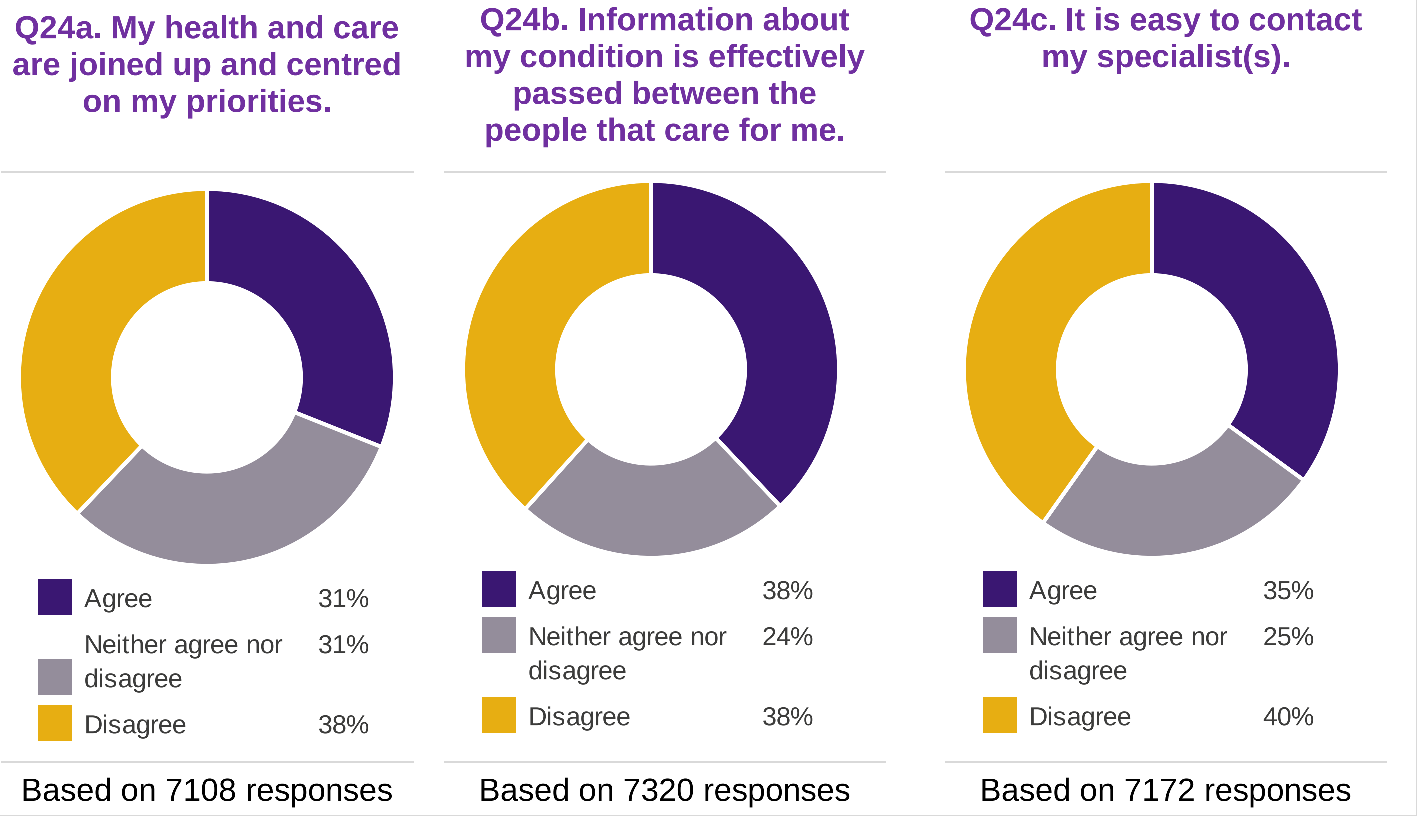


Fig 42. Joined up care and communication – adult respondents

45% (n=1742) disagreed that they got the care they needed once they returned at home after their hospital visit.

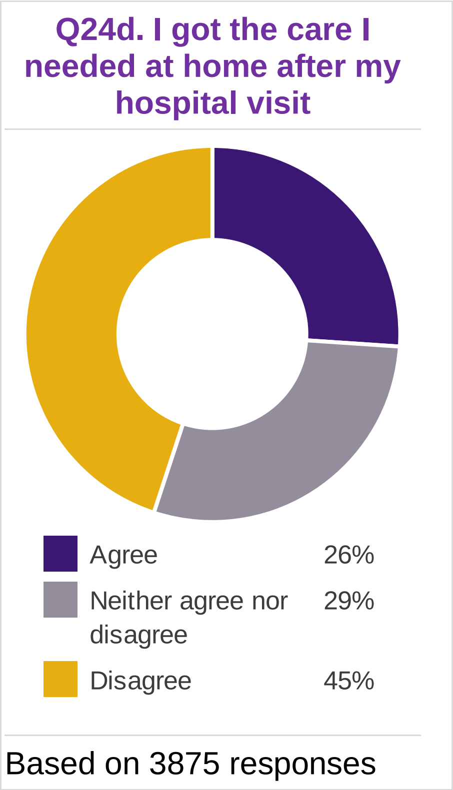


Fig 43. Care after hospital visits – adult respondents

A much smaller proportion of respondents in 2021 agreed that they got the care they needed once they returned at home after their hospital visit, compared to those in 2018.

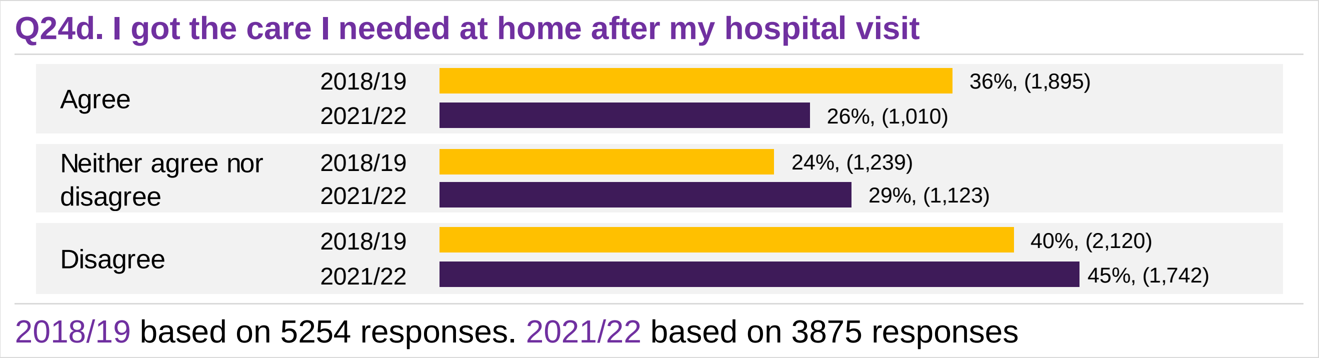


Fig 44. Year on year care after hospital visits – adult respondents

3.9 Support for neurological condition(s)

There still appears to be an issue surrounding care and support plans with 79% (n=5696) of respondents not being offered one in the last three years. Only 21%(n=1525) of respondents had a care plan. In consultation with our steering group, a care plan was defined in the questionnaire as “A care and support plan should outline what treatment is offered to you, who to contact for further information about your treatment, care, or support, what to do if your symptoms change and who to contact in an emergency. It could be written or online.”

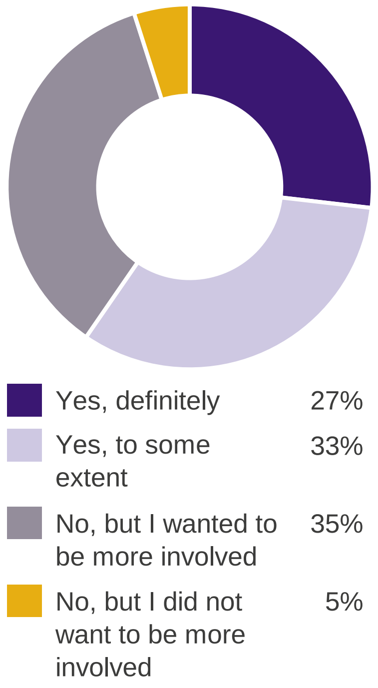
Q25. Within the last three years have you been offered a care and support plan to help you manage your neurological condition?

Based on 7221 responses.

Fig 45. Offered a care plan – adult respondents

Of those who felt it was applicable to them, 27% (n=938) of respondents agree that they were involved in developing a care and support plan centred on their priorities, and 33% (n=1144) felt involved to some extent. However, more than one third (35%, n=1240) don't think they were involved as much as they wanted. Just 5% (n=172) didn’t feel involved but did not want to be.

Q26. Were you involved as much as you wanted to be in developing and agreeing your care and support plan, so that it is centred on your priorities?



Based on 3494 responses

Fig 46. Involvement in developing a care plan – adult respondents

3.10 Mental Wellbeing

1.2.2 Effect of neurological condition on mental wellbeing

The majority of respondents (78%, n=6081) say that their neurological condition has made their mental wellbeing worse (from slightly to much worse). 17% of the respondents (n=1364) have not been affected.

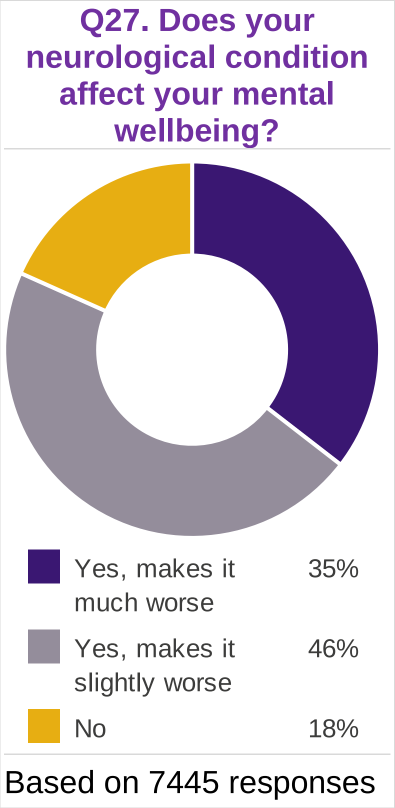


Fig 47. Mental wellbeing – adult respondents

In the last three years, well over half of respondents (60%, n=4373) had not been asked about their mental wellbeing by a health or social care professional.

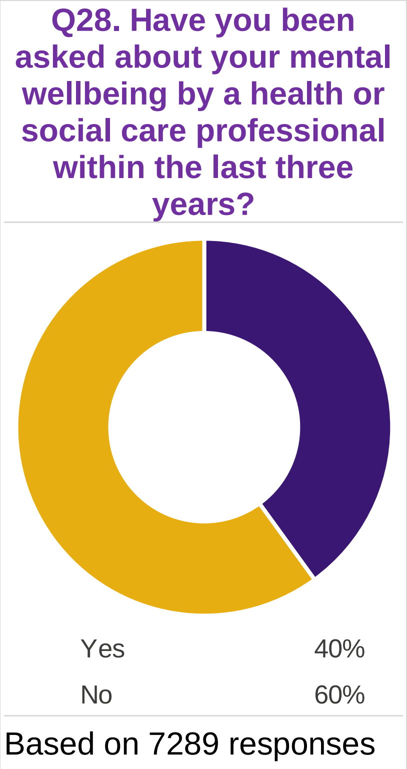


Fig 48. Mental wellbeing and healthcare professionals – adult respondents

1.2.3 Support for mental wellbeing

In the last 3 years, nearly a quarter (23%, n=1706) of respondents have been referred or directed to support their mental wellbeing, whilst 36% (n=2626) have not experienced this but would like to have done. There were two fifths of respondents (41%, n=3009) who did not receive a referral or direction to support but who didn't want or need it.

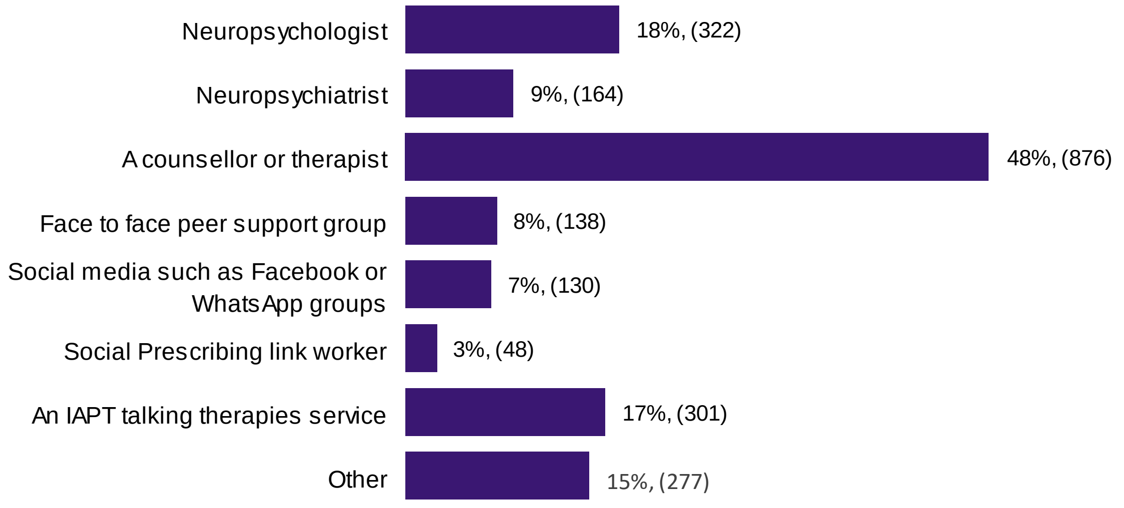
Q29. Have you been referred or directed to support for your mental wellbeing by a health professional within the last three years?

Based on 7341 responses.

Fig 49. Referral or directed to support for mental wellbeing – adult respondents

Respondents who said that they received a referral or direction to support were asked to indicate where they were sent (they could tick all that applied). 48% (n=876) were referred to a counsellor or therapist, followed by 18%(n=322) that were referred to a neuropsychologist and a further 17% (n= 301) that was referred to an Improving Access to Psychological Therapies (IAPT) service.

Q30. Where were you referred or directed to? Tick all that apply



Based on 2256 responses. **Tick all that apply question**

Fig 50. Support received for mental wellbeing – adult respondents

61% (n= 848) of the respondents that accessed the support felt it helped them to feel better and more positive. However, the remaining 39% (n=543) after receiving the same support did not think it had had any positive effect on them.

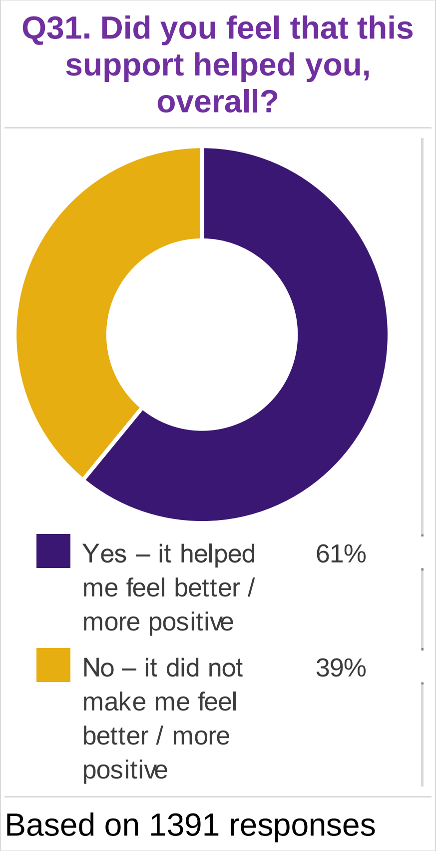


Fig 51. Support received for mental wellbeing – adult respondents

3.10.1 Meeting mental wellbeing needs

Of those who felt that it was applicable to them the results indicate that the majority of respondents 41% (n=2448) do not feel their mental wellbeing needs are being met. 26% (n=1505) only feel their needs are met to a small extent and 24% (n=1393) say they are met to a moderate extent. Just 9% (n=553) said that their mental wellbeing needs are met to a great extent.

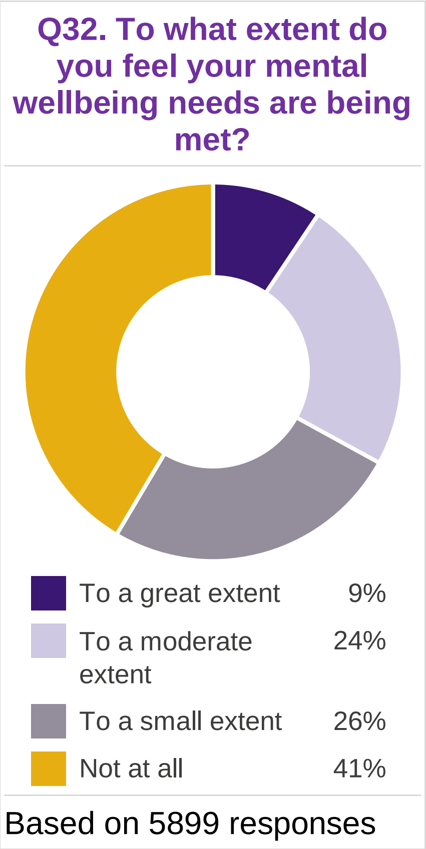


Fig 52. Meeting mental wellbeing needs – adult respondents

People responding to the 2021 survey were less positive that their mental wellbeing needs are being met, compared to those who answered the 2018 survey.

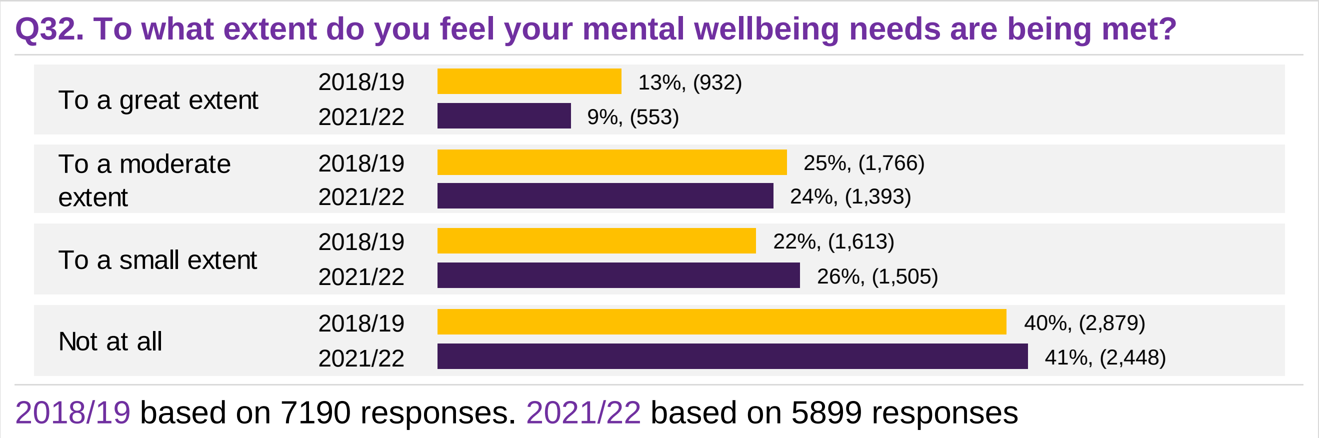


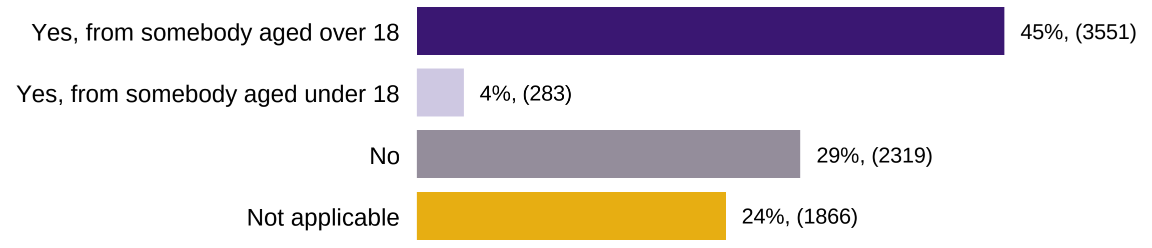
Fig 53. Year on year meeting mental wellbeing needs – adult respondents

3.11 Social care

3.11.1 Unpaid help

The majority of respondents 45% (n=3551) receive care from a friend or family member who is over the age of 18 although there is a small contingent who get this care from someone is under 18, 4% (n=283).

Q33. Do you receive unpaid help with your day-to-day life at home? This could be from a family member, or a friend or neighbour. Tick all that apply



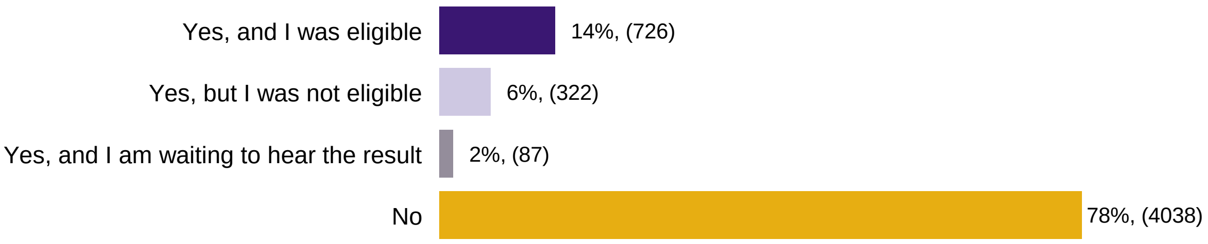
Based on 8019 responses. **Tick all that apply question**

Fig 54. Unpaid help – adult respondents

1.2.1 Assessments for funded care and support

Where it was applicable to their circumstances, the vast majority of respondents (78%=4038) had not been assessed by their local council to see if they were eligible to receive care or support.

Q34. Has your local council assessed your care and support needs to see if you are eligible to receive funded care or support?

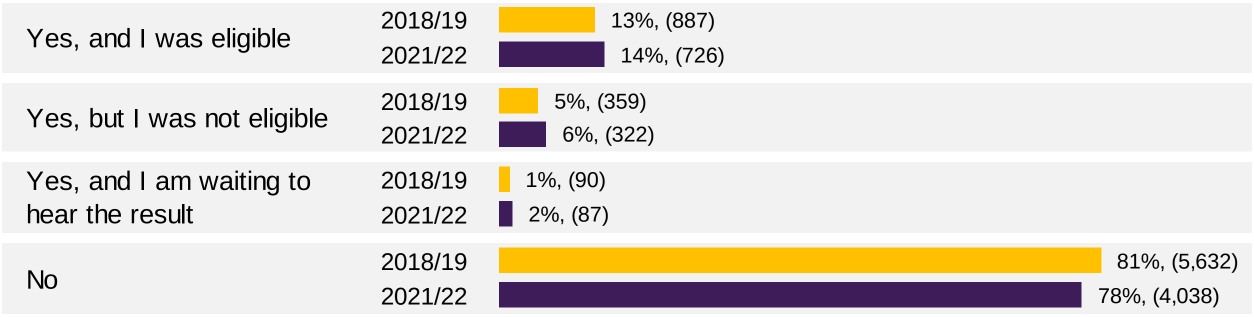


Based on 5173 responses.

Fig 55. Assessments for funded care and support – adult respondents

There has been a slight improvement around respondents saying that they have had an assessment for funded care /support in 2021/22 compared to 2018/19.

Q34. Has your local council assessed your care and support needs to see if you are eligible to receive funded care or support?



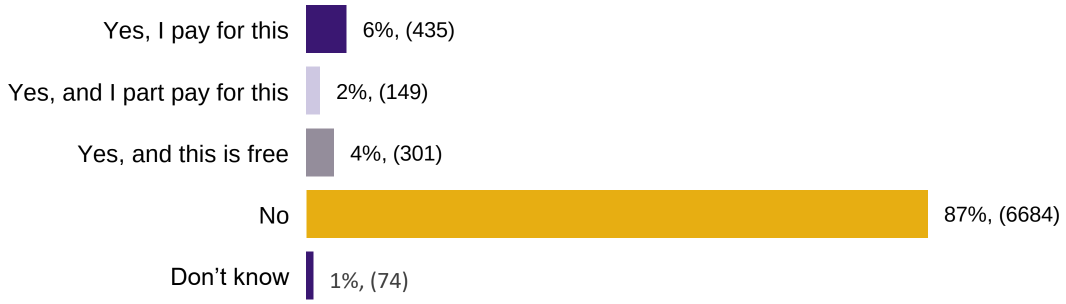
2018/19 based on 6968 responses. 2021/22 based on 5173 responses

Fig 56. Year on year assessments for funded care and support meeting mental wellbeing needs – adult respondents

1.2.2 Sources of social care

The following charts illustrate what types of social care respondents report that they receive. In each case the majority of people said that they do not receive that type of social support/care.

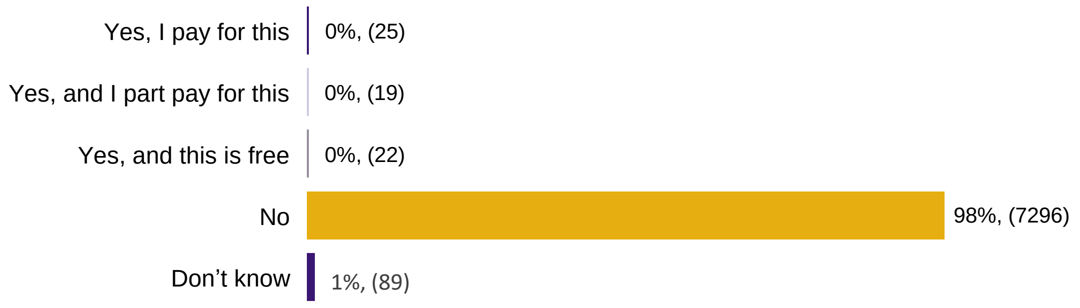
Q35a. Are you receiving any of the following sources of social care? Homecare (e.g. help in your home)



Based on 7643 responses.

Fig 57. In receipt of Homecare – adult respondents

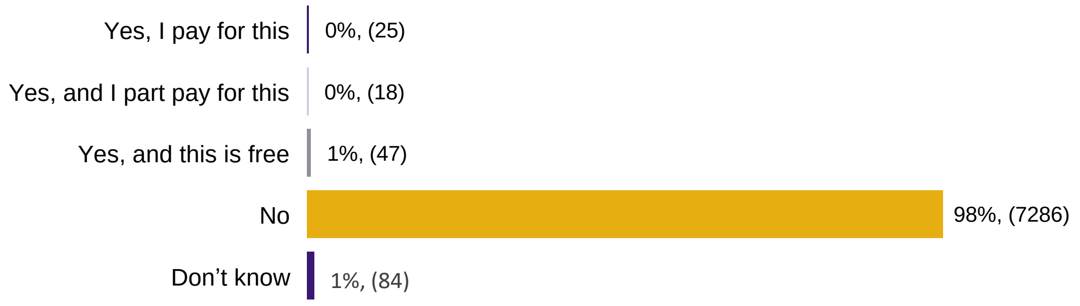
Q35b. Are you receiving any of the following sources of social care? Residential Care (e.g. living in a care home)



Based on 7451 responses.

Fig 58. In receipt of Residential care – adult respondents

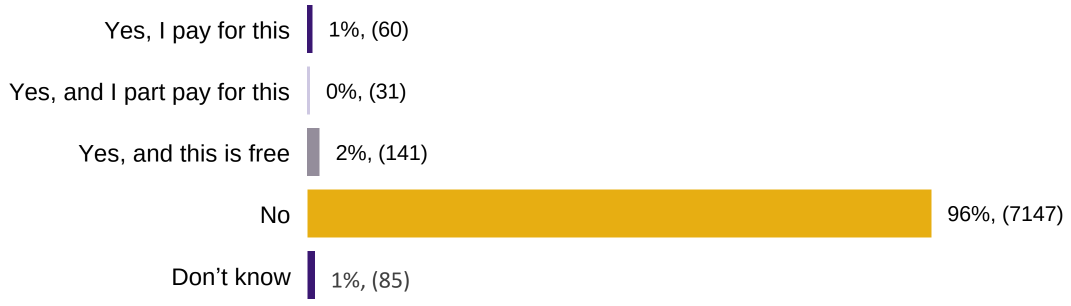
Q35c. Are you receiving any of the following sources of social care? Day services (e.g. attending day centre)



Based on 7460 responses.

Fig 59. In receipt of Day services – adult respondents

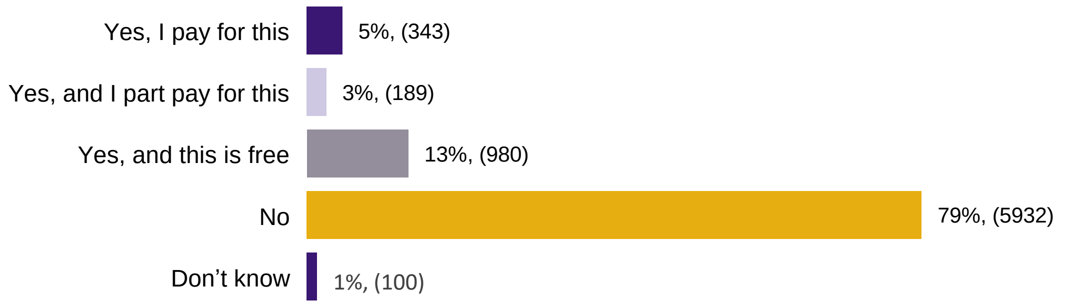
Q35d. Are you receiving any of the following sources of social care? Community Transport



Based on 7464 responses.

Fig 60. In receipt of Community transport – adult respondents

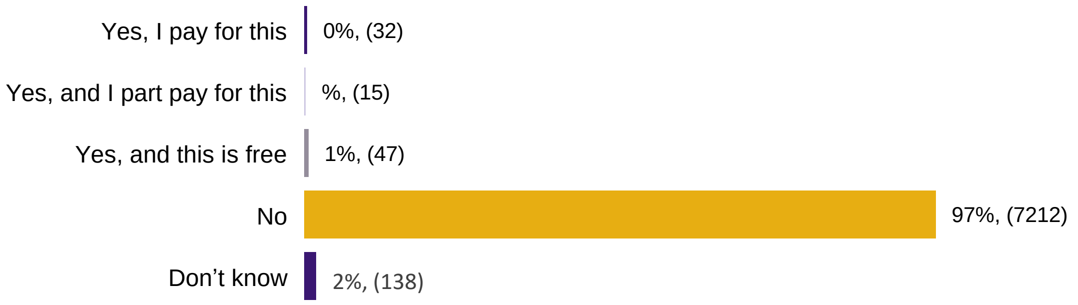
Q35e. Are you receiving any of the following sources of social care? Home adaptations



Based on 7544 responses.

Fig 61. In receipt of Home adaptations – adult respondents

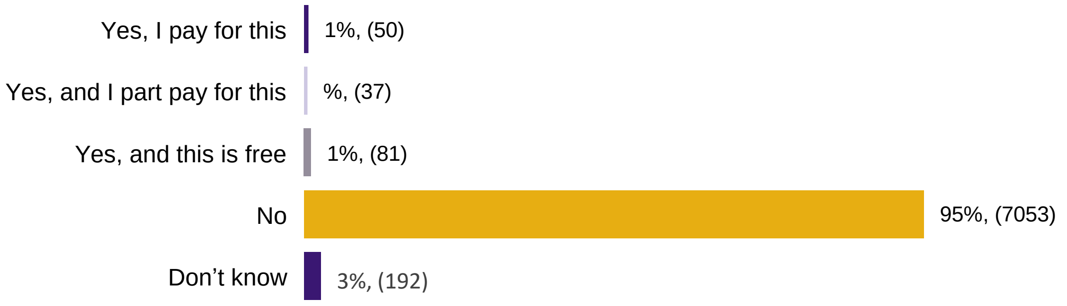
Q35f. Are you receiving any of the following sources of social care? Respite care



Based on 7444 responses.

Fig 62. In receipt of Respite care – adult respondents

Q35g. Are you receiving any of the following sources of social care? Supported living

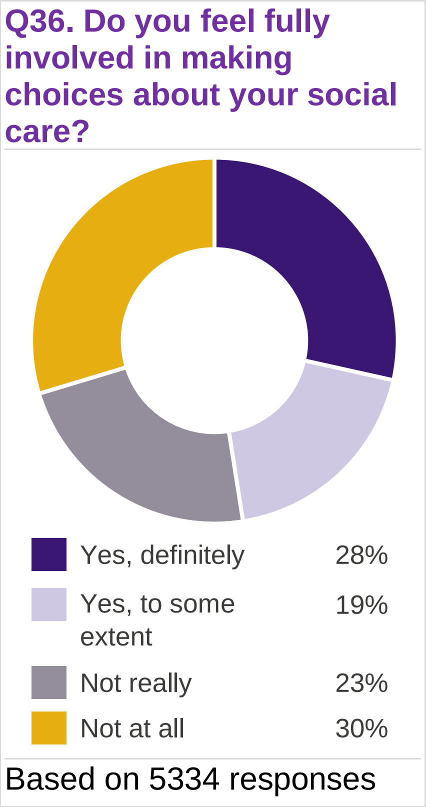


Based on 7413 responses.

Fig 63. In receipt of Supported living – adult respondents

1.2.3 Involvement in social care

Nearly half of the respondents (47%, n=2534) feel involved or involved to some extent with their choices about their social care. However, the majority of the people 53% (n=2800) don't feel they have been involved in their choices.


Q36. Do you feel fully involved in making choices about your social care?

Based on 5334 responses

Fig 64. Involvement in social care – adult respondents

1.2.4 Overall views of social care

Where it was applicable to their circumstances:

- Nearly two fifths of people (39%, n=1182) disagree that the social care they have received meets their needs
- Nearly half of respondents (47%, n=1220) disagree that social care they receive has improved in the past three years
- Just over a quarter (26% n= 657) agree that the social care they have received in the last 3 years has declined

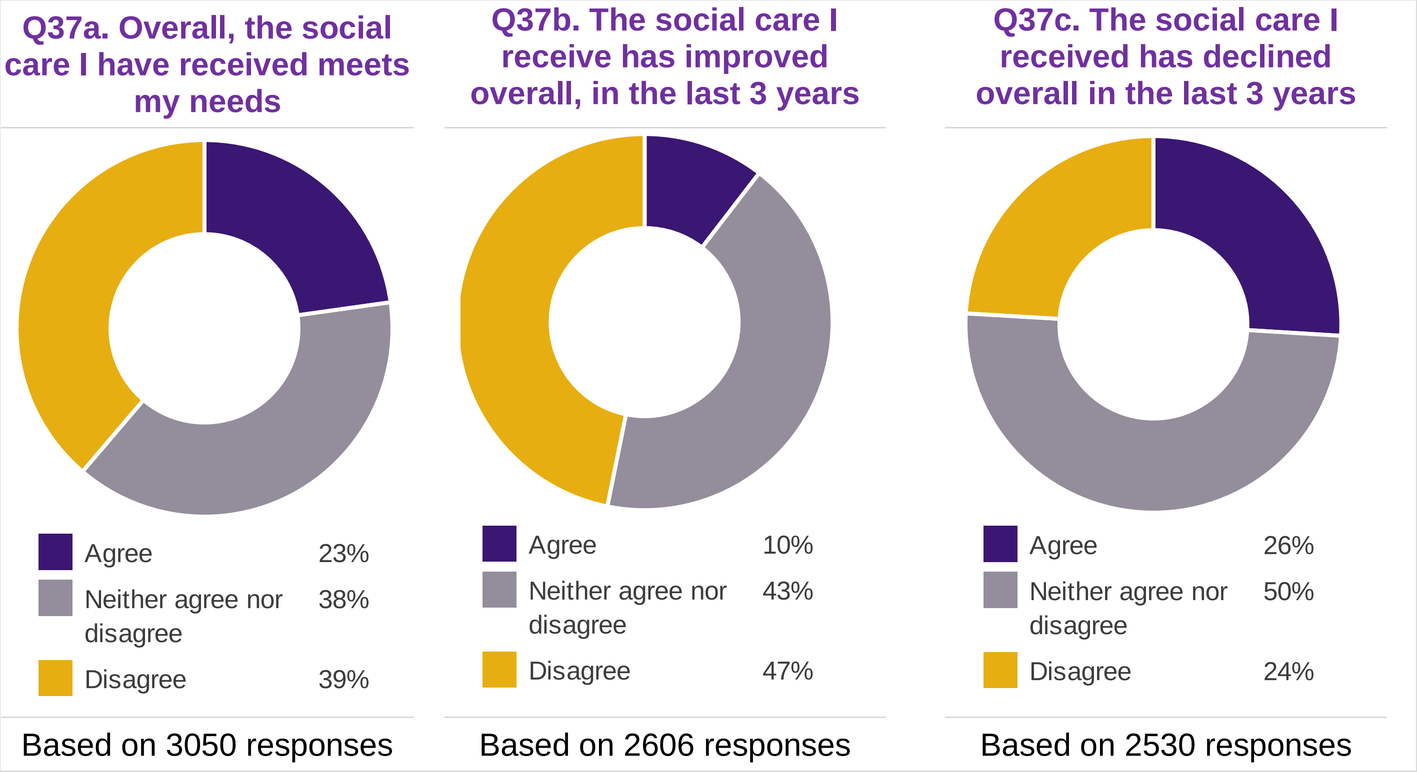


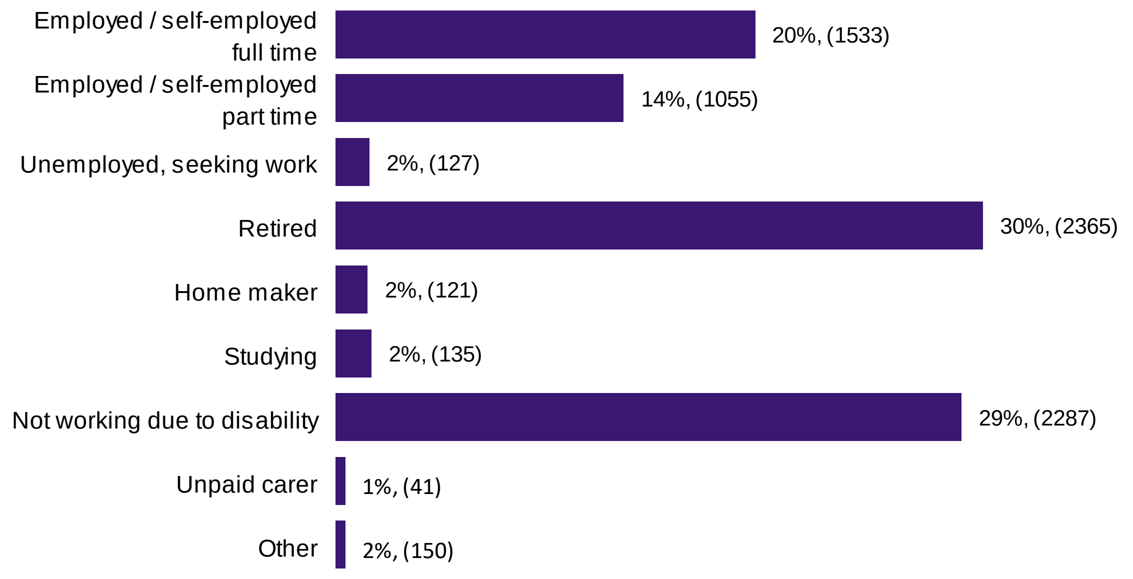
Fig 65. Overall views of social care – adult respondents

3.12 Employment and welfare

3.12.1 Current employment status

The chart below illustrates the employment status of the survey respondents. Nearly one third of the respondents are retired (30%, n=2365), and a further 29% (n=2287) cannot work due to disabilities. However, 20% (n=1533) reported working full time and 14% (n=1055) working part time.

Q38. What is your current work situation?



Based on 7814 responses.

Fig 66. Employment status – adult respondents

3.12.2 Impact of neurological condition on employment

Where it was appliable to their circumstances, there was quite an even split between respondents who agreed that they have been able to continue working since having a neurological condition (47%, n=2629), and those who disagreed (42%, n=2336).

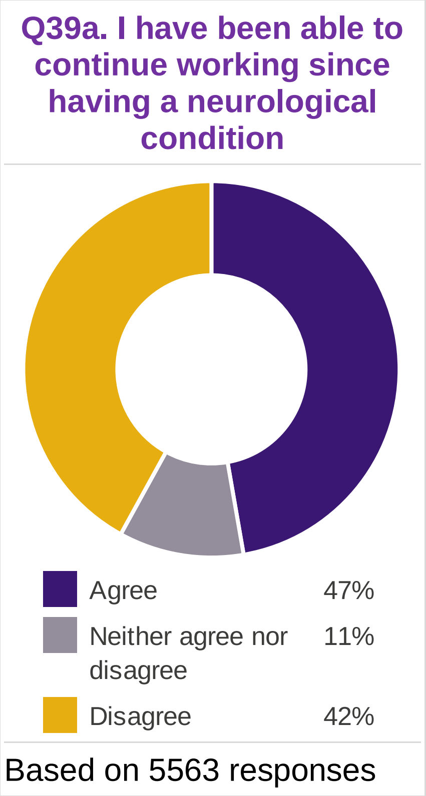


Fig 67. Continue working – adult respondents

However, of those who it applied to 58% (n=3060) agree that they have stopped working due to their neurological condition symptoms.

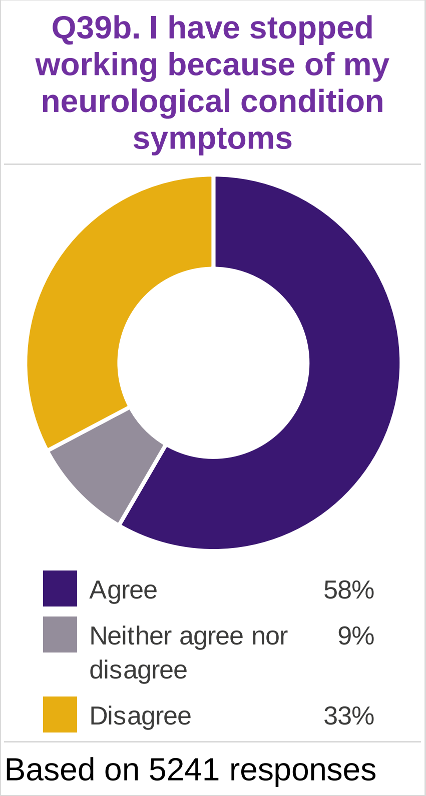


Fig 68. Stopped working – adult respondents

3.12.3 Employers and discrimination at work

Of those who it applied to 28% of respondents (n=1182) reported that they had to leave their job due to their employer's actions / inaction.

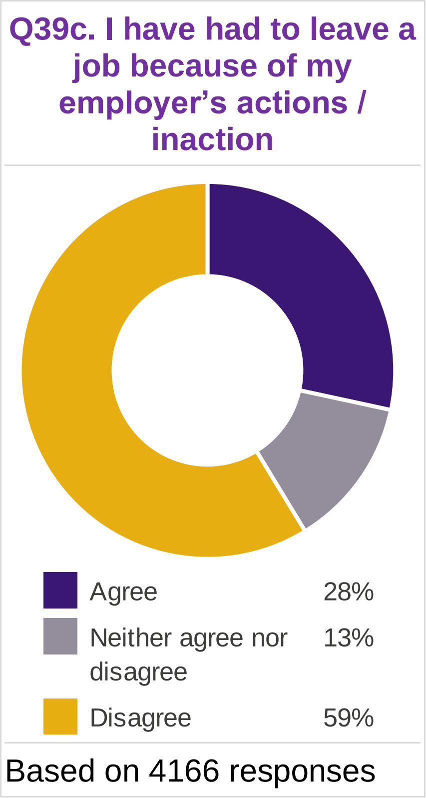


Fig 69. Left work due to employer – adult respondents

There were also a third of people (32%, n=1423) who felt they had been discriminated against at work due to attitudes towards their neurological condition

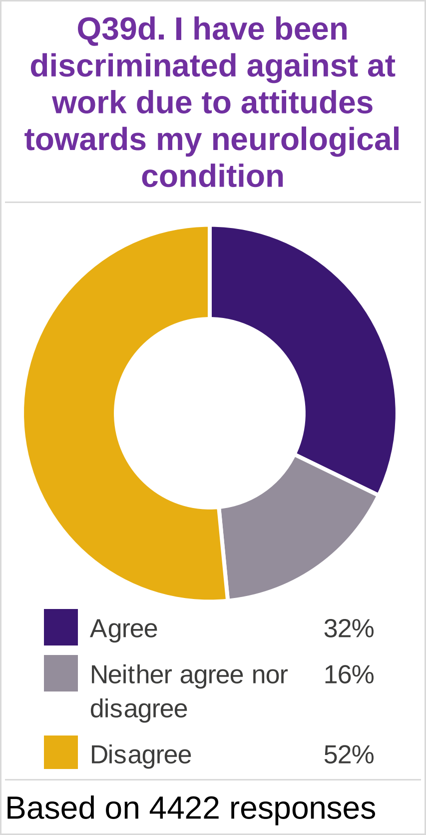


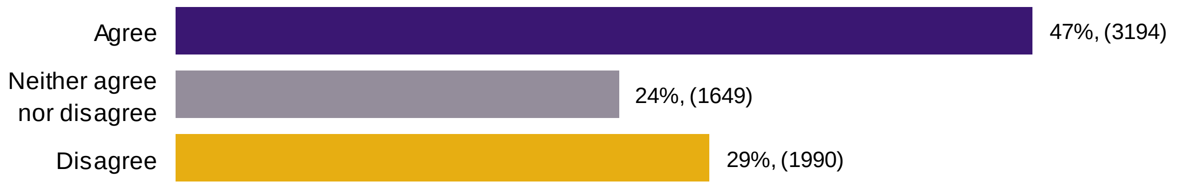
Fig 70. Discriminated against at work – adult respondents

3.12.4 Finances

The charts in this section indicate the response from the people who felt that the statements were applicable to them.

47% of the respondents (n= 3194) agreed they have enough money to manage well, although 29%(n=1990) disagreed.

Q40a. We / I have enough money to manage well

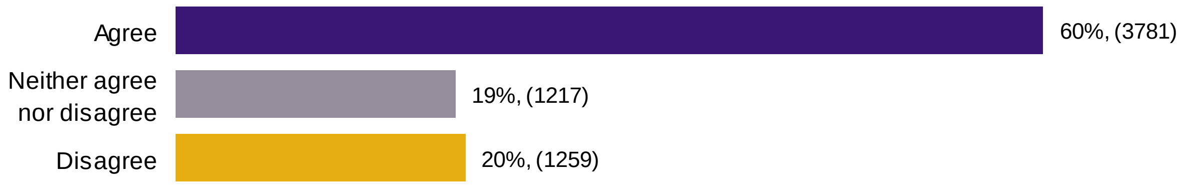


Based on 6833 responses.

Fig 71. Have enough money to manage – adult respondents

60% of respondents (n= 3781) agreed they have enough money to get by while of a fifth disagreed (20%, n=1259).

Q40b. We / I have enough money to get by

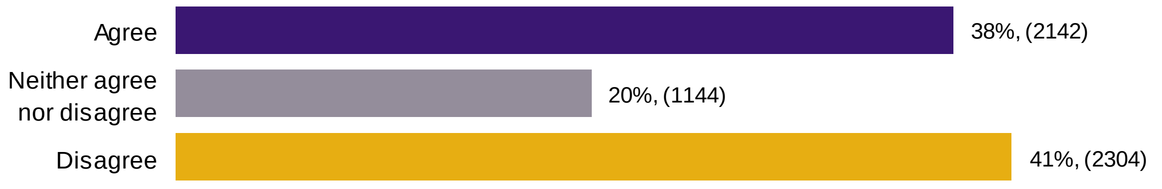


Based on 6257 responses.

Fig 72. Have enough money to get by – adult respondents

Nearly two fifths of respondents (38%, n= 2142) agreed they have enough money to manage by but need to use their savings, 41%(n=2304) disagreed with the same statement.

Q40c. We / I have enough money to get by but are dependent on using our savings



Based on 5590 responses.

Fig 73. Dependent on savings – adult respondents

23% of the people with neurological conditions (n=1308) agree that they struggle to cover their costs, although over half (55%, n=3139) disagreed.

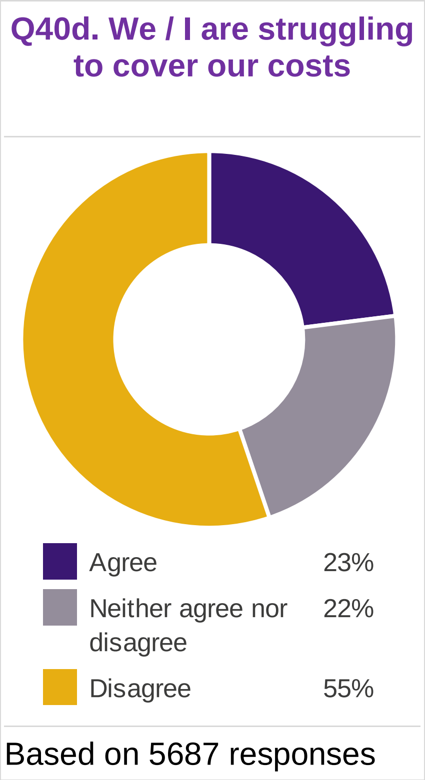


Fig 74. Struggling to cover costs – adult respondents

The majority of respondents disagreed (71% n=3917) that they don’t have enough money to cover their basic needs, however there are 606 people (11%) who agreed with the statement.

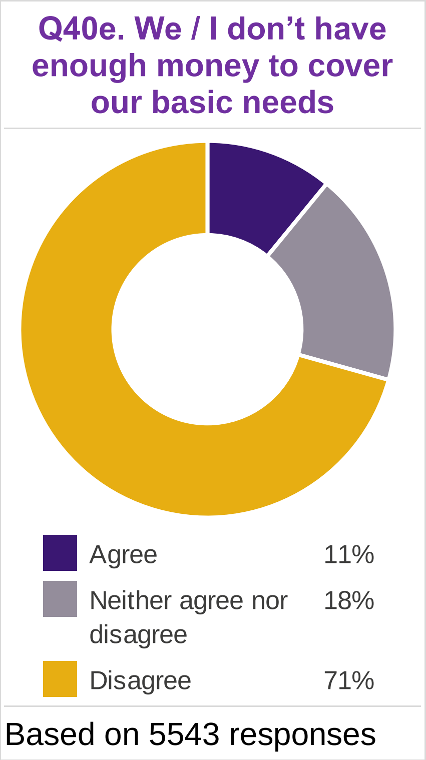


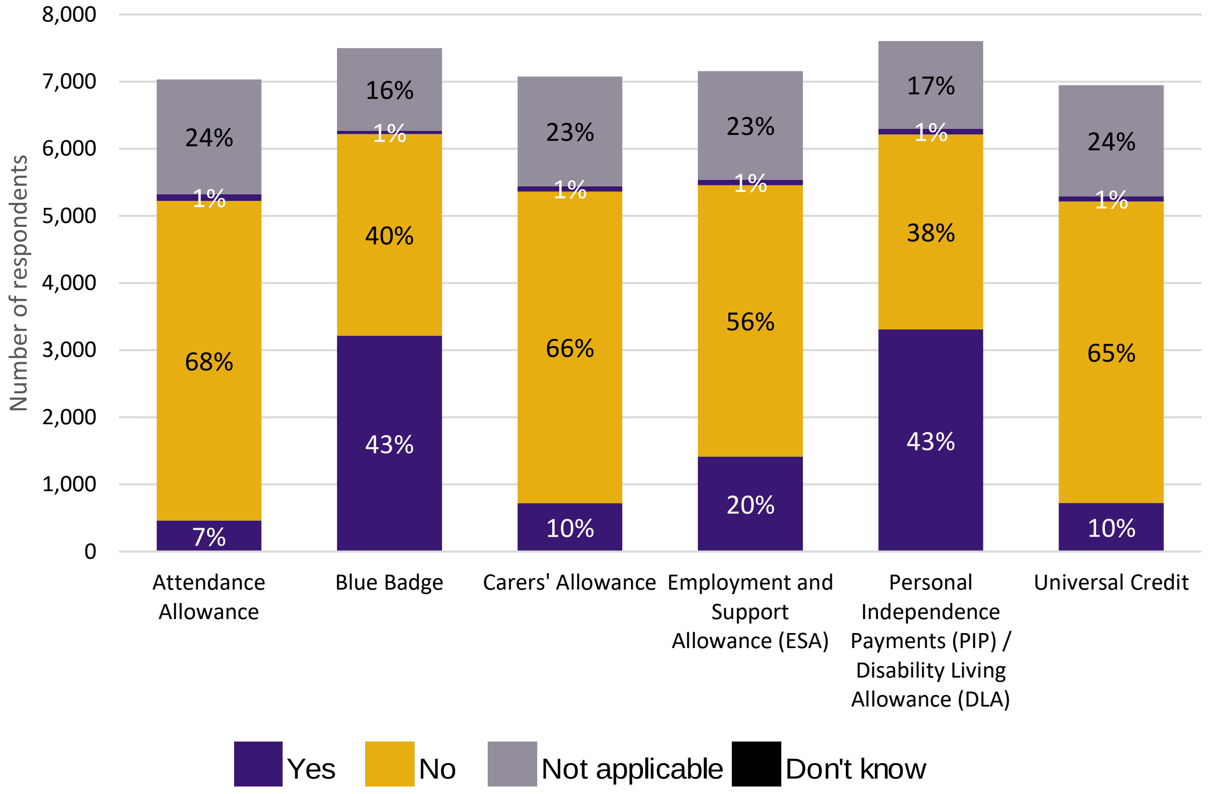
Fig 75. Unable to cover basic needs – adult respondents

3.12.5 Additional financial support and benefits

The chart below illustrates what additional financial support and benefits respondents or people who care for them receive. Not all respondents reported that these were applicable to them.

- 7% (n=461) receive an Attendance Allowance
- 43% (n= 3217) have a Blue Badge
- 66% (n= 4642) do not receive Carers' Allowance
- 56% (n=4043) do not receive Employment and Support Allowance (ESA)
- 43% (n= 3308) receive Personal Independence Payment (PIP)/Disability Living Allowance (DLA)
- 65% (n= 4490) do not receive Universal Credit (UC)

Q41. Are you, or a family / friend who cares for you, in receipt of any of the following?



Based on responses for: Attendance Allowance – 7034, Blue Badge – 7501, Carers' Allowance – 7076, Employment and Support Allowance (ESA) – 7157, Personal Independence Payments (PIP) / Disability Living Allowance (DLA) – 7605 and Universal Credit – 6945.

Fig 76. Additional financial support and benefits – adult respondents

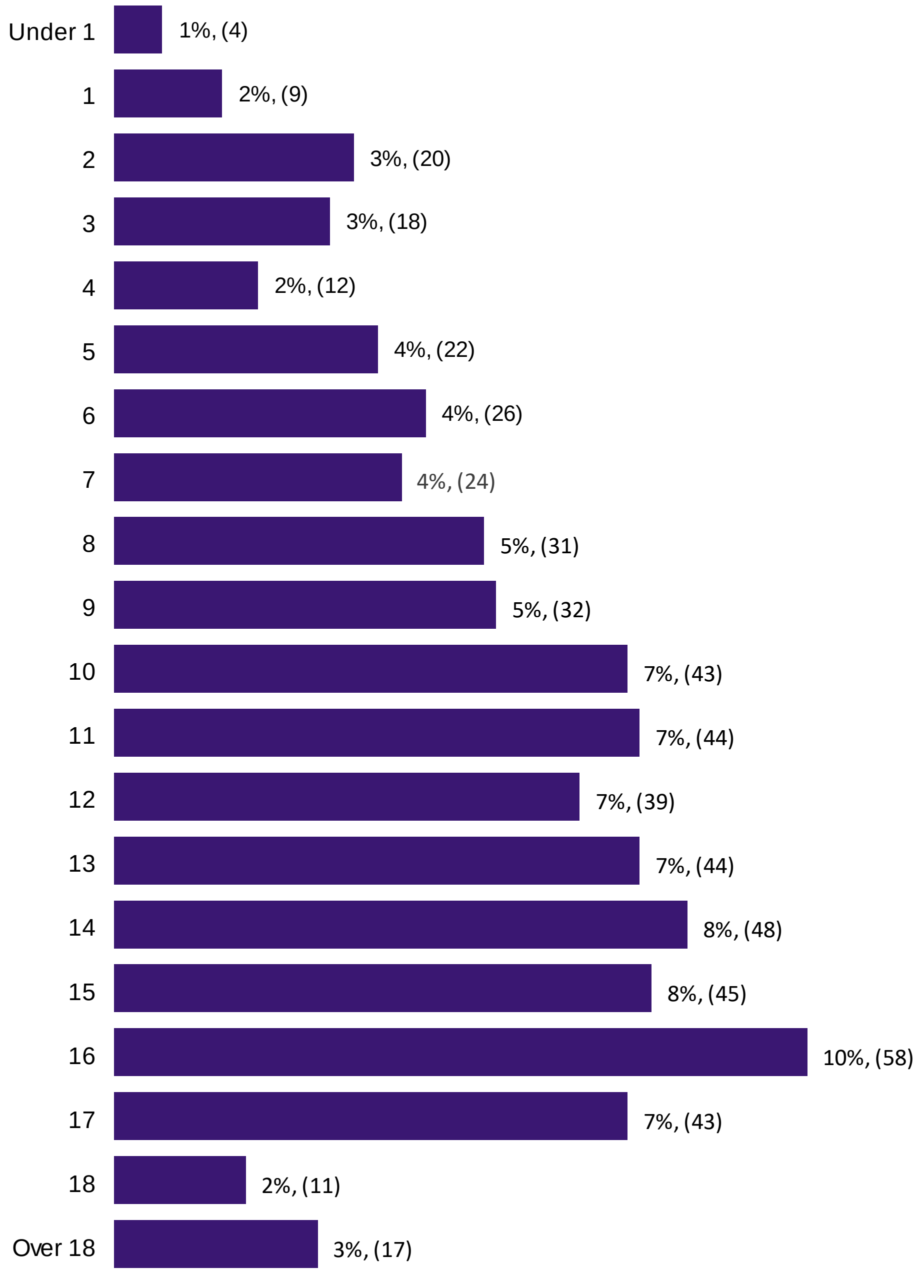
4. Results of the Paediatric questionnaire

4.1 Respondent characteristics

4.1.1 Age

Just over two thirds of respondents (64%) were aged between 10 and 18. 33% of respondents were aged between 1 and 9. 1% were under the age of one and 3% were aged over 18. [3]

Q46. Age Band (derived from "What is your year of birth?")



Based on 590 responses.

Fig 77. Age range of paediatric respondents

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[3] Percentages do not add up to exactly 100% due to rounding.

4.1.2 Ethnicity

As with the adult survey, the majority of respondents identified themselves as ‘White’ - either English / Welsh / Scottish / Northern Irish / British – or Irish / other White background (92% n=570).

The numbers of those identifying themselves as Black (including African, Caribbean and other Black background), Asian (including Bangladeshi, Indian, Chinese and other Asian background), Mixed Heritage (including White & Asian, White & Black African, White & Black Caribbean and other Mixed background), Arab or any other ethnicity except White, is very low (just 8% n=50).

Nine respondents did not answer this question.

4.1.3 Gender

309 respondents (50% overall) identified themselves as female. 47% (n=293) identified themselves as male. 10 respondents describe themselves as non-binary and 8 individual respondents preferred to not to say their gender.

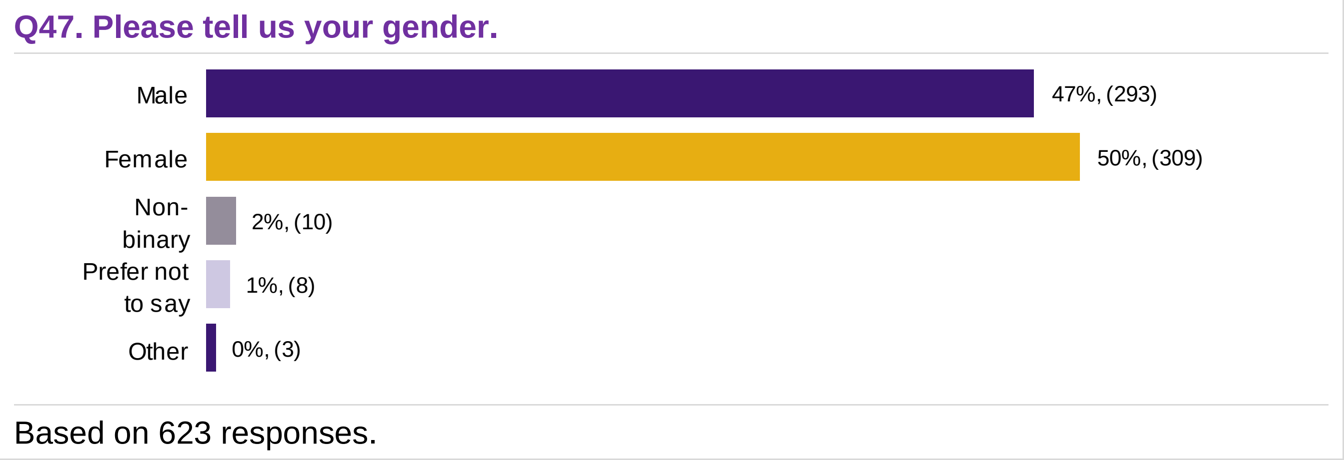


Fig 78. Gender breakdown of paediatric respondents

Only 7 respondents identified themselves as trans whilst 1%(n=6) were unsure and 1%(n=9) preferred to not say.

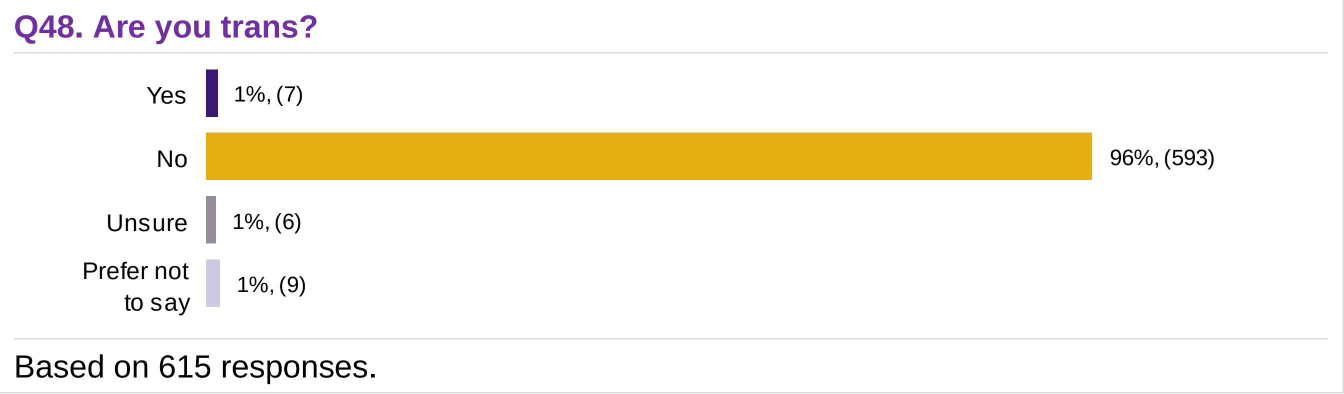


Fig 79. Transgender breakdown of paediatric respondents

4.1.4 Co-morbidities

Less than half of the respondents with neurological conditions (44% n=273) live with other conditions.

Q45. Apart from your neurological conditions, do you live with any other conditions?

Based on 614 responses.

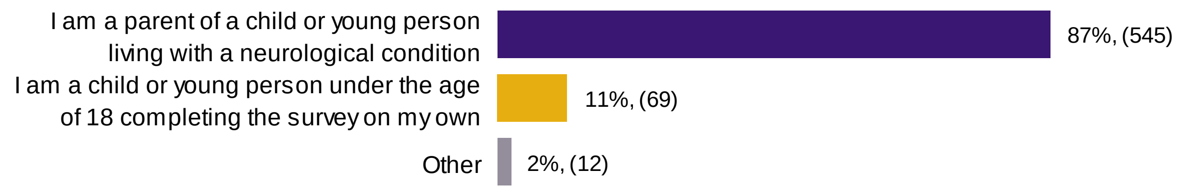
Fig 80. Co-morbidities of paediatric respondents

4.2 Introductory questions

4.2.1 Completing the questionnaire

The majority of respondents (87%, n=545) were parents filling the survey on behalf of a child or young person with a neurological condition (or conditions). 11% (n= 69) were responses from children or young people under the age of 18 filling the survey on their own.

Q1. In what capacity are you filling in this survey?



Based on 626 responses.

Fig 81. Method of survey completion for paediatric respondents

4.2.2 Conditions

Respondents were asked to report what neurological condition(s) they have, from a list of 48 conditions. [4]

601 respondents reported at least one condition, 68 said they are awaiting a diagnosis (of which 22 do not have a diagnosis of any other neurological condition) and 6 did not answer.

Of those respondents who were able to report having a condition, 331 (55%) reported living with one condition while 270 (45%) reported living with more than one condition.

The five conditions with the highest number of paediatric respondents were:

Epilepsy	179
Hydrocephalus	119
Tourette syndrome	118
Autism	102
Functional neurological Disorder (FND)	64

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[4] Respondents were able to select multiple responses to this question

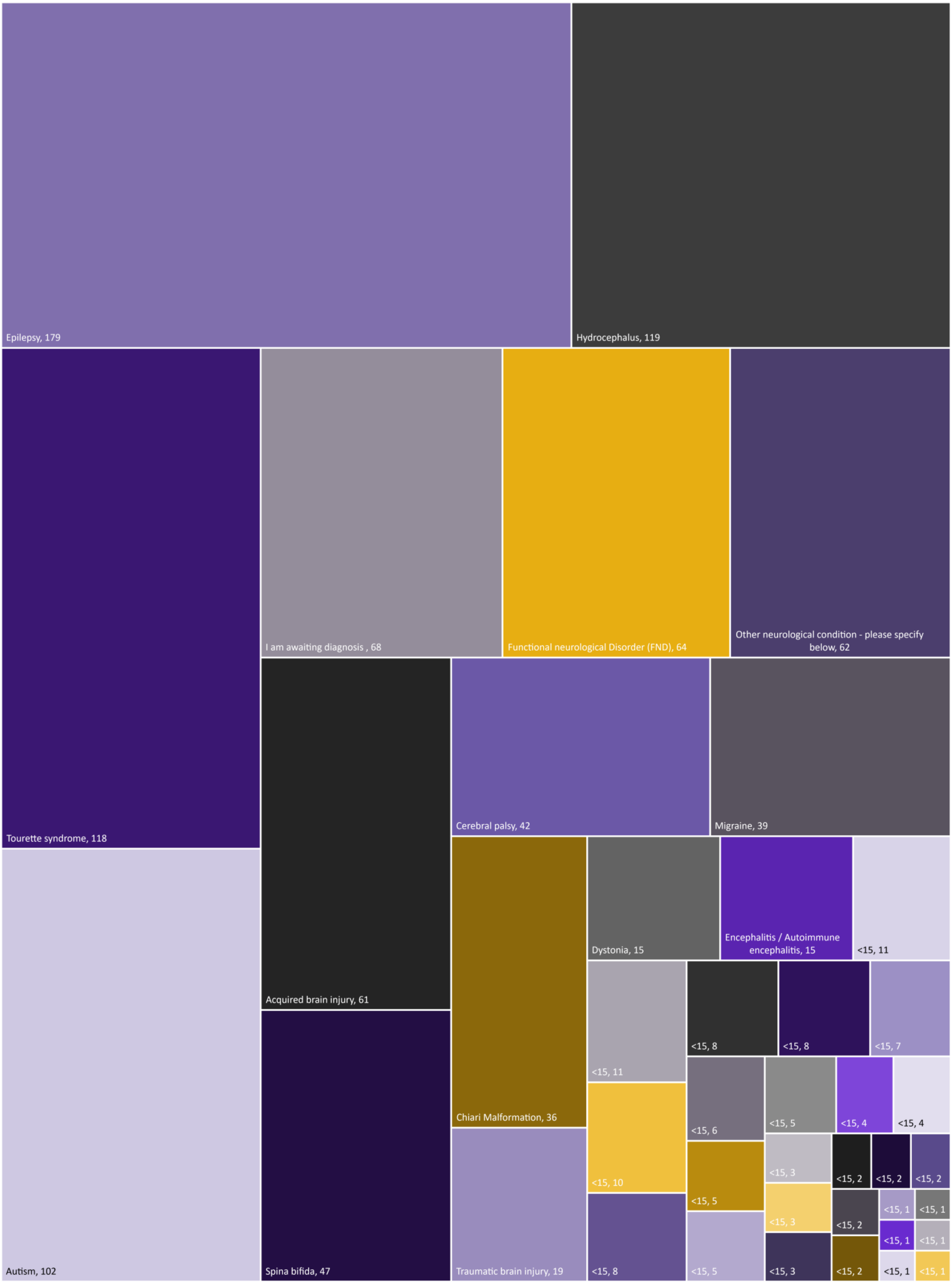


Fig.82 Condition representation for paediatric respondents

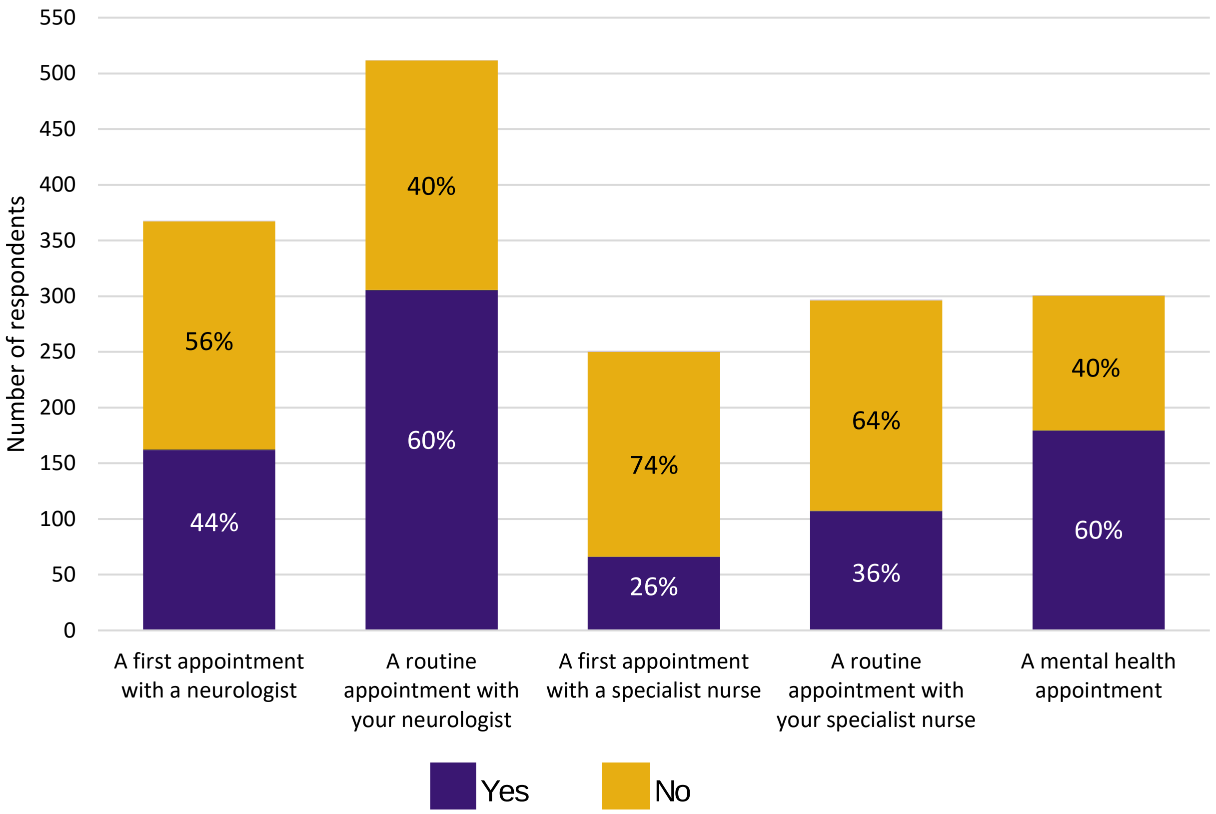
4.3 Care during the COVID-19 pandemic

4.3.1 Delays to care and treatment

Where it was applicable to their circumstances in the last 12 months:

- 44% (n= 162) experienced a delay with their first appointment with a neurologist
- 60% (n=305) experienced delays at being seen by a neurologist for their routine appointment
- 26% (n= 66)) faced delays at being seen by a specialist nurse for the first time
- 36% (n= 107) experienced delays at seeing a specialist nurse for their routine appointments
- 60%(n=179) experienced delays with a mental health appointment

Q3. Have you experienced delays to your neurological care or treatment in the past 12 months? Appointments



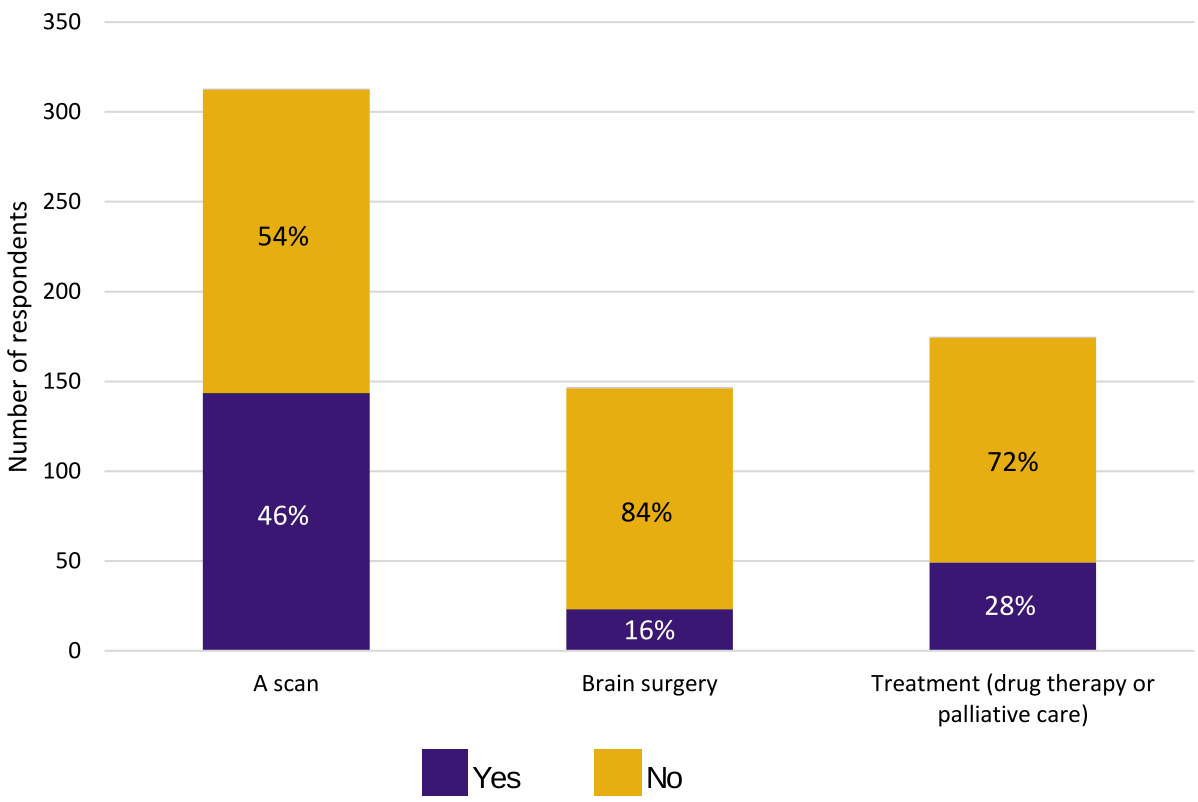
Based on responses for: A first appointment with a neurologist – 367, A routine appointment with your neurologist – 511, A first appointment with a specialist nurse – 250, A routine appointment with your specialist nurse – 296 and A mental health appointment – 300

Fig 83. Delays to appointments – paediatric respondents

Where it was applicable to their circumstances in the last 12 months:

- 46% (n=143) experienced a delay in getting a scan
- 16% (n=23) experienced delays to neurosurgery
- 28% of respondents (n=49) faced delays at receiving drug therapy in hospital

Q3. Have you experienced delays to your neurological care or treatment in the past 12 months? Hospital scans and treatment



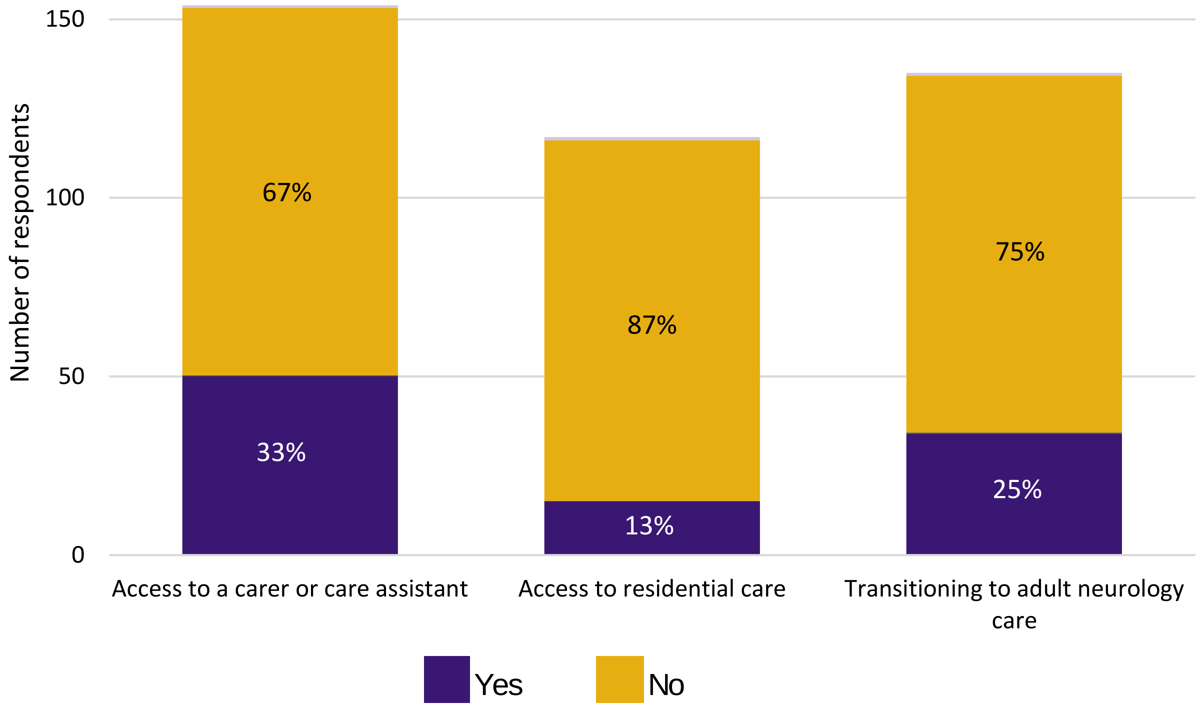
Based on responses for: A scan – 312, Brain surgery – 146 and Treatment – 174

Fig 84. Delays to hospital scans and treatment – paediatric respondents

Where it was applicable to their circumstances in the last 12 months:

- 33% (n= 50) of respondents experienced a delay accessing a carer or care assistant
- 13% (n=15) faced delays accessing residential care
- 25% (n= 34) experienced delays with transitioning to adult care

Q3. Have you experienced delays to your neurological care or treatment in the past 12 months? Additional care needs



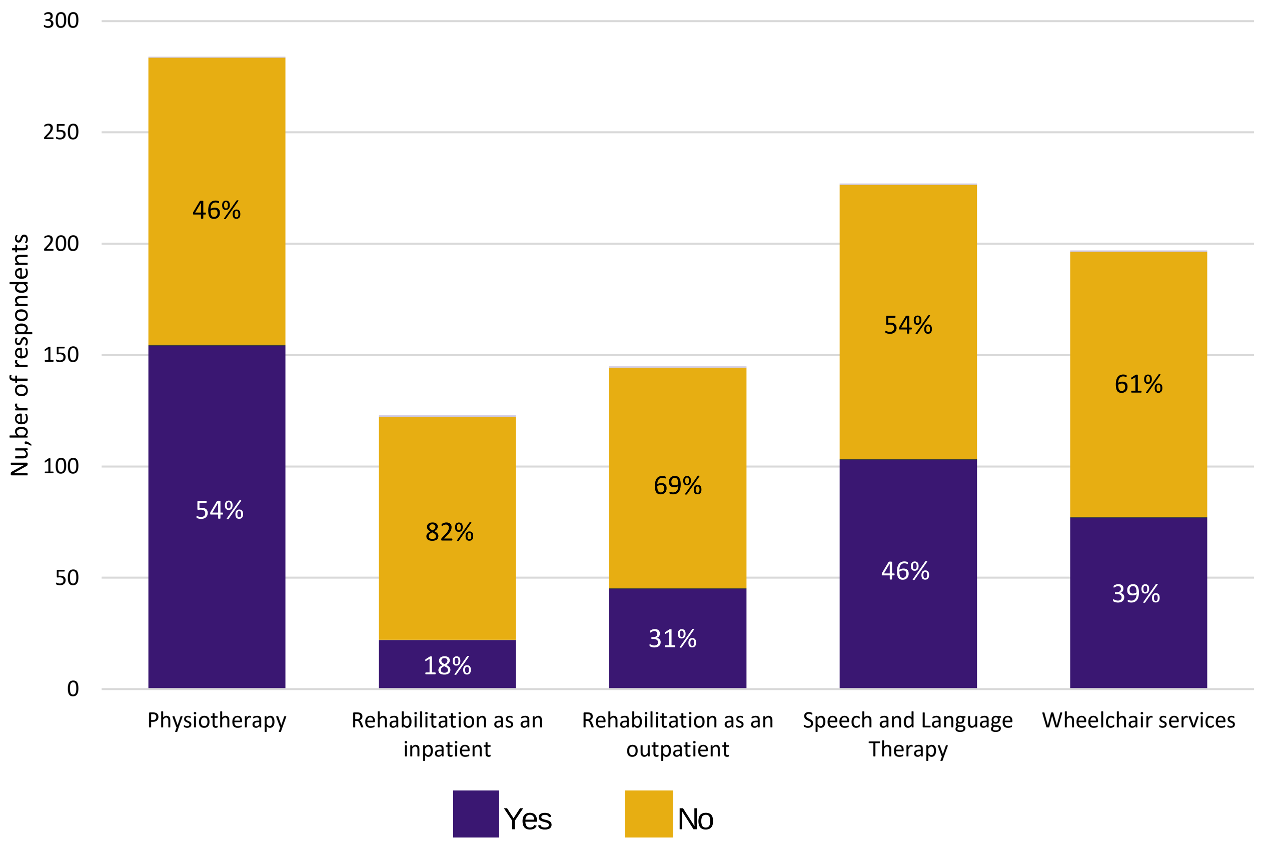
Based on responses for: Access to a carer or care assistant – 153, Access to residential care – 116, and Transitioning to adult neurology care – 134

Fig 85. Delays to additional care needs – paediatric respondents

Where it was applicable to their circumstances in the last 12 months:

- More than half of respondents (54%, n=154) reported delays accessing Physiotherapy
- 18% (n=22) of people experienced delays to access Rehabilitation as an inpatient
- Just under a third (31%, n=45) of respondents faced delays with Rehabilitation as an outpatient
- Nearly half (46%, n=103) reported a delay with Speech and Language therapy
- 39% (n=77) experienced delays to access to Wheelchair services.

Q3. Have you experienced delays to your neurological care or treatment in the past 12 months? Rehabilitation and physical therapies



Based on responses for: Physiotherapy – 283, Rehabilitation as an inpatient – 122, Rehabilitation as an outpatient – 144, Speech and Language Therapy– 226 and Wheelchair services – 196

Fig 86. Delays to rehabilitation and physical therapies – paediatric respondents

4.3.2 Remote appointments

The majority of children/young people 73% (n=445), said that they like talking to their doctor/healthcare professional in person the most. 10% (n=61) like a video conference while 7% (44) like talking over the phone the most. 66 individuals were not sure.

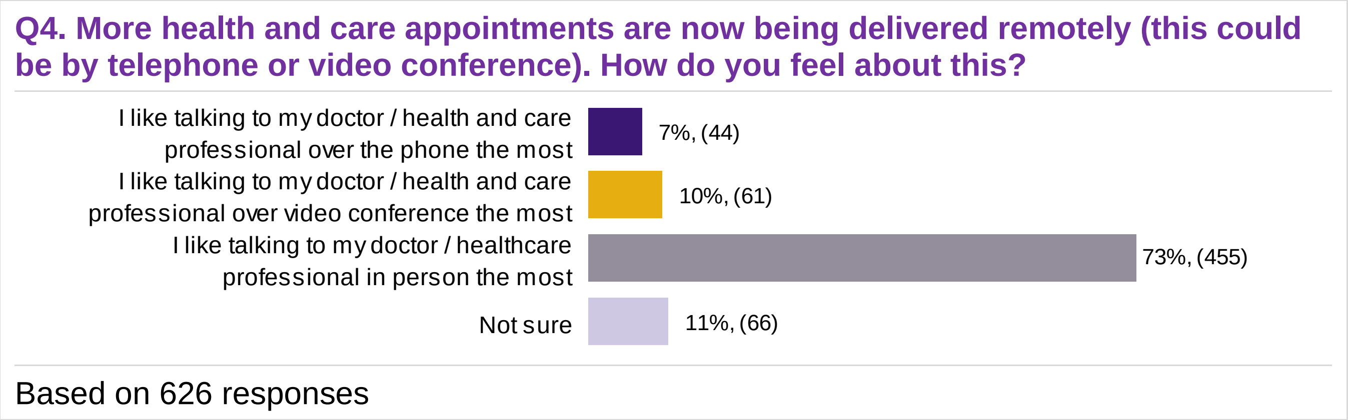


Fig 87. Preferences for remote appointments – paediatric respondents

49%(n=279) of respondents agreed that the remote appointments were useful, followed by 32% of people (n =183) neither agreeing nor disagreeing. 19% (n=110) disagreed that their remote appointments were useful.

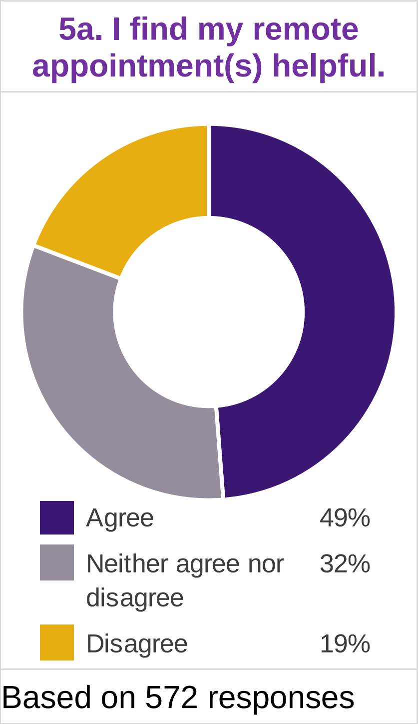
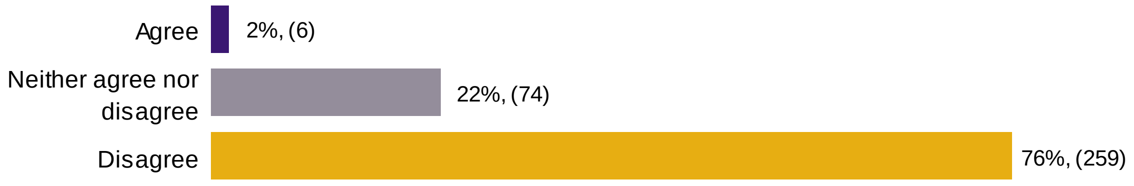


Fig 88. Helpfulness of remote appointments – paediatric respondents

Only 2% of respondents (n=6) reported not having a remote appointment because they couldn’t access the right technology. 76%(n=259) indicated that this was not the case and 22% (n=74) gave a neutral response.

Q5b. I have not had a remote appointment because I don’t have access to the right technology.

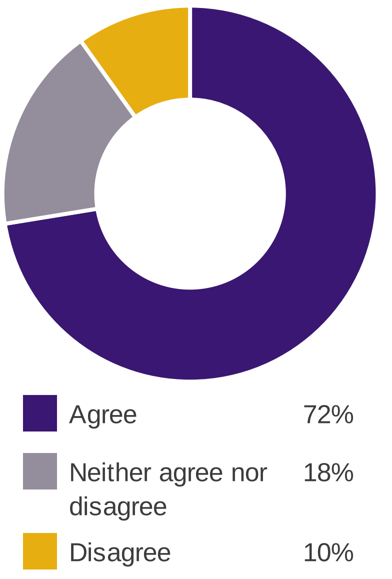


Based on 339 responses.

Fig 89. Access to technology for remote appointments – paediatric respondents

Nearly three quarters of respondents (72%, n=410) agree that they feel confident in using the technology followed by nearly one fifth (18%, n=100) that neither agree nor disagree. A further 10% (n=56) do not feel confident in using technology.

5c. I feel confident in using the technology



Based on 566 responses

Fig 90. Confidence in using technology – paediatric respondents

The majority of children/young people (78% n=439) have access to a suitable space for remote appointments. 7% (n=38) indicated this was not the case followed by 15% (n =83) that neither agree nor disagree.

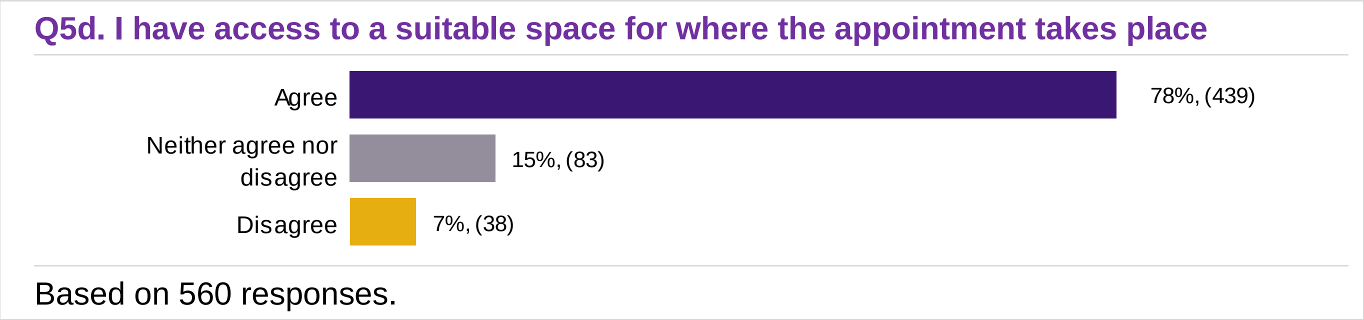


Fig 91. Access to a suitable space for remote appointments – paediatric respondents

A quarter of respondents (25%, n=139) think that the remote appointments are not useful, followed by 36% (n =199) that neither agree nor disagree while 36%(n=219) disagreed

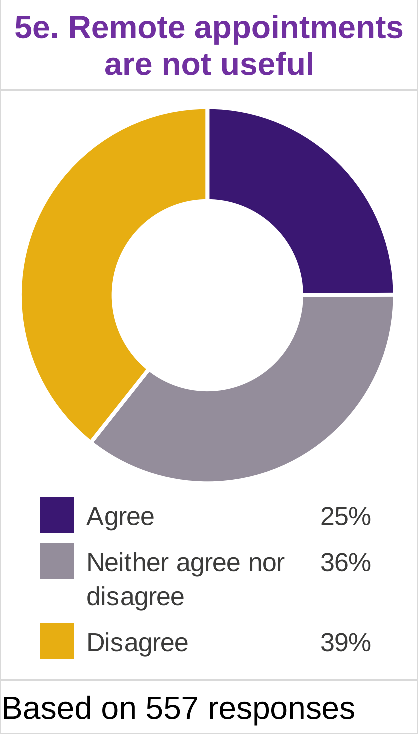


Fig 92. Remote appointments are not useful – paediatric respondents

The majority of respondents (55%, n=304) agree that their health / care professional(s) call them when they expect them to, followed by 25% of people (n =140) that neither agreeing nor disagreeing. However, 20% (n=112) of the respondents disagreed that this is the case.

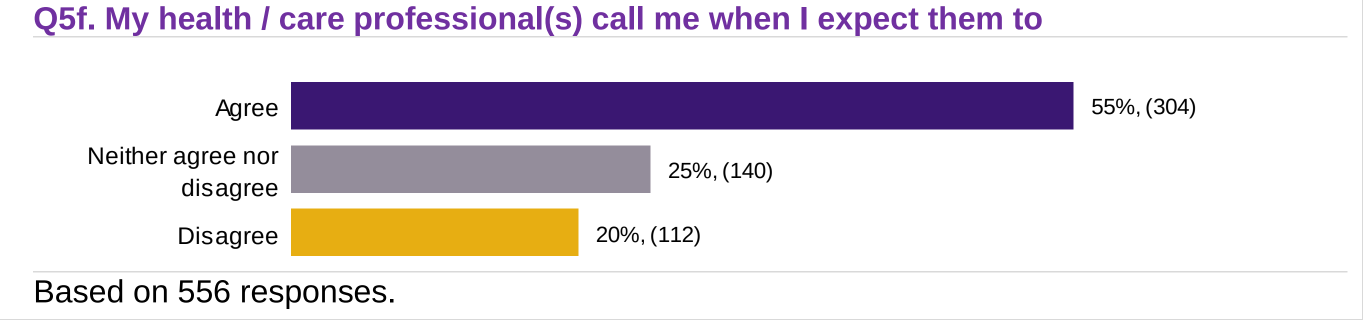


Fig 93. Healthcare professionals calling when expected – paediatric respondents

Nearly two thirds of respondents 63% (n= 349) do feel that their mental health has been affected by the pandemic. 33%(n=186) feel their mental health has remained the same leaving only 4%(n=23) of the respondents that say their mental health has improved.

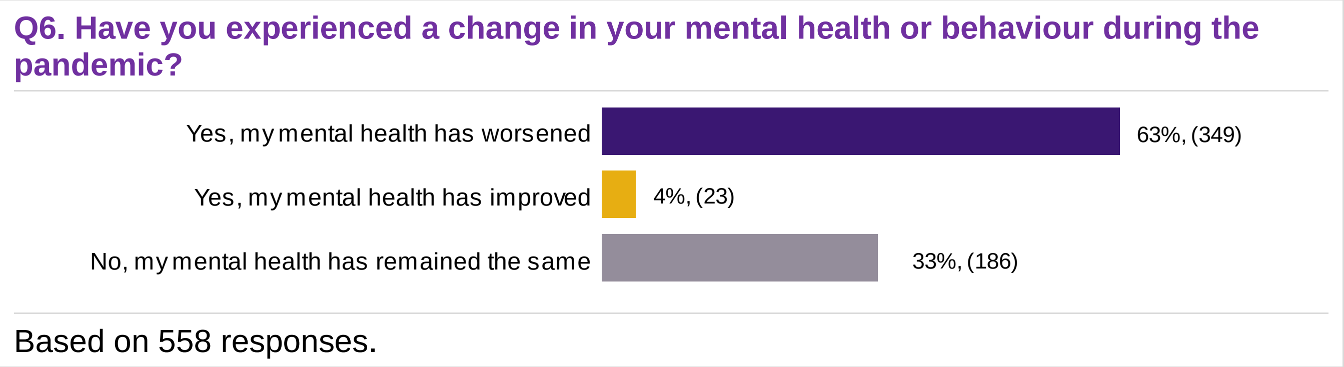


Fig 94. Change to mental health needs due to Covid-19 – paediatric respondents

4.4 Overall impact of neurological conditions

43%(n=263) of respondents reported that their neurological condition affected their quality of life to a great extent (the most severe response option). A further 33% (n=205) reported that their neurological condition affected their quality of life to a moderate extent followed by a 18% (n=114) that were affected to a small extent. Just 6% (n=36) of respondents reported that their neurological condition did not affect their quality of life at all.

73% (n=453) of respondents reported that their neurological condition affected their day-to-day activities to a moderate or great extent.

In terms of pain or discomfort caused by neurological conditions, nearly half of the respondents (47%, n=264) reported that their condition caused pain or discomfort to a moderate or great extent.

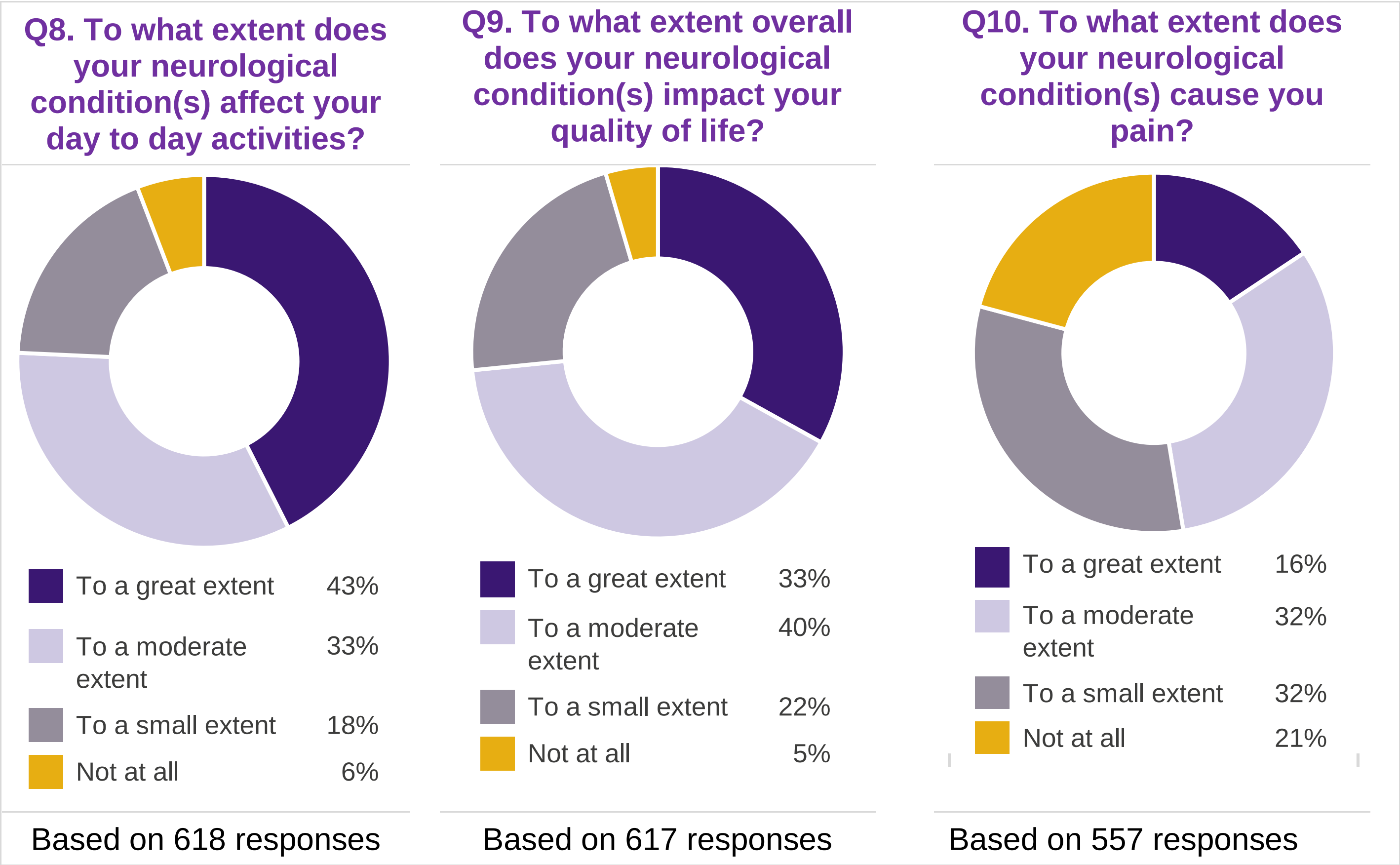


Fig 95. Overall impact of neurological conditions – paediatric respondents

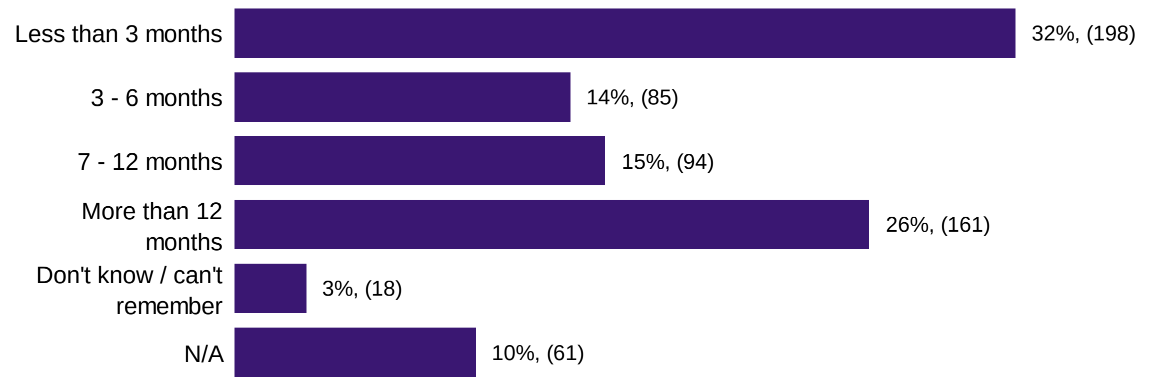
4.5 Before diagnosis

4.5.1 Waiting for a diagnosis

Children and young people report slightly more favourably than adult respondents for obtaining a confirmed and accurate diagnosis for their neurological condition, however there is still improvement needed

- Nearly a third of respondents (32%, n=198) waited less than 3 months from first experiencing symptoms to getting a diagnosis
- 14% (n=85) received a diagnosis in 3-6 months
- 15% (n=94) were diagnosed in 7-12 months
- Over a quarter (26%, n=161) waited over 12 months for a diagnosis.

Q11a. How long were you waiting between first experiencing symptoms to getting a diagnosis?



Based on 617 responses.

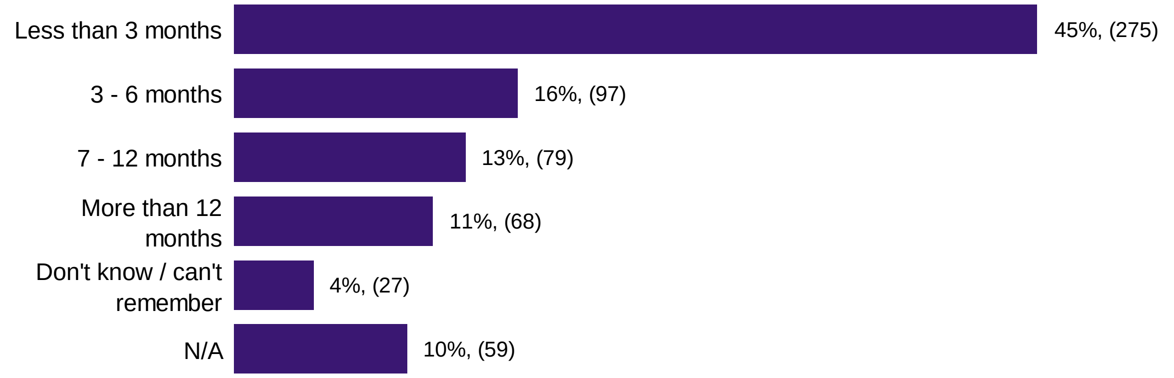
Fig 96. Waiting for a diagnosis – paediatric respondents

4.5.2 Waiting to see a hospital based paediatrician

The majority of children/young people did wait less than 3 months to see a hospital based paediatrician (45%, n=275).

- 16%, (n=97) waited 3-6 months
- 13% (n=79) waited 7-12 months
- 11% (n=68) waited over 12 months

Q11b. How long were you waiting between first seeing a GP (or having an emergency admission) to seeing a hospital based paediatrician?



Based on 617 responses.

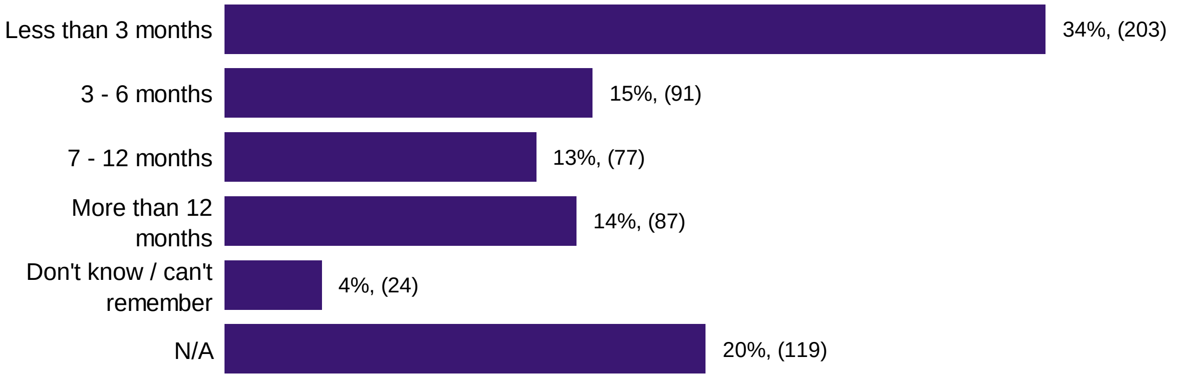
Fig 97. Waiting to see a hospital paediatrician – paediatric respondents

4.5.3 Waiting to see a neurologist

There were slightly longer waits for children/young people to see a neurologist after they first saw a paediatrician

- Just over a third (34%, n=203) waited less than 3 months
- 15% (n=91) waited 3-6 months
- 13% (n=77) waited 7-12 months
- 14% (n=87) waited over 12 months

Q11c. How long were you waiting between first seeing a paediatrician to seeing a neurologist?



Based on 617 responses.

Fig 98. Waiting to see a neurologist – paediatric respondents

4.5.4 Time since diagnosis

Over three quarters of respondents (79%, n= 494) answering the survey have had their confirmed diagnosis within the last 10 years, 12%(n=76) had their diagnosis over 10 years ago and 9%(n=56) have not had a diagnosis.

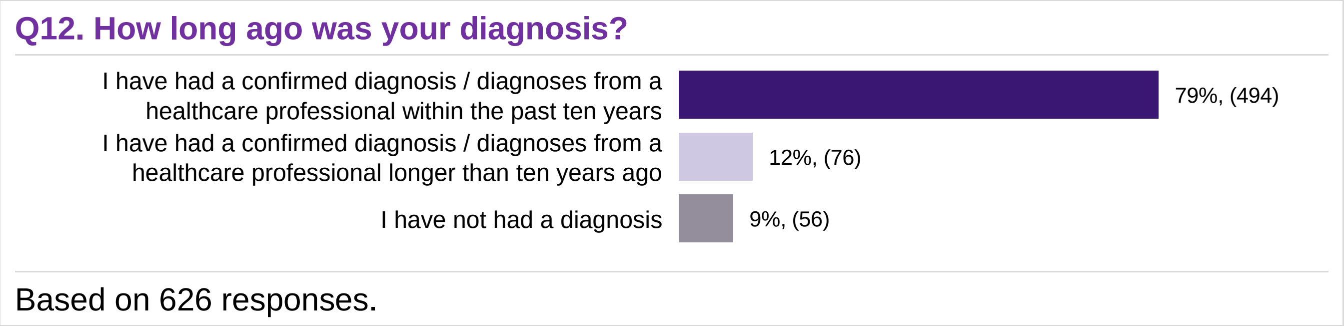


Fig. 99Time since diagnosis – paediatric respondents

4.6 Diagnosis - Finding out about your neurological condition(s)

This section was answered by 494 respondents who had a confirmed diagnosis within the last 10 years.

4.6.1 Diagnosis delivery

Nearly one third (31%, n=144) of respondents felt their diagnosis was handled in an excellent manner and a further quarter (26% n= 123) felt it was good. However, there is room to improve consistency as just over two fifths of respondents (43%, n=199) felt that their diagnosis was handled in an average to poor way.

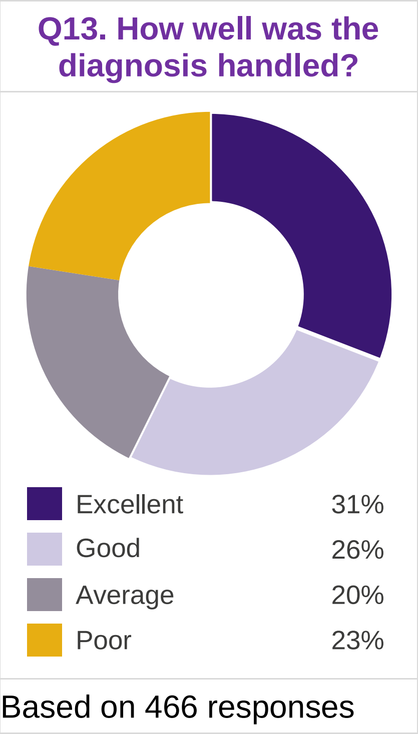


Fig 100. Diagnosis delivery – paediatric respondents

4.6.2 Explanation of diagnosis

Only one quarter of respondents completely understood the explanation they were given about their condition (n=112), more than half (55%, n= 243) understood only some of it and one fifth (n=89) were not given any explanation.

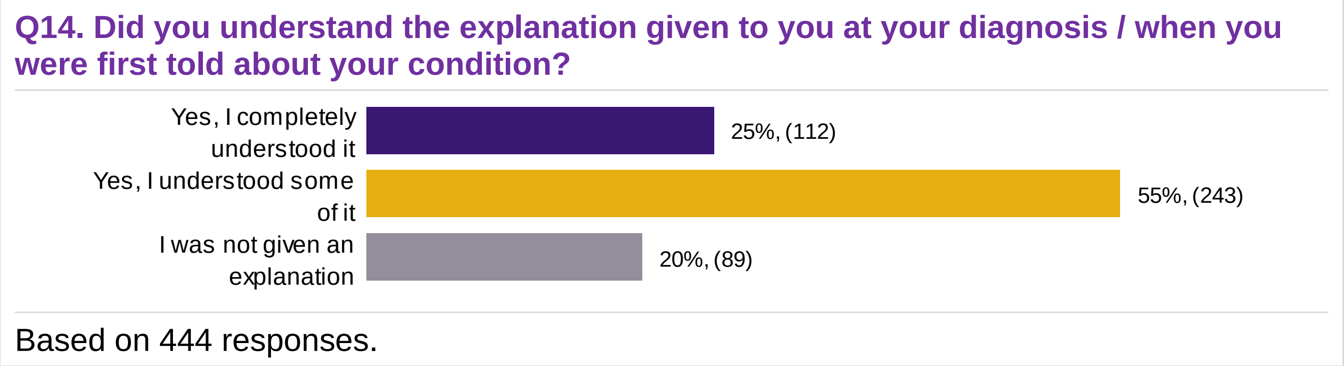


Fig 101. Explanation of diagnosis – paediatric respondents

4.7 Information about your neurological condition(s)

This section was only answered by 494 respondents who had a confirmed diagnosis within the last 10 years.

4.7.1 Written information

Respondents were asked to select all the kinds of written information they were given:

- A third of respondents (n=165) were **not** offered or directed to any form of written information.
- Just over a third (34%, n=171) were directed to a specific charity/patient organisation
- 30% (n=151) were handed written information produced by the NHS and a further 12% (n=61) were directed to an NHS website.
- A fifth (n= 100) of respondents were handed written information from a specific charity/patient organisation.

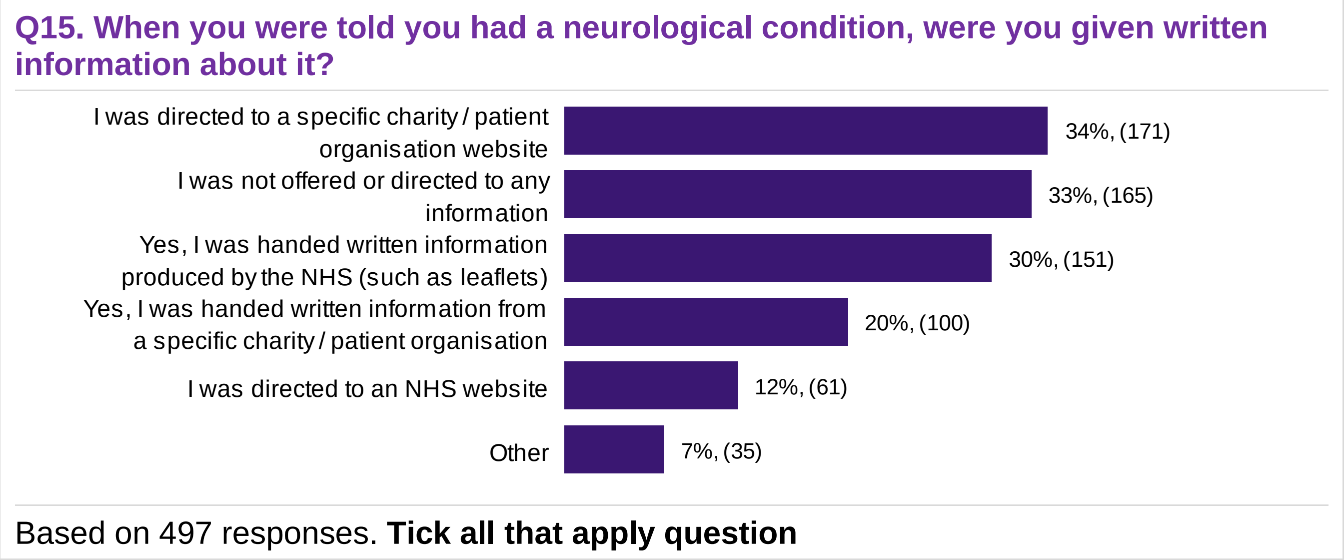
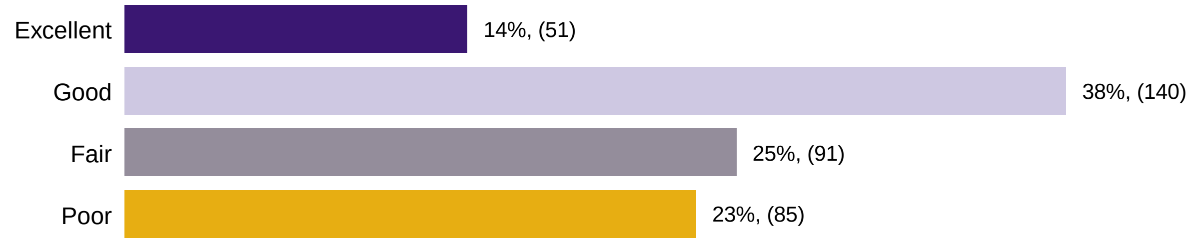


Fig 102. Written information – paediatric respondents

4.7.2 Quality of information

14% (n=51) of respondents rated the quality of the information they received as Excellent, 38% (n= 140) as Good and a quarter (n=91) as Fair. However, nearly a quarter of respondents (23%, n=85) considered the quality of the information they received to be Poor.

Q16. How useful was the information, overall? Please think about how good the information was about your condition and how accessible it was for your needs.



Based on 367 responses.

Fig. 103. Quality of information – paediatric respondents

4.8 Treatment and care

4.8.1 Prescriptions

Of those who it applied to, the majority of respondents did not have any difficulty affording their prescriptions.[5]

Q17. Do you ever have difficulty affording your prescriptions?

Based on 258 responses.

Fig 104. Affording prescriptions – paediatric respondents

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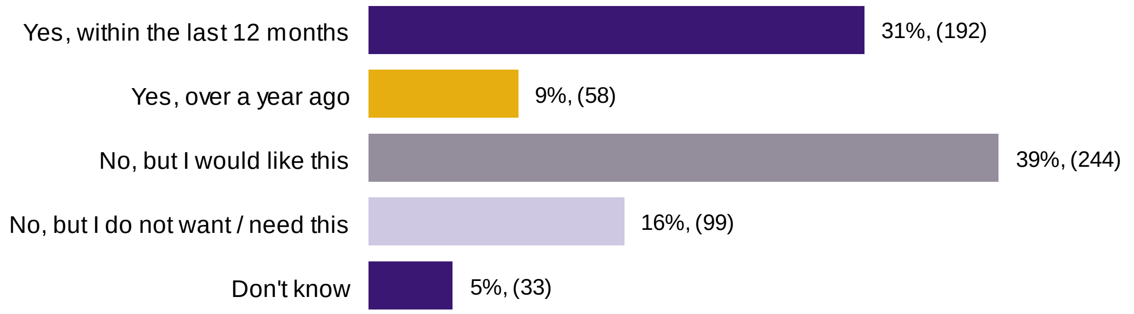
[5] Note that prescriptions are free of charge in Northern Ireland, Scotland and Wales. In England under 16s also receive free prescriptions https://www.nhs.uk/nhs-services/prescriptions-and-pharmacies/who-can-get-free-prescriptions/

4.8.2 Specialist Nurses

In the last 12 months, 31% (n=192) of respondents had access to a specialist nurse for their specific neurological condition, followed by a further 9% (n= 58) that saw the specialist nurse more than one year ago. However, nearly two fifths of respondents (39%, n=244), could not access this service even though they would have liked to. 16% of respondents (n= 99) did not want or need to see a specialist nurse for their condition.

Q18. Have you had an appointment with a specialist nurse for your neurological condition(s)? A specialist nurse (also called a clinical nurse specialist) is a nurse who provides expert care for people living with your condition.



Based on 626 responses.

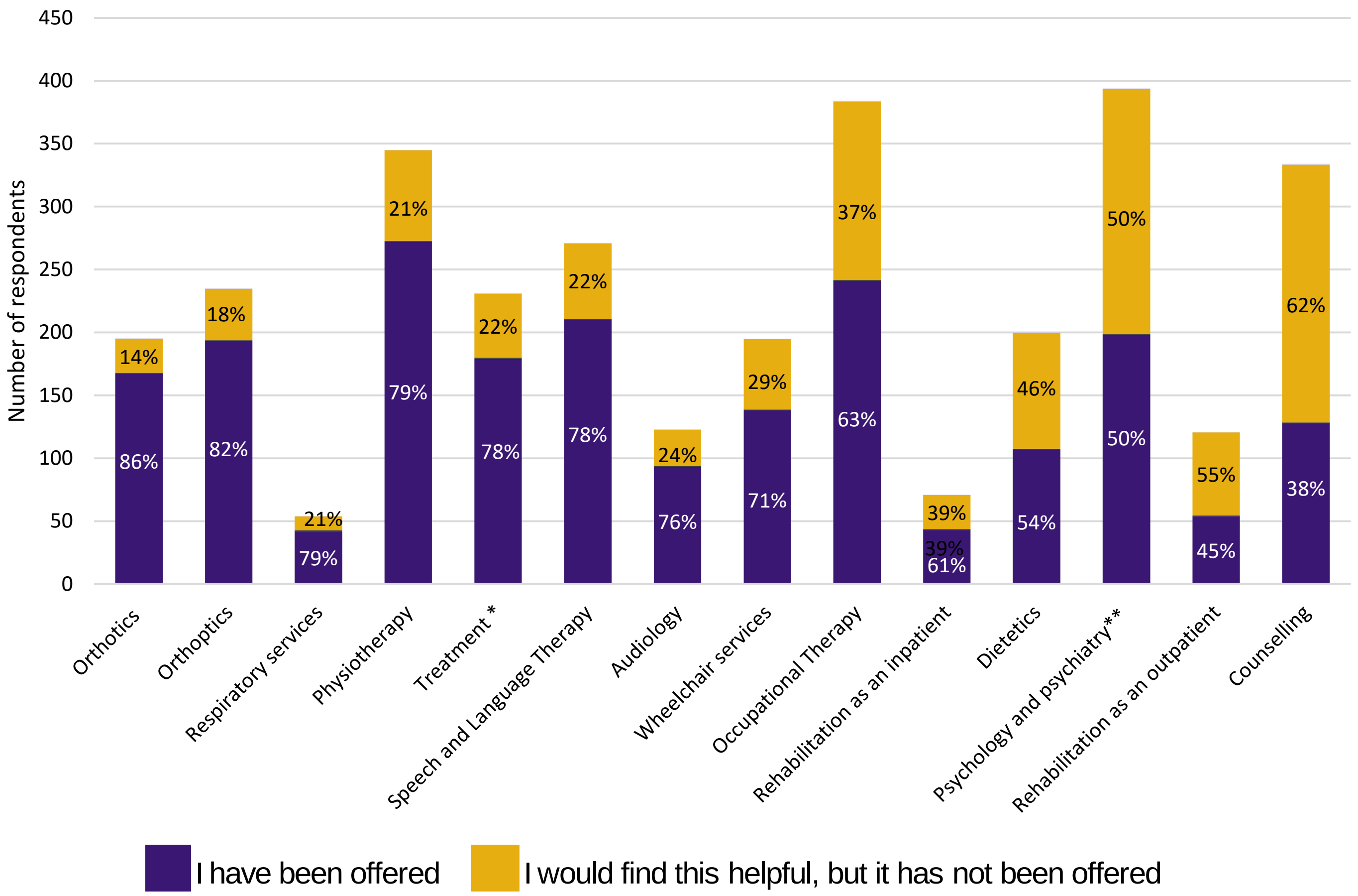
Fig 105. Access to Specialist Nurses - paediatric respondents

4.8.3 Treatments and therapies

Scores for Q19 were more positive from the paediatric respondents than from the adult survey.

Of the treatments and therapies available (and where it was appliable to the respondents), Psychology and Psychiatry was only offered to half of the respondents (n=198) and less than half (45%, n= 54) were offered Rehabilitation as an outpatient. Counselling was offered only to 128 individuals (38%).

Q19. Please tell us which treatments and therapies you have been offered, or you believe may help you to manage your neurological condition(s)



* Treatment (drug therapy or palliative care)

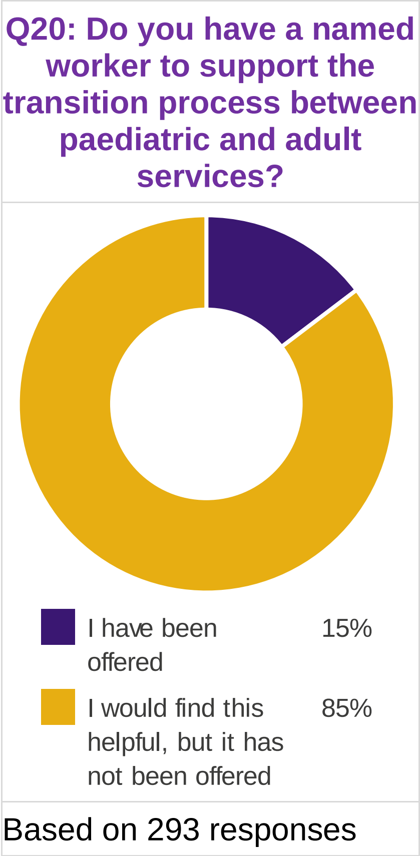
** Psychology and psychiatry (including educational psychology)

Based on responses from: Orthotics – 194, Orthoptics – 234, Respiratory services – 53, Physiotherapy – 344, Treatment * - 230, Speech and Language Therapy – 270, Audiology – 122, Wheelchair services – 194, Occupational Therapy – 383, Rehabilitation as an inpatient – 70, Dietetics – 199, Psychology and psychiatry** – 393, Rehabilitation as an outpatient – 120 and Counselling - 333

Fig 106. Treatments and therapies offered – paediatric respondents

4.8.4 Transition to adult services

For those who it was applicable to, the vast majority of the respondents (85%, n=250) have not been offered a named worker to support them in the transition process between paediatric and adult service despite the fact that it may be helpful.



Based on 293 responses

Fig 107. Transition to adult services – paediatric respondents

4.8.5 Involvement in healthcare

Respondents were asked if they (or for younger children if the parent) felt fully involved in making choices about their healthcare.

Nearly one third (30%, n=184) agreed that they feel involved in making these choices with a further 42%(n=258) feeling involved to some extent. However, 19% (n= 117) don’t feel involved as much as they would like while 9% (n=52) don’t feel involved at all.

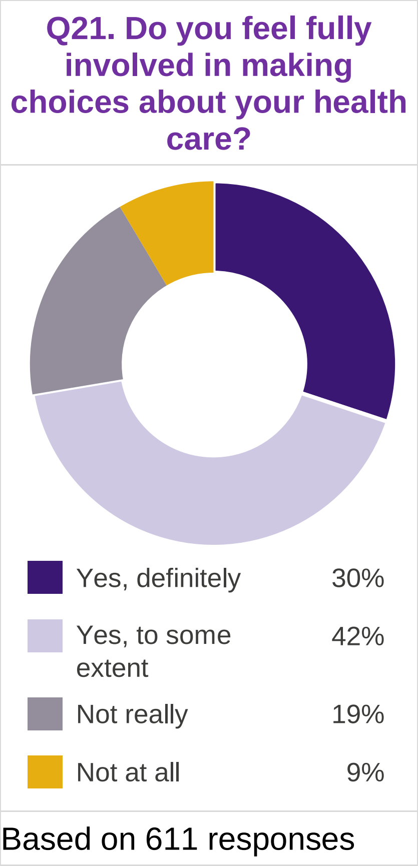
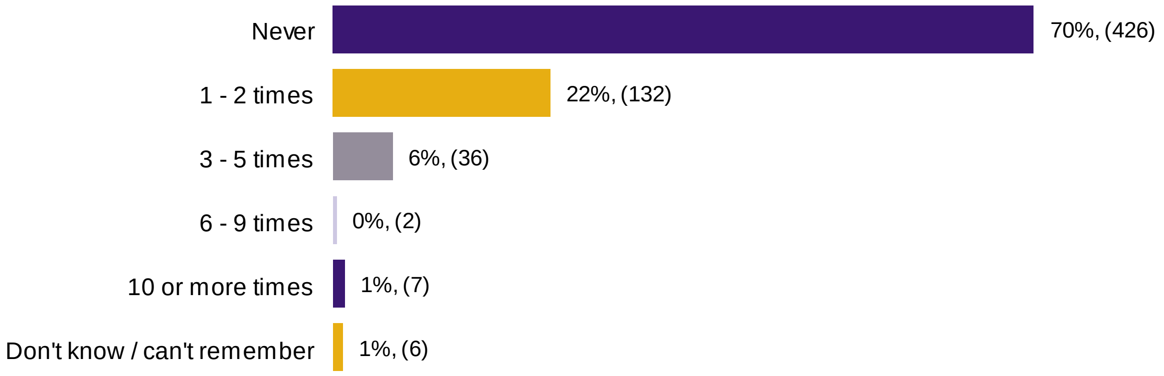


Fig 108. Involvement in healthcare – paediatric respondents

4.8.6 Admissions to hospital

In the last two years nearly three quarters (n=426) of respondents did not need to have a planned admission to the hospital relating to their neurological condition. 22%(n=132) had to visit the hospital 1-2 times, 6% (n=36) 3-5 times, 2 individuals between 6-9 times and 1% (n=7) more than 10 times.

Q22a. Thinking only about your neurological condition(s), over the past two years how many times have you had a planned admission to hospital (i.e., a scheduled stay in hospital)?



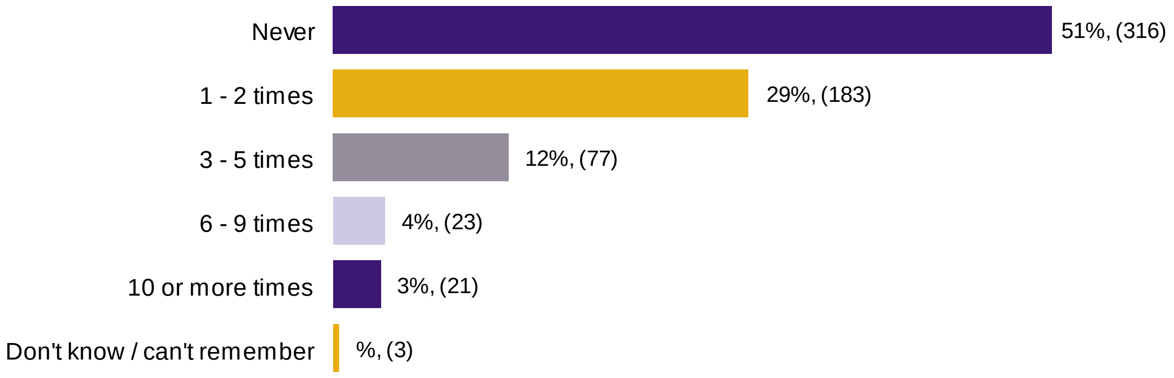
Based on 609 responses.

Fig 109. Planned hospital admissions – paediatric respondents

4.8.7 Emergency admissions

In the last two years more than half of the respondents (51%, n=316) of respondents did not need to have an emergency admission to the hospital (relating to their neurological condition). However, 29% (n=183) had to visit the hospital 1-2 times, 12% (n=77) 3-5 times, 4% (n=23) had to visit the hospital between 6-9 times and 3% (n=21) more than 10 times.

Q22b. Thinking only about your neurological condition(s), over the past two years how many times have you: Had an emergency admission (i.e., an unscheduled stay in hospital)?



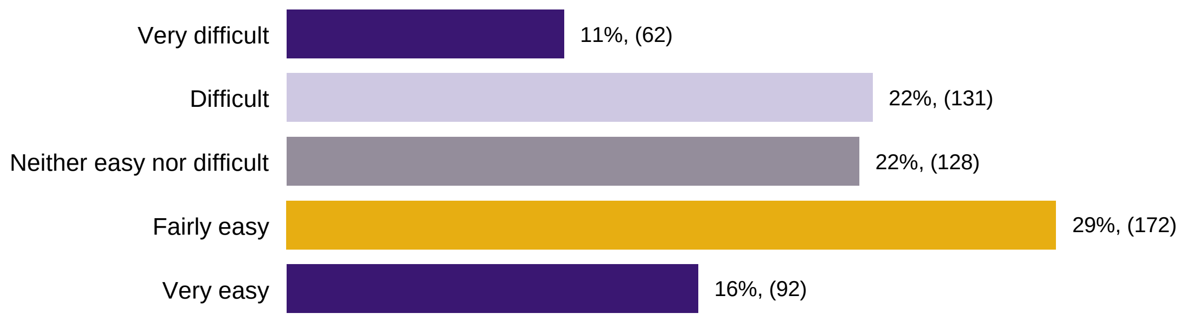
Based on 623 responses.

Fig 110. Emergency admissions – paediatric respondents

4.8.8 Travelling to appointments

One third (n=193) of respondents find it difficult or very difficult to travel to the majority of their appointments, 22% (n=128) find it neither easy nor difficult. 45% (n= 264) of respondents say that travelling to appointments is fairly/very easy.

Q23. How difficult do you find it to travel to the majority of your appointments for your neurological condition?



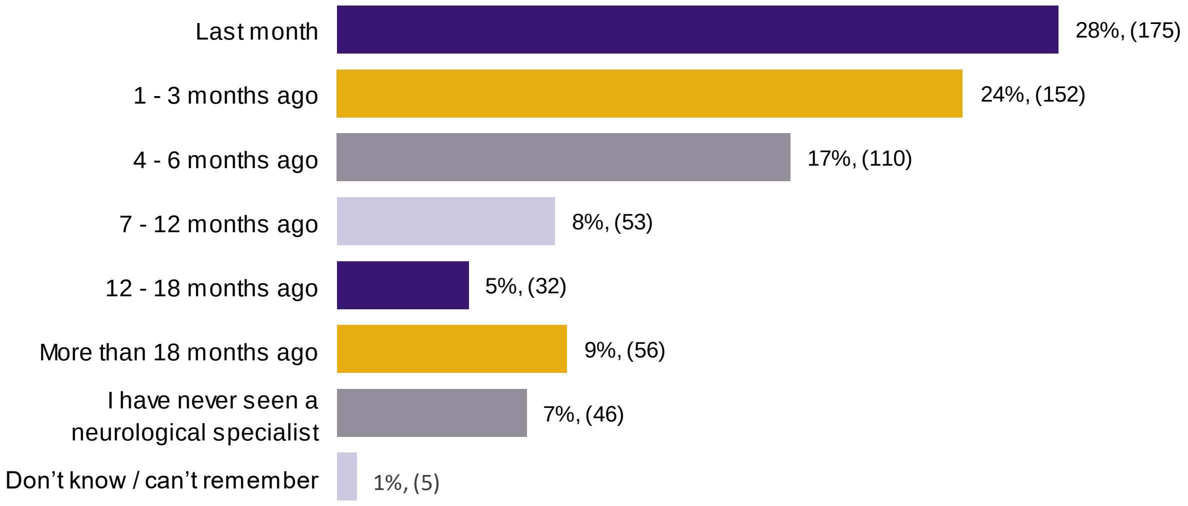
Based on 585 responses.

Fig 111. Ease of travelling to appointments – paediatric respondents

4.8.9 Appointments with specialists

28% (n=175) of the respondents saw a specialist for their neurological condition the previous month, followed by nearly a quarter (24%, n=152) that saw a specialist between 1 and 3 months ago. 9% (n=56) saw a specialist more than 18 months ago and 7%(n=46) have never seen a neurological specialist.

Q24. When did you last have an appointment with a specialist for your neurological condition? A specialist could include a specialist nurse for your condition, a neurologist, neurophysiotherapist, neuropsychologist or neuropsychiatrist



Based on 629 responses.

Fig 112. Appointments with specialists – paediatric respondents

4.8.10 Care and communication

Results show that nearly two fifths (39%, n=236) of respondents do not find easy to contact their specialist. The same proportion also disagreed that information about their condition is effectively passed between the people that care for them (39%, n=235). 37% (n=168) disagreed that they got the care they needed once they returned at home after their hospital visit.

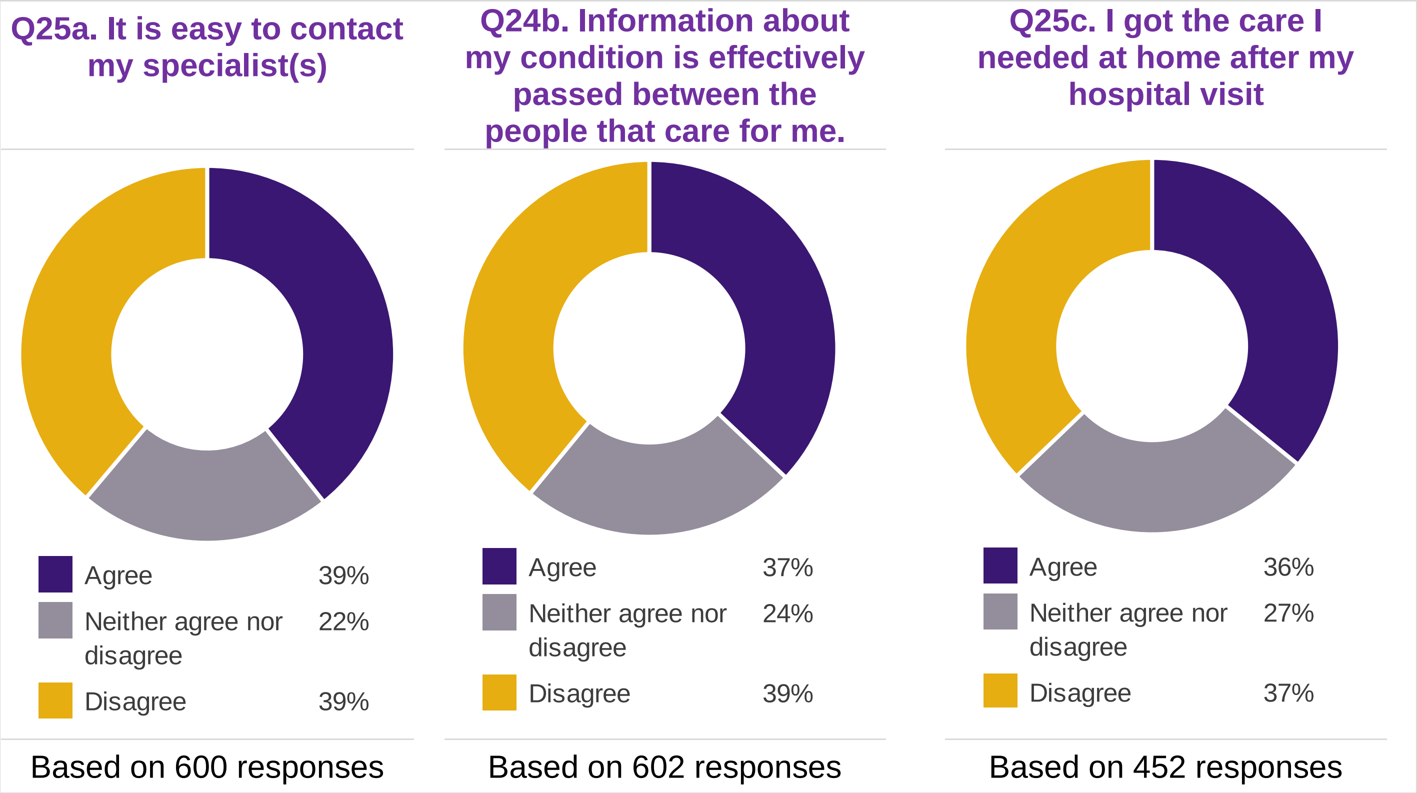


Fig.113 Joined up care and communication – paediatric respondents

4.9 Support for neurological condition(s)

As with the adult survey there are issues surrounding care and support plans with nearly two thirds (73%, n=412) of respondents not being offered one in the last three years. In the children and young people's survey, following consultation with our steering group, we defined a care and support plan as "A care and support plan should outline what treatment is offered to you, who to contact for further information about your information about your treatment, care, or support, what to do if your symptoms change and who to contact in an emergency. It could be written or online. This might be referred to as a 'comprehensive care plan' or 'continuing health care' and could be provided by health or social care. It does not relate to education / school.

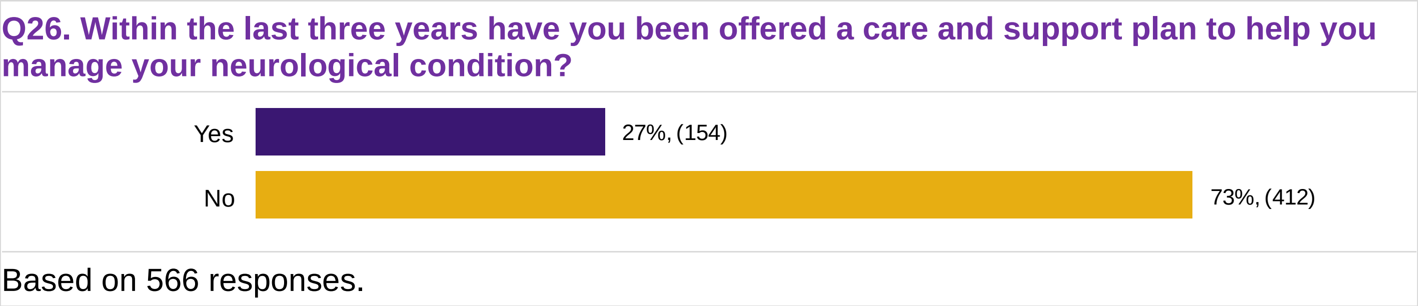
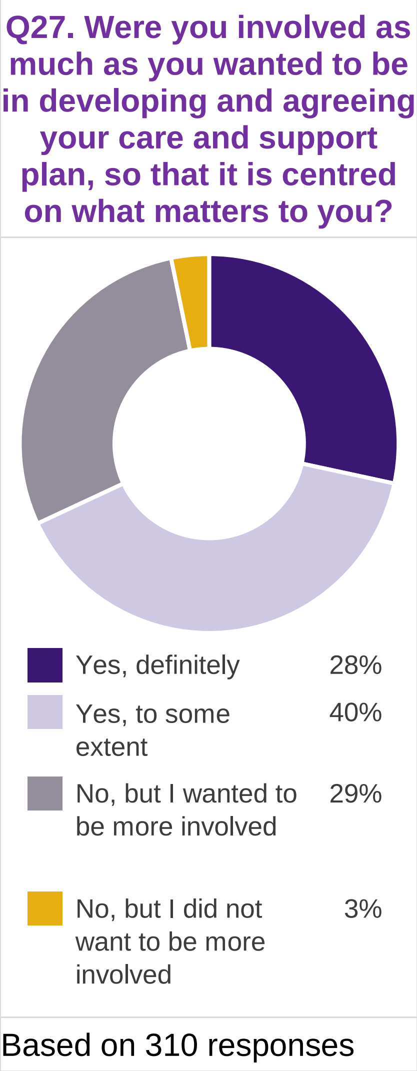


Fig 114. Offered a care plan – paediatric respondents

Of those who felt it was applicable to them, 28% (n=88) of respondents (or parents for younger children) agree that they were involved in developing a care and support plan centred on what matters to them and 40% (n=123) felt involved to some extent. However, more than a quarter (29%, n=89) don't think they were involved as much as they wanted. Just 3% (n=10) didn't feel involved but did not want to be.



Q27. Were you involved as much as you wanted to be in developing and agreeing your care and support plan, so that it is centred on what matters to you?

Based on 310 responses

Fig 115. Involvement in developing a care plan – paediatric respondents

4.10 Mental Wellbeing

4.10.1 Affect of neurological condition on mental wellbeing

The majority of respondents (89%, n=506) say that their neurological condition has made their mental wellbeing worse (from slightly to much worse). 11% (n=62) of the respondents have not been affected.

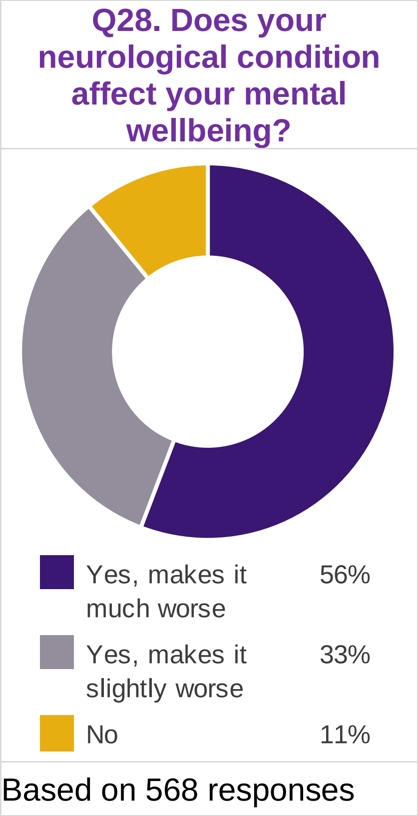


Fig 116. Mental wellbeing – paediatric respondents

In the last three years, over half of respondents (52%, n=296) have not been asked about their mental wellbeing by a health and social care professional

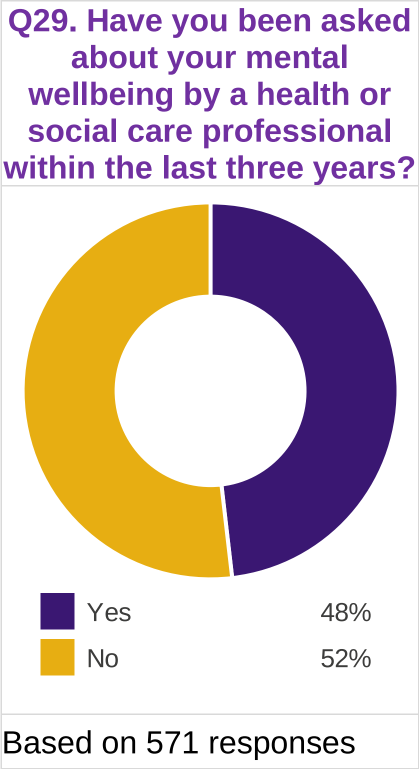


Fig 117. Mental wellbeing and healthcare professionals – paediatric respondents

4.10.2 Support for mental wellbeing

In the last 3 years, nearly two fifths (39%, n= 225) of respondents have been referred or directed to support their mental wellbeing, whilst 36% (n=211) have not experienced this, but would have like to have done. A quarter of respondents (n=144) did not receive a referral or direction to support but these respondents confirmed they didn't want or need it.

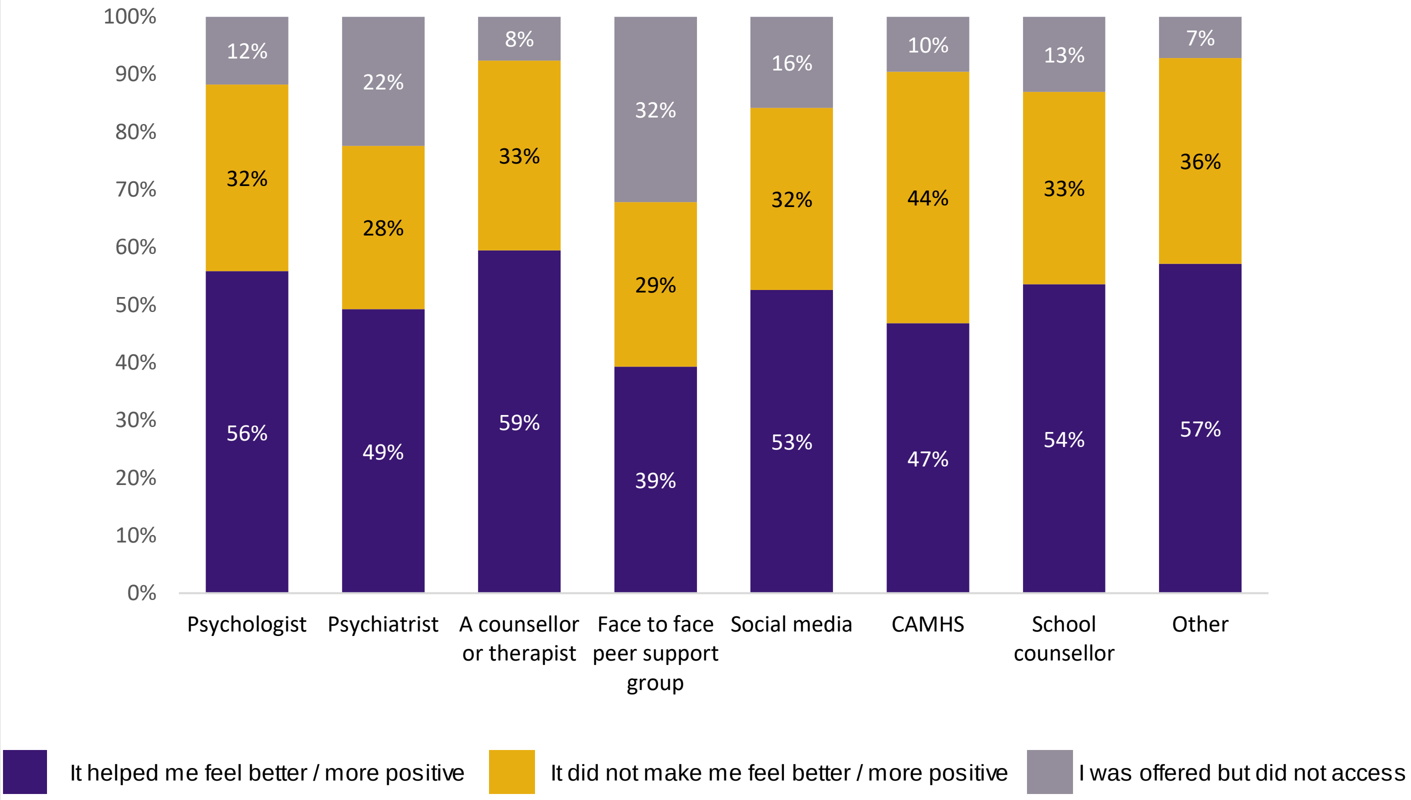
Q30. Have you been referred or directed to support for your mental wellbeing by a health professional within the last three years?

Based on 580 responses.

Fig 118. Referral or directed to support for mental wellbeing – paediatric respondents

Respondents who said that they received a referral or direction to support were asked to indicate what services these were and how helpful they were. Counselling and psychology services were reported on most positively.

Q31. Please select which services you were referred or directed to, and how they helped you overall:



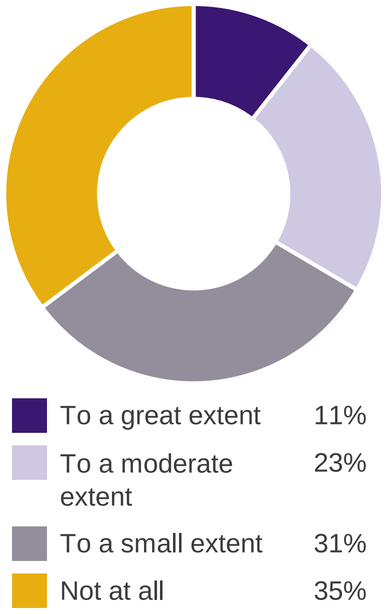
Based on responses for: Psychologist – 102, Psychiatrist – 67, A counsellor or therapist – 79, Face to face peer support group – 28, Social media – 38, CAMHS – 126, School counsellor – 69 and Other - 14

Fig 119. Support received for mental wellbeing – paediatric respondents

4.10.3 Meeting mental wellbeing needs

Of those who felt that it was applicable to them the results indicate two thirds of respondents 67% (n=338) do not feel their mental wellbeing needs are being met or are only met to a small extent. 23% (n=116) say their needs are met to a moderate extent and 11% (n=54) said that their mental wellbeing needs are met to a great extent.

Q32. To what extent do you feel your mental wellbeing needs are being met?



Based on 508 responses

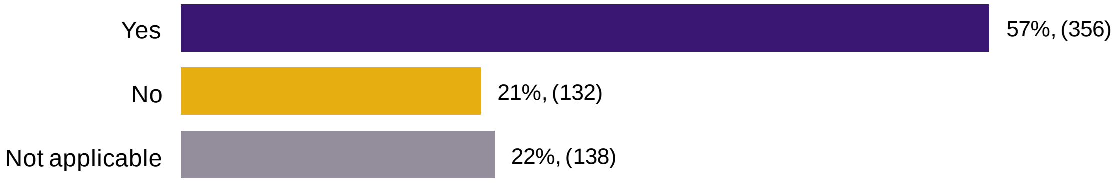
Fig 120. Meeting mental wellbeing needs – paediatric respondents

4.11 Social care

4.11.1 Unpaid help

More than one fifth of respondents (21%, n=132) do not receive any care from friends, family members or neighbours. However, of the remainder more than half (57%, n=356) receive unpaid care.

Q33. Do you receive unpaid help with your day-to-day life at home (e.g., washing, dressing, cooking, cleaning)? This could be from a family member, or a friend or neighbour



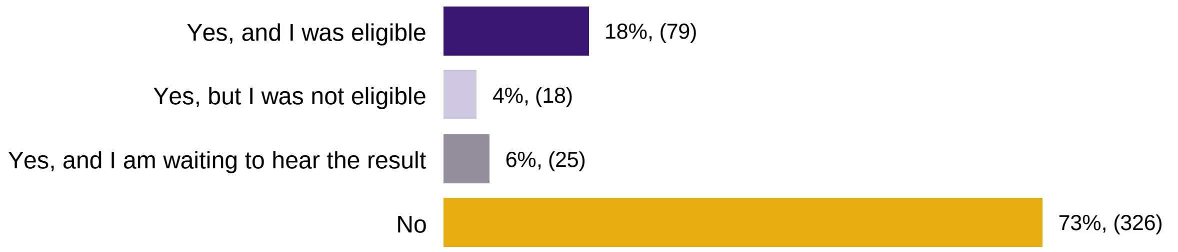
Based on 626 responses.

Fig 121. Unpaid help – paediatric respondents

4.11.2 Assessments for funded care and support

Where it was applicable to their circumstances, the majority of respondents (73%, n=326) had not been assessed by their local council to see if they were eligible to receive care or support.

Q34. Has your local council assessed your care and support needs to see if you are eligible to receive funded care or support?



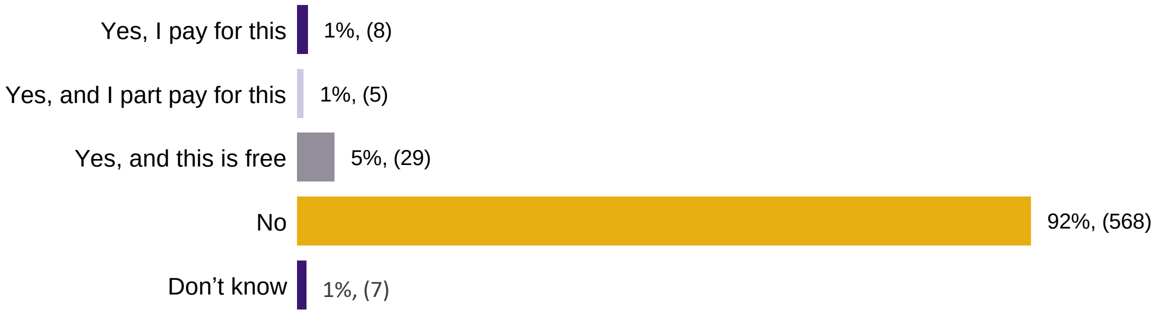
Based on 448 responses.

Fig 122. Assessments for funded care and support – paediatric respondents

4.11.3 Sources of social care

The following charts illustrate what types of social care respondents report that they receive. In each case the majority of people said that they do not receive that type of social support/care.

Q35a. Are you receiving any of the following sources of social care? Homecare (e.g., help in your home)



Based on 617 responses.

Fig 123. In receipt of Homecare – paediatric respondents

Q35b. Are you receiving any of the following sources of social care? Residential Care (e.g., living in a care home)

Based on 608 responses.

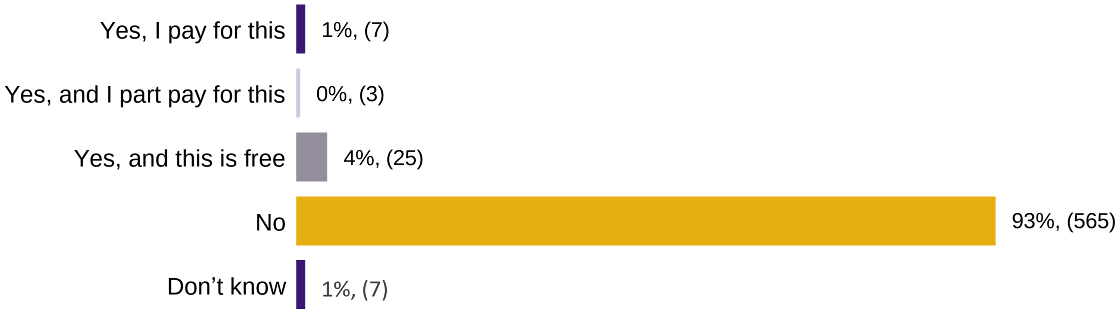
Fig 124. In receipt of Residential care – paediatric respondents

Q35c. Are you receiving any of the following sources of social care? Day services (e.g., attending day centre)

Based on 609 responses.

Fig 125. In receipt of Day services – paediatric respondents

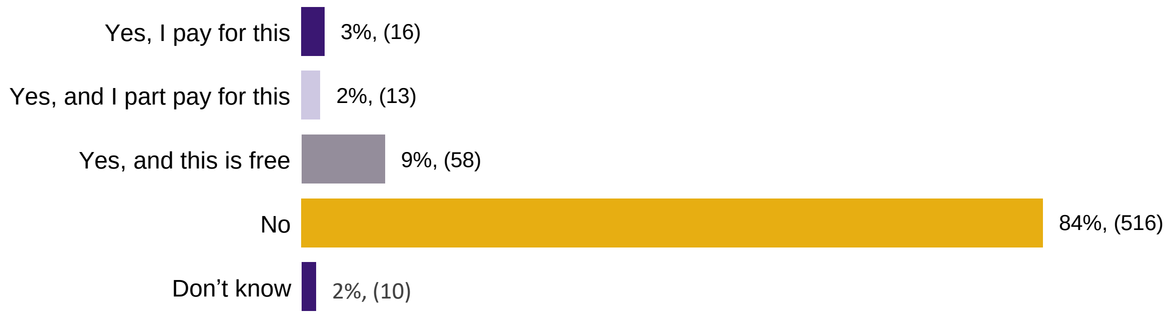
Q35d. Are you receiving any of the following sources of social care? Community Transport



Based on 607 responses.

Fig 126. In receipt of Community transport – paediatric respondents

Q35e. Are you receiving any of the following sources of social care? Home adaptations



Based on 613 responses.

Fig 127. In receipt of home adaptations – paediatric respondents

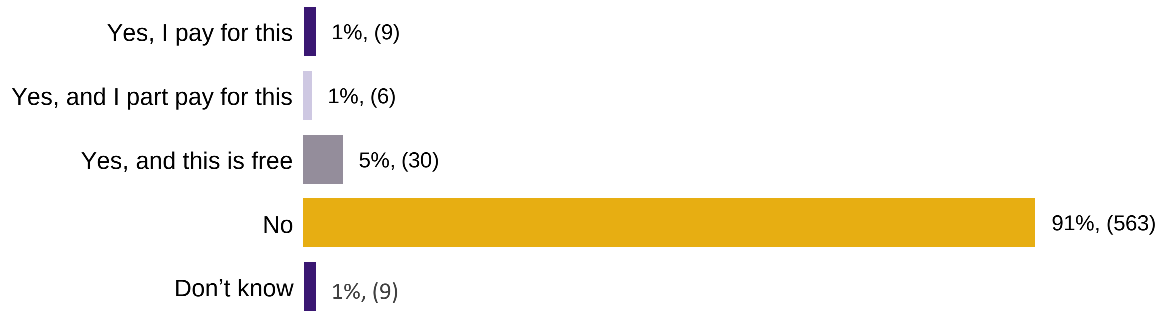
Q35f. Are you receiving any of the following sources of social care? Respite care

Based on 601 responses.

Fig 128. In receipt of Respite care – paediatric respondents

or partially paying for it.

Q35g. Are you receiving any of the following sources of social care? Supported living

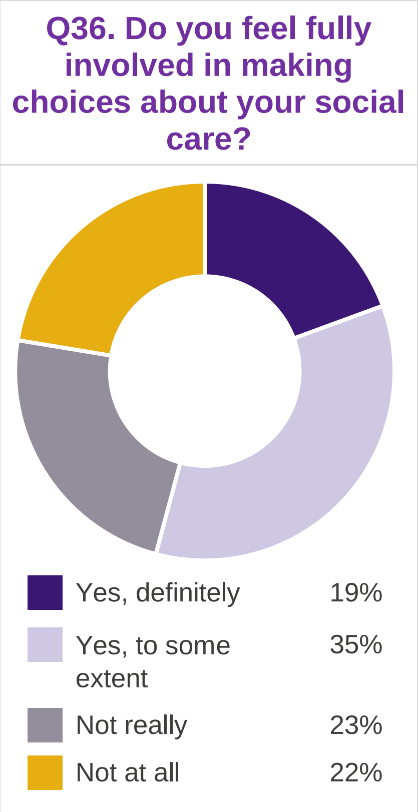


Based on 617 responses.

Fig 129. In receipt of Supported living care – paediatric respondents

4.11.4 Involvement in social care

54% (n=254) of respondents (or parents for younger children), feel involved or involved to some extent with their choices about their social care. However, 46% (n=215) don't feel they have been involved in their choices.



Based on 469 responses

Fig 130. Involvement in social care – paediatric respondents

4.11.5 Overall views of social care

Where it was applicable to their circumstances:

- Over two fifths of people (43%, n= 139) disagree that the social care they have received meets their needs
- 41% (n=116) disagree that social care they receive has improved in the past three years
- One fifth (20% n= 57) agree that the social care they have received in the last 3 years has declined

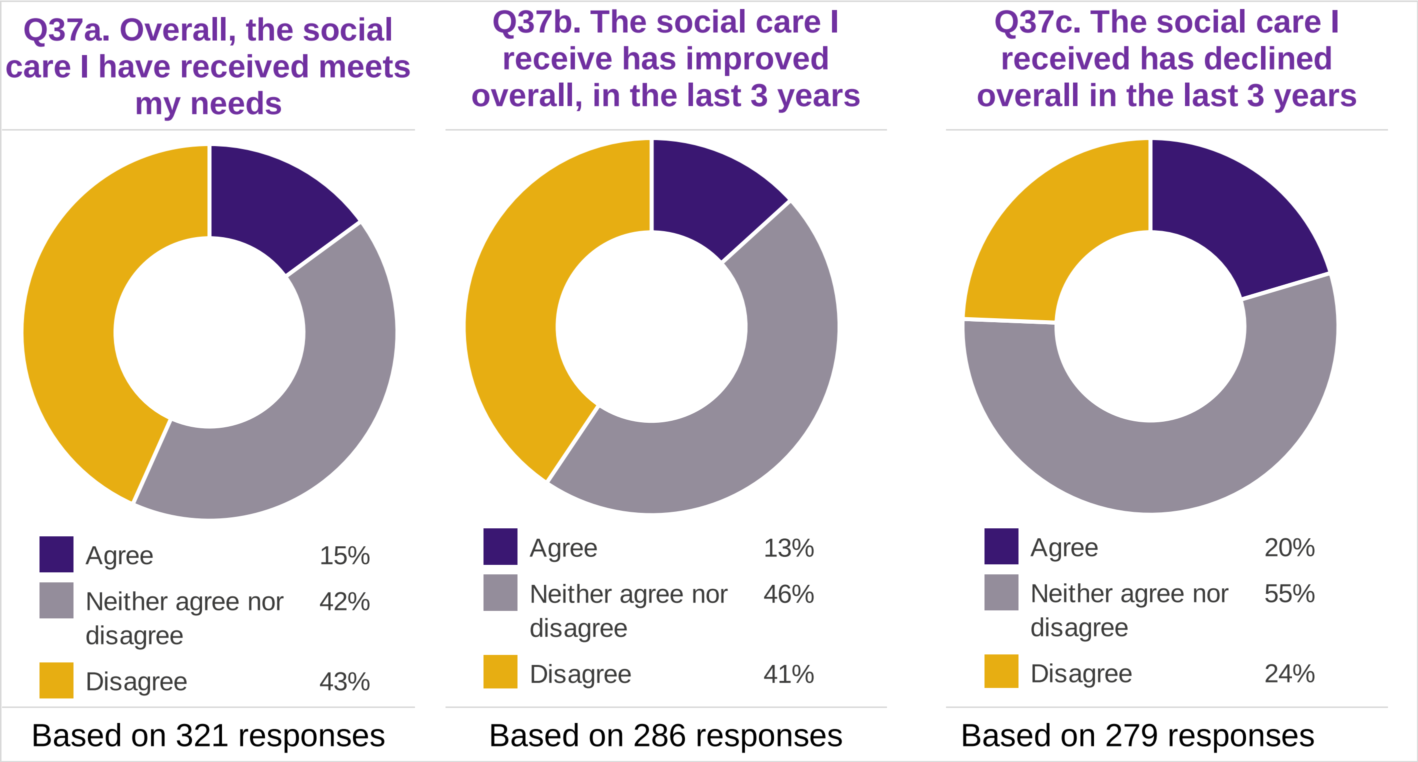


Fig 131. Overall views of social care – paediatric respondents

4.12 Education and welfare

4.12.1 Current place of education

The chart below illustrates where the children/young people are receiving their education. The majority attend mainstream schools – mainstream secondary school (32%(n=199) and mainstream primary school; 28% (n=173) Just 13%(n=81) of respondents attend a specialist school.

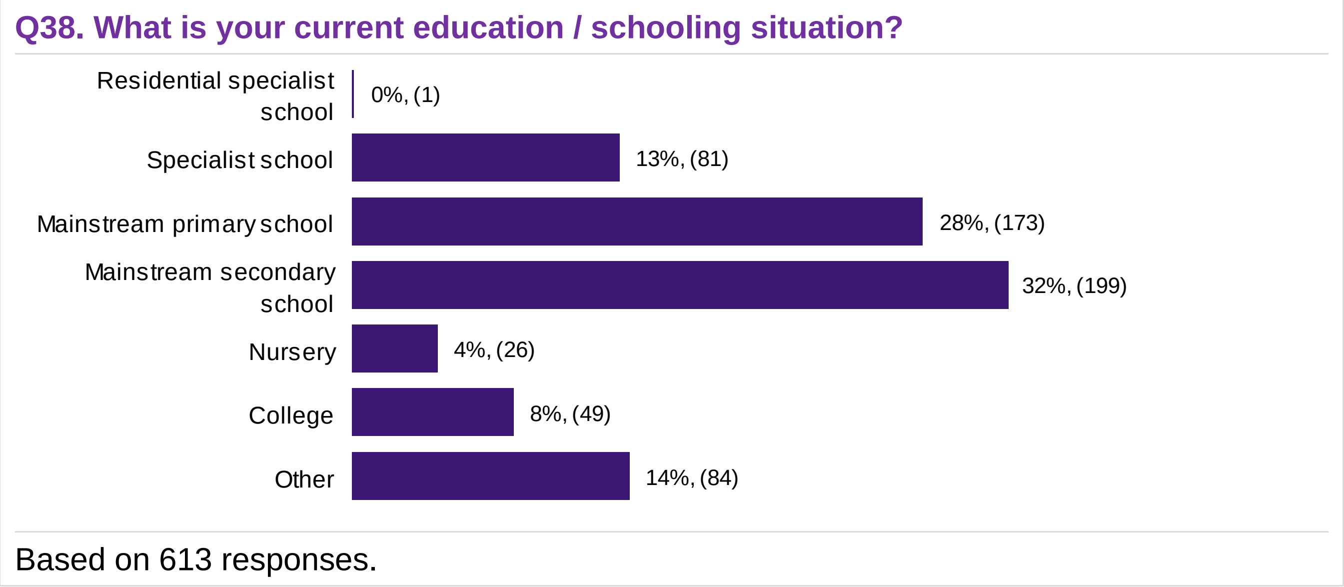


Fig 132. Place of education – paediatric respondents

4.12.2 Education and health and care (EHC) plan

Half of the respondents (n=298) say they have not been assessed for an EHC plan. 43%(n=255) were assessed and offered an EHC plan and a final 7%(n=41) were assessed but not offered any plan.

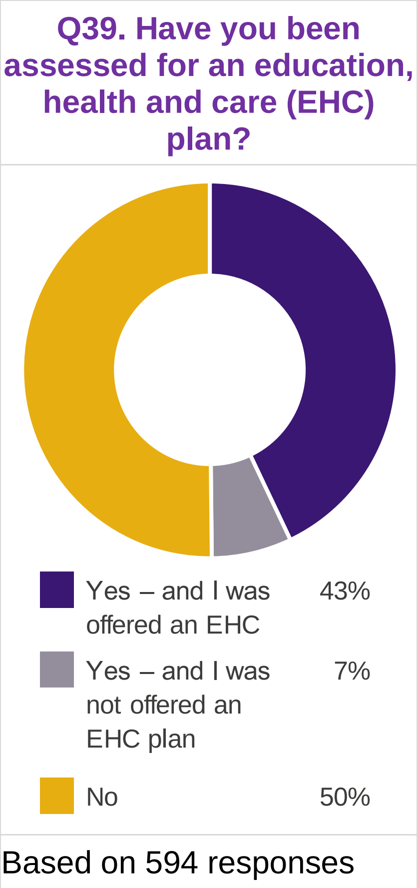


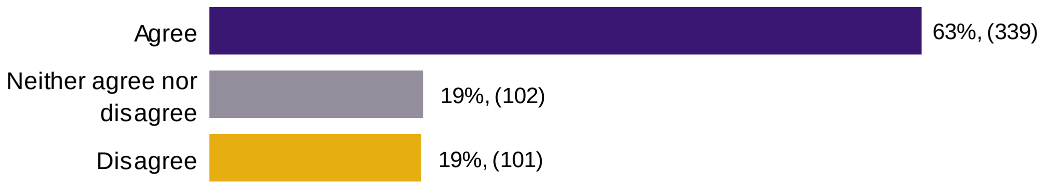
Fig 133. EHC plans – paediatric respondents

4.12.3 Experience of education with a neurological condition

Respondents were asked to say how much they agreed with a number of statements relating to school. The charts show the opinions of the respondents who felt each statement was applicable to them.

Over three fifths of the respondents (63%, n=339) agree that the school made useful changes to help them to attend.

Q40a. My school has made useful changes to help me to attend

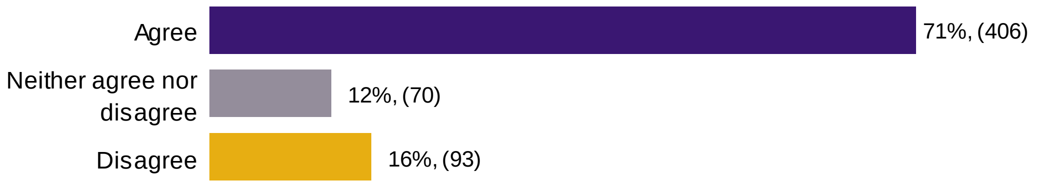


Based on 542 responses.

Fig 134. School adaptations – paediatric respondents

71% (n=406) of respondents say their neurological condition affects their attendance

Q40b. My attendance at school has been affected due to my neurological condition



Based on 569 responses.

Fig 135. School attendance – paediatric respondents

59% of children/young people (n= 336) agree that other children are friendly to them. 30%(n=170) neither agree nor disagree and 11%(n=64) disagree.

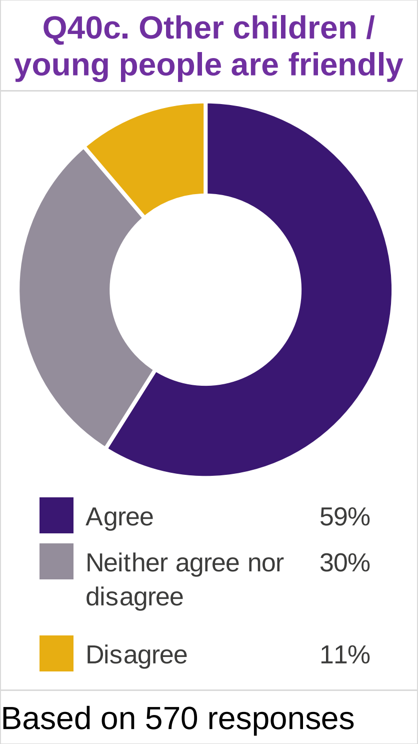


Fig 136. Friendliness of peers – paediatric respondents

62% (n= 353) of respondents agree that adults in school listen to them, however 16%(n=89) disagree

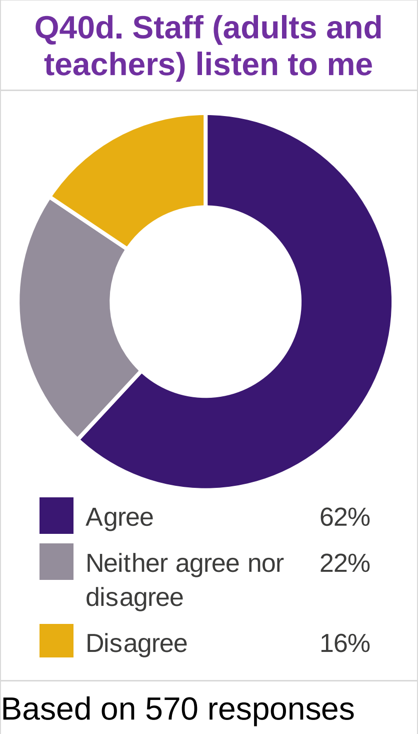
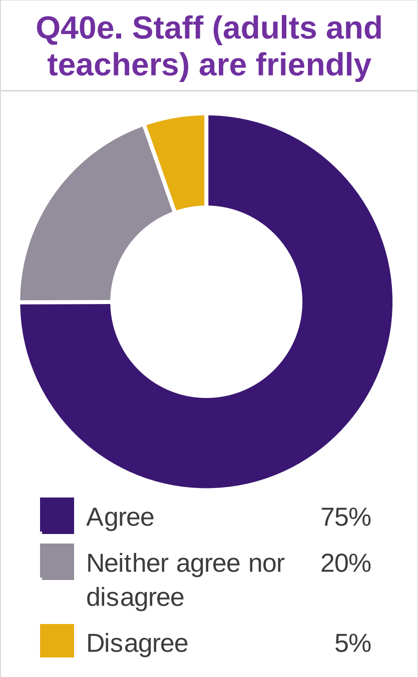


Fig 137. Listened to by school staff – paediatric respondents

Three quarters (n= 431) of the respondents agree that their teachers and staff in school are friendly, 20%(n=113) neither agreeing nor disagreeing and 5% (n=31) feel this is not the case.



Based on 575 responses

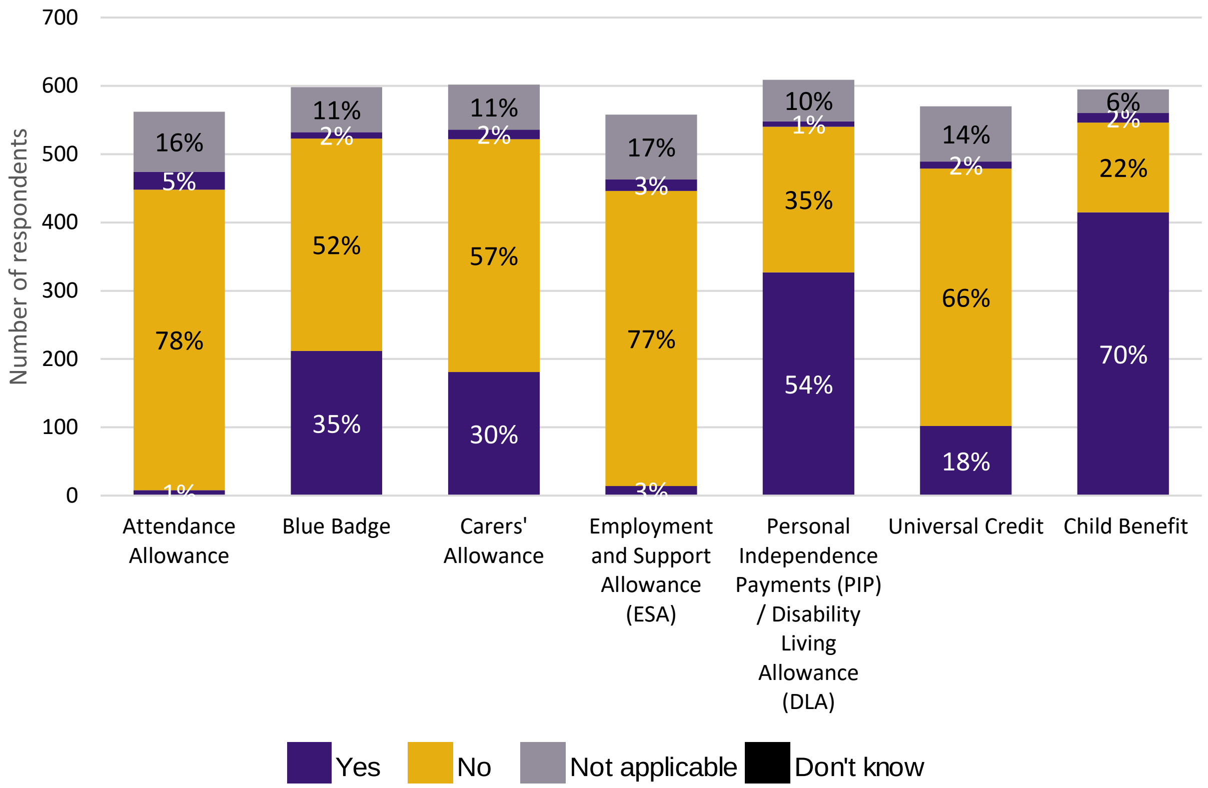
Fig 138. Friendliness of staff – paediatric respondents

4.12.4 Additional financial support and benefits

The chart below illustrates what additional financial support and benefits respondents or people who care for them receive. Not all respondents reported that these were applicable to them.

- 1% (n=8) receive Attendance Allowance
- 35% (n=212) have a Blue Badge
- 57% (n=641) do not receive Carers' Allowance
- 77% (n=432) do not receive Employment and Support Allowance
- 54% (n=327) receive Personal Independence Payments (PIP)/Disability Living Allowance (DLA)
- 66% (n=377) do not receive Universal Credit
- 70% (n=415) receive Child Benefit

Q41. Are you, or a family / friend who cares for you, in receipt of any of the following?



Based on responses for: Attendance Allowance – 562, Blue Badge – 598, Carers' Allowance – 602, Employment and Support Allowance (ESA) – 558, Personal Independence Payments (PIP) / Disability Living Allowance (DLA) – 609, Universal Credit – 570 and Child Benefit – 595.

Fig 139. Additional financial support and benefits – paediatric respondents

5. Clinic breakdown

We remain very grateful to the following organisation/neurological units who took part in this year's survey and received a response of at least 1 person. Only those with a response of over 21 individuals will receive an individual breakdown, to protect the identity of those who took part.

Adult Survey

Organisation name	Organisation name
Aberdeen Royal Infirmary	Oxford Children's Hospital
Cambridgeshire and Peterborough NHS Foundation Trust	Poole Hospital
Cardiff & Vale University Health Board	Powys Teaching Health Board (Newton Hospital)
Central Middlesex Hospital	Princess Royal University Hospital
Chelsea and Westminster Hospital	Queen Alexandra Hospital
Community Neuro Physiotherapist - Downend Clinic	Queen Elizabeth Hospital, Birmingham
Croydon University Hospital	Queen Elizabeth, University Hospital, Glasgow
Gloucester Royal Hospital	Royal Cornwall Hospitals NHS Trust
Headway South Cumbria	Royal United Hospital, Bath
Huntington's Disease Clinic at Cardiff University	Royal Victoria Infirmary
Kingston Hospitals	Sheffield Teaching Hospitals NHS Foundation Trust
Musgrove Park Hospital	St Georges Hospital
NHS Grampian	Sunderland Royal Hospital
NHS Lothian	Swansea Bay University Health Board (Morriston Hospital)
NHS Shetland	The National Hospital for Neurology & Neurosurgery
NHS Western Isles	The Walton Centre
Northwick Park	Ulster Hospital
Nottingham University Hospitals NHS Trust	University College London Hospitals NHS Foundation Trust

Fig 140. Table of Clinics who participated in the Adult survey

Paediatric Survey

Organisation name	Organisation name
Bristol Royal Hospital for Children	Poole Hospital
Oxford Children's Hospital	Tayside Children's Hospital

Fig 141. Table of Clinics who participated in the Paediatric survey

6. Additional data analysis - Adult

6.1 Introduction to additional analysis

To help identify issues where individuals may be in need of additional services and support, further analysis was undertaken using the following key variables:

- Neurological condition
- Geographical region
- Age
- Ethnicity
- Gender
- The person who completed the survey (individual with a neurological condition, or family/friend/carer).

Analysis was carried out on the following questions:

COVID-19

- Q3a Experienced delays with:

  A first appointment with a neurologist

  A routine appointment with their neurologist

  A first appointment with a specialist nurse

  A routine appointment with their specialist nurse

  A mental health appointment

  A scan

  Physiotherapy
- Q7 Change in mental health needs due to COVID-19

Overall impact

- Q8 Impact on quality of life
- Q9 Affect on day to day activities
- Q10 Pain

Before diagnosis

- Q11a Time between symptoms and diagnosis
- Q11b Time between first seeing a GP and seeing a neurologist

Diagnosis

- Q14 Understanding of the explanation of diagnosis
- Q15 Given written information

Treatment and care

- Q18 Access to a specialist nurse
- Q20 Involvement in choices about healthcare
- Q24a Health and care are joined up on and centred on their priorities
- Q24b Information about condition is effectively shared
- Q24d Care needed at home after hospital visit

Support for condition

- Q25 Have been offered a care plan

Mental wellbeing

- Q27 Does condition affect their mental wellbeing
- Q28 Have they been asked about their mental wellbeing by HCP in last 3 years
- Q29 Have they been referred or directed to support for mental wellbeing by HCP in last 3 years
- Q32 To what extent do they feel their mental wellbeing needs are being met

Social care

- Q34 Had an assessment of care and support needs by local council
- Q37a Overall social care received meets their needs

Employment and Welfare

- Q39a Have been able to continue working since having neurological condition
- Q39b Have stopped working because of neurological condition

6.2 Neurological condition breakdowns

6.2.1 Single and multiple neurological conditions

The majority of respondents who completed the survey had a single neurological condition - 5407 compared to 2295 people with multiple neurological conditions. People with a single condition reported more positive experiences across nearly every question.

A two-tailed t-test on proportions for significant differences has been carried out on the key questions. Where differences are reported, there is a significant difference level of at least 95%, however most were at 99%.

COVID-19

Respondents with a single condition were **less likely** to experience delays with:

A first neurologist appointment - 71% v 59%

A routine appointment with their neurologist - 47% v 40%

A first appointment with a specialist nurse - 77% v 64%

A mental health appointment - 64% v 43%

A scan - 67% v 53%

Physiotherapy - 52% v 41%

Respondents with multiple conditions were more likely to say that their mental health has **worsened** due to COVID-19 - 54% v 40%

Overall impact

Respondents with multiple conditions were more likely to say that their neurological condition impacts their quality of life to a great/moderate extent - 89% v 77%

Respondents with multiple conditions were more likely to say that their neurological condition affects their day-to-day activities to a great/moderate extent - 89% v 74%

Respondents with multiple conditions were more likely to say that their neurological condition causes them pain to a great/moderate extent - 75% v 51%

Before diagnosis

A larger proportion of respondents with multiple conditions reported waiting more than 12 months between first experiencing symptoms to getting a diagnosis - 41% v 33%

A larger proportion of respondents with multiple conditions reported waiting more than 12 months between first seeing a GP to seeing a neurologist - 24% v 18%

Diagnosis

Respondents with a single condition were more likely to say they completely understood the explanation they were given at their diagnosis / first told about their condition - 36% vs 25%. While a larger proportion of respondents with multiple conditions said they were not given an explanation - 26% vs 18%

Treatment and care

Respondents with a single condition were more likely to say they have had an appointment with a specialist nurse for their neurological condition within the last 12 months - 32% vs 21%. While a larger proportion of respondents with multiple conditions said they have not had an appointment with a special nurse, but would like one- 47% vs 29%

Respondents with a single condition were more positive that they were involved in making choices about their healthcare (definitely or to some extent) - 75% vs 63%

Respondents with a single condition were more likely to agree that their health and care are joined up and centred on their priorities - 35% vs 22%

Respondents with a single condition were more likely to agree that information about their condition is effectively passed between the people that care for them - 42% vs 29%

Respondents with a single condition were more likely to agree that they got the care they needed at home after their hospital visit - 29% vs 21%

Support for condition

Respondents with a single condition were more likely to say that they have been offered a care and support plan to help them manage their neurological condition - 23% vs 18%

Mental wellbeing

Respondents with multiple conditions were more likely to say that their neurological condition affects their mental wellbeing - 87% vs 79%

There was significant difference between respondents with multiple conditions and respondents with a single condition reporting that they had been asked about their mental wellbeing by HCP in last 3 years - 45% vs 38%

Respondents with multiple conditions were more likely to say they had been referred or directed to support for mental wellbeing by HCP in last 3 years - 30% vs 21%

Respondents with a single condition were more likely to say that their mental wellbeing needs are being met to a great/moderate extent - 35% vs 30%

Social care

Respondents with a single condition were more likely to say that they **had not** had an assessment of care and support needs by local council - vs 81% vs 72%

Respondents with a single condition were more likely to agree that overall, social care received meets their needs - 25% vs 18%

Employment and Welfare

Respondents with a single condition were more likely to agree that they have been able to continue working since having neurological condition - 52% vs 35%

Respondents with multiple conditions were more likely to agree that they have stopped working because of neurological condition - 69% vs 53%

6.2.2 Differences between neurological conditions

The data was broken down by neurological condition, and the different ways people with these conditions answered the following questions.[6]

There were 49 conditions that had respondents over the suppression threshold of 21. However, this ranged from 1245 respondents to 28 respondents. For this section of the analysis, we have only included the 29 conditions that had 100 or more people saying they had the condition.

We have charted the top and bottom three scoring conditions for the following questions:

Diagnosis

Q15 Were you given written information?

Treatment and care

Q20 Involvement in choices about healthcare

Q24a Health and care are joined up on centred on their priorities

Q24b Information about condition is effectively shared

Support for condition

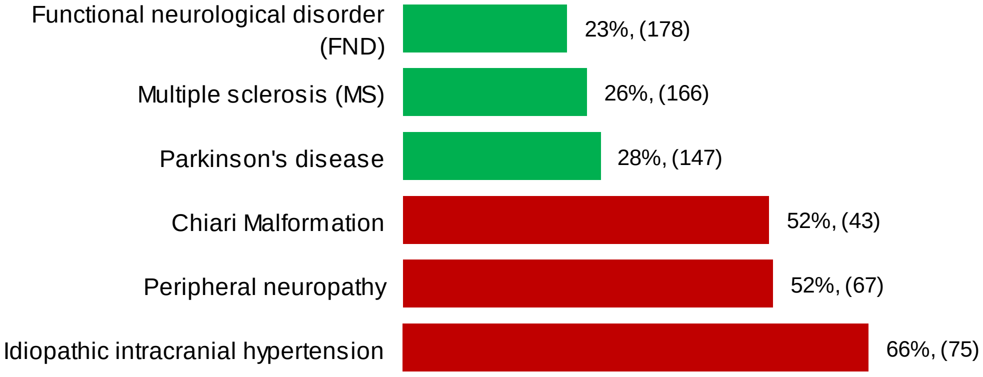
Q25 Have been offered a care plan

Mental wellbeing

Q27 Does condition affect their mental wellbeing

Q28 Have they been asked about their mental wellbeing by HCP in last 3 years

Q15 When you were told you had a neurological condition, were you given written information about it?



Respondents who answered ‘I was not offered or directed to any information’

Based on responses for: Functional neurological disorder (FND) – 762, Multiple sclerosis (MS) – 636, Parkinson's disease– 526, Chiari Malformation– 83, Peripheral neuropathy - 128, Idiopathic intracranial hypertension – 114

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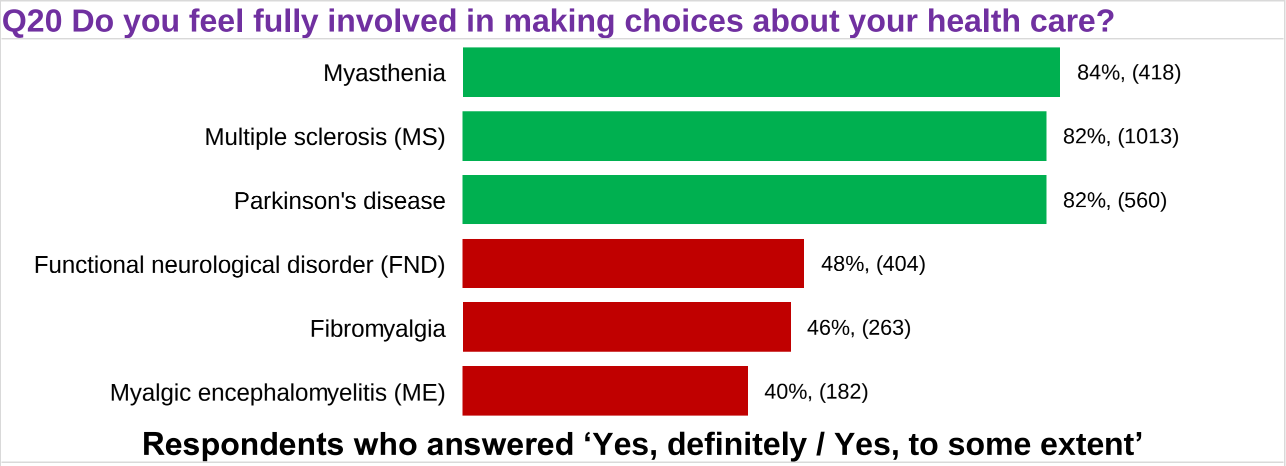
[6] Conditions were collected from Q2 - Please tell us which neurological condition(s) you have. As this question was a tick all that apply, respondents may have selected more than one condition, and we cannot be sure which condition may take precedence when they answered the question. For this reason these results should be treated with a degree of caution.

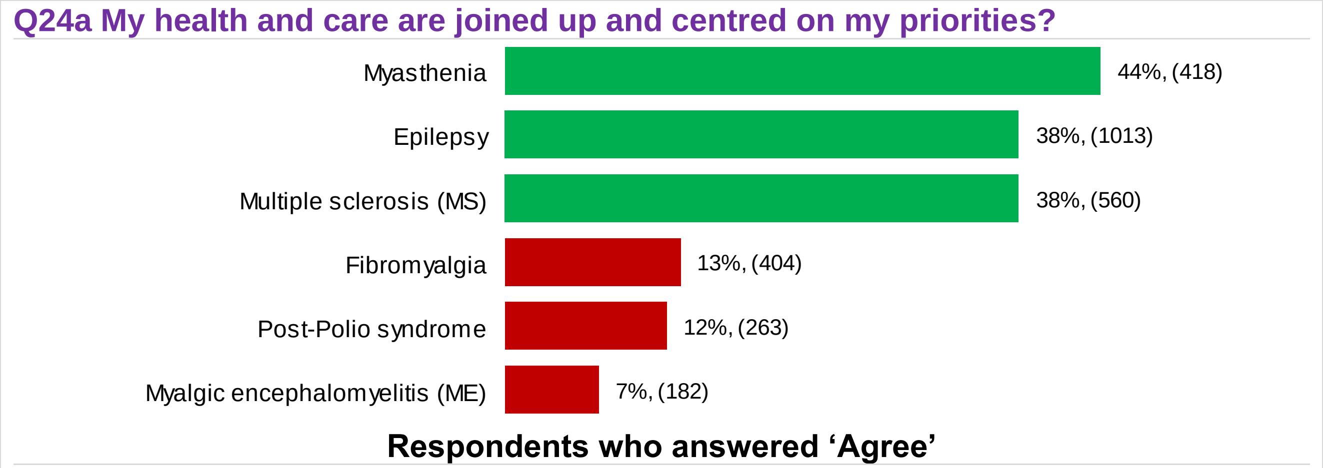
Fig 142. Written information – adult respondents by condition


Q20 Do you feel fully involved in making choices about your health care?

Respondents who answered ‘Yes, definitely / Yes, to some extent’

Based on responses for: Myasthenia – 495, Multiple sclerosis (MS) – 1232, Parkinson's disease – 683, Functional neurological disorder (FND) – 831, Fibromyalgia – 565, Myalgic encephalomyelitis (ME) – 461

Fig 143. Involvement in healthcare – adult respondents by condition

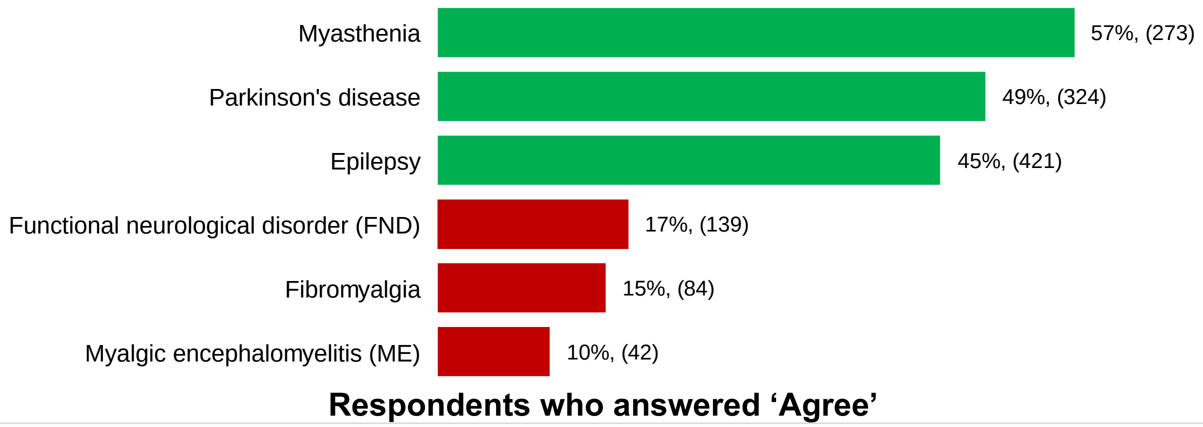

Q24a My health and care are joined up and centred on my priorities?

Respondents who answered ‘Agree’

Based on responses for: Myasthenia – 454, Epilepsy – 914, Multiple sclerosis (MS) – 1183, Fibromyalgia – 535, Post-Polio syndrome – 95, Myalgic encephalomyelitis (ME) – 427

Fig 144. Joined up care – adult respondents

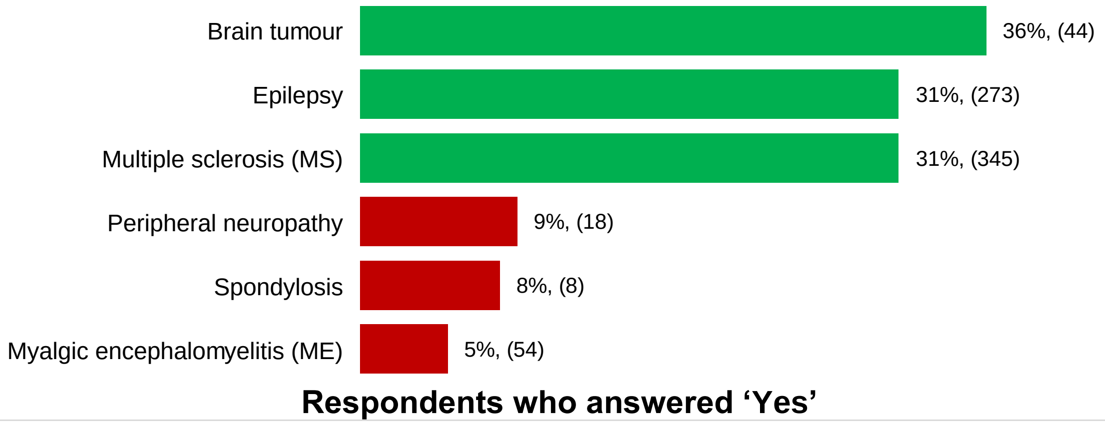
Q24b Information about my condition is effectively passed between the people that care for me (such as my specialists, GP, family carer)



Based on responses for: Myasthenia – 483, Parkinson's disease – 657, Epilepsy – 935, Functional neurological disorder (FND) – 824, Fibromyalgia– 544, Myalgic encephalomyelitis (ME) – 426

Fig 145. Communication – adult respondents

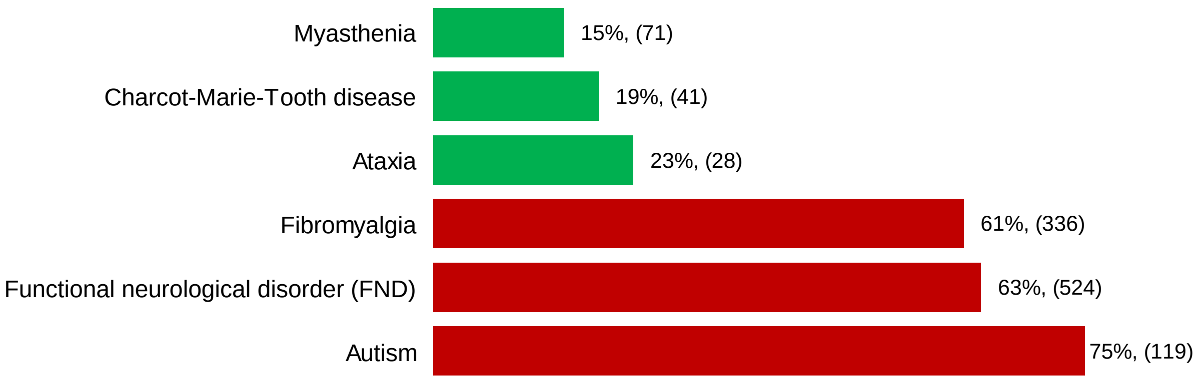
Q25 Within the last three years have you been offered a care and support plan to help you manage your neurological condition?



Based on responses for: Brain tumour – 121, Epilepsy – 889, Multiple sclerosis (MS) – 1113, Peripheral neuropathy – 193, Spondylosis – 96, Myalgic encephalomyelitis (ME) – 459

Fig 146. Offered a care plan – adult respondents

Q27 Does your neurological condition affect your mental wellbeing?

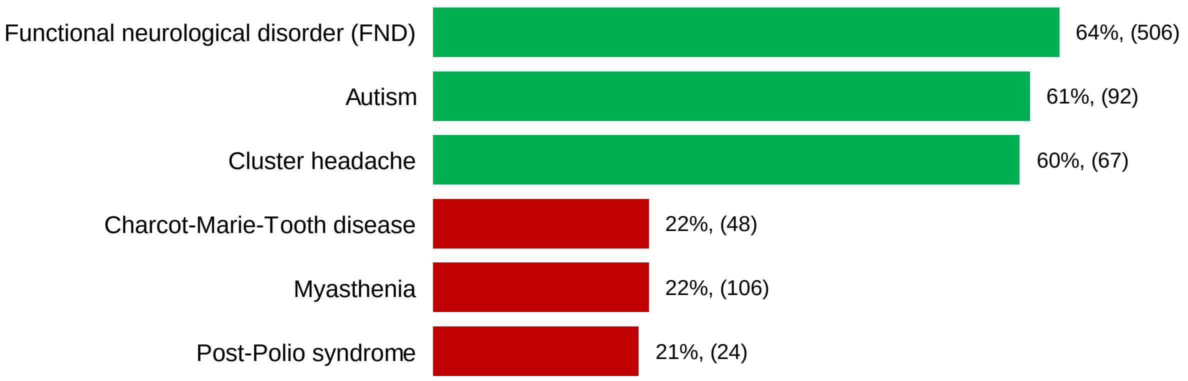


Respondents who answered 'Yes, makes it much worse'

Based on responses for: Myasthenia – 479, Charcot-Marie-Tooth disease – 220, Ataxia – 123, Fibromyalgia – 533, Functional neurological disorder (FND) – 829, Autism – 159

Fig 147. Mental wellbeing – adult respondents

Q28 Have you been asked about your mental wellbeing by a health or social care professional within the last three years?



Respondents who answered 'Yes'

Based on responses for: Functional neurological disorder (FND) – 792, Autism – 152, Cluster headache – 112, Charcot-Marie-Tooth disease – 215, Myasthenia – 481, Post-Polio syndrome – 113

Fig 148. Mental wellbeing and healthcare professionals – adult respondents

6.3 Geographical breakdowns

6.3.1 Nation breakdowns

The following section charts the results across England, Scotland, Wale and Norther Ireland for the key questions

Results have been presented as 100% stacked bar charts for visualisation purposes; however, it should be noted that the number of responses for each country are very different, with England receiving significantly more than Scotland, Wales and Northern Ireland.

Number of responses to the adult questionnaire by nation

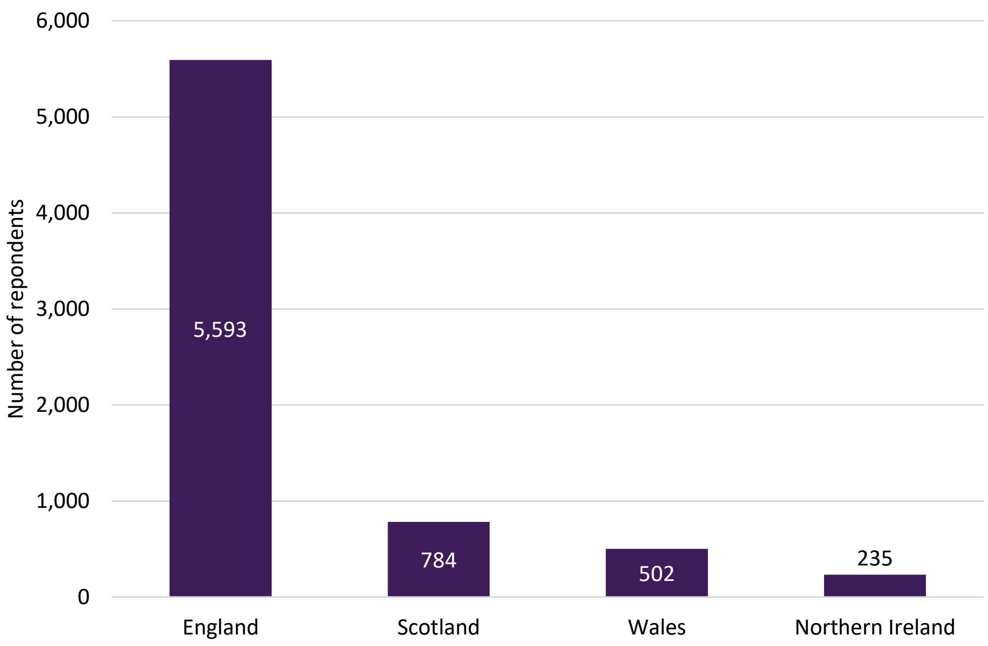
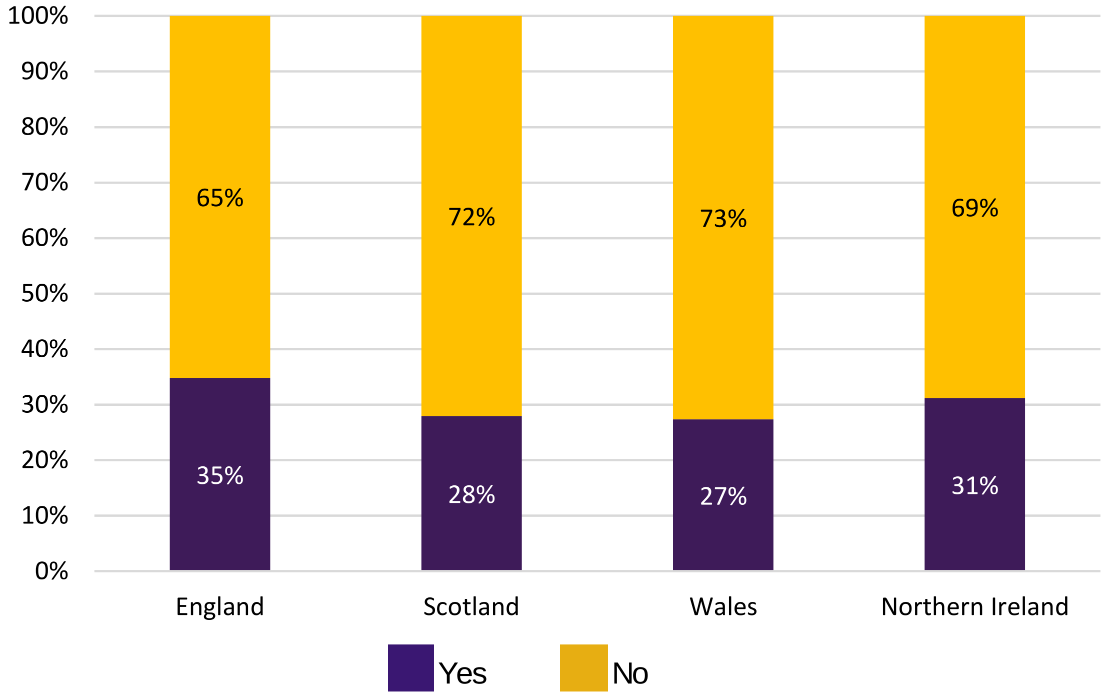


Fig 149. Geographical distribution – adult respondents

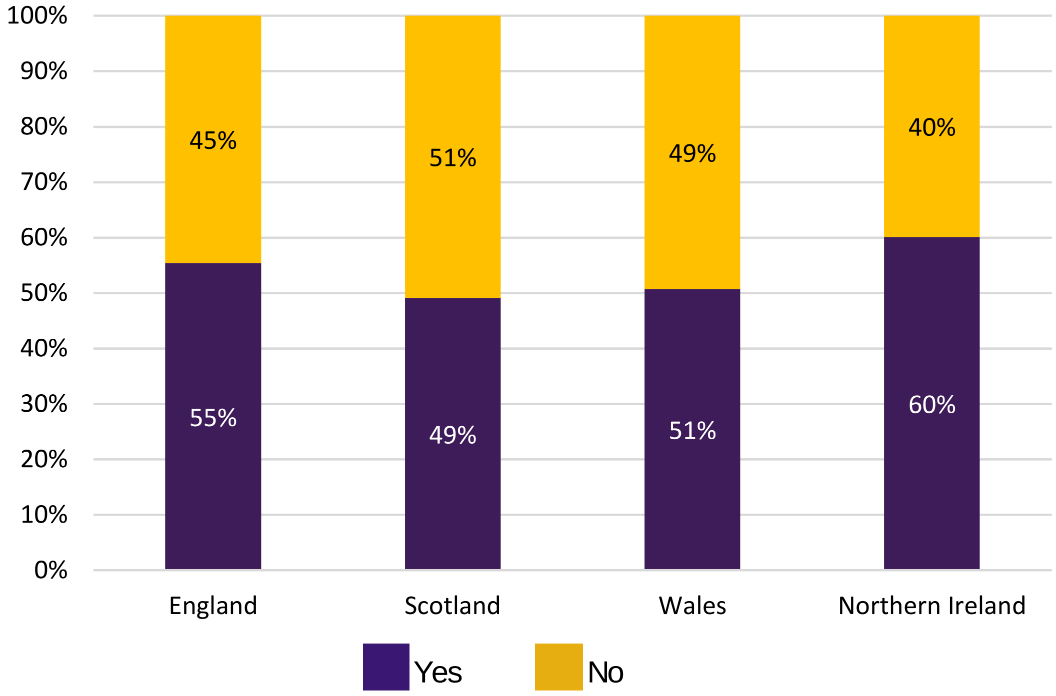
Q3a_1. Experienced delays for: A first appointment with a neurologist



Based on responses for: England – 2221, Scotland – 336, Wales – 201, Northern Ireland – 93

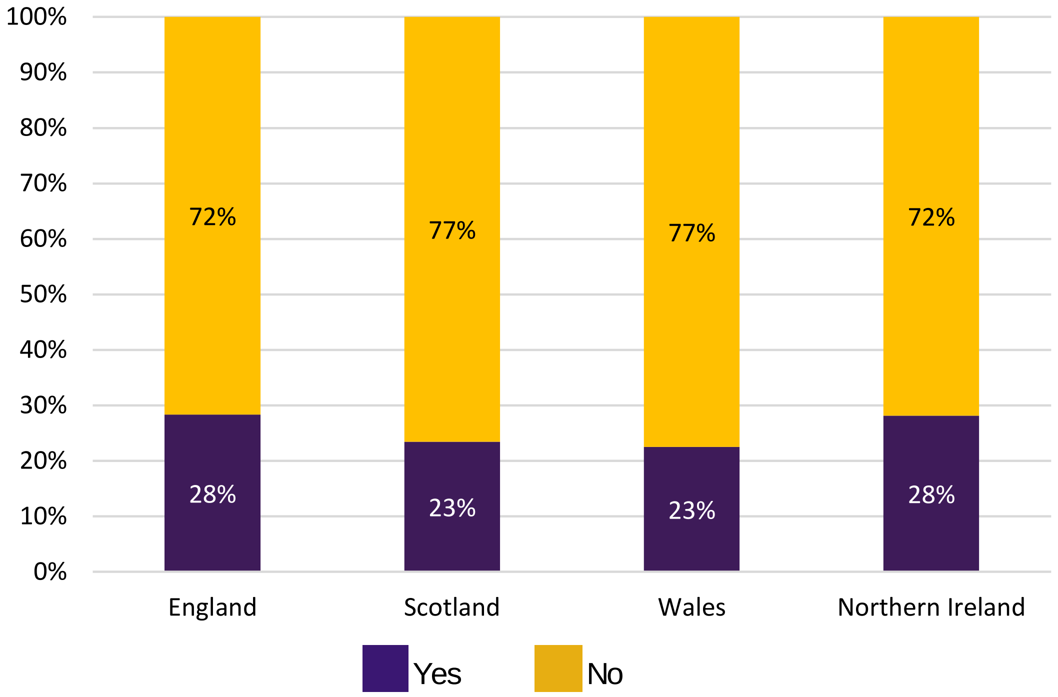
Fig 150. Delays for a first appointment with a neurologist – adult respondents by nation

Q3a_2. Experienced delays for: A routine appointment with your neurologist



Based on responses for: England – 3835, Scotland – 519, Wales – 342, Northern Ireland – 178

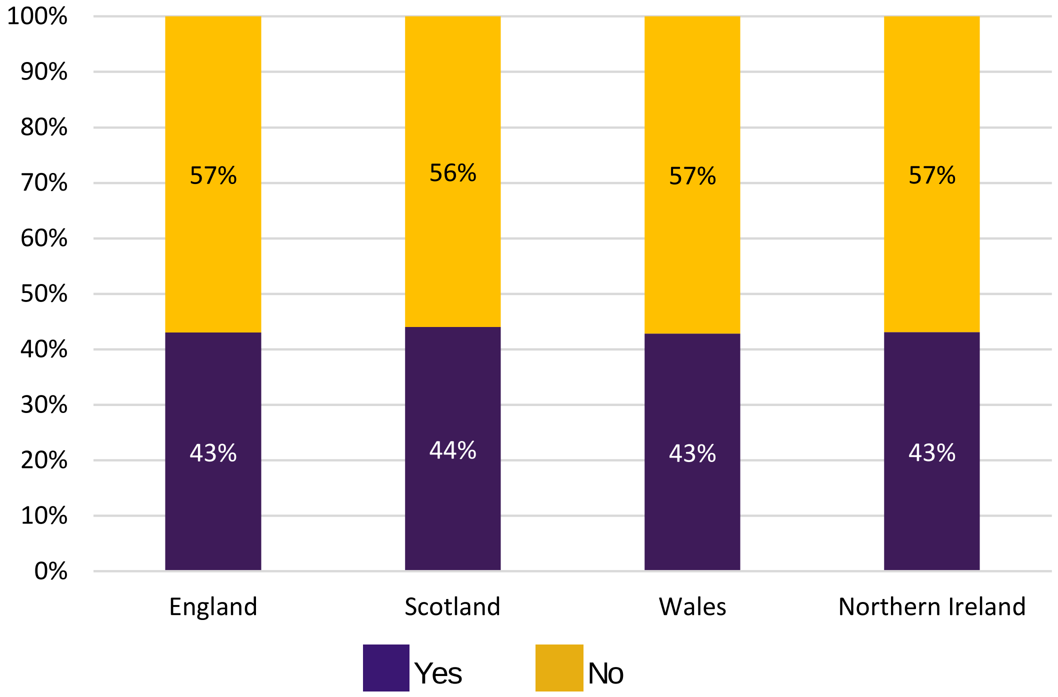
Fig 151. Delays for a routine appointment with your neurologist – adult respondents by nation



Q3a_3. Experienced delays for: A first appointment with a specialist nurse

Based on responses for: England – 1549, Scotland – 239, Wales – 151, Northern Ireland – 71

Fig 152. Delays for a first appointment with a specialist nurse – adult respondents by nation

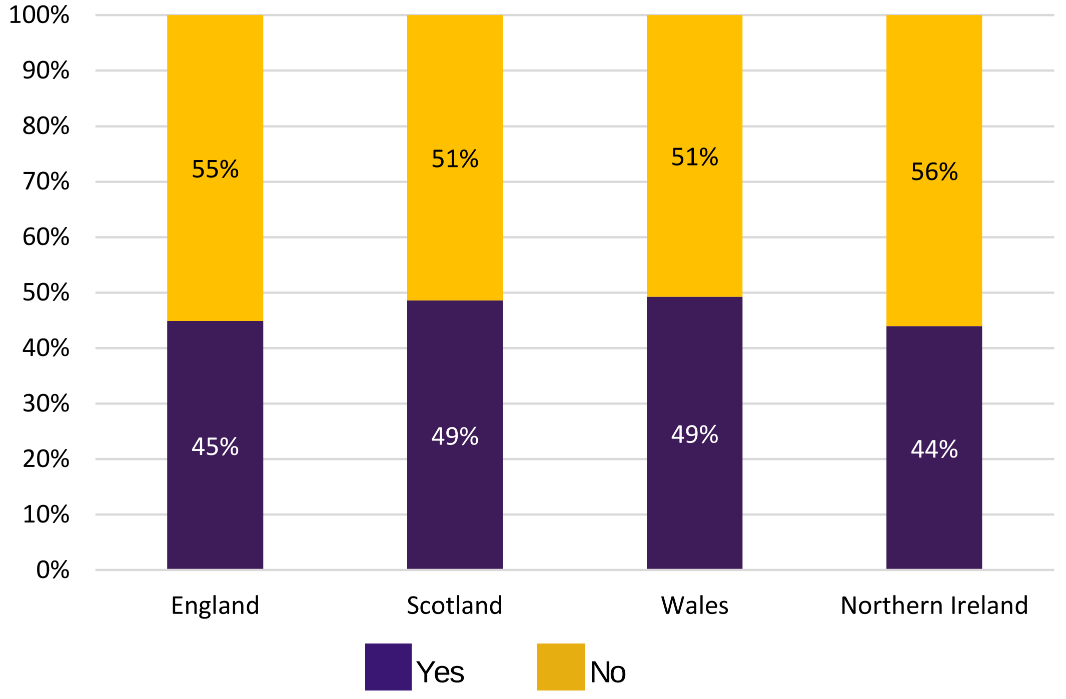


Q3a_4. Experienced delays for: A routine appointment with your specialist nurse

Based on responses for: England – 2332, Scotland – 375, Wales – 238, Northern Ireland – 109

Fig 153. Delays for a routine appointment with your specialist nurse – adult respondents by nation

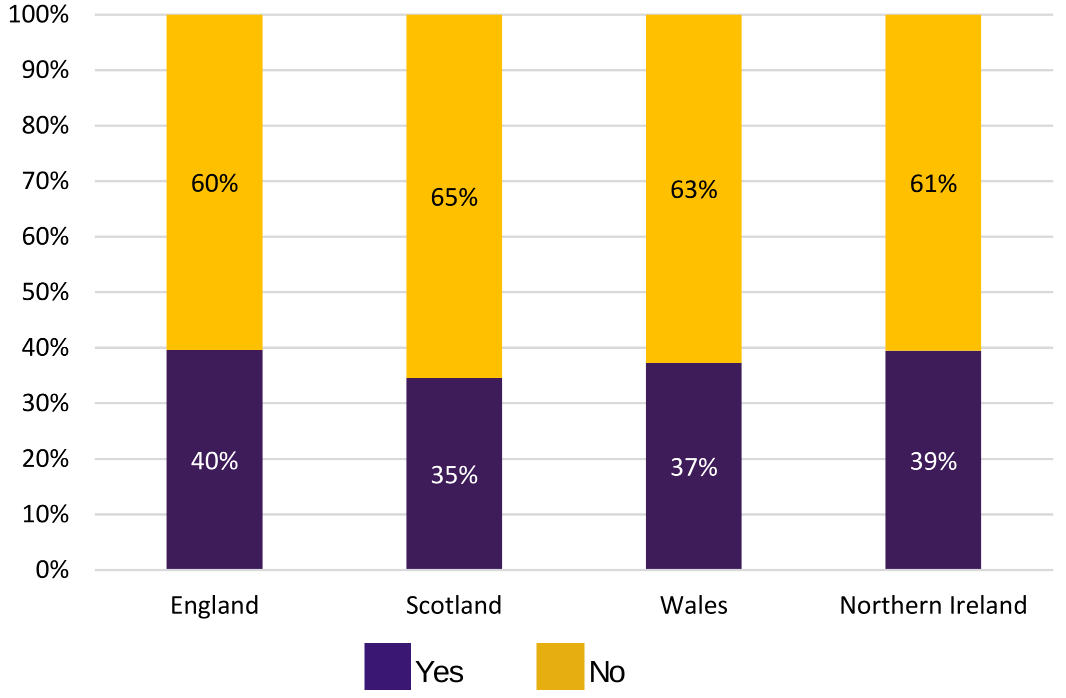
Q3a_5. Experienced delays for: A mental health appointment



Based on responses for: England – 1542, Scotland – 245, Wales – 136, Northern Ireland – 66

Fig 154. Delays for a routine appointment for a mental health appointment – adult respondents by nation

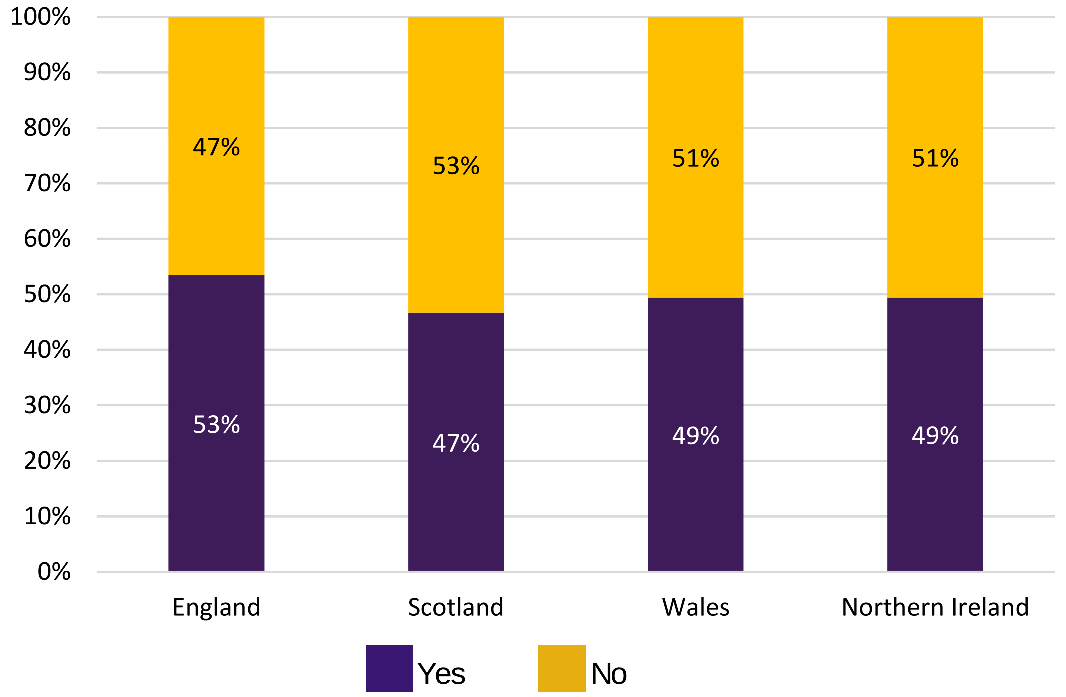
Q3a_8. Experienced delays for: A scan



Based on responses for: England – 2206, Scotland – 324, Wales – 217, Northern Ireland – 114

Fig 155. Delays for a scan – adult respondents by nation

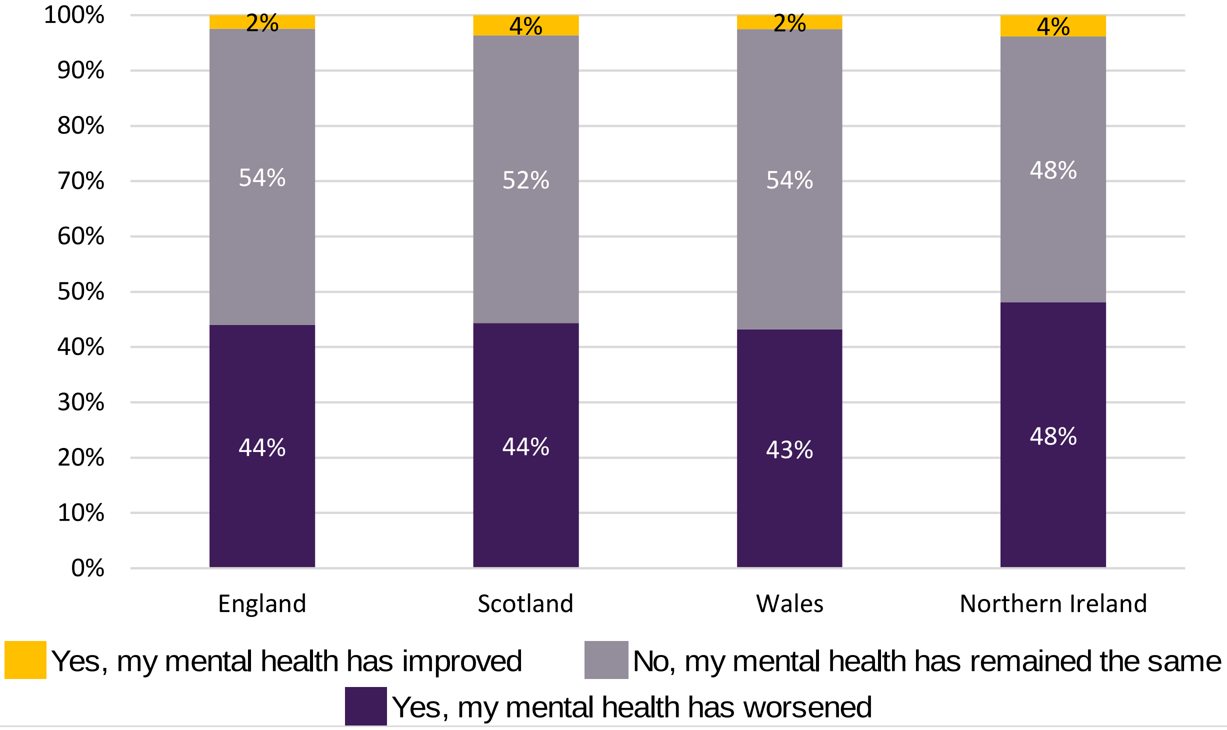
Q3b_2. Experienced delays for: Physiotherapy



Based on responses for: England – 1964 Scotland – 304, Wales – 170, Northern Ireland – 91

Fig 156. Delays for physiotherapy – adult respondents by nation

Q7. Have you experienced a change in your mental health needs due to Covid-19?

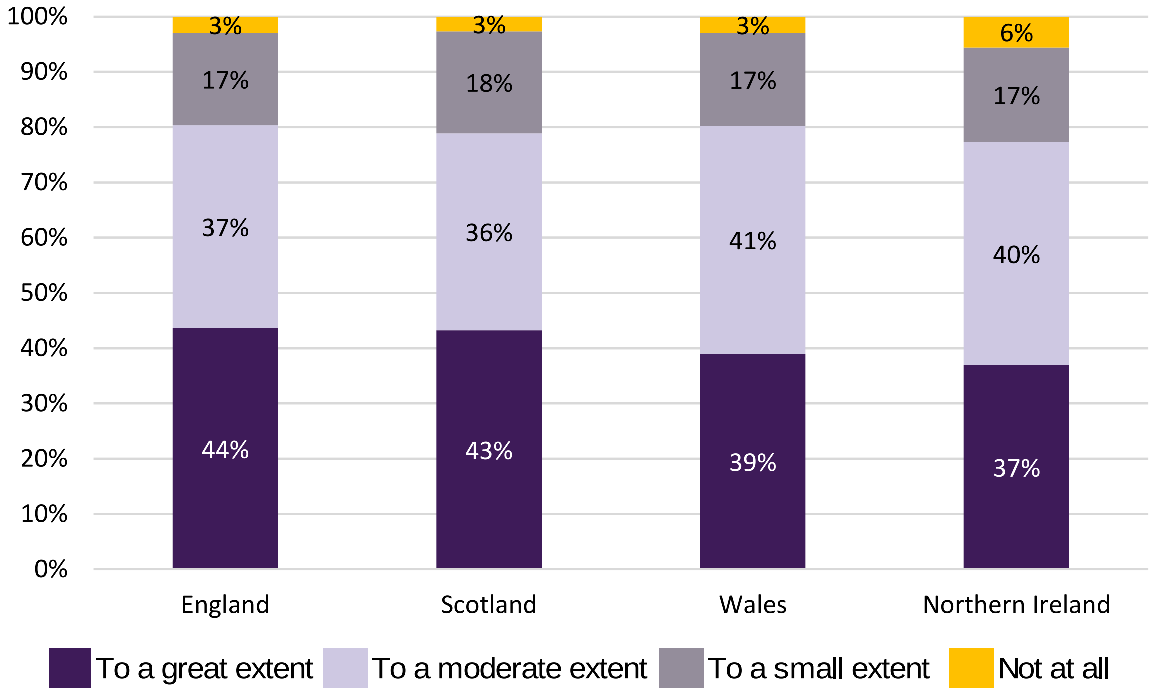


Based on responses for: England – 4885 Scotland – 685, Wales – 442 Northern Ireland – 210

Fig 157. Change to mental health needs due to Covid-19 – adult respondents by nation

Overall impact

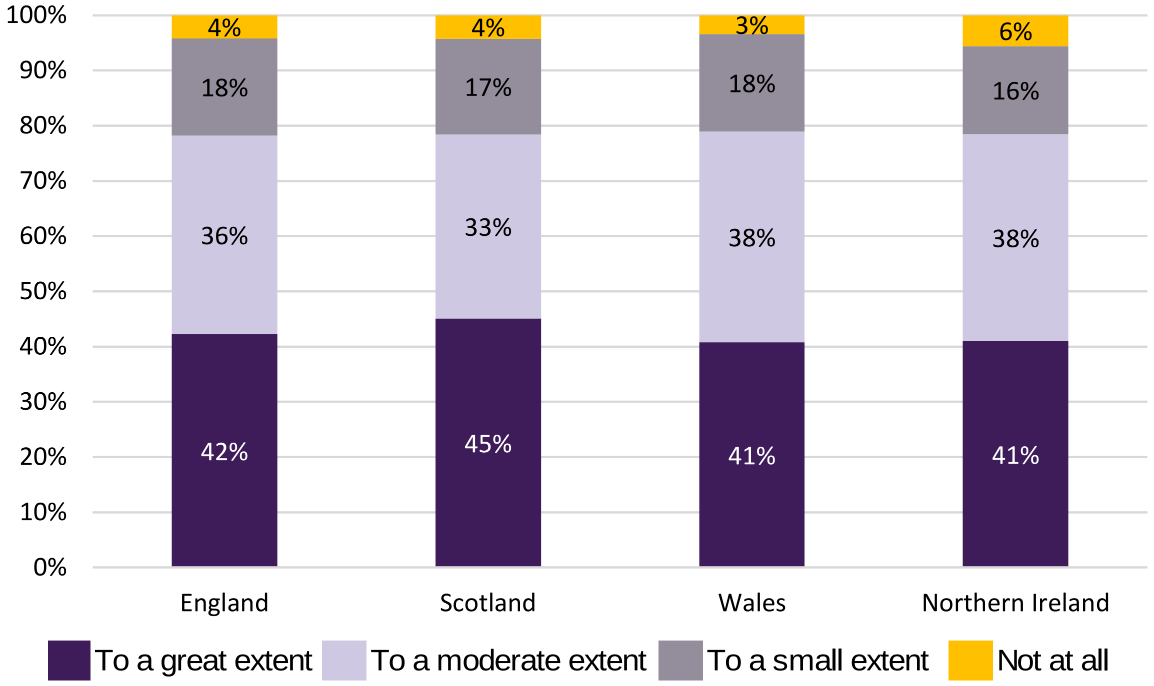
Q8. To what extent overall does your neurological condition(s) impact your quality of life?



Based on responses for: England – 5546, Scotland – 777, Wales – 495, Northern Ireland – 233

Fig 158. Overall impact of neurological conditions on quality of life – adult respondents by nation

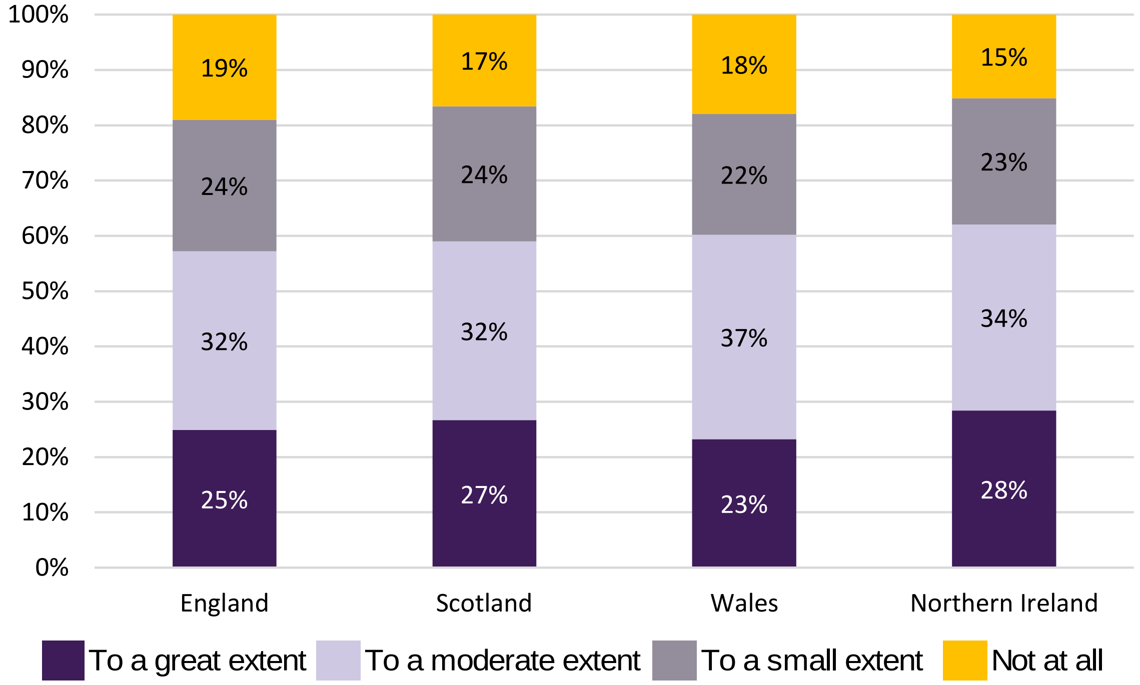
Q9. To what extent overall does your neurological condition(s) impact your day to day activities?



Based on responses for: England – 5557, Scotland – 778, Wales – 498, Northern Ireland – 232

Fig 159. Impact of neurological conditions day to day activities – adult respondents by nation

Q10. To what extent overall does your neurological condition(s) cause you pain?

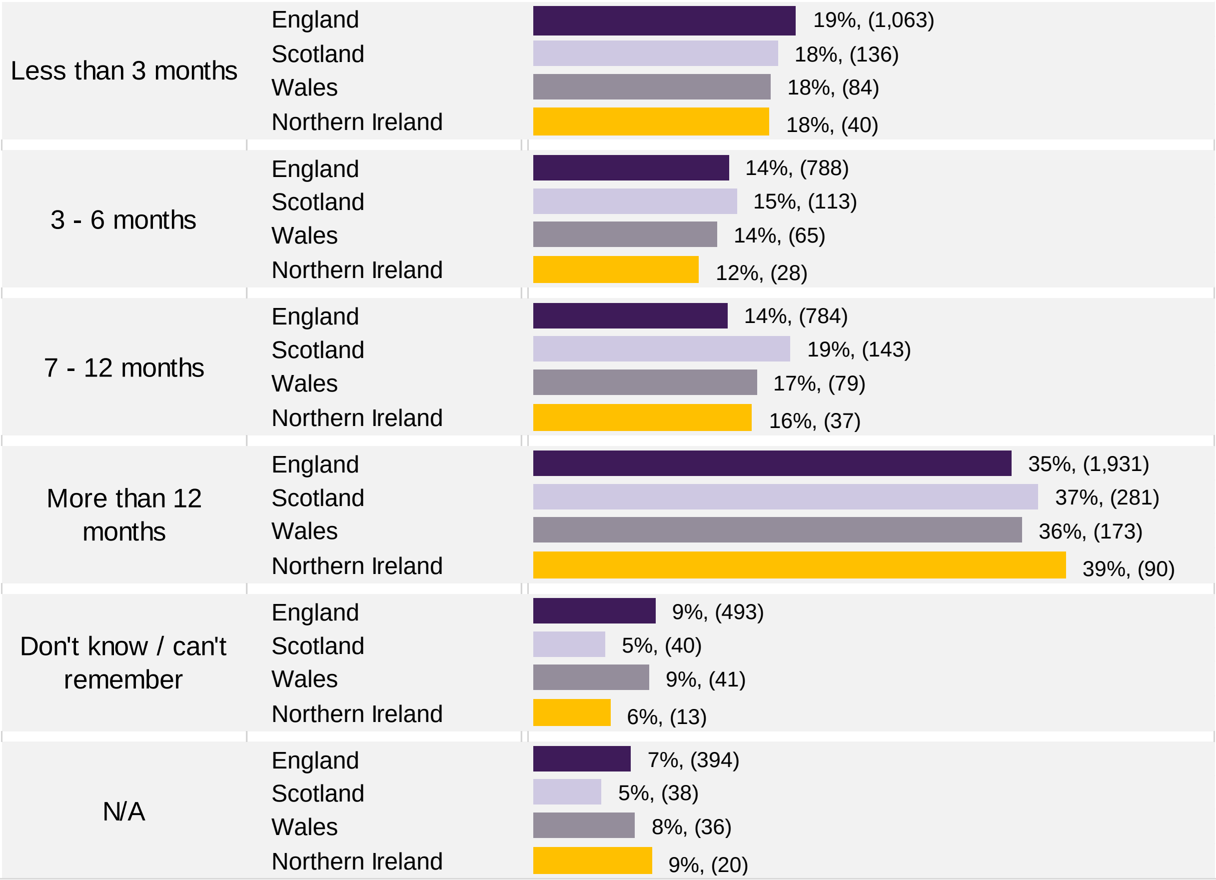


Based on responses for: England – 5503, Scotland – 768, Wales – 495, Northern Ireland – 232

Fig 160. Pain caused by neurological conditions – adult respondents by nation

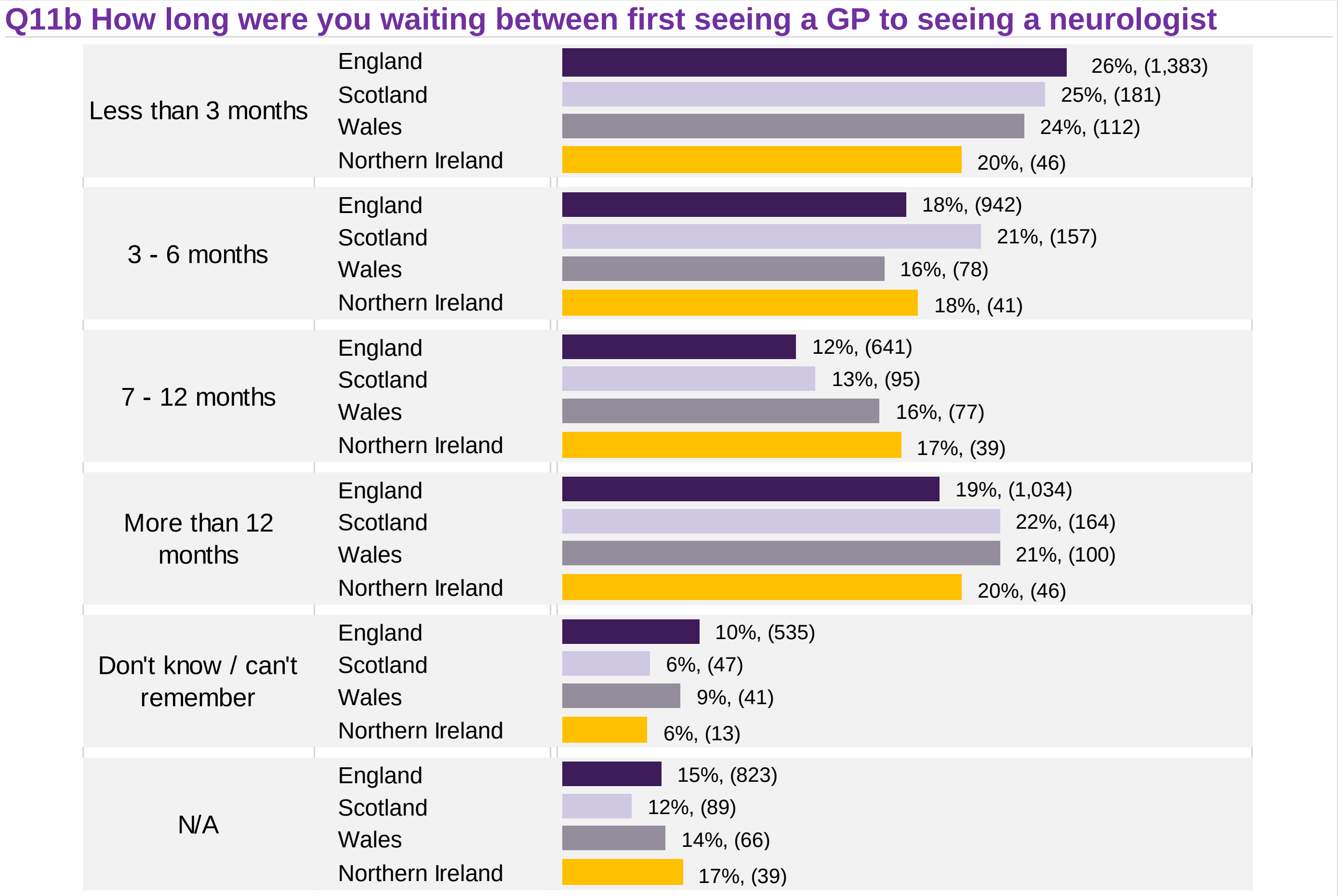
Before diagnosis

Q11a How long were you waiting between first experiencing symptoms to getting a diagnosis?



Based on responses for: England – 5453, Scotland – 751, Wales – 478, Northern Ireland – 228

Fig 161. Waiting for a diagnosis – adult respondents by nation

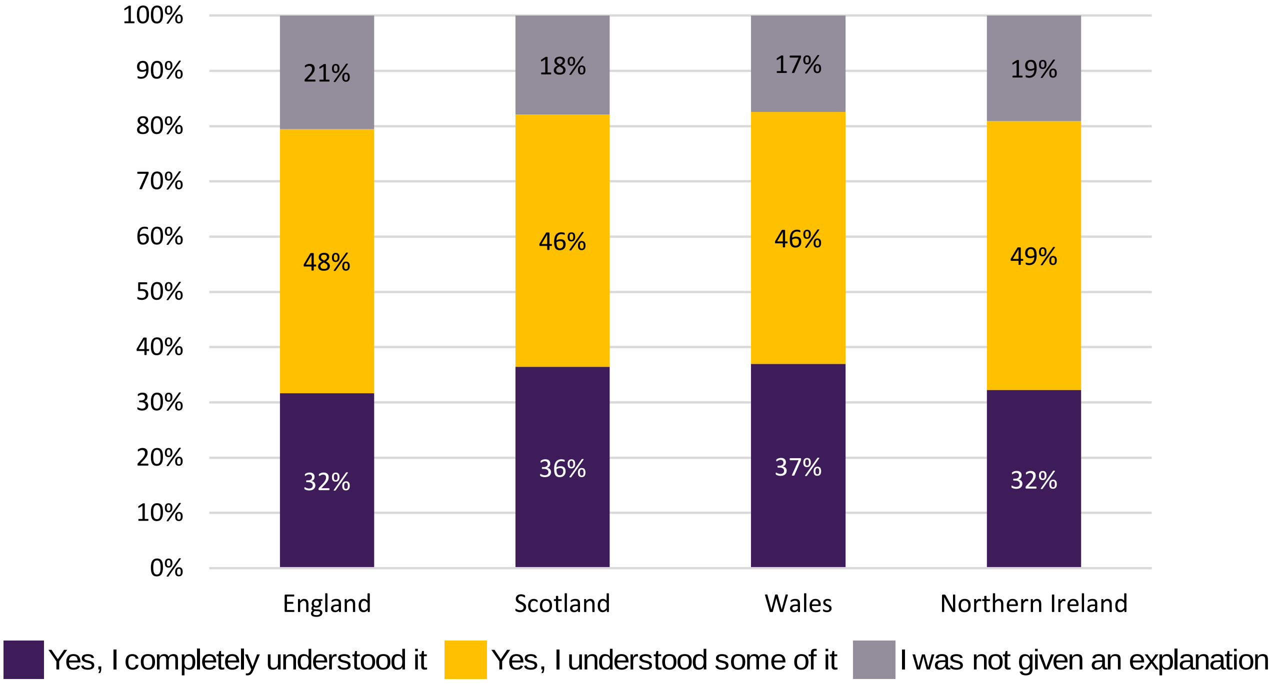


Based on responses for: England – 5358, Scotland – 733, Wales – 474, Northern Ireland – 225

Fig 162. Waiting to see a neurologist – adult respondents by nation

Diagnosis

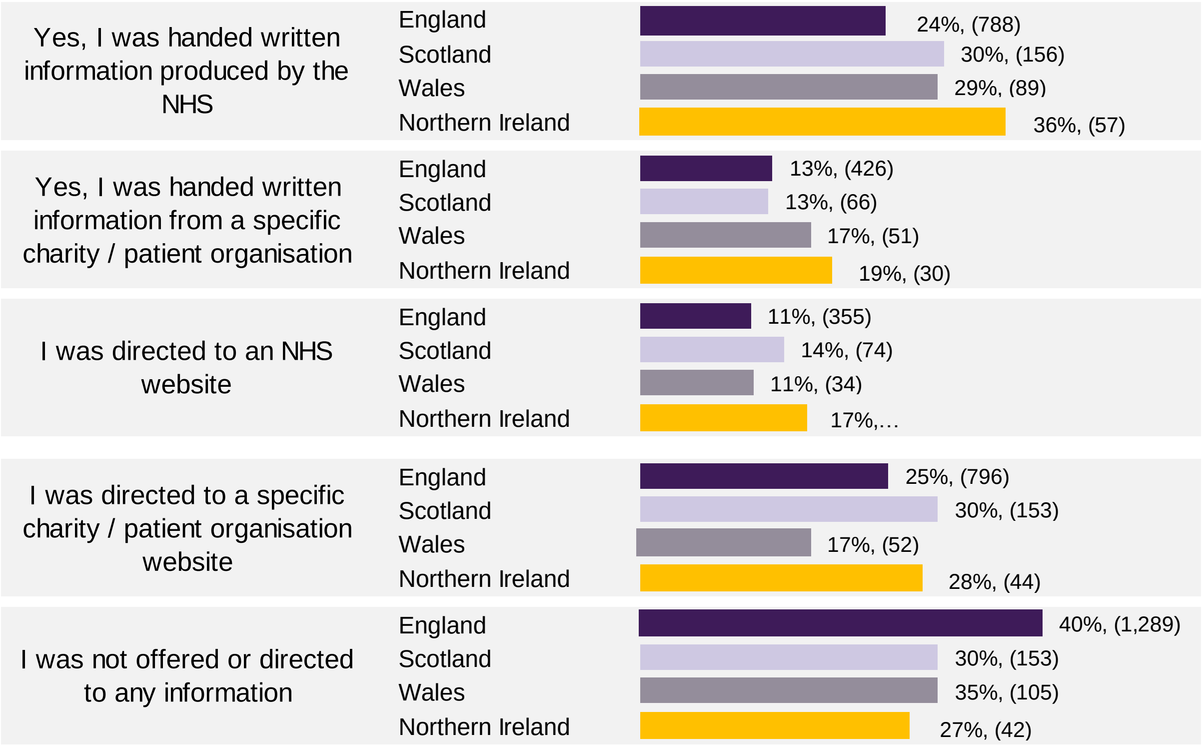
Q14 Did you understand the explanation given to you at your diagnosis / when you were first told about your condition?



Based on responses for: England – 3083, Scotland – 491, Wales – 287, Northern Ireland – 152

Fig 163. Explanation of diagnosis – adult respondents by nation

Q15 When you were told you had a neurological condition, were you given written information about it? Please tick all that apply

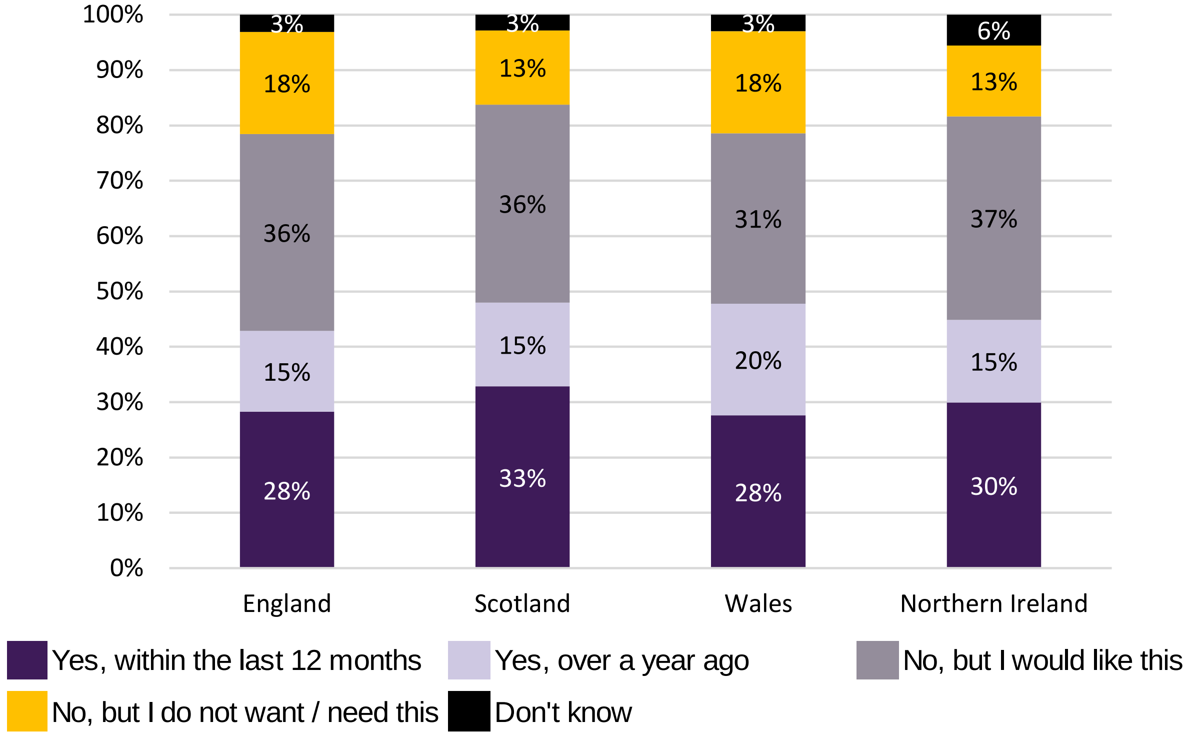


Based on responses for: England – 3231, Scotland – 518, Wales – 301, Northern Ireland – 157

Fig 164. Written information –adult respondents by nation

Treatment and care

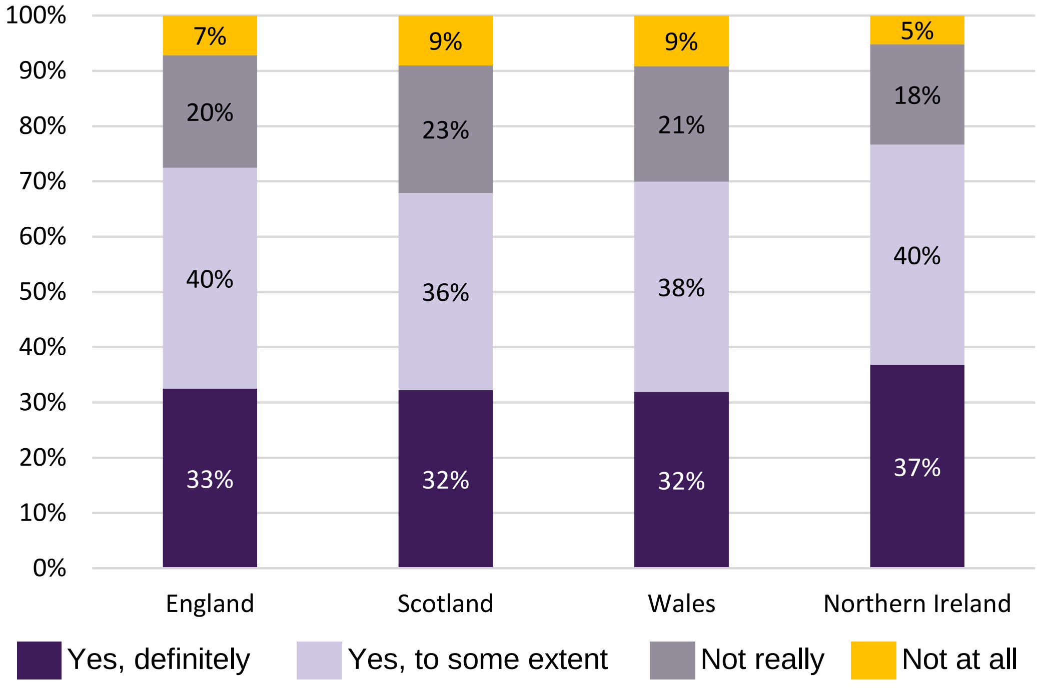
Q18 Have you had an appointment with a specialist nurse for your neurological condition(s)?



Based on responses for: England – 5564, Scotland – 777, Wales – 500, Northern Ireland – 234

Fig 165. Access to Specialist Nurses – adult respondents by nation

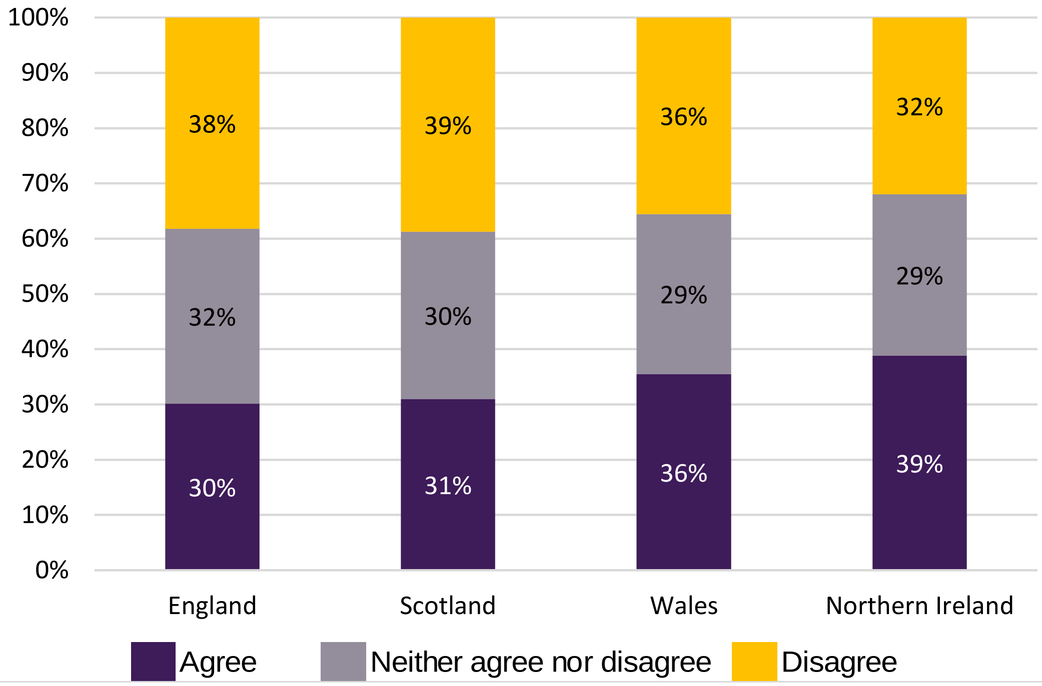
Q20 Do you feel fully involved in making choices about your health care?



Based on responses for: England – 5467, Scotland – 766, Wales – 492, Northern Ireland – 231

Fig 166. Involvement in healthcare – adult respondents by nation

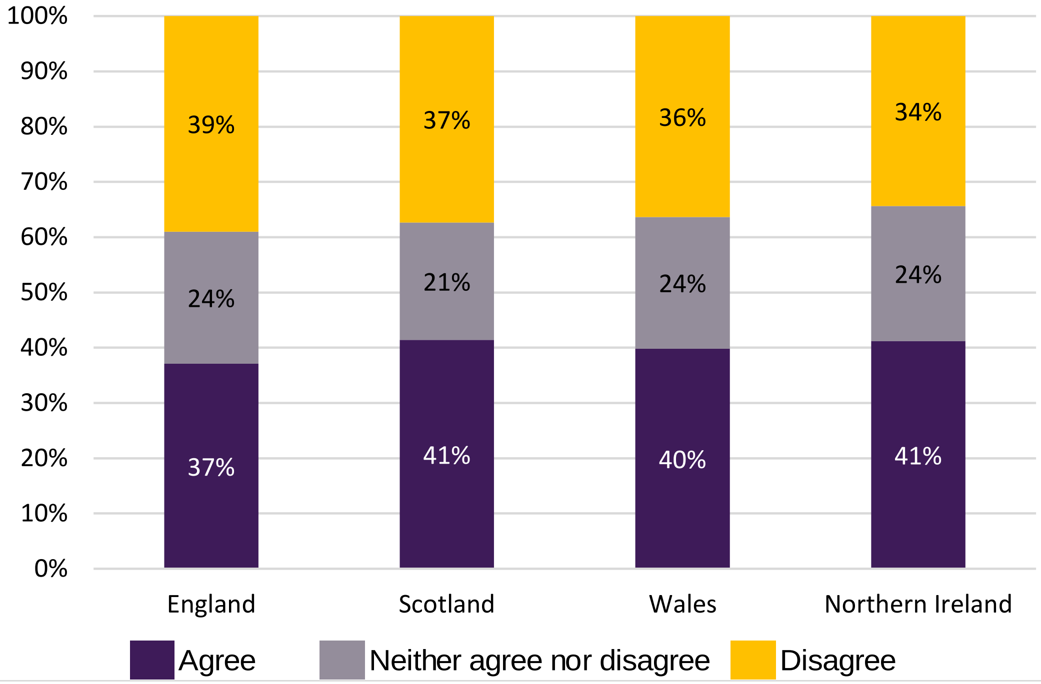
Q24a My health and care are joined up and centred on my priorities



Based on responses for: England – 5085, Scotland – 694, Wales – 459, Northern Ireland – 219

Fig 167. Joined up care – adult respondents by nation

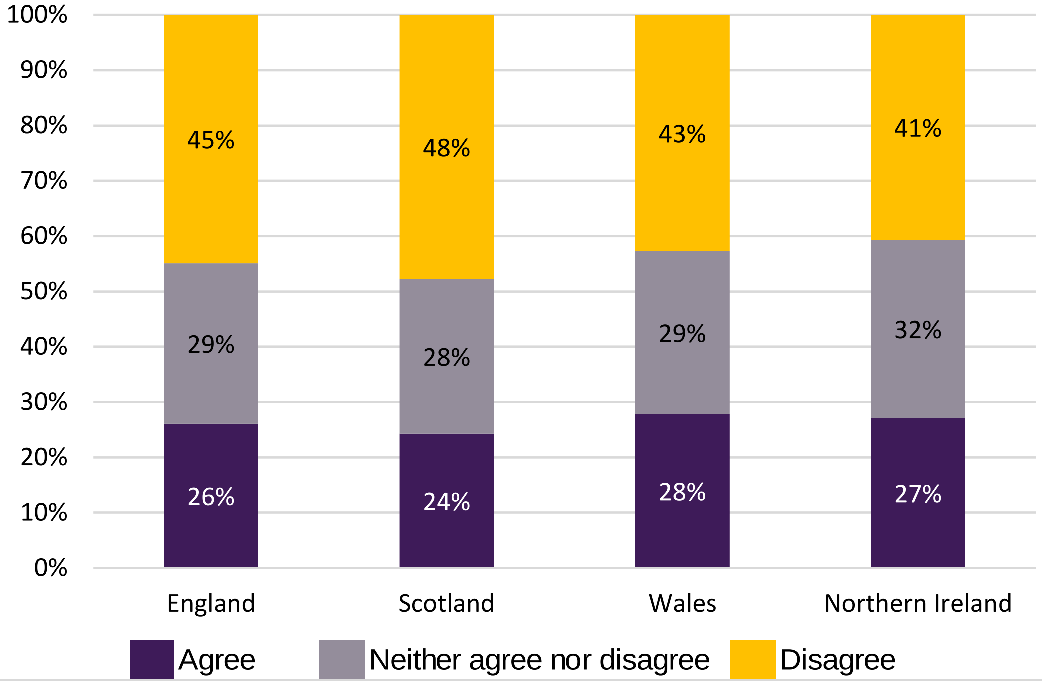
Q24b Information about my condition is effectively passed between the people that care for me (such as my specialists, GP, family carer)



Based on responses for: England – 5228, Scotland – 720, Wales – 462, Northern Ireland – 221

Fig 168. Communication – adult respondents by nation

Q24d I got the care I needed at home after my hospital visit

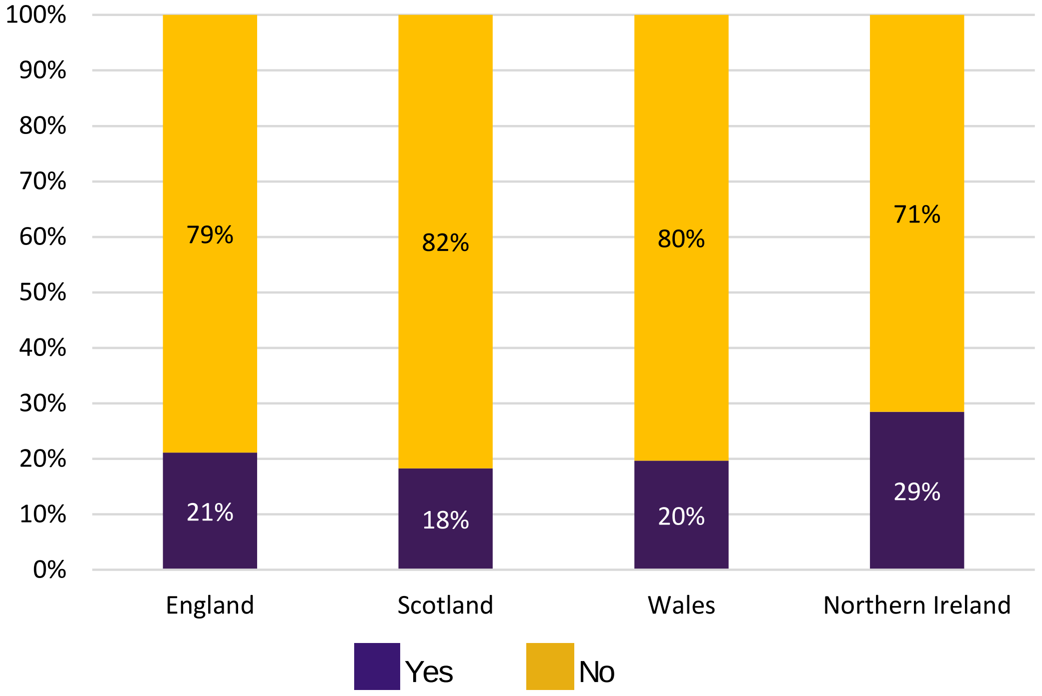


Based on responses for: England – 2781, Scotland – 362, Wales – 248, Northern Ireland – 118

Fig 169. Care after hospital visits – adult respondents by nation

Support for condition

Q25 Within the last three years have you been offered a care and support plan to help you manage your neurological condition?

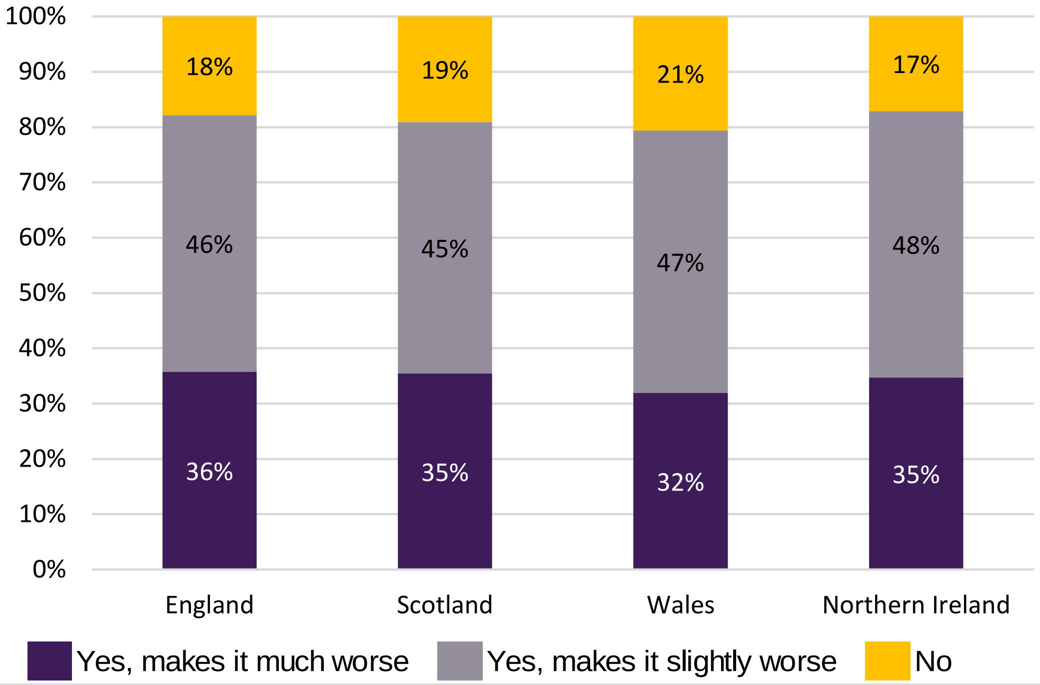


Based on responses for: England – 5152, Scotland – 716, Wales – 448, Northern Ireland – 214

Fig 170. Offered a care plan – adult respondents by nation

Mental wellbeing

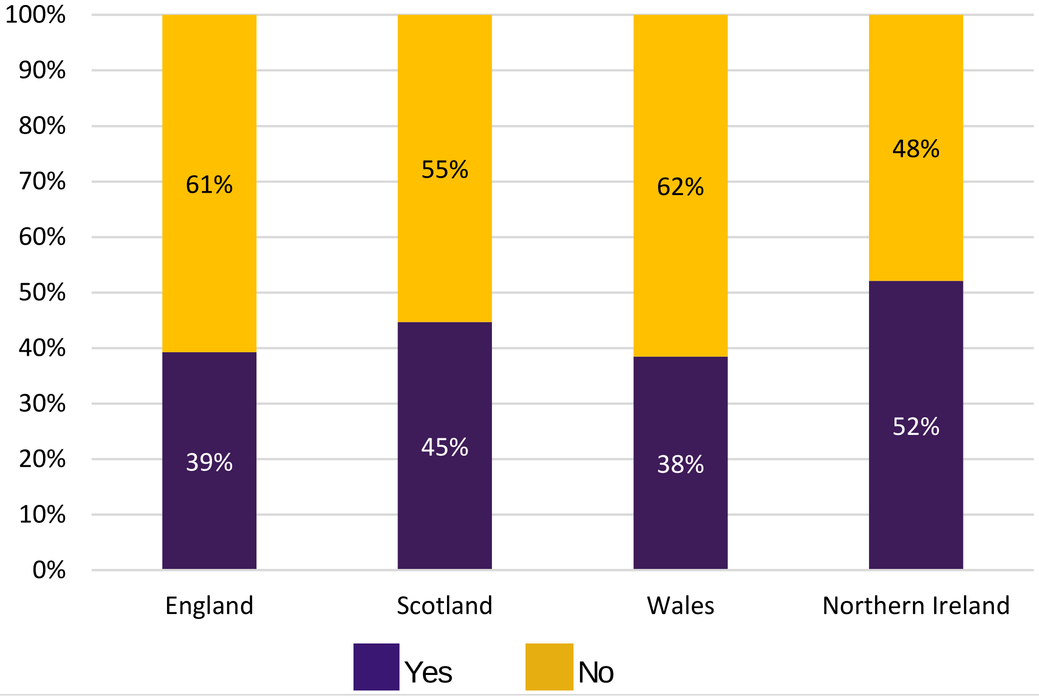
Q27 Does your neurological condition affect your mental wellbeing?



Based on responses for: England – 5304, Scotland – 737, Wales – 470, Northern Ireland – 222

Fig 171. Mental wellbeing – adult respondents by nation

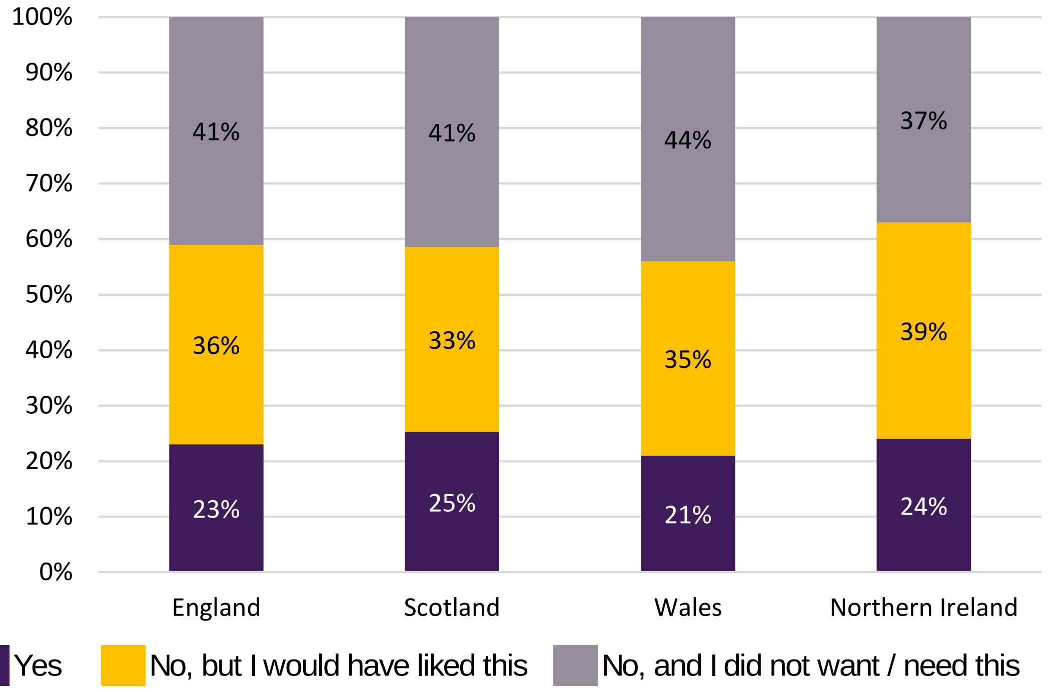
Q28 Have you been asked about your mental wellbeing by a health or social care professional within the last three years?



Based on responses for: England – 5169, Scotland – 732, Wales – 473, Northern Ireland – 213

Fig 172. Mental wellbeing and healthcare professionals – adult respondents by nation

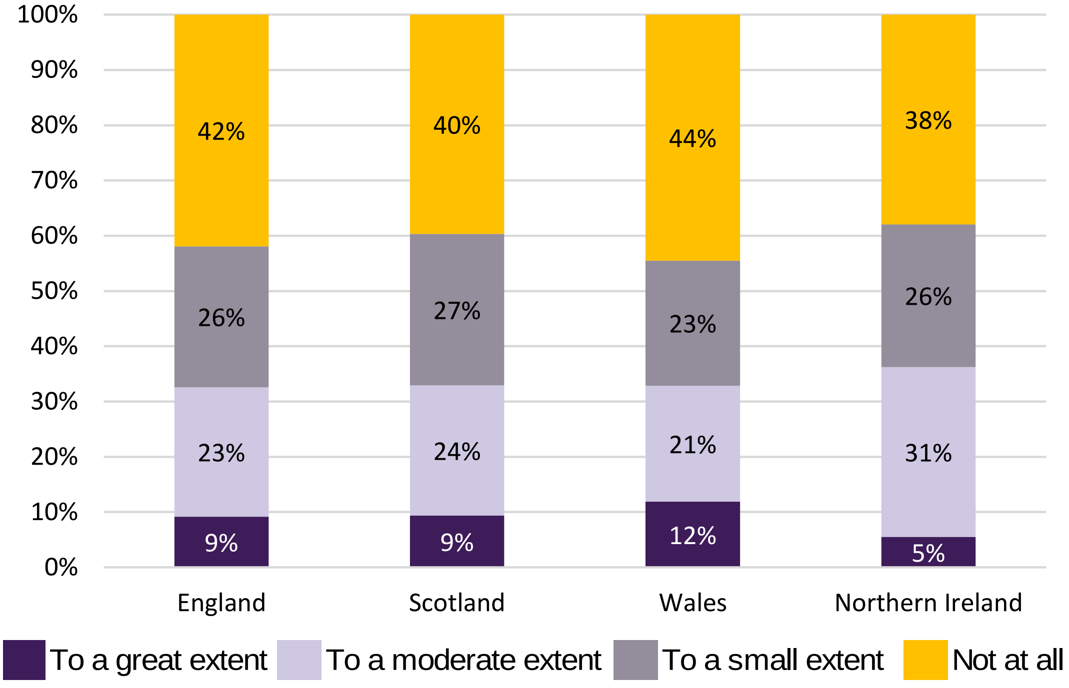
Q29 Have you been referred or directed to support for your mental wellbeing by a health professional within the last three years?



Based on responses for: England – 5223, Scotland – 732, Wales – 475, Northern Ireland – 214

Fig 173. Referral or directed to support for mental wellbeing – adult respondents by nation

Q32 To what extent do you feel your mental wellbeing needs are being met?

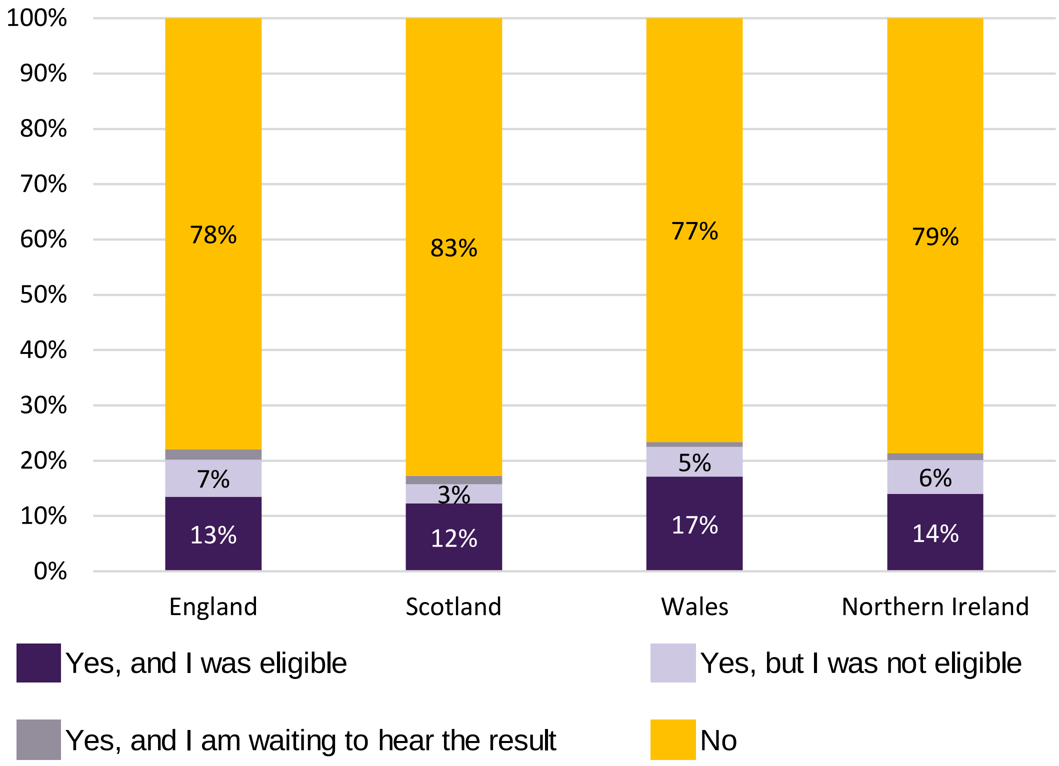


Based on responses for: England – 4228, Scotland – 577, Wales – 371, Northern Ireland – 182

Fig 174. Meeting mental wellbeing needs – adult respondents by nation

Social care

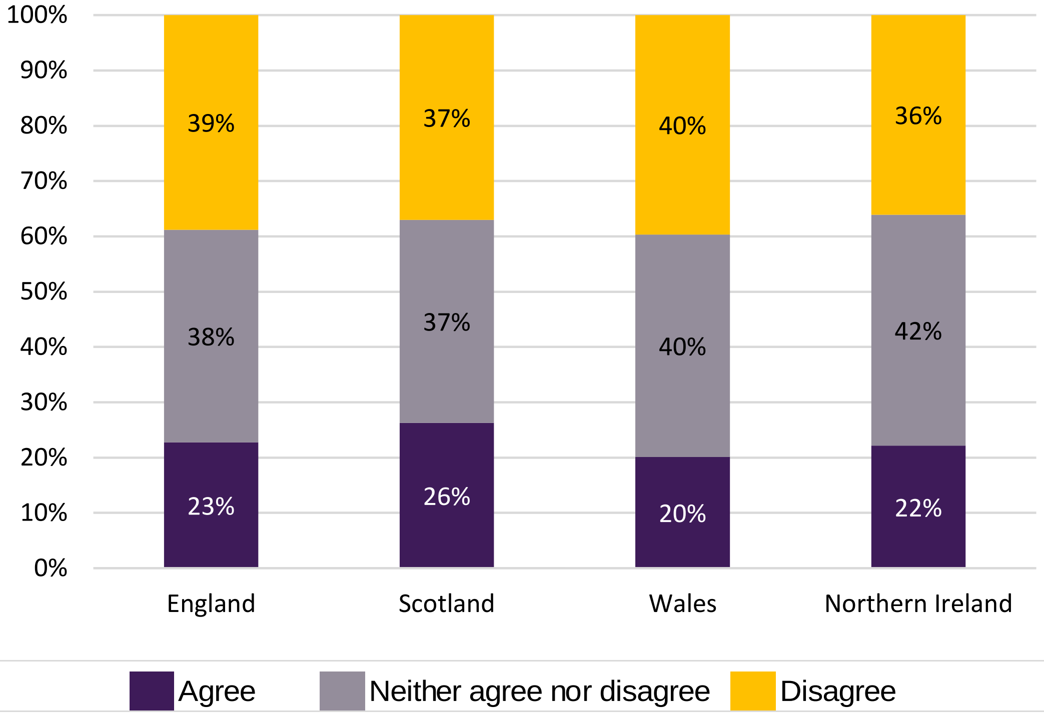
Q34 Has your local council assessed your care and support needs to see if you are eligible to receive funded care or support?



Based on responses for: England – 3653, Scotland – 521, Wales – 351, Northern Ireland – 164

Fig 175. Assessments for funded care and support – adult respondents by nation

Q37a Overall, the social care I have received meets my needs

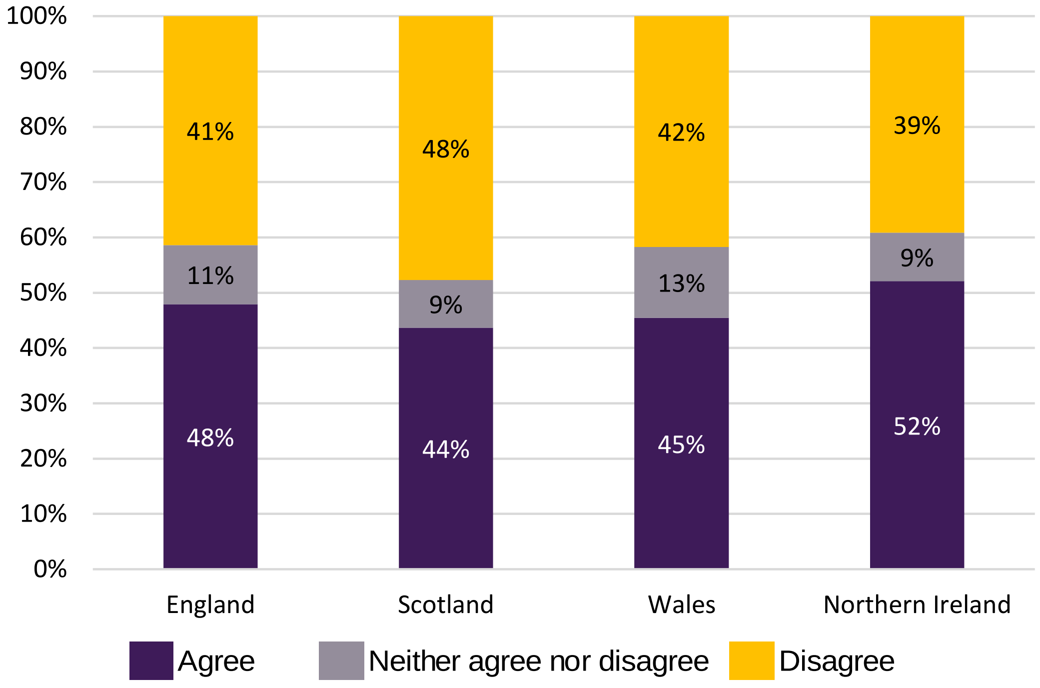


Based on responses for: England – 2152, Scotland – 289, Wales – 184, Northern Ireland – 122

Fig 176. Overall views of social care – adult respondents by nation

Employment and Welfare

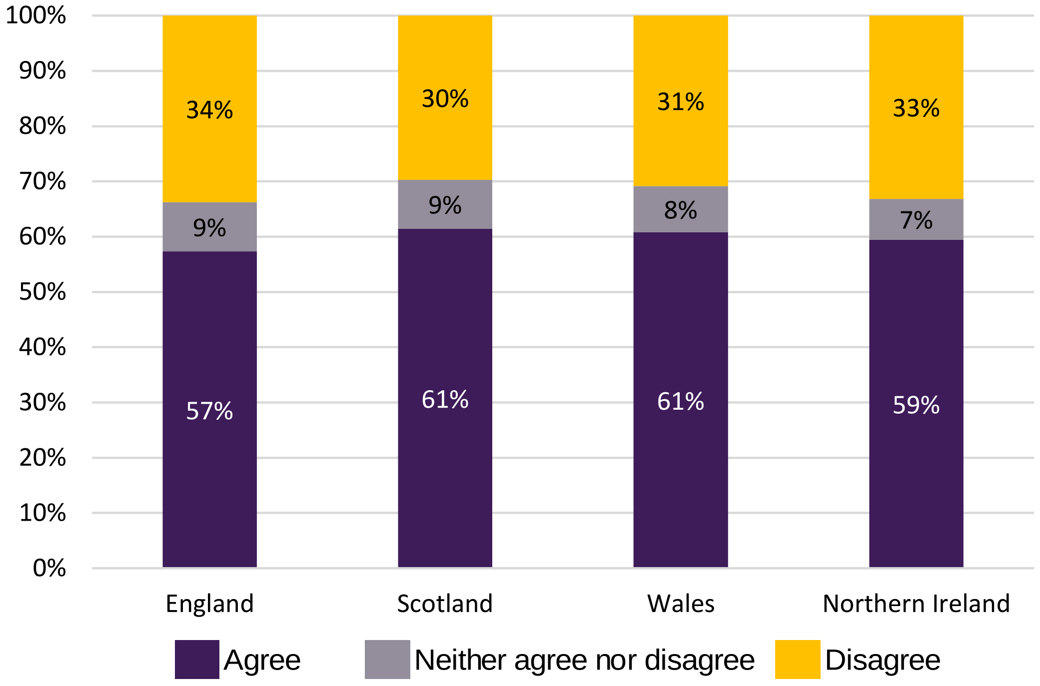
Q39a I have been able to continue working since having a neurological condition



Based on responses for: England – 3970, Scotland – 570, Wales – 350, Northern Ireland – 194

Fig 177. Continue working – adult respondents by nation

Q39b I have stopped working because of my neurological condition symptoms



Based on responses for: England – 3737, Scotland – 545, Wales – 334, Northern Ireland – 175

Fig 178. Stopped working – adult respondents by nation

6.3.2 Regional breakdowns

The data has also been mapped to geographical areas. Going forward we plan to publish more data sets including by:

- England NHS Clinical Commissioning Group (CCG)
- England Integrated Care Board (ICB)
- Northern Ireland Health Trust
- Wales Health Board
- Scotland Health Board
- Scotland Health Trust Region

6.4 Age breakdowns

The following section illustrates how the results compare across the different age groups.

Results have been presented as 100% stacked bar charts for visualisation purposes; however, it should be noted that there is variation in the number respondents within each group, in particular the smaller number of 18-24 year olds who participated.

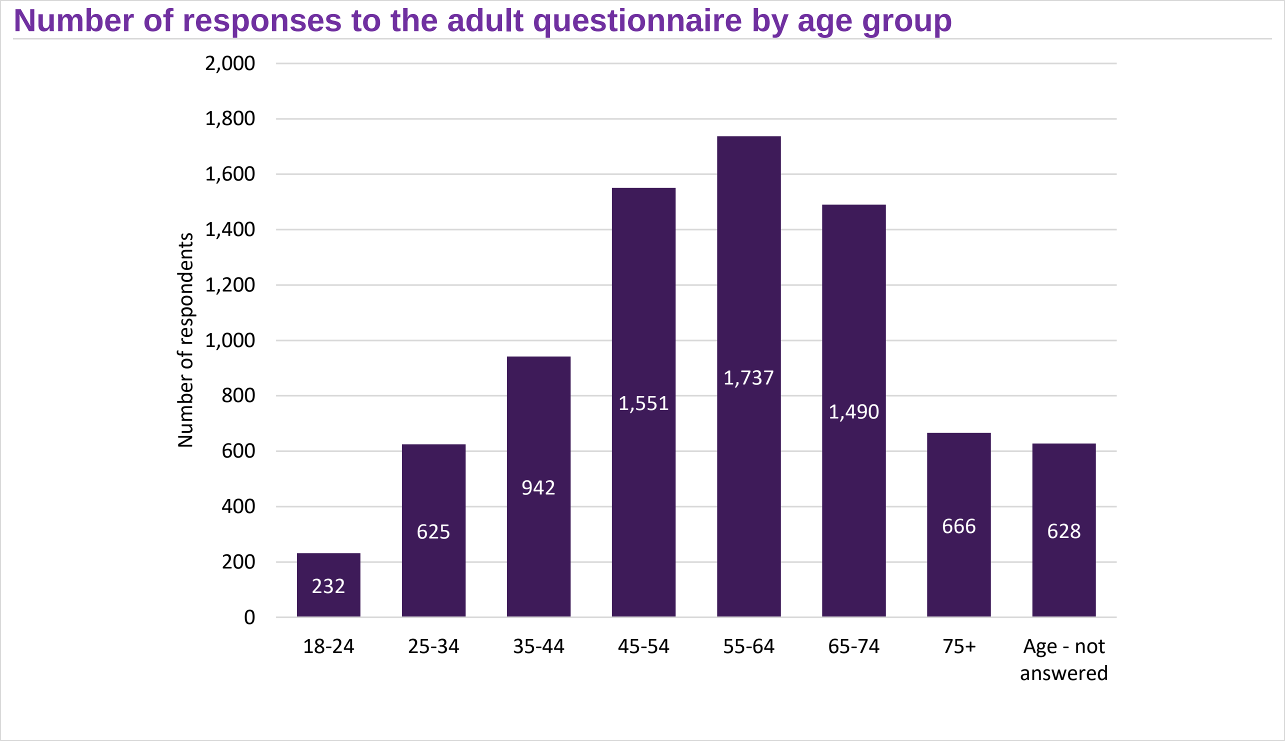
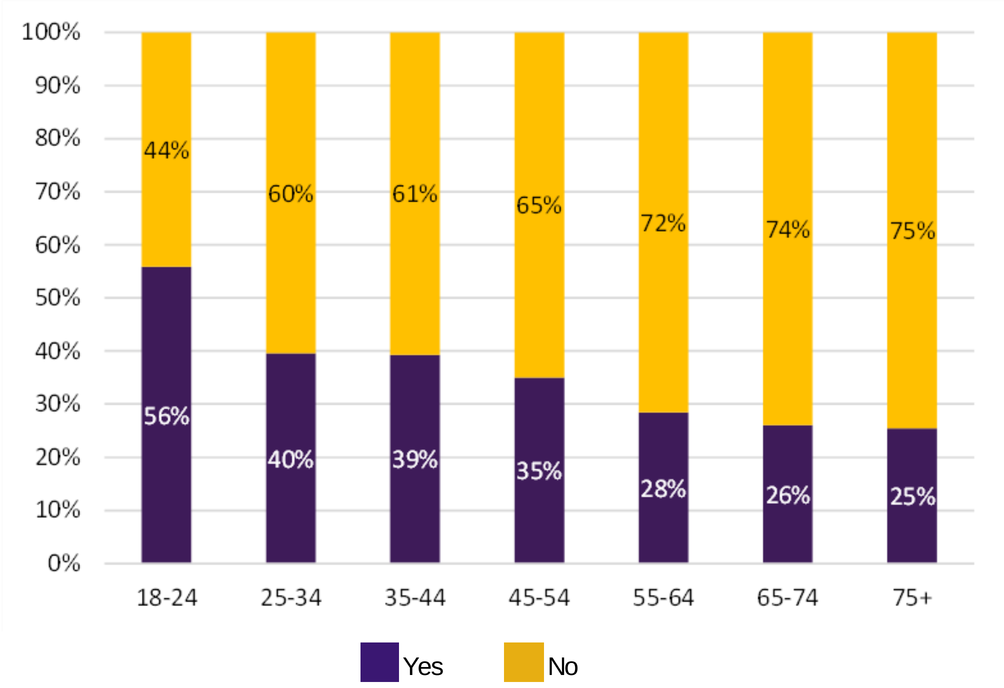


Fig 179. Age distribution – adult respondents

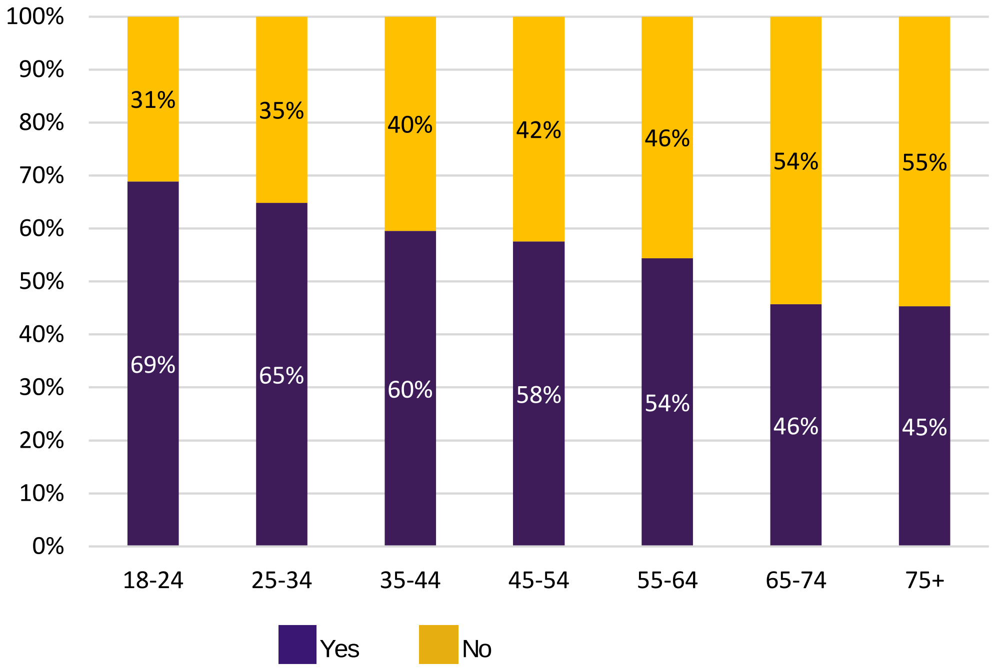
Q3a_1. Experienced delays for: A first appointment with a neurologist



Based on responses for: 18-24– 136, 25-34 – 293, 35-44 – 417, 45-54 – 620, 55-64 – 640, 65-64 – 537, 75+ – 267

Fig 180. Delays for a first appointment with a neurologist – adult respondents by age group

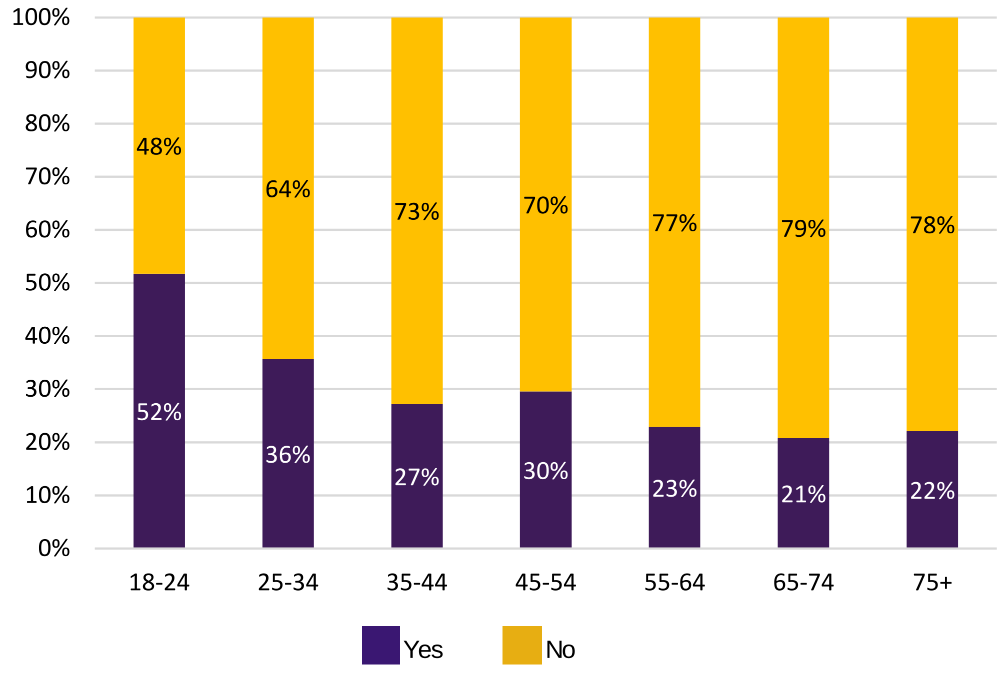
Q3a_2. Experienced delays for: A routine appointment with your neurologist



Based on responses for: 18-24– 164, 25-34 – 441, 35-44 – 650, 45-54 – 1027 55-64 – 1215, 65-64 – 1026, 75+ – 448

Fig 181. Delays for a routine appointment with your neurologist – adult respondents by age group

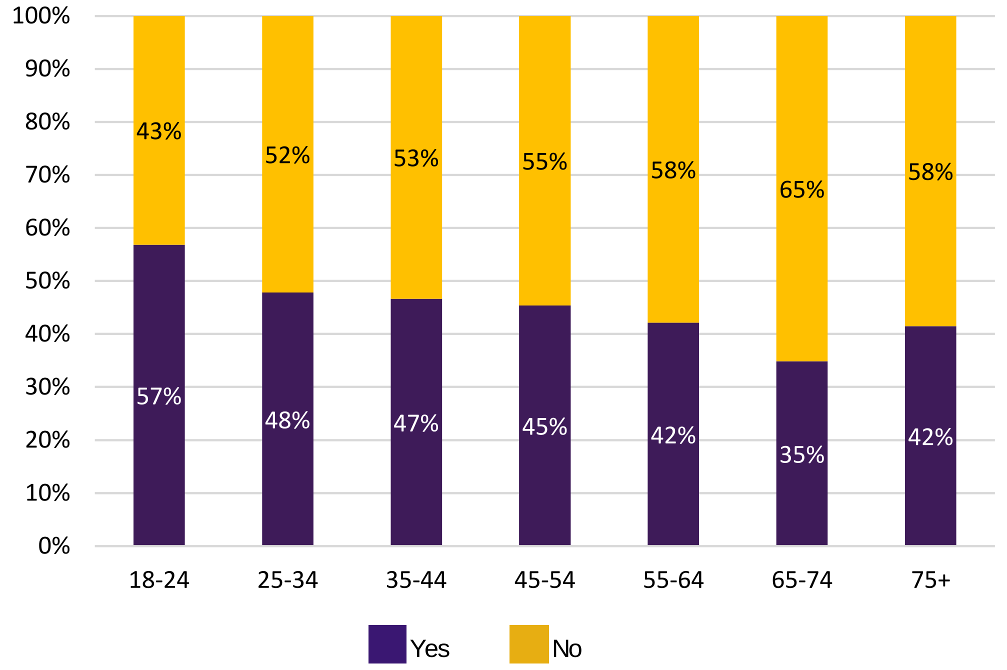
Q3a_3. Experienced delays for: A first appointment with a specialist nurse



Based on responses for: 18-24 – 87, 25-34 – 199, 35-44 – 305, 45-54 – 433, 55-64 – 476, 65-64 – 390, 75+ – 172

Fig 182. Delays for a first appointment with a specialist nurse – adult respondents by age group

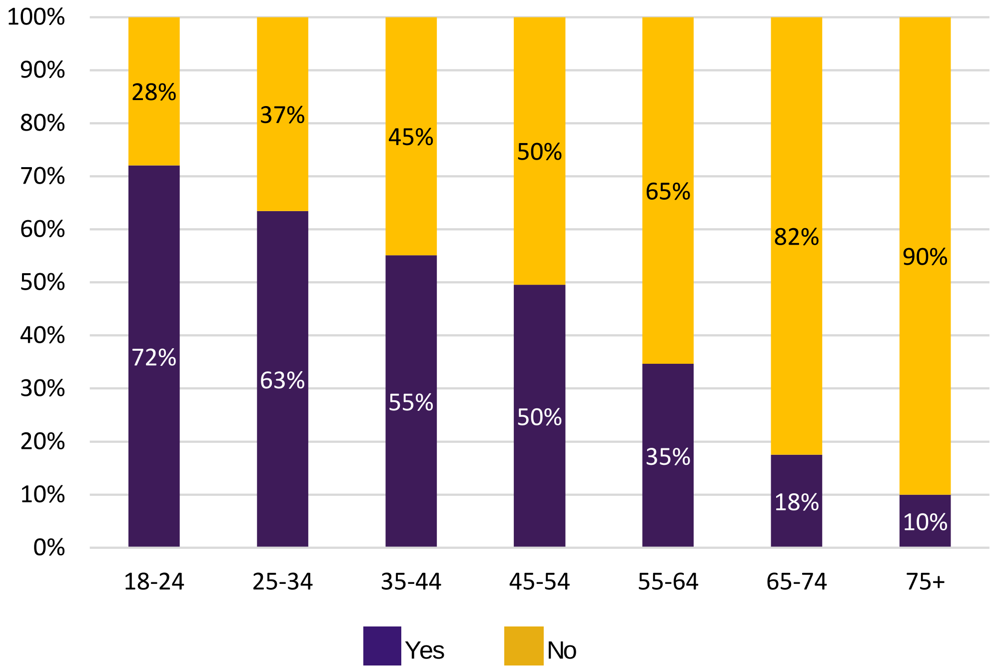
Q3a_4. Experienced delays for: A routine appointment with your specialist nurse



Based on responses for: 18-24 – 102, 25-34 – 276, 35-44 – 435, 45-54 – 652, 55-64 – 769, 65-64 – 643, 75+ – 253

Fig 183. Delays for a routine appointment with your specialist nurse – adult respondents by age group

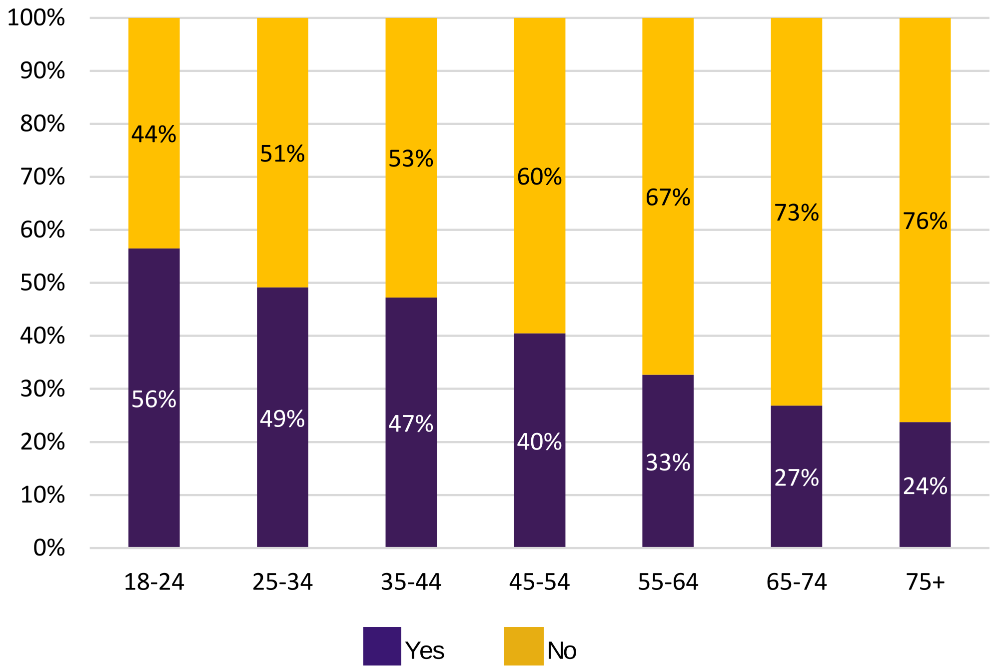
Q3a_5. Experienced delays for: A mental health appointment



Based on responses for: 18-24 – 129, 25-34 – 271, 35-44 – 350, 45-54 – 482, 55-64 – 433, 65-64 – 274, 75+ – 110

Fig 184. Delays for a routine appointment for a mental health appointment – adult respondents by age group

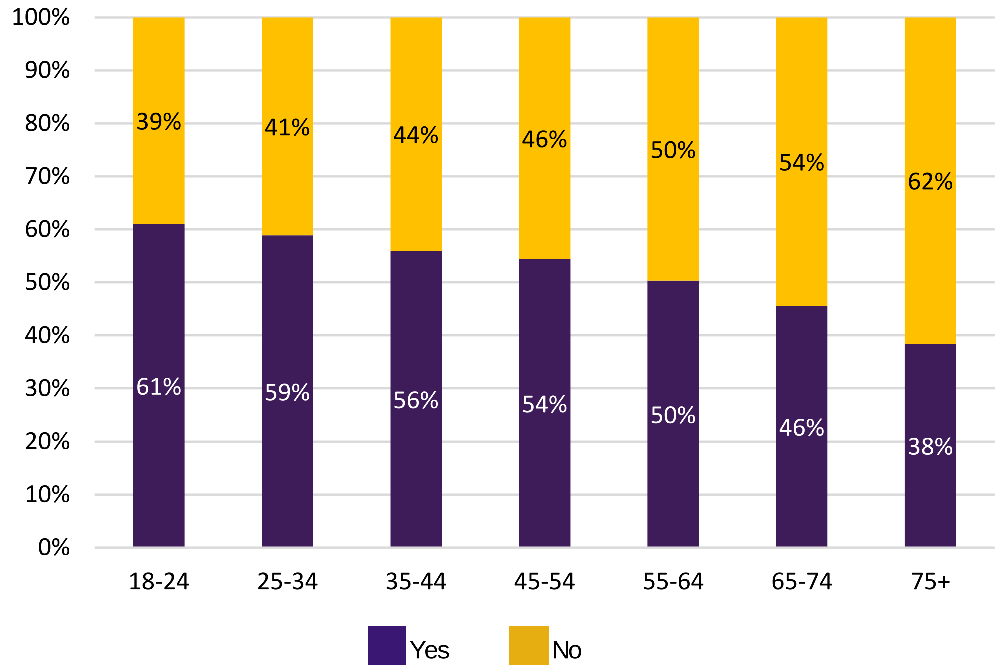
Q3a_8. Experienced delays for: A scan



Based on responses for: 18-24 – 131, 25-34 – 344, 35-44 – 474, 45-54 – 650, 55-64 –646, 65-64 – 465, 75+ – 198

Fig 185. Delays for a scan – adult respondents by age group

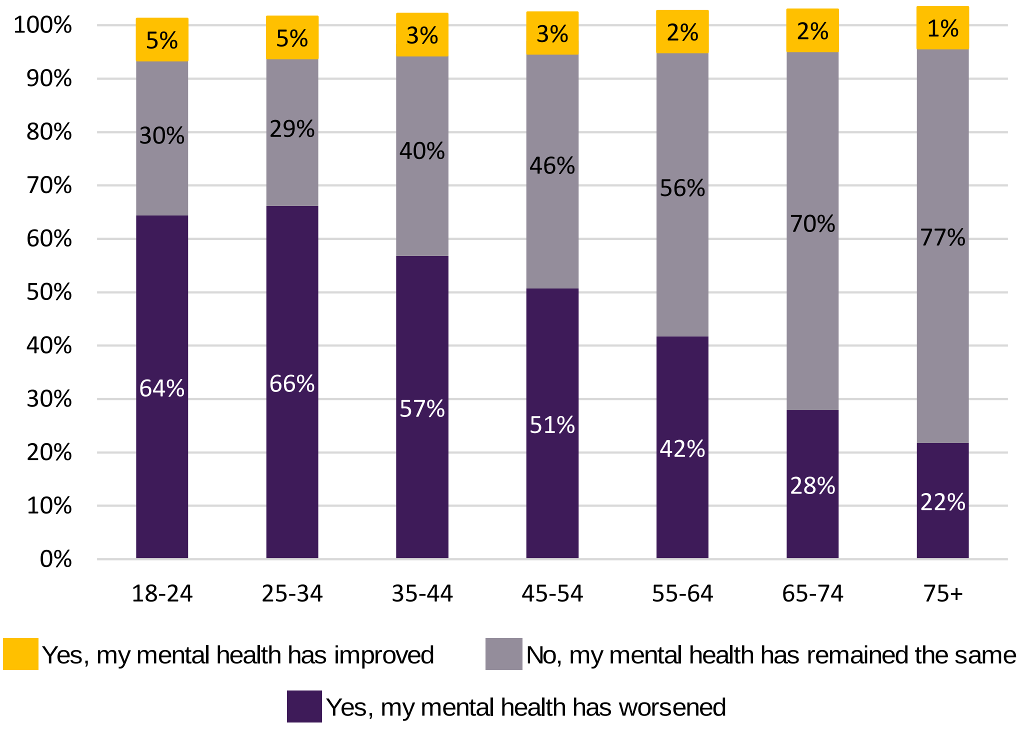
Q3b_2. Experienced delays for: Physiotherapy



Based on responses for: 18-24 – 95, 25-34 – 248, 35-44 – 370, 45-54 – 572, 55-64 – 628, 65-64 – 478, 75+ – 221

Fig 186. Delays for physiotherapy – adult respondents by age group

Q7. Have you experienced a change in your mental health needs due to Covid-19?

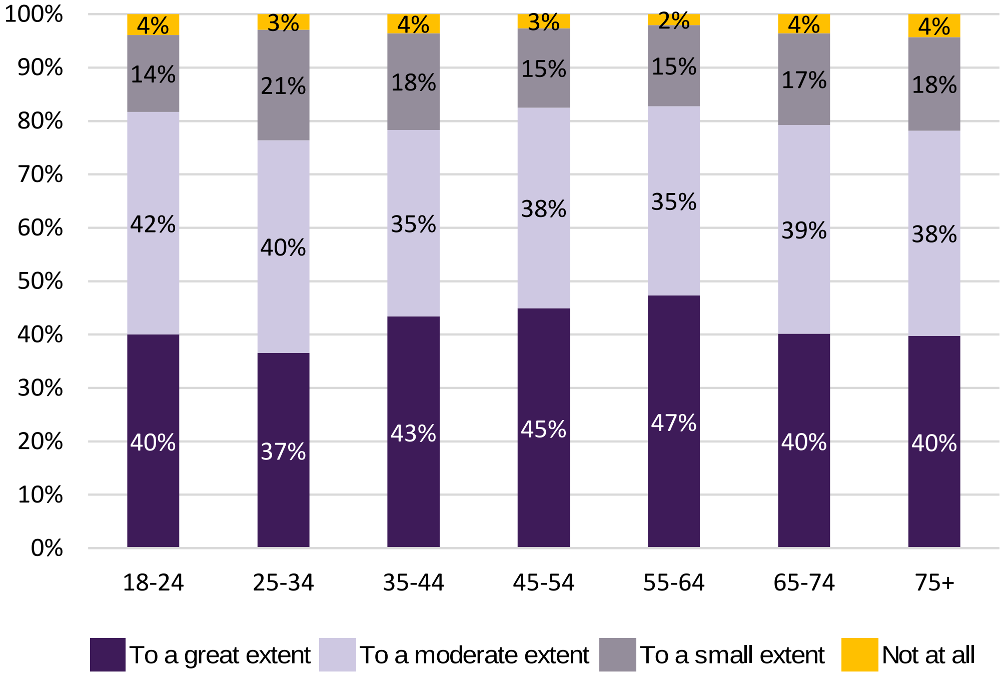


Based on responses for: 18-24 – 205, 25-34 – 567, 35-44 – 833, 45-54 – 1371, 55-64 – 1530, 65-64 – 1275, 75+ – 569

Fig 187. Change to mental health needs due to Covid-19 – adult respondents by age group

Overall impact

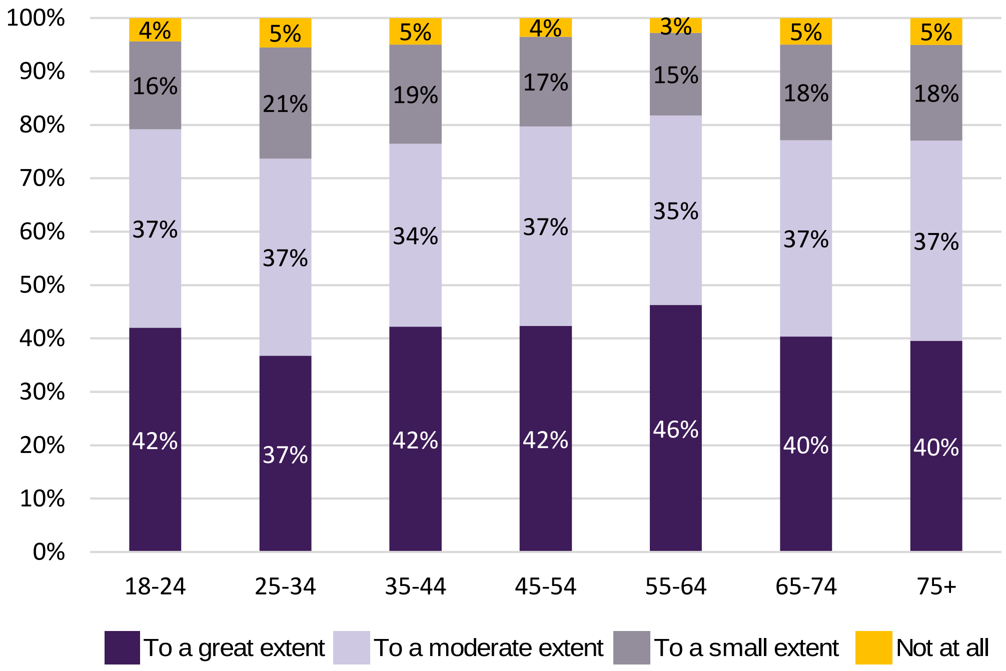
Q8. To what extent overall does your neurological condition(s) impact your quality of life?



Based on responses for: 18-24 – 230, 25-34 – 623, 35-44 – 933, 45-54 – 1537, 55-64 – 1726, 65-64 – 1470, 75+ – 656

Fig 188. Overall impact of neurological conditions on quality of life – adult respondents by age group

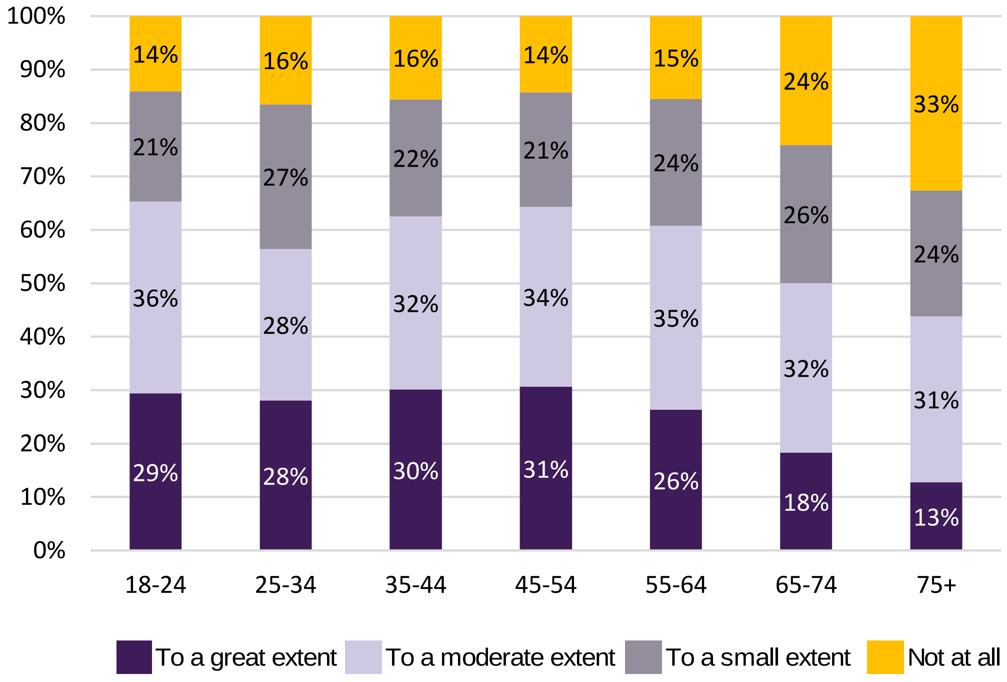
Q9. To what extent overall does your neurological condition(s) impact your day to day activities?



Based on responses for: 18-24 – 231, 25-34 – 620, 35-44 – 935, 45-54 – 1541, 55-64 – 1724, 65-64 – 1483, 75+ – 662

Fig 189. Impact of neurological conditions day to day activities – adult respondents by age group

Q10. To what extent overall does your neurological condition(s) cause you pain?

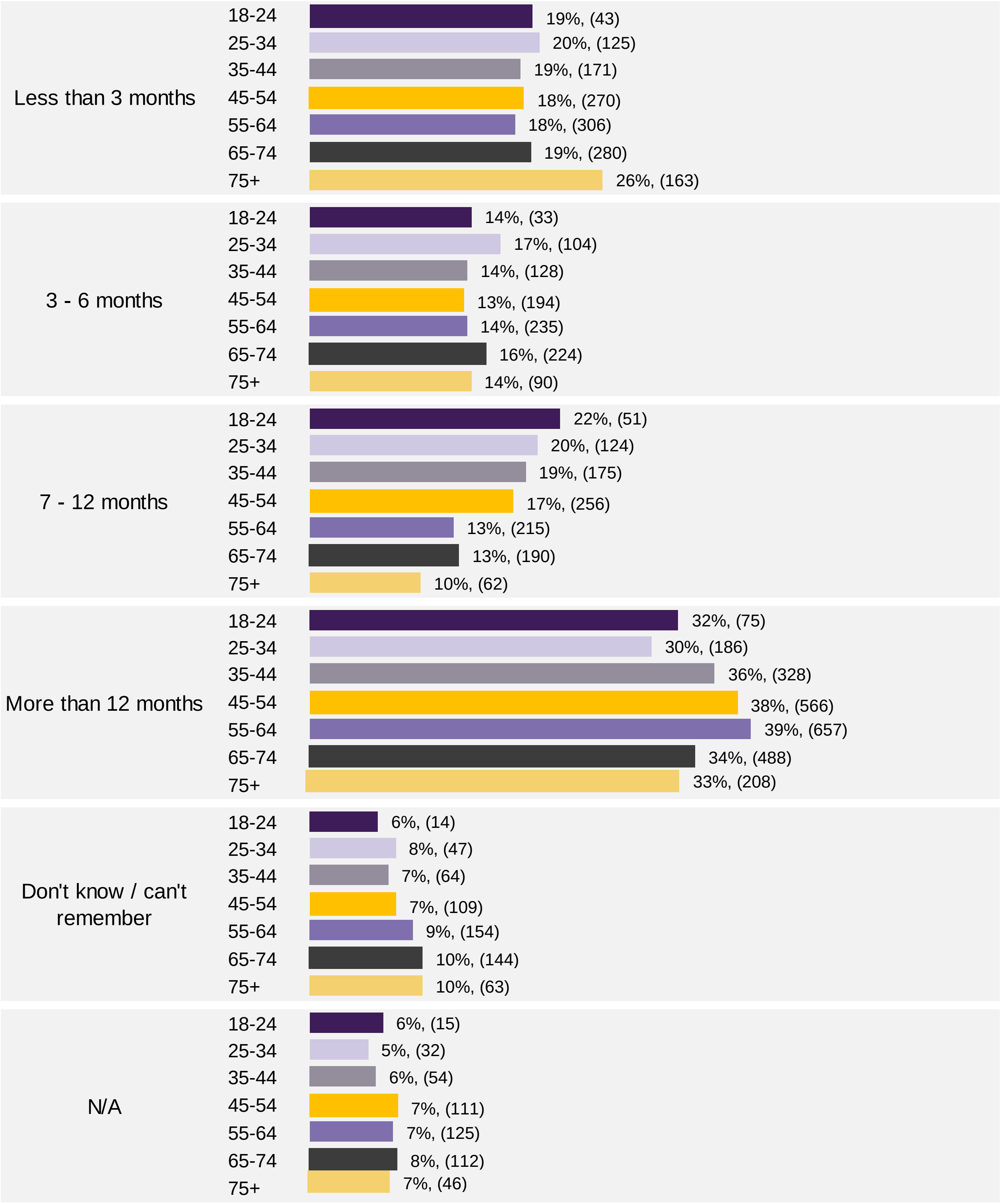


Based on responses for: 18-24 – 228, 25-34 – 613, 35-44 – 926, 45-54 – 1532, 55-64 – 1713, 65-64 – 1467, 75+ – 650

Fig 190. Pain caused by neurological conditions – adult respondents by age group

Before diagnosis

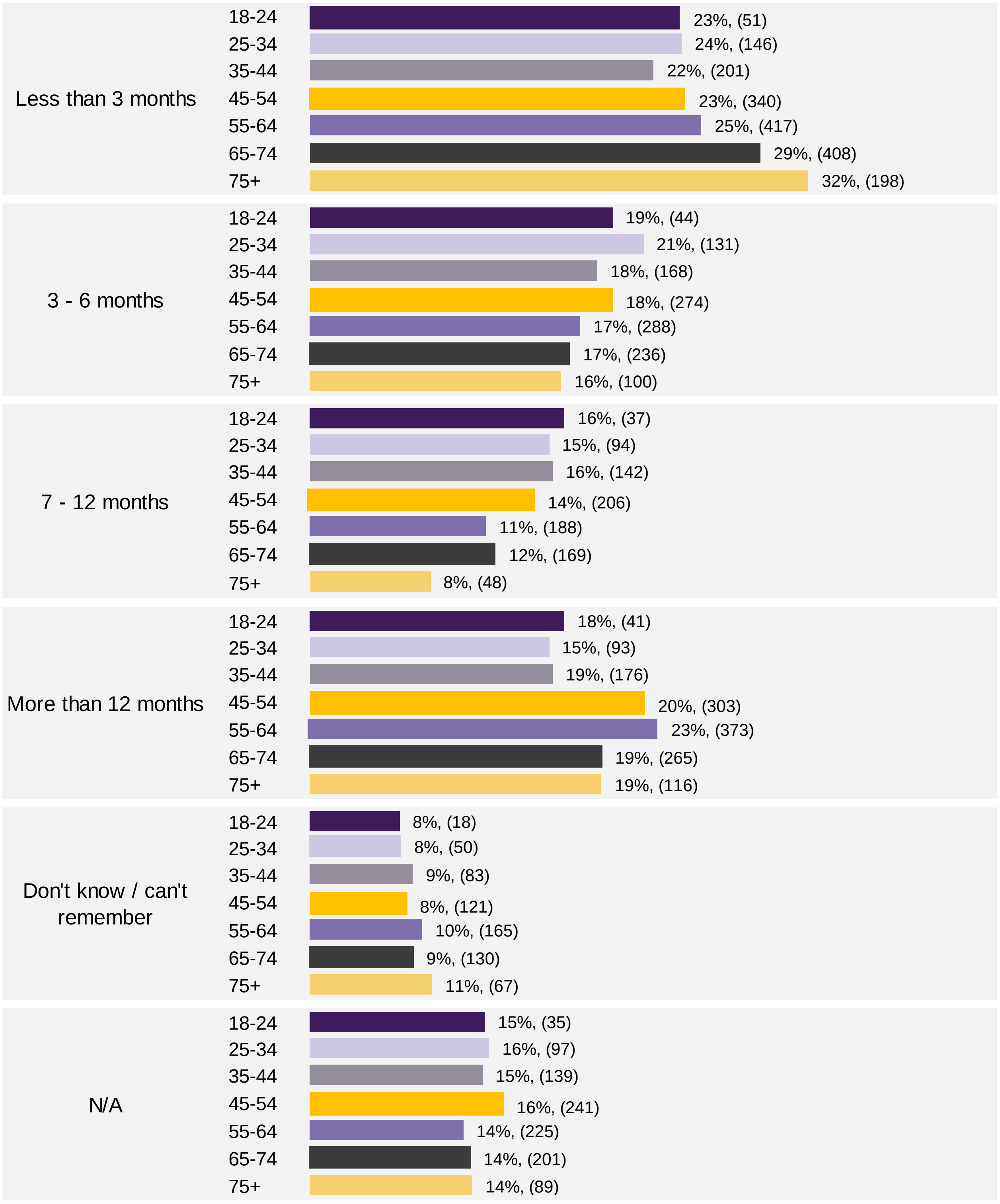
Q11a How long were you waiting between: First experiencing symptoms to getting a diagnosis?



Based on responses for: 18-24 – 202, 25-34 – 539, 35-44 – 802, 45-54 – 1286, 55-64 – 1413, 65-64 – 1182, 75+ – 523

Fig 191. Waiting for a diagnosis – adult respondents by age group

Q11b How long were you waiting between: First seeing a GP to seeing a neurologist

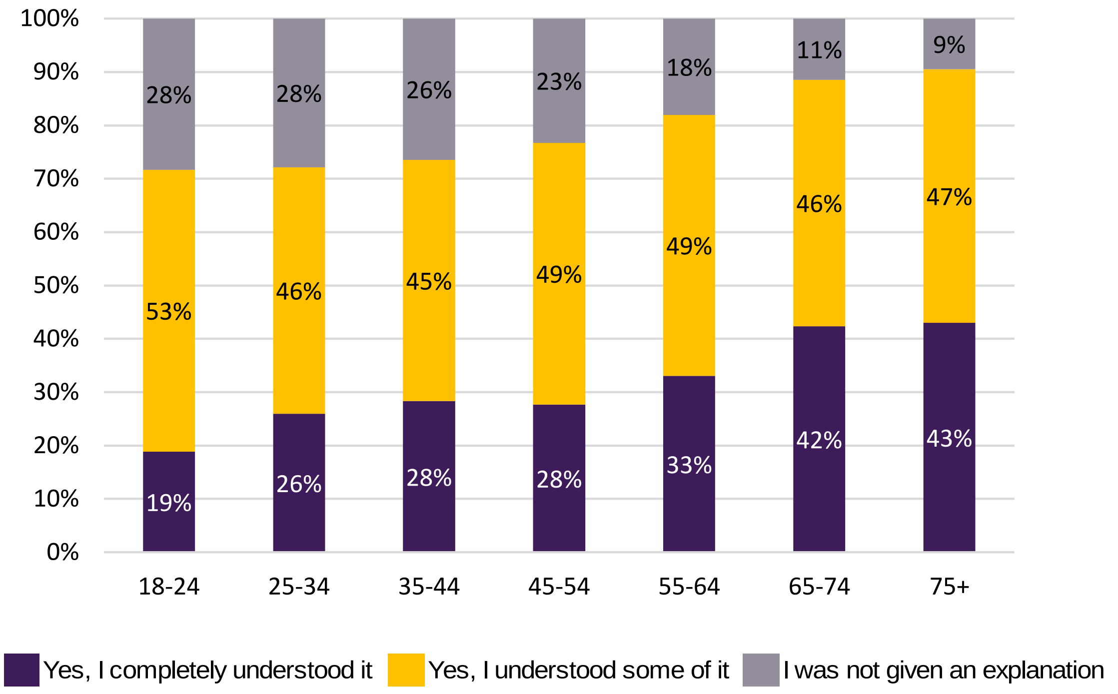


Based on responses for: 18-24 – 173, 25-34 – 464, 35-44 – 687, 45-54 – 1123, 55-64 – 1266, 65-64 – 1078, 75+ – 462

Fig 192. Waiting to see a neurologist – adult respondents by age group

Diagnosis

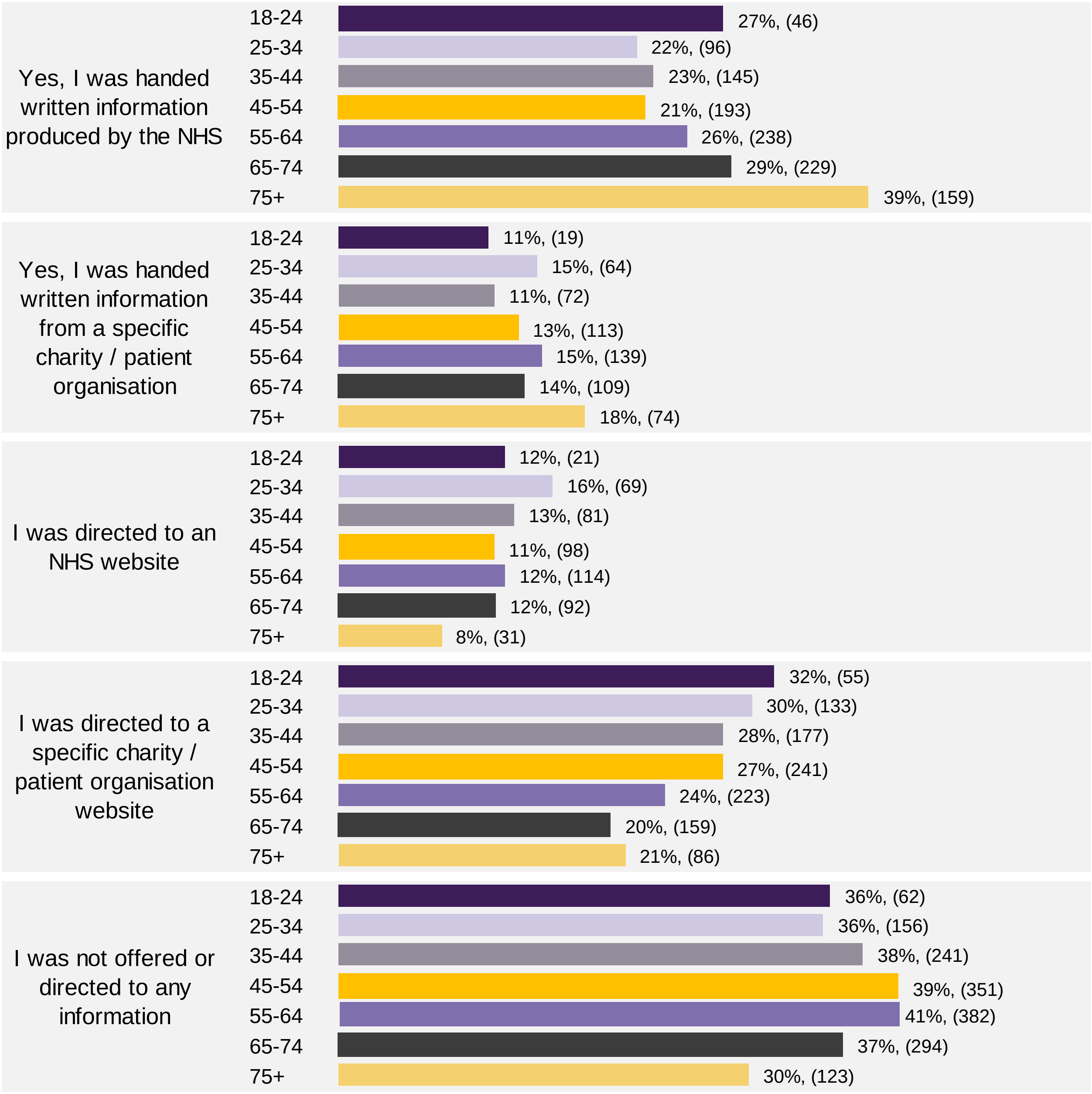
Q14 Did you understand the explanation given to you at your diagnosis / when you were first told about your condition?



Based on responses for: 18-24 – 159, 25-34 – 424, 35-44 – 604, 45-54 – 860, 55-64 – 893, 65-64 – 760, 75+ – 379

Fig 193. Explanation of diagnosis – adult respondents by age group

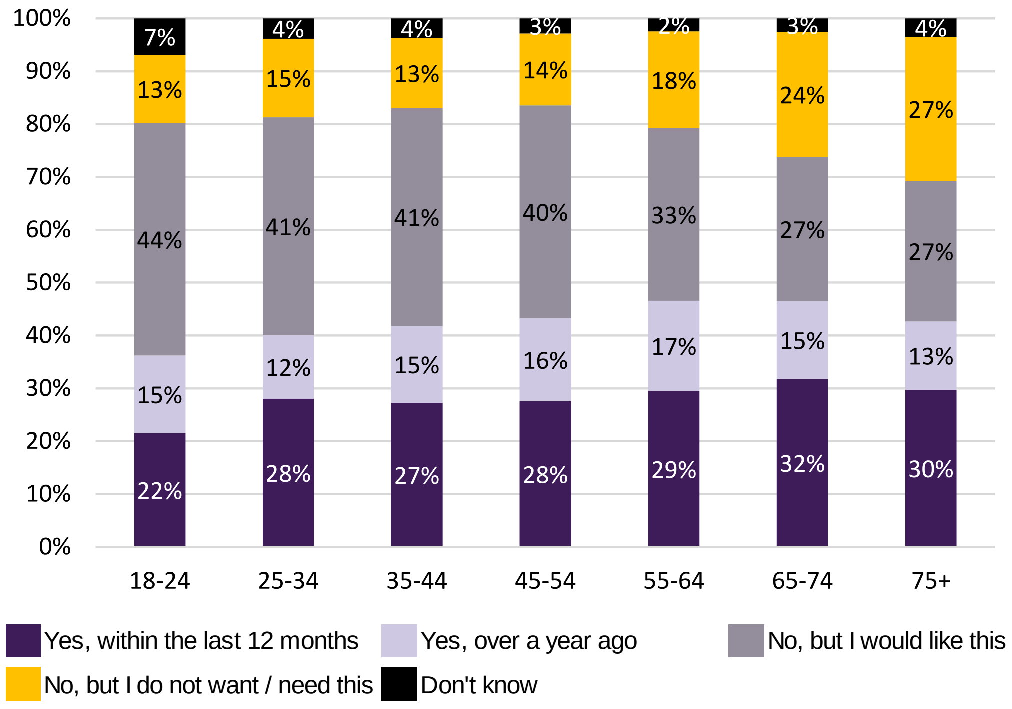
Q15 When you were told you had a neurological condition, were you given written information about it? Please tick all that apply



Based on responses for: 18-24 – 172, 25-34 – 439, 35-44 – 627, 45-54 – 903, 55-64 – 932, 65-74 – 795, 75+ – 409

Fig 194. Written information – adult respondents by age group

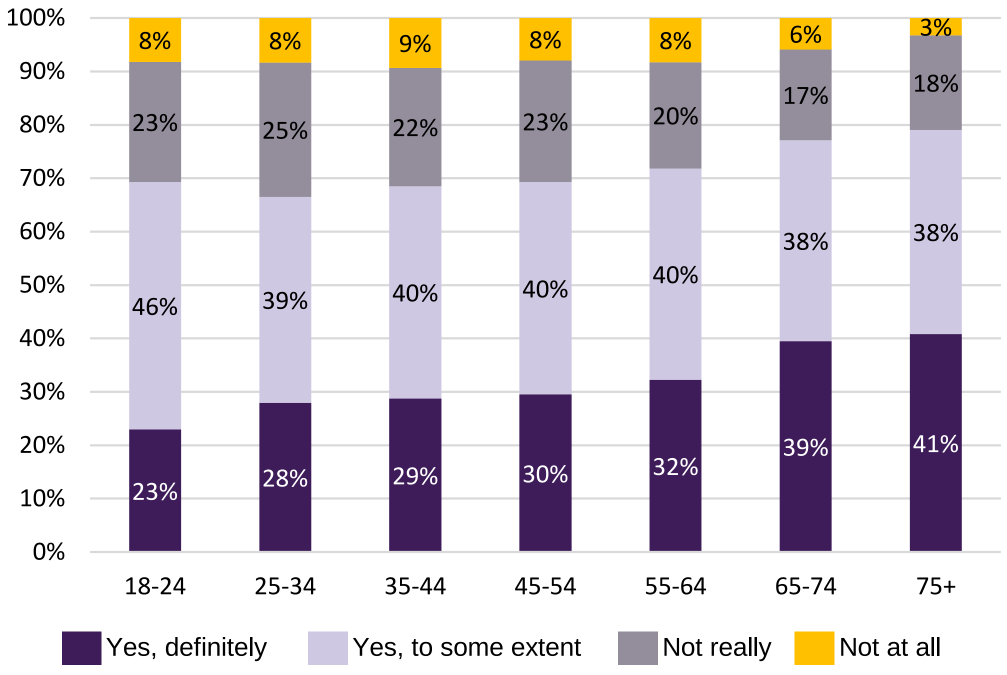
Q18 Have you had an appointment with a specialist nurse for your neurological condition(s)?



Based on responses for: 18-24 – 232, 25-34 – 624, 35-44 – 935, 45-54 – 1546, 55-64 – 1730, 65-64 – 1478, 75+ – 656

Fig 195. Access to Specialist Nurses – adult respondents by age group

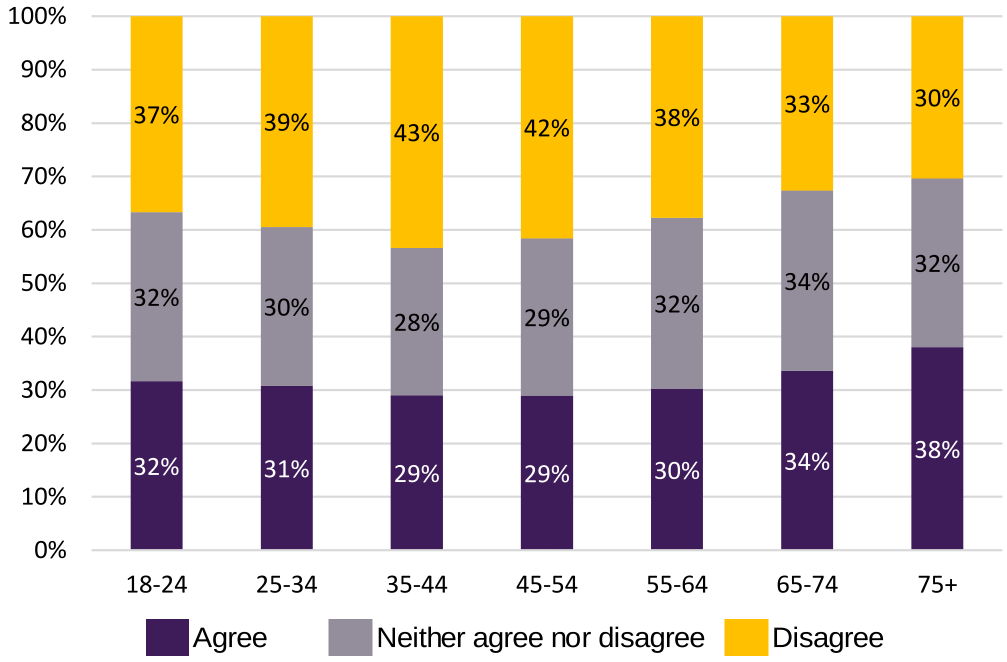
Q20 Do you feel fully involved in making choices about your health care?



Based on responses for: 18-24 – 231, 25-34 – 612, 35-44 – 918, 45-54 – 1522, 55-64 – 1692, 65-64 – 1459, 75+ – 644

Fig 196. Involvement in healthcare – adult respondents by age group

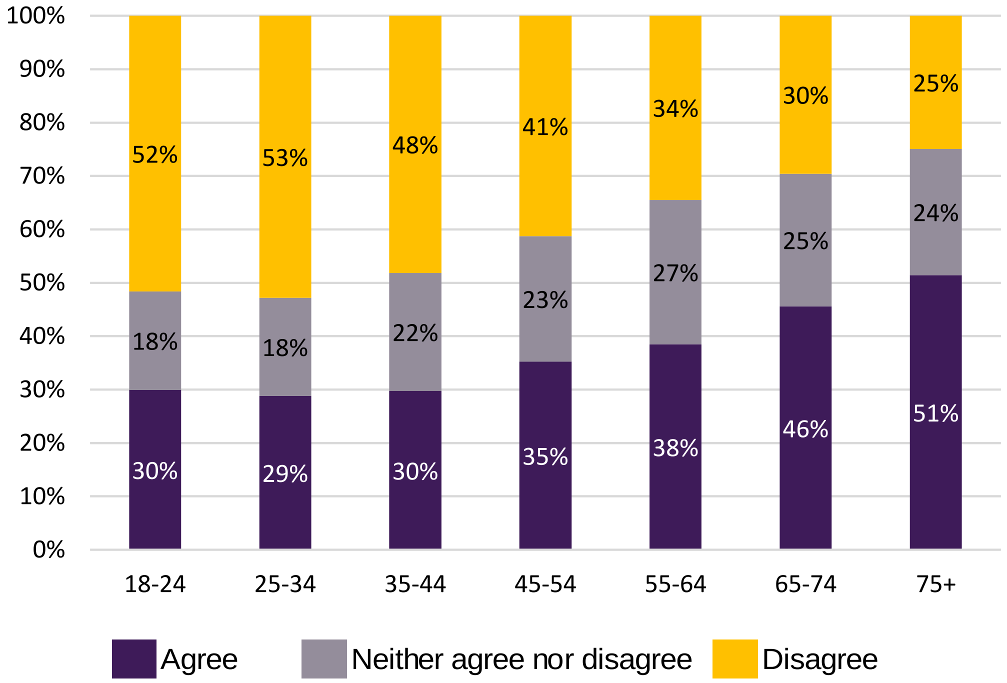
Q24a My health and care are joined up and centred on my priorities



Based on responses for: 18-24 – 218, 25-34 – 588, 35-44 – 869, 45-54 – 1438, 55-64 – 1594, 65-64 – 1305, 75+ – 547

Fig 197. Joined up care – adult respondents by age group

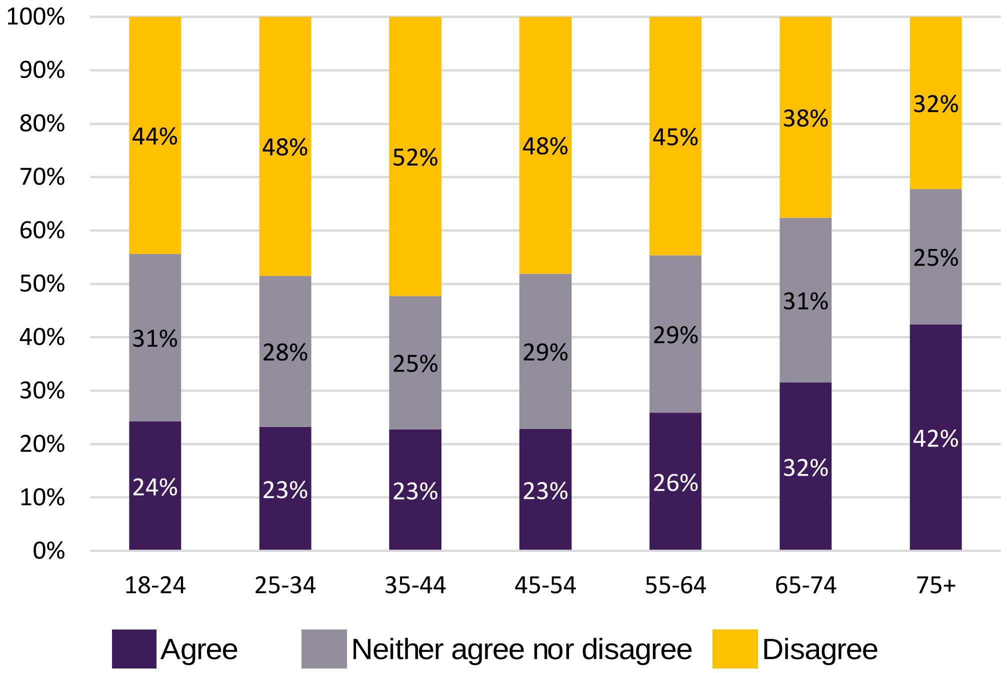
Q24b Information about my condition is effectively passed between the people that care for me (such as my specialists, GP, family carer)



Based on responses for: 18-24 – 217, 25-34 – 600, 35-44 – 885, 45-54 – 1463, 55-64 – 1642, 65-64 – 1360, 75+ – 581

Fig 198. Communication – adult respondents by age group

Q24d I got the care I needed at home after my hospital visit

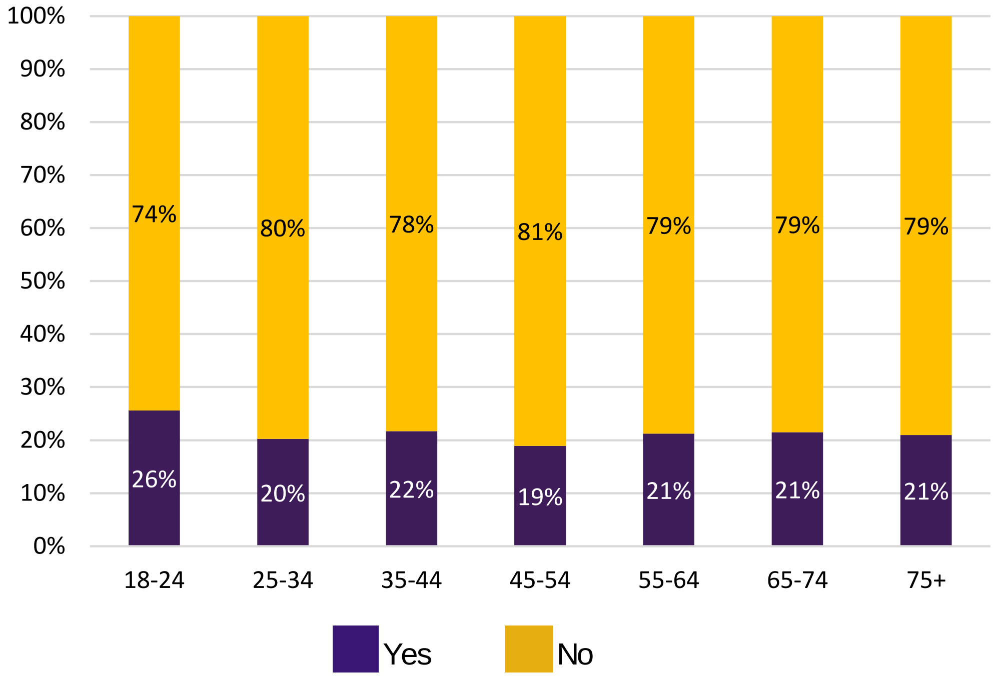


Based on responses for: 18-24 – 169, 25-34 – 392, 35-44 – 532, 45-54 – 805, 55-64 – 815, 65-64 – 574, 75+ – 245

Fig 199. Care after hospital visits – adult respondents by age group

Support for condition

Q25 Within the last three years have you been offered a care and support plan to help you manage your neurological condition?

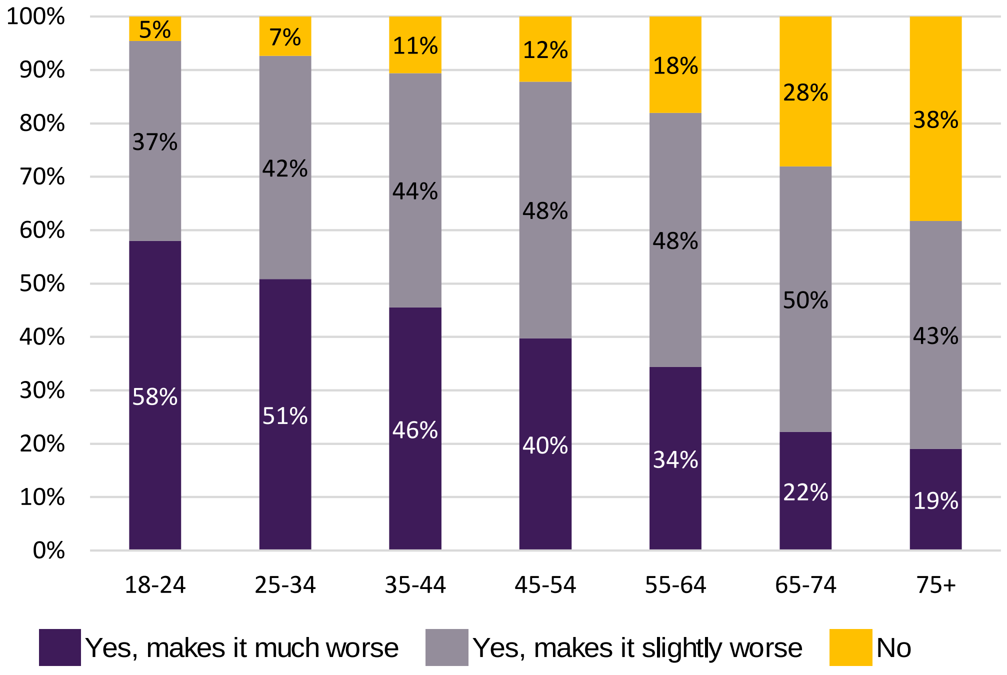


Based on responses for: 18-24 – 203, 25-34 – 568, 35-44 – 862, 45-54 – 1419, 55-64 – 1607, 65-64 – 1393, 75+ – 605

Fig 200. Offered a care plan – adult respondents by age group

Mental wellbeing

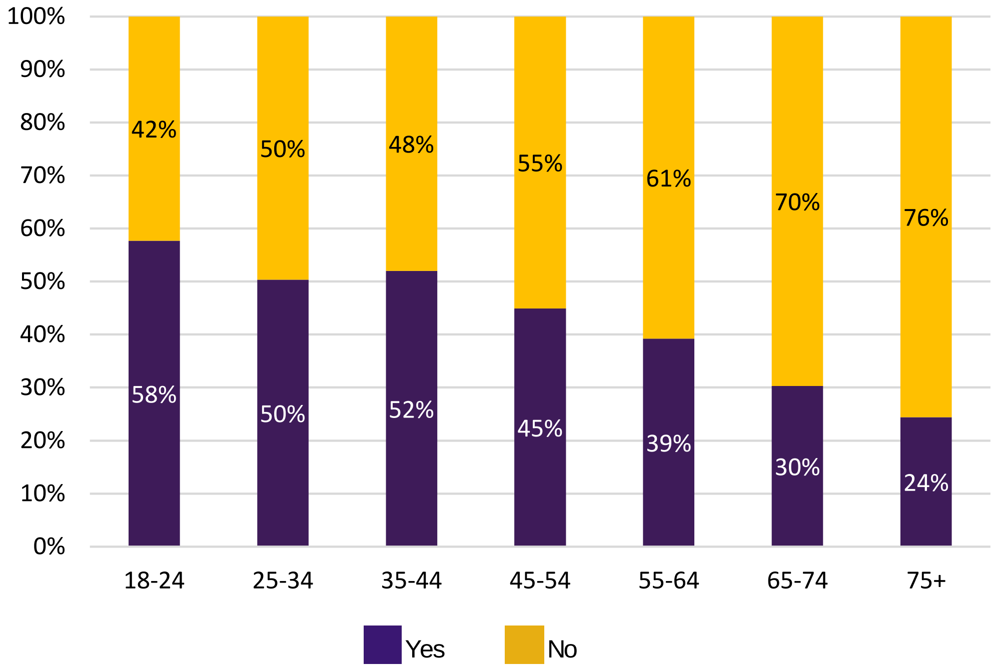
Q27 Does your neurological condition affect your mental wellbeing?



Based on responses for: 18-24 – 219, 25-34 – 598, 35-44 – 909, 45-54 – 1473, 55-64 – 1648, 65-64 – 1397, 75+ – 614

Fig 201. Mental wellbeing – adult respondents by age group

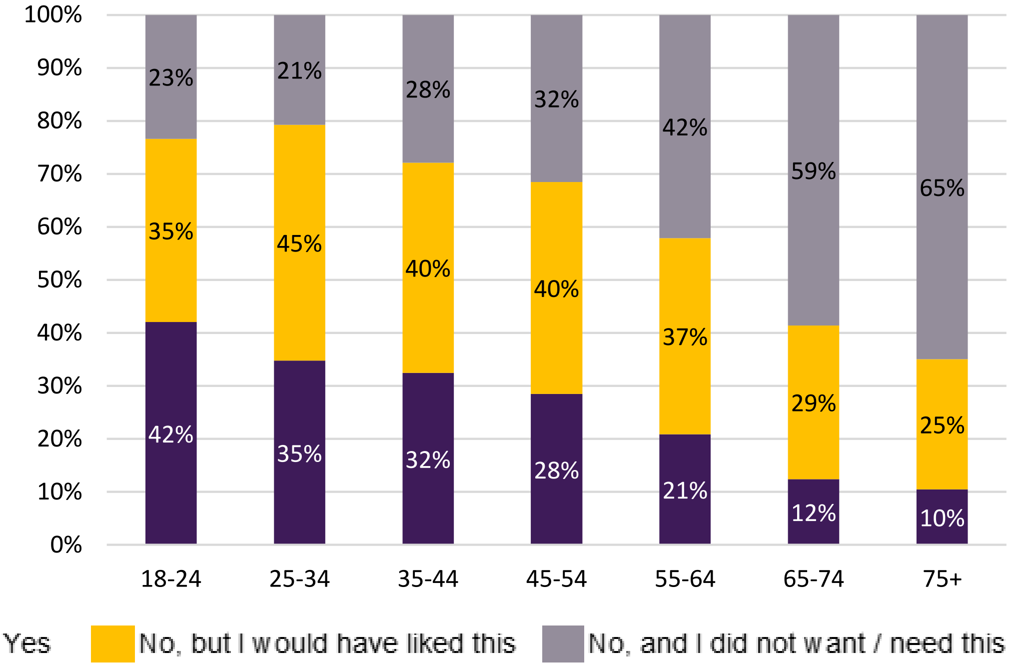
Q28 Have you been asked about your mental wellbeing by a health or social care professional within the last three years?



Based on responses for: 18-24 – 208, 25-34 – 576, 35-44 – 877, 45-54 – 1440, 55-64 – 1616, 65-64 – 1392, 75+ – 606

Fig 202. Mental wellbeing and healthcare professionals – adult respondents by age group

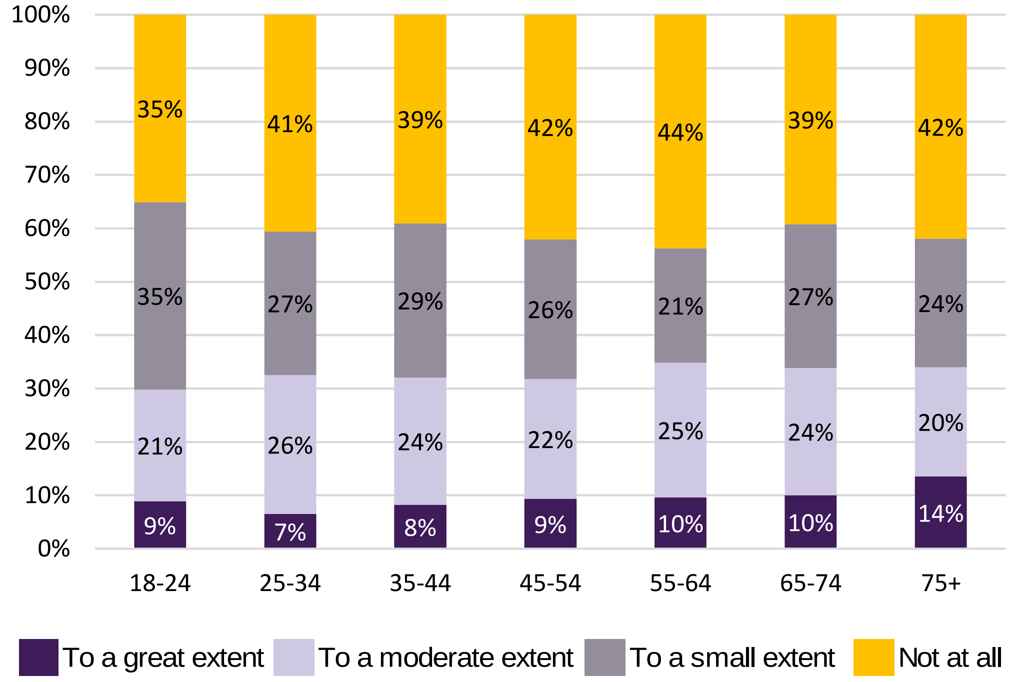
Q29 Have you been referred or directed to support for your mental wellbeing by a health professional within the last three years?



Based on responses for: 18-24 – 214, 25-34 – 584, 35-44 – 890, 45-54 – 1444, 55-64 – 1636, 65-64 – 1391, 75+ – 611

Fig 203. Referral or directed to support for mental wellbeing – adult respondents by age group

Q32 To what extent do you feel your mental wellbeing needs are being met?

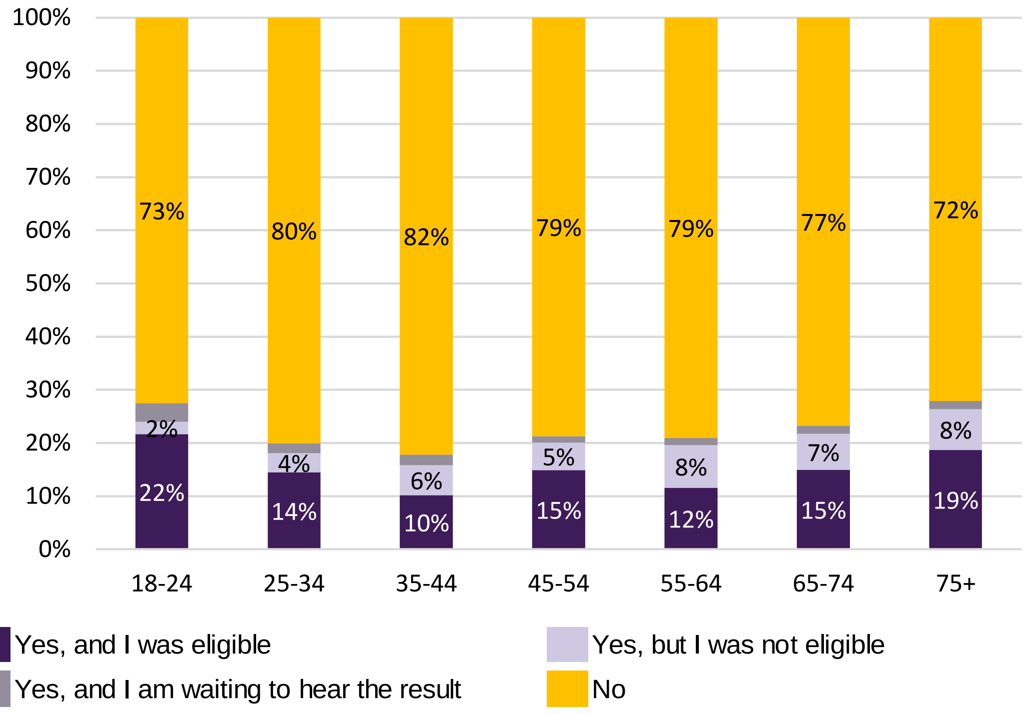


Based on responses for: 18-24 – 191, 25-34 – 535, 35-44 – 776, 45-54 – 127, 55-64 – 1320, 65-64 – 974, 75+ – 391

Fig 204. Meeting mental wellbeing needs – adult respondents by age group

Social care

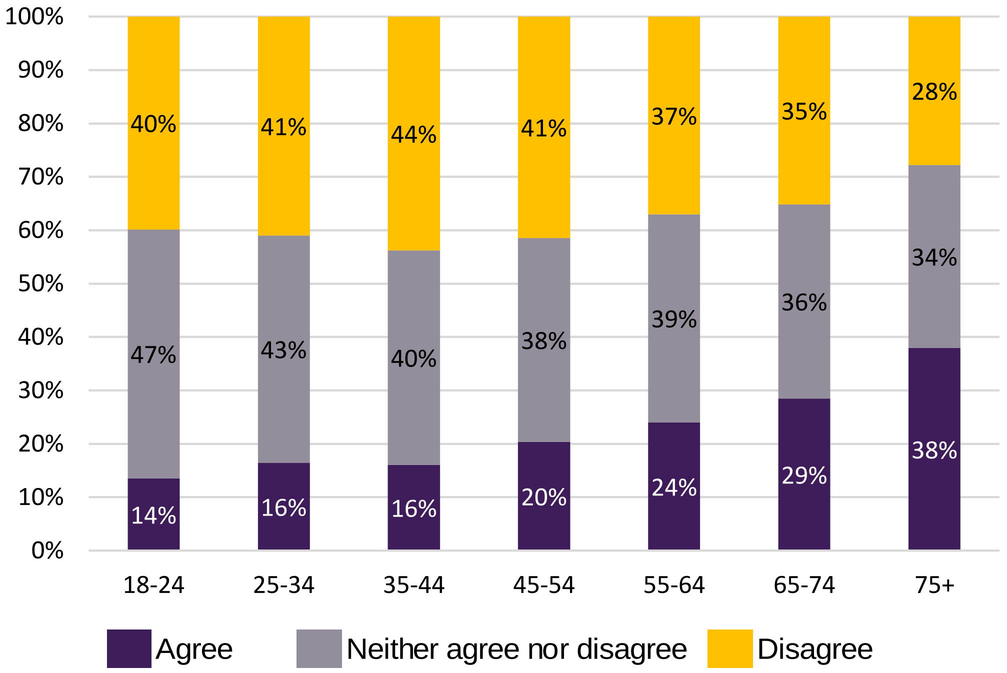
Q34 Has your local council assessed your care and support needs to see if you are eligible to receive funded care or support?



Based on responses for: 18-24 – 171, 25-34 – 421, 35-44 – 669, 45-54 – 1026, 55-64 – 1123, 65-64 – 917, 75+ – 444

Fig 205. Assessments for funded care and support – adult respondents by age group

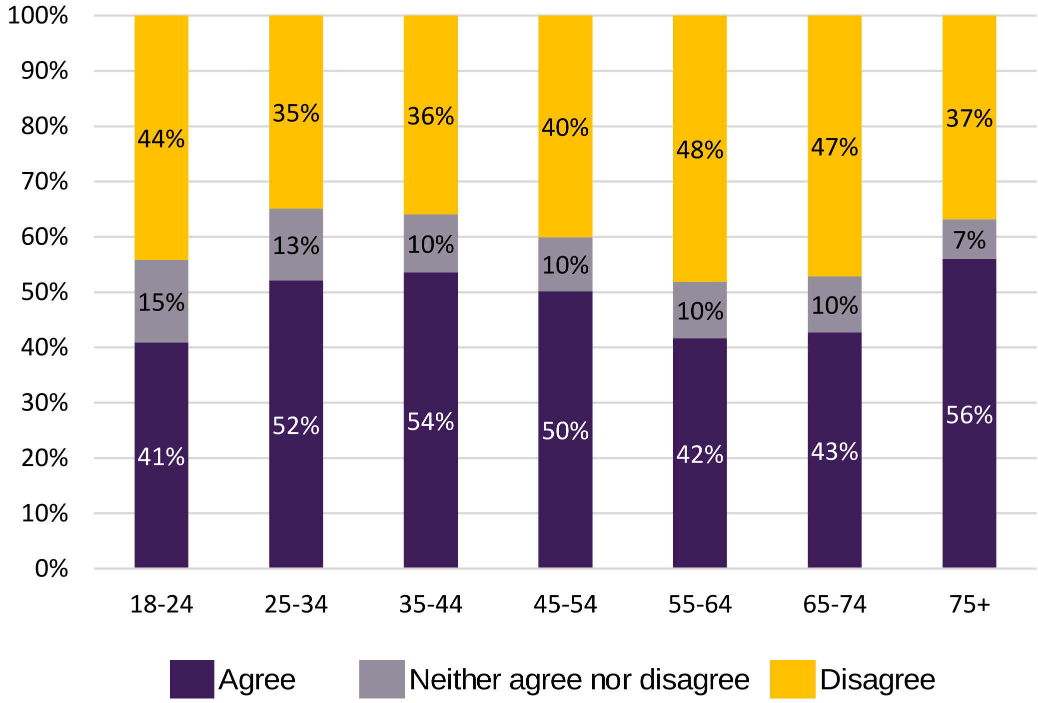
Q37a Overall, the social care I have received meets my needs



Based on responses for: 18-24 – 118, 25-34 – 261, 35-44 – 379, 45-54 – 627, 55-64 – 678, 65-64 – 498, 75+ – 245

Fig 206. Overall views of social care – adult respondents by age group

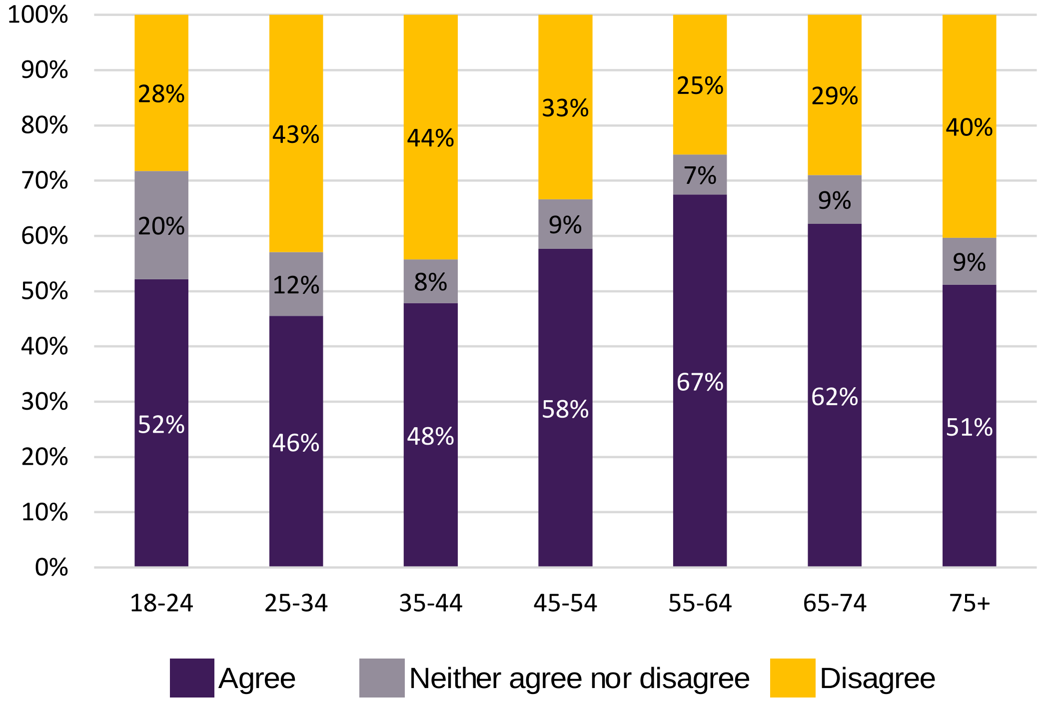
Q39a I have been able to continue working since having a neurological condition



Based on responses for: 18-24 – 181, 25-34 – 570, 35-44 – 862, 45-54 – 1392, 55-64 – 1407, 65-64 – 615, 75+ – 125

Fig 207. Continue working – adult respondents by age group

Q39b I have stopped working because of my neurological condition symptoms



Based on responses for: 18-24 – 163, 25-34 – 501, 35-44 – 760, 45-54 – 1236, 55-64 – 1375, 65-64 – 680, 75+ – 129

Fig 208. Stopped working – adult respondents by age group

6.5 Ethnicity

More white respondents completed the survey than non-white (7448 compared to 292).

A two-tailed t-test on proportions for significant differences has been carried out on the key questions. Where differences are reported, there is a significant difference level of at least 95%.

COVID-19

White respondents were **less likely** to experience delays with:

A first neurologist appointment - 67% v 58%

A first appointment with a specialist nurse- 73% v 60%

A routine appointment with a specialist nurse- 58% v 47%

A scan - 62% v 50%

Physiotherapy - 49% v 37%

Non-white respondents were more likely to say that their mental health has **worsened** due to COVID-19 - 54% v 44%

Overall impact

Non-white respondents were more likely to say that their neurological condition causes them pain to a great/moderate extent - 64% v 57%

Before diagnosis

There were no significant differences with the key questions in this section.

Diagnosis

White respondents were more likely to say when they were told they had a neurological condition they **were not** offered or directed to any information – 38% vs 29%

Treatment and care

There were no significant differences with the key questions in this section.

Support for condition

There were no significant differences at 95% with the key questions in this section.

Mental wellbeing

Non-white respondents were more likely to say they had been referred or directed to support for mental wellbeing by HCP in last 3 years - 29% vs 23%

Social care

White respondents were more likely to agree that overall, social care received meets their needs - 23% vs 16%

Employment and Welfare

There were no significant differences with the key questions in this section.

6.6 Gender breakdowns

6.6.1 Comparisons between male and female respondents

More female respondents completed the survey than male respondents (5279 compared to 2368). Male respondents reported more positive experiences across nearly every question.

A two-tailed t-test on proportions for significant differences has been carried out on the key questions. Where differences are reported, there is a significant difference level of at least 95%.

COVID-19

Male respondents were **less likely** to experience delays with:

A first neurologist appointment - 74% v 64%

A routine appointment with their neurologist - 50% v 44%

A first appointment with a specialist nurse -75% v 71%

A routine appointment with a specialist nurse - 40% v 44%

A mental health appointment - 60% v 56%

A scan - 68% v 59%

Physiotherapy - 57% v 45%

Female respondents were more likely to say that their mental health has **worsened** due to COVID-19 - 48% v 35%

Overall impact

Female respondents were more likely to say that their neurological condition impacts their quality of life to a great/moderate extent - 81% v 78%

Female respondents were more likely to say that their neurological condition affects their day to day activities to a great/moderate extent - 80% v 79%

Female respondents were more likely to say that their neurological condition causes them pain to a great/moderate extent - 62% v 47%

Before diagnosis

A larger proportion of female respondents reported waiting more than 12 months between first experiencing symptoms to getting a diagnosis - 38% v 30%

A larger proportion of female respondents reported waiting more than 12 months between first seeing a GP to seeing a neurologist - 21% v 16%

Diagnosis

Male respondents were more likely to say they completely understood the explanation they were given at their diagnosis / first told about their condition - 42% vs 28%. While a larger proportion of female respondents said they were not given an explanation - 24% vs 11%

Female respondents were more likely to say when they were told they had a neurological condition they **were not** offered or directed to any information - 40% vs 32%

Treatment and care

Male respondents were more likely to say they have had an appointment with a specialist nurse for their neurological condition within the last 12 months - 32% vs 27%. While a larger proportion of female respondents said they have not had an appointment with a special nurse, but would like one - 38% vs 27%

Male respondents were more positive that they were involved in making choices about their healthcare (definitely or to some extent) - 77% vs 70%

Male respondents were more likely to agree that their health and care are joined up and centred on their priorities - 37% vs 28%

Male respondents were more likely to agree that information about their condition is effectively passed between the people that care for them - 45% vs 35%

Male respondents were more likely to agree that they got the care they needed at home after their hospital visit - 35% vs 23%

Support for condition

Male respondents were more likely to say that they have been offered a care and support plan to help them manage their neurological condition - 24% vs 20%

Mental wellbeing

Female respondents were more likely to say that their neurological condition affects their mental wellbeing - 84% vs 75%

Female respondents were more likely to say they had been referred or directed to support for mental wellbeing by HCP in last 3 years - 25% vs 18%

Male respondents were more likely to say that their mental wellbeing needs are being met to a great/moderate extent - 37% vs 31%

Social care

Male respondents were more likely to say that they **have** had an assessment of care and support needs by local council - 24% vs 21%

Employment and Welfare

Male respondents were more likely to agree that they have been able to continue working since having neurological condition - 51% vs 46%

6.6.2 Non-binary respondents

Due to the low number of returns it is not possible to make any definite comparisons between non-binary respondents and those who identify as male/female. However, as an overview, out of all three respondent ‘gender groups’, they report least positively across the key questions.

6.7 Survey completion

The first question in the survey asked who was completing the questionnaire. The majority of people (7258) who answered this question said that they were the person living with the neurological condition (s) i.e., self-completion. 478 people said that they were a carer/friend/family member completing the questionnaire on behalf of the person living with the neurological condition i.e., assisted completion.

A two-tailed t-test on proportions for significant differences has been carried out on the key questions. Where differences are reported, there is a significant difference level of at least 95%.

COVID-19

Assisted completers were **less likely** to say there were delays with a routine appointment with a specialist nurse - 48% v 58%

Assisted completers were more likely to report that mental health has **worsened** due to COVID-19 - 51% v 44%

Overall impact

Assisted completers were more likely to say that the neurological condition impacts on quality of life to a great/moderate extent - 91% v 79%

Assisted completers were more likely to say that the neurological condition impacts on day to day activities to a great/moderate extent - 92% v 78%

Before diagnosis

A larger proportion of self-completers reported waiting more than 12 months between first experiencing symptoms to getting a diagnosis - 36% v 30%

Diagnosis

Self-completers were more likely to say they completely understood the explanation they were given at their diagnosis / first told about their condition - 33% vs 24%

Treatment and care

Assisted completers were more likely to say there has been an appointment with a specialist nurse for the neurological condition within the last 12 months - 35% vs 28%. While a larger proportion of self-completers said they have not had an appointment with a special nurse, but would like one - 35% vs 30%

Self-completers were more positive that they were involved in making choices about their healthcare (definitely or to some extent) - 72% vs 67%

Assisted completers were more likely to agree that the person living with the neurological condition(s) got the care they needed at home after their hospital visit - 37% vs 25%

Support for condition

There were no significant differences with the key questions in this section.

Mental wellbeing

Assisted completers were more likely to say that the neurological condition effects mental wellbeing - 91% vs 82%

Assisted completers were more likely to say that a health or social care professional had asked about mental wellbeing in last 3 years - 50% vs 40%

Social care

Assisted completers were more likely to say that there **had been** an assessment of care and support needs by local council - vs 46% vs 20%

Employment and Welfare

Self-completers were more likely to agree that they have been able to continue working since having a neurological condition – 48% vs 21%

Assisted completers were more likely to agree that the person living with the neurological condition(s) have stopped working because of their neurological condition - 71% vs 58%

7. Additional data analysis - Paediatric

7.1 Introduction to additional analysis

To help identify issues where individuals may be in need of additional services and support, further analysis was undertaken using the following key variables:

- Neurological condition
- Geographical region
- Age
- Gender

Particular focus was placed on the following questions:

COVID-19

- Q3a Experienced delays with:

  A first appointment with a with a specialist for your neurological disorder

  A routine appointment with a specialist for their neurological disorder

  A first appointment with a specialist nurse

  A routine appointment with their specialist nurse

  A mental health appointment

  A scan

  Physiotherapy
- Q6 Change in mental health needs due to COVID-19

Overall impact

- Q8 Effect on day to day activities
- Q9 Impact on quality of life
- Q10 Pain

Before diagnosis

- Q11a Time between first experiencing symptoms to getting a diagnosis
- Q11b Time between first seeing a GP to seeing a hospital based paediatrician
- Q11c Time between first seeing a paediatrician to seeing a neurologist

Diagnosis

- Q14 Understanding of the explanation of diagnosis
- Q15 Given written information

Treatment and care

- Q18 Access to a specialist nurse
- Q20 Named worker to support the transition process between paediatric and adult services
- Q21 Involvement in choices about healthcare
- Q25b Information about condition is effectively shared
- Q25c Care needed at home after hospital visit

Support for condition

- Q26 Have been offered a care plan

Mental wellbeing

- Q28 Does condition effect their mental wellbeing
- Q29 Have they been asked about their mental wellbeing by HCP in last 3 years
- Q30 Have they been referred or directed to support for mental wellbeing by HCP in last 3 years
- Q32 To what extent do they feel their mental wellbeing needs are being met

Social care

- Q34 Had an assessment of care and support needs by local council
- Q37a Overall social care received meets their needs

Education and Welfare

- Q39a Assessed for an education, health and care (EHC) plan
- Q40 School has made useful changes to help them to attend
- Q41 Attendance at school has been affected due to their neurological condition

It should be noted that the number of children and young people responding to the survey was smaller than the adult cohort, therefore these results should be treated with a degree of caution.

7.2 Neurological condition breakdowns

7.2.1 Single and multiple neurological conditions

The majority of children/young people who completed the survey had a single neurological condition - 288 compared to 237 people with multiple neurological conditions.

A two-tailed t-test on proportions for significant differences has been carried out on the key questions. Where differences are reported below, there is a significant difference level of at least 95%.

COVID-19

Respondents with a single condition were **less likely** to experience delays with:

A scan - 63% vs 46%

Physiotherapy - 56% vs 35%

Overall impact

Children/young people with multiple conditions were more likely to say that their neurological condition affect their day-to-day activities to a great/moderate extent - 85% vs 70%

A larger proportion of children/young people with multiple conditions were more likely to say that their neurological condition impacts their quality of life to a great/moderate extent - 80% vs 68%

Before diagnosis

There were no significant differences with the key questions in this section.

Diagnosis

There were no significant differences with the key questions in this section.

Treatment and care

There were no significant differences with the key questions in this section.

Support for condition

There were no significant differences with the key questions in this section.

Mental wellbeing

Children/young with multiple conditions were more likely to say that their neurological condition affects their mental wellbeing - 93% vs 86%

Social care

There were no significant differences with the key questions in this section.

Education and Welfare

A larger proportion of children/young people with multiple conditions agreed that they been assessed for an education, health and care (EHC) plan - 67% vs 39%

7.2.2 Differences between neurological conditions

The data was broken down by neurological condition, and the different ways people with these conditions answered the following questions.[7]

There were 10 conditions that had respondents over the suppression threshold of 21. However, this ranged from 179 respondents to 36 respondents.

We have charted the top and bottom three scoring conditions for the following questions:

Diagnosis

Q15 Were you given written information?

Treatment and care

Q21 Involvement in choices about healthcare

Q25b Information about condition is effectively shared

Support for condition

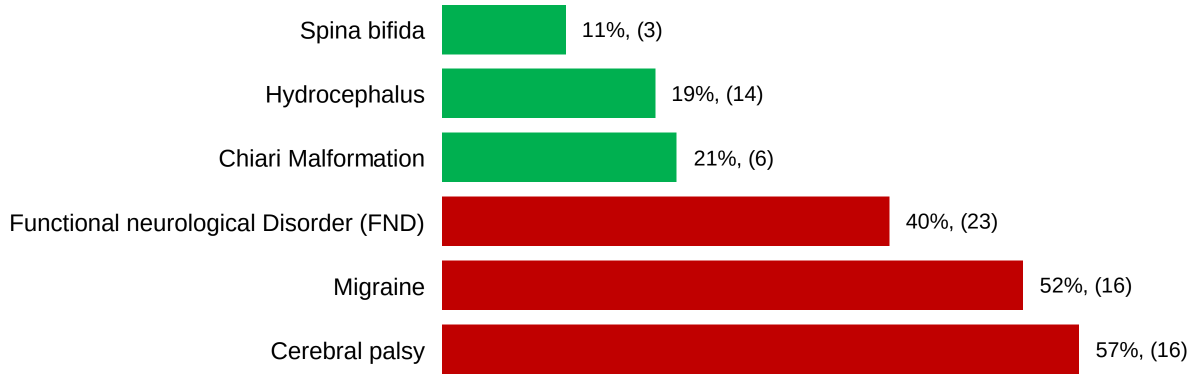
Q26 Have been offered a care plan

Mental wellbeing

Q28 Does condition affect their mental wellbeing

Q29 Have they been asked about their mental wellbeing by HCP in last 3 years

Q15 When you were told you had a neurological condition, were you given written information about it?



Respondents who answered ‘I was not offered or directed to any information’

Based on responses for: Spina bifida – 27, Hydrocephalus – 75, Chiari Malformation – 28, Functional neurological Disorder (FND) – 58, Migraine - 31, Cerebral palsy – 28

Fig 209. Written information – paediatric respondents by condition

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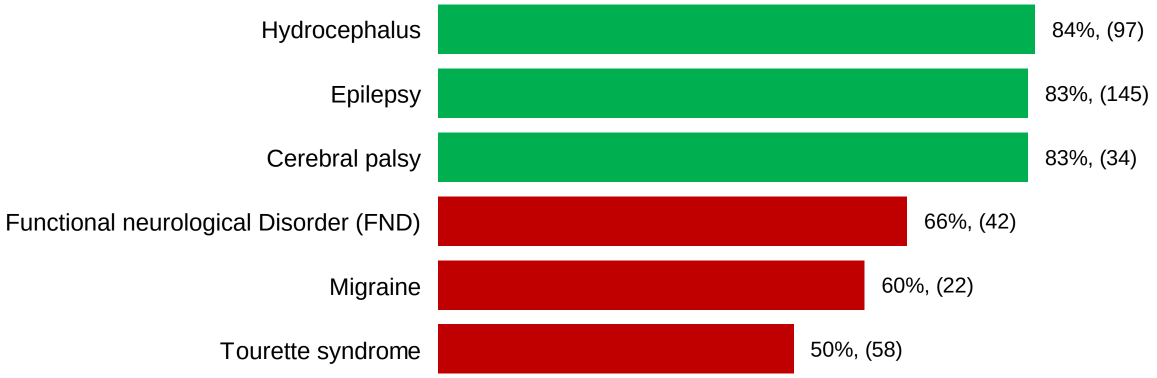
[7] Conditions were collected from Q2 - Please tell us which neurological condition(s) you have. As this question was a tick all that apply, respondents may have selected more than one condition, and we cannot be sure which condition may take precedence when they answered the question. For this reason these results should be treated with a degree of caution.

Q21 Do you feel fully involved in making choices about your health care? For younger children this might be the extent to which the parent is included to make decisions?

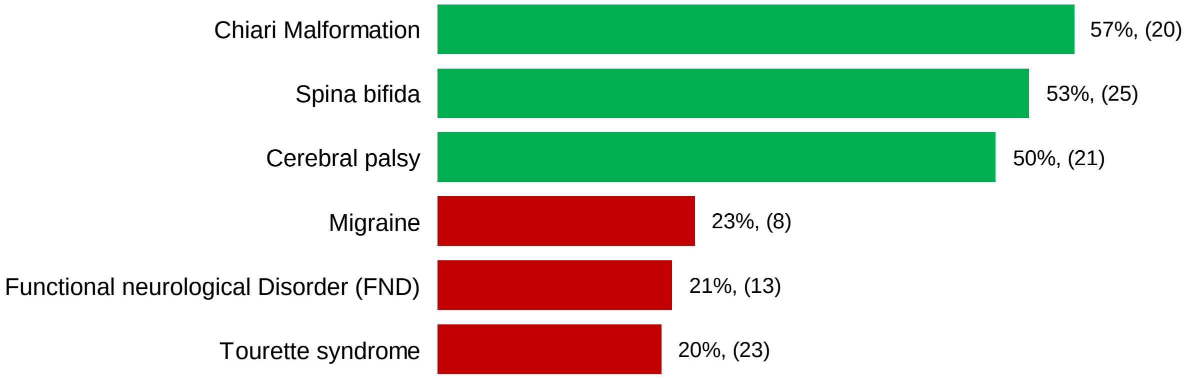


Respondents who answered ‘Yes, definitely / Yes, to some extent’

Based on responses for: Hydrocephalus – 116, Epilepsy – 174, Cerebral palsy – 41, Functional neurological Disorder (FND) – 63, Migraine - 37, Tourette syndrome – 116

Fig 210. Involvement in healthcare – paediatric respondents by condition

Q25b Information about my condition is effectively passed between the people that care for me (such as my specialists, GP, family carer)

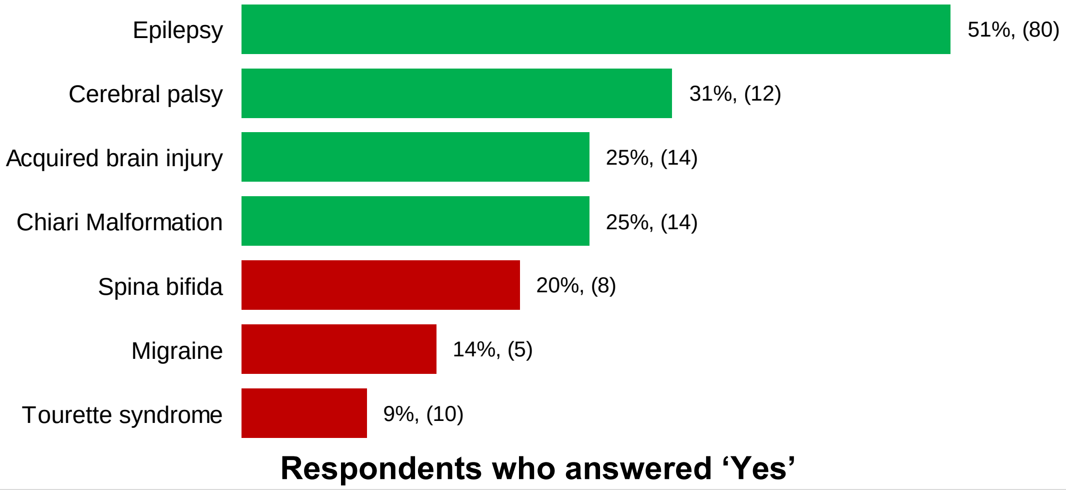


Respondents who answered ‘Agree’

Based on responses for: Chiari Malformation – 35, Spina bifida – 47, Cerebral palsy – 42, Migraine – 35, Functional neurological Disorder (FND) – 62, Tourette syndrome – 113

Fig 211. Communication – paediatric respondents by condition

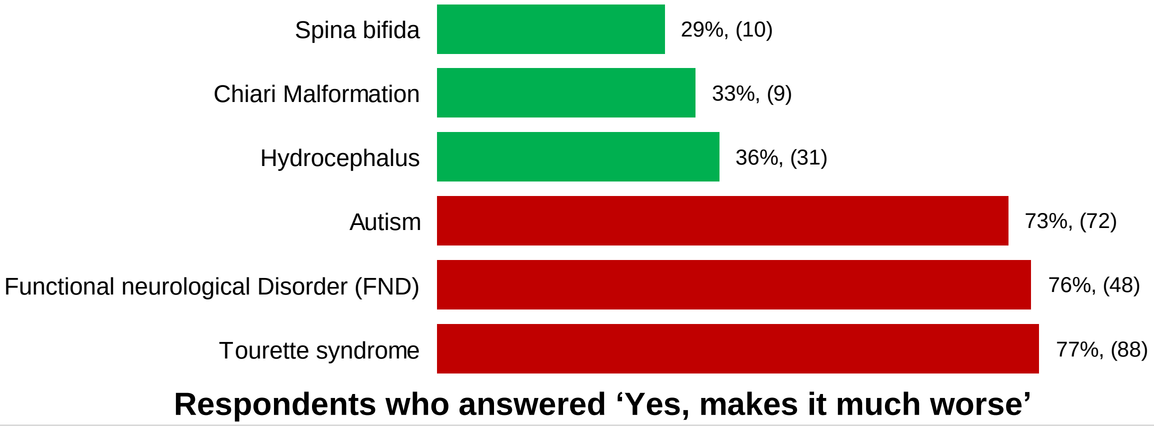
Q26 Within the last three years have you been offered a care and support plan to help you manage your neurological condition?



Based on responses for: Epilepsy – 156, Cerebral palsy – 39, Acquired brain injury – 56, Chiari Malformation – 32, Spina bifida – 11, Migraine – 37, Tourette syndrome – 115

Fig 212. Offered a care plan – paediatric respondents by condition

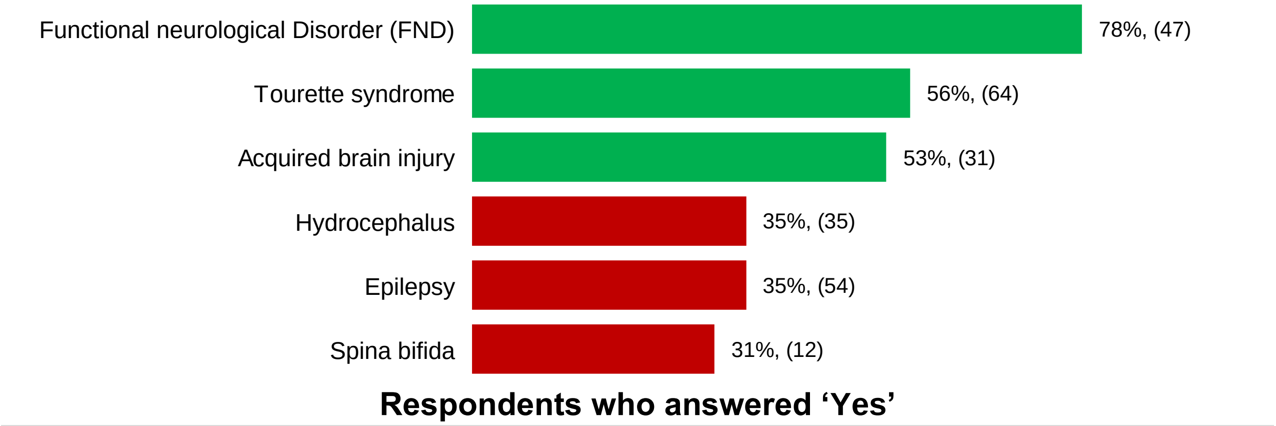
Q28 Does your neurological condition affect your mental wellbeing?



Based on responses for: Spina bifida – 35, Chiari Malformation – 27, Hydrocephalus – 86, Autism – 99, Functional neurological Disorder (FND) – 63, Tourette syndrome – 115

Fig 213. Mental wellbeing – paediatric respondents by condition

Q29 Have you been asked about your mental wellbeing by a health or social care professional within the last three years?



Based on responses for: Functional neurological Disorder (FND) – 60, Tourette syndrome – 114, Acquired brain injury – 58, Hydrocephalus – 100, Epilepsy – 156, Tourette syndrome – 114

Fig 214. Mental wellbeing and healthcare professionals – paediatric respondents by condition

7.3 Geographical breakdowns

7.3.1 Nation breakdowns

The following section charts the results across England, Scotland, Wales and Northern Ireland for the key questions

Results have been presented as 100% stacked bar charts for visualisation purposes; however, it should be noted that the number of responses for each country are very different, with England receiving significantly more than Scotland, Wales and Northern Ireland.

Number of responses to the paediatric questionnaire by nation

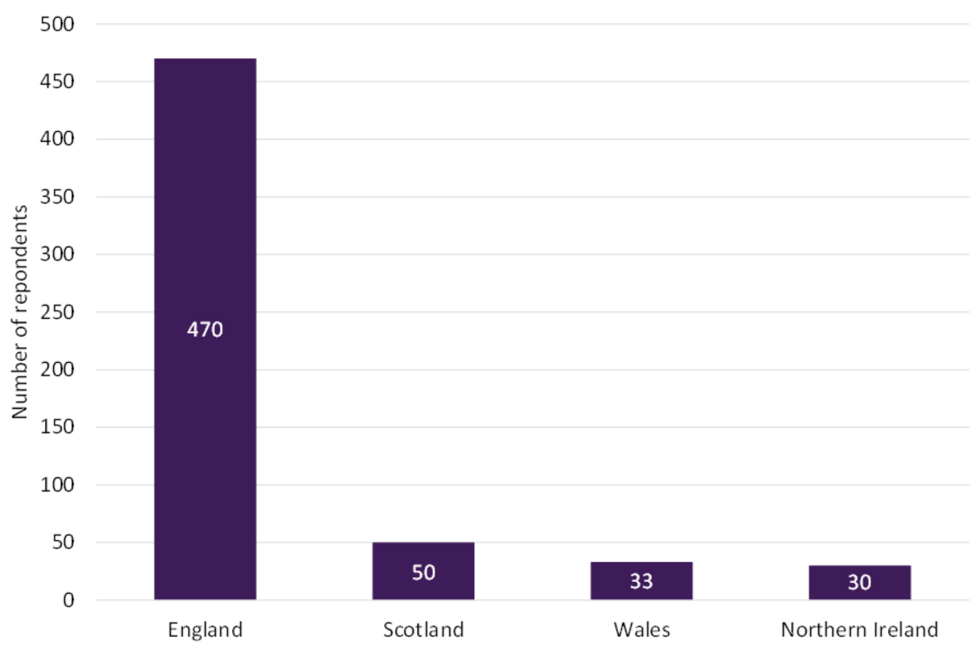
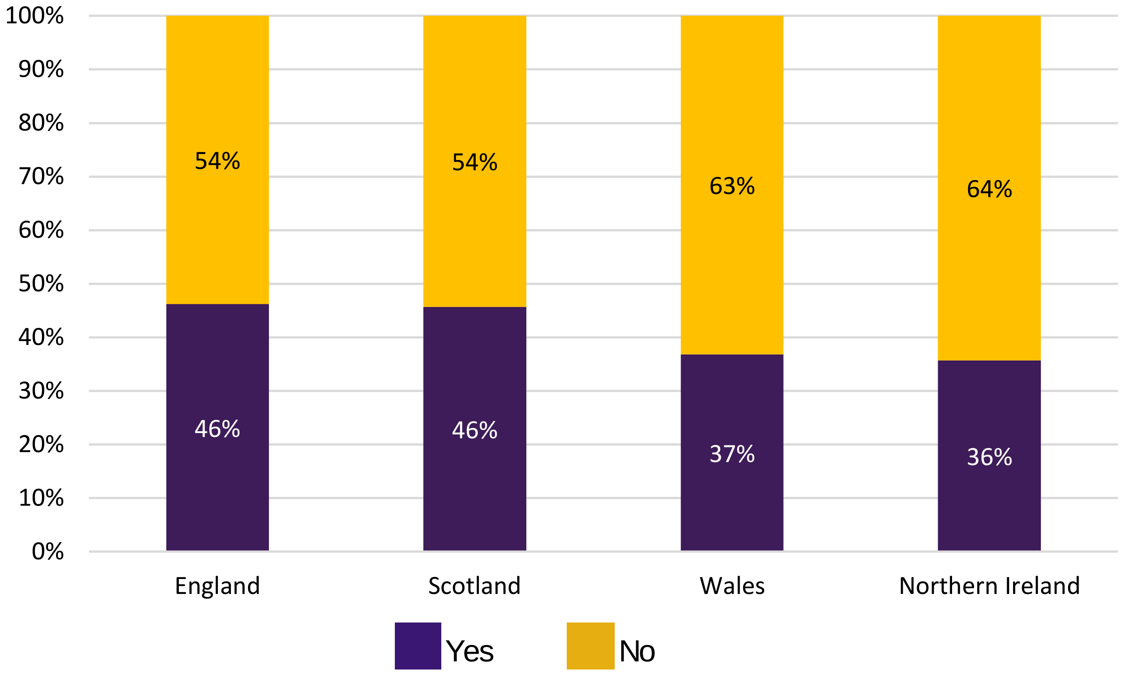


Fig 215. Geographical distribution – paediatric respondents

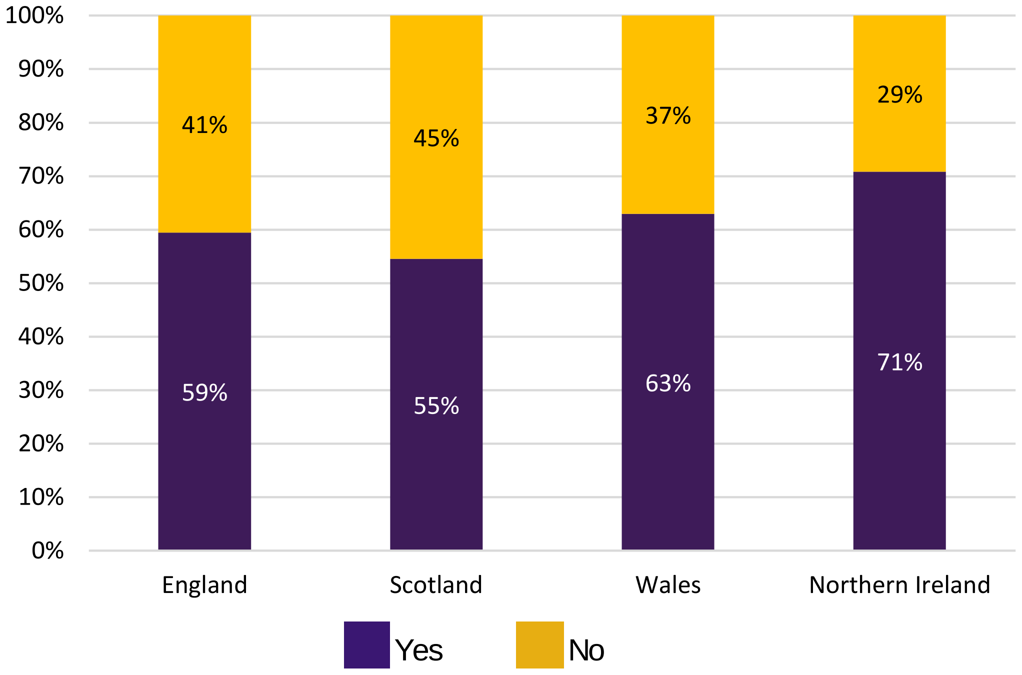
Q3a_1. Experienced delays for: A first appointment with a specialist for your neurological disorder



Based on responses for: England – 132, Scotland – 35, Wales – 19, Northern Ireland – 14

Fig 216. Delays for a first appointment with a specialist – paediatric respondents by nation

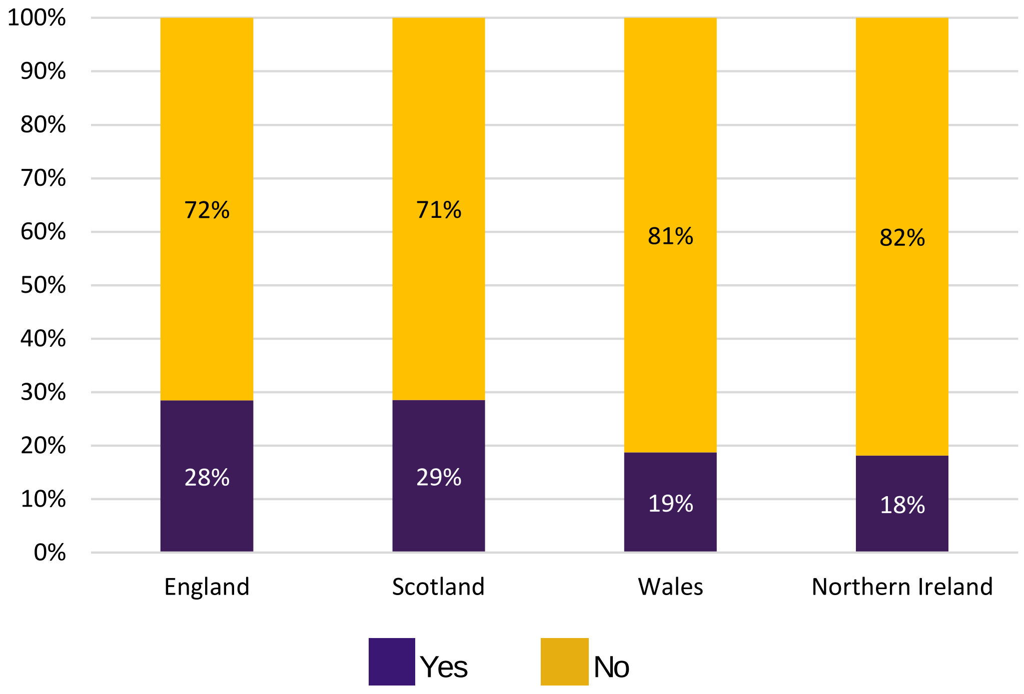
Q3a_2. Experienced delays for: A routine appointment with a specialist for your neurological disorder



Based on responses for: England – 380, Scotland – 44, Wales – 27, Northern Ireland – 24

Fig 217. Delays for a routine appointment with your specialist – paediatric respondents by nation

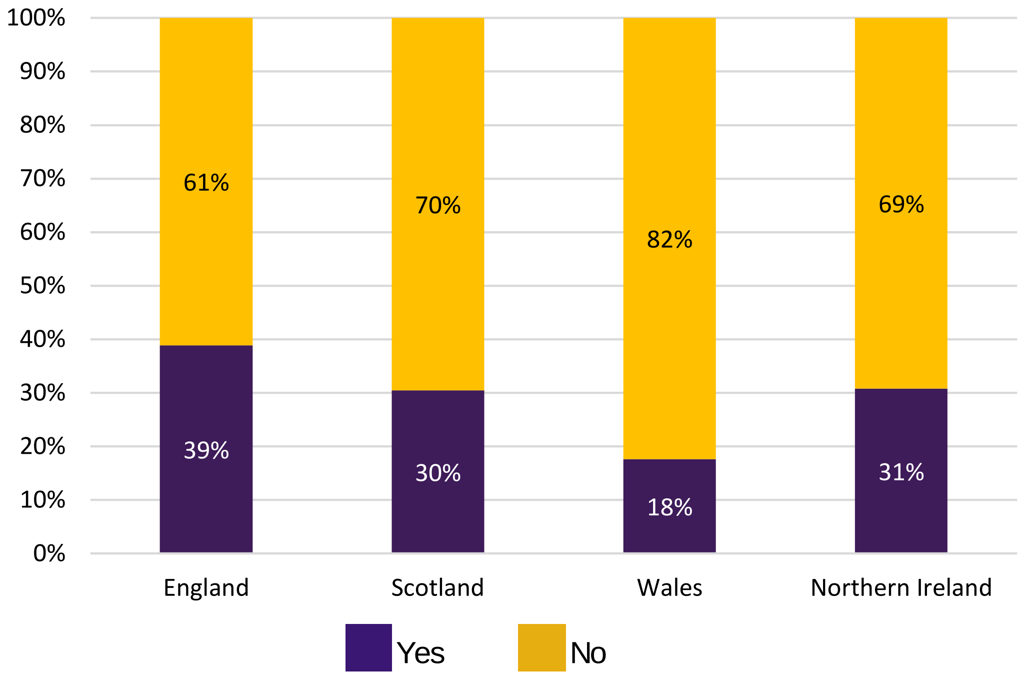
Q3a_3. Experienced delays for: A first appointment with a specialist nurse



Based on responses for: England – 179, Scotland – 21, Wales – 16, Northern Ireland – 11

Fig 218. Delays for a first appointment with a specialist nurse – paediatric respondents by nation

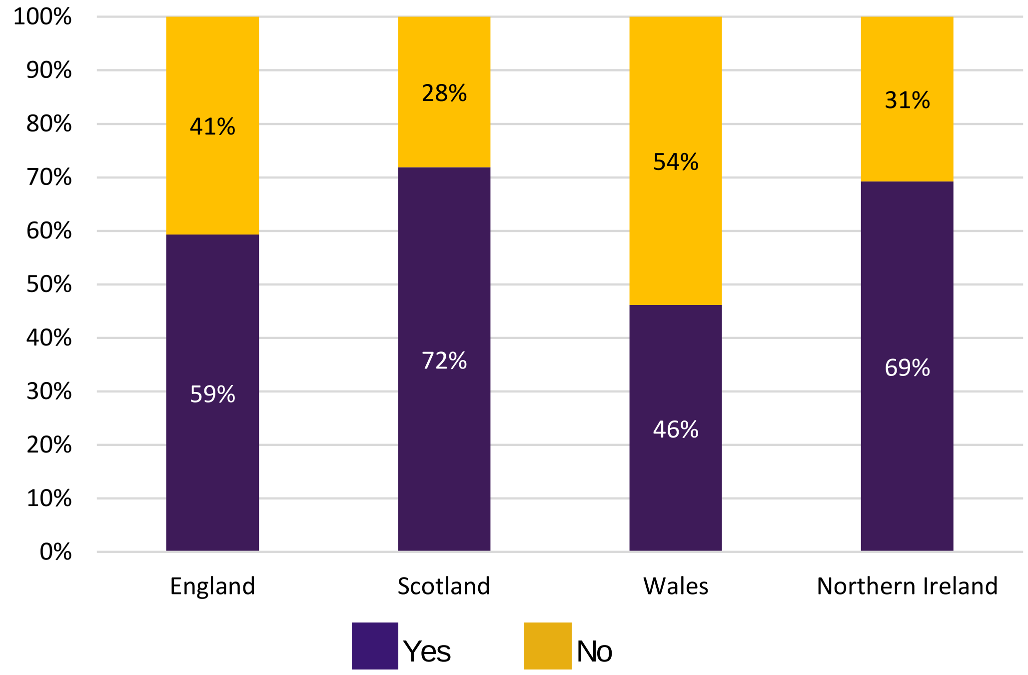
Q3a_4. Experienced delays for: A routine appointment with your specialist nurse



Based on responses for: England – 216, Scotland – 23, Wales – 17, Northern Ireland – 13

Fig 219. Delays for a routine appointment with a specialist nurse – paediatric respondents by nation

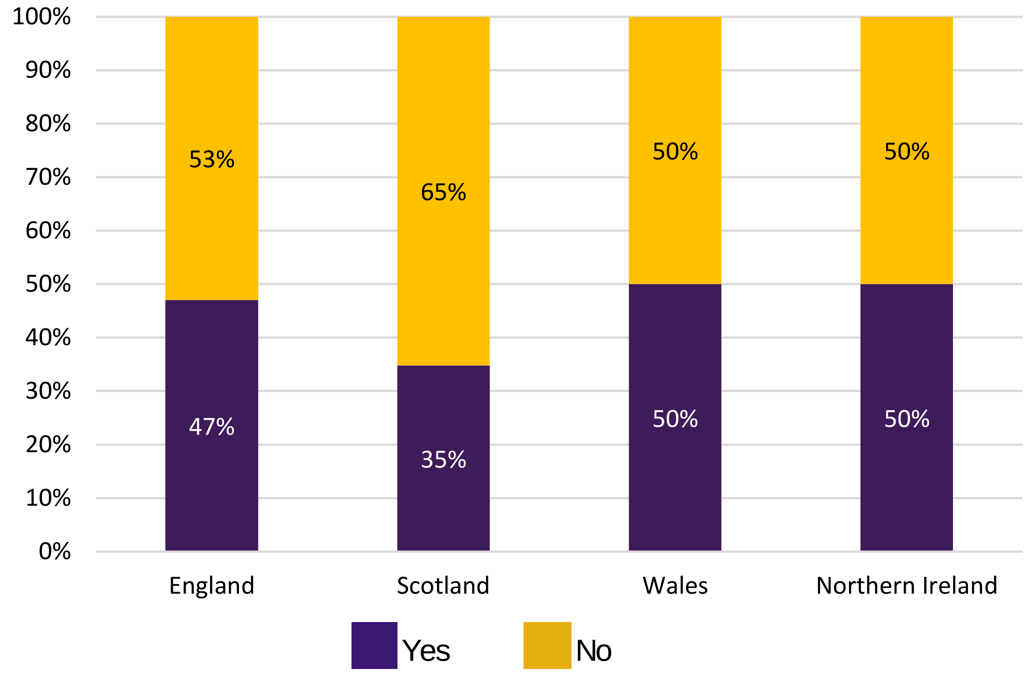
Q3a_5. Experienced delays for: A mental health appointment



Based on responses for: England – 214, Scotland – 32, Wales – 13, Northern Ireland – 13

Fig 220. Delays for a routine appointment for a mental health appointment – paediatric respondents by nation

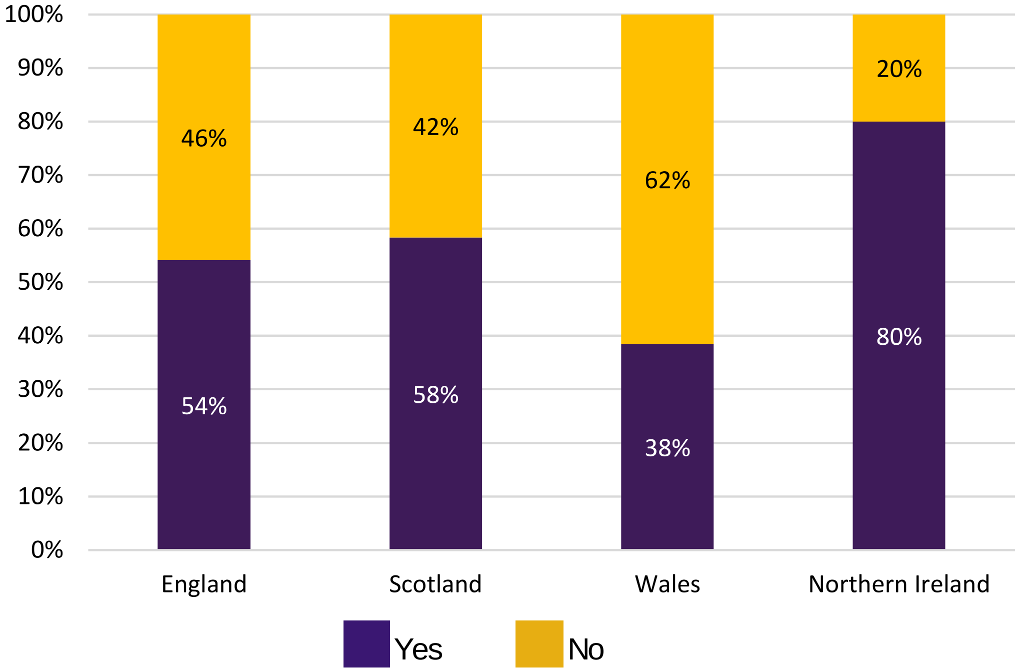
Q3a_8. Experienced delays for: A scan



Based on responses for: England – 221, Scotland – 23, Wales – 20, Northern Ireland – 18

Fig 221. Delays for a scan – paediatric respondents by nation

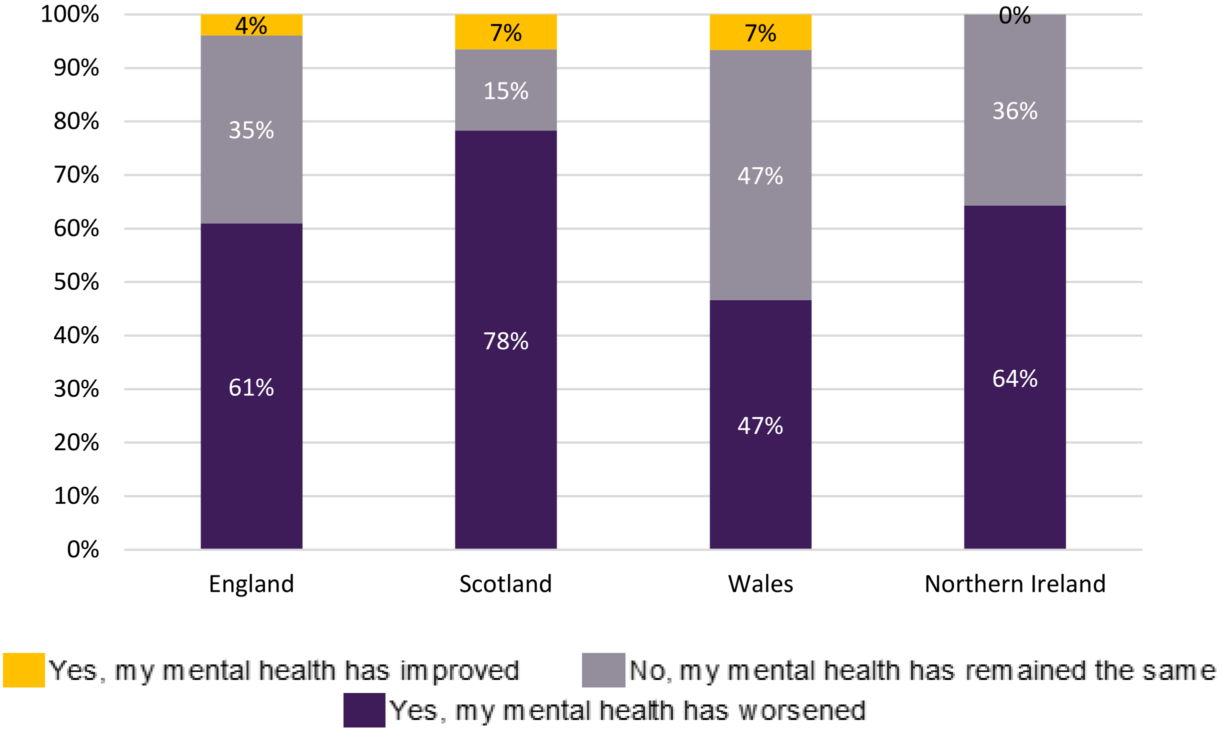
Q3a_10. Experienced delays for: Physiotherapy



Based on responses for: England – 207, Scotland – 24, Wales – 13, Northern Ireland – 20

Fig 222. Delays for physiotherapy – paediatric respondents by nation

Q6. Have you experienced a change in your mental health or behaviour during the pandemic?

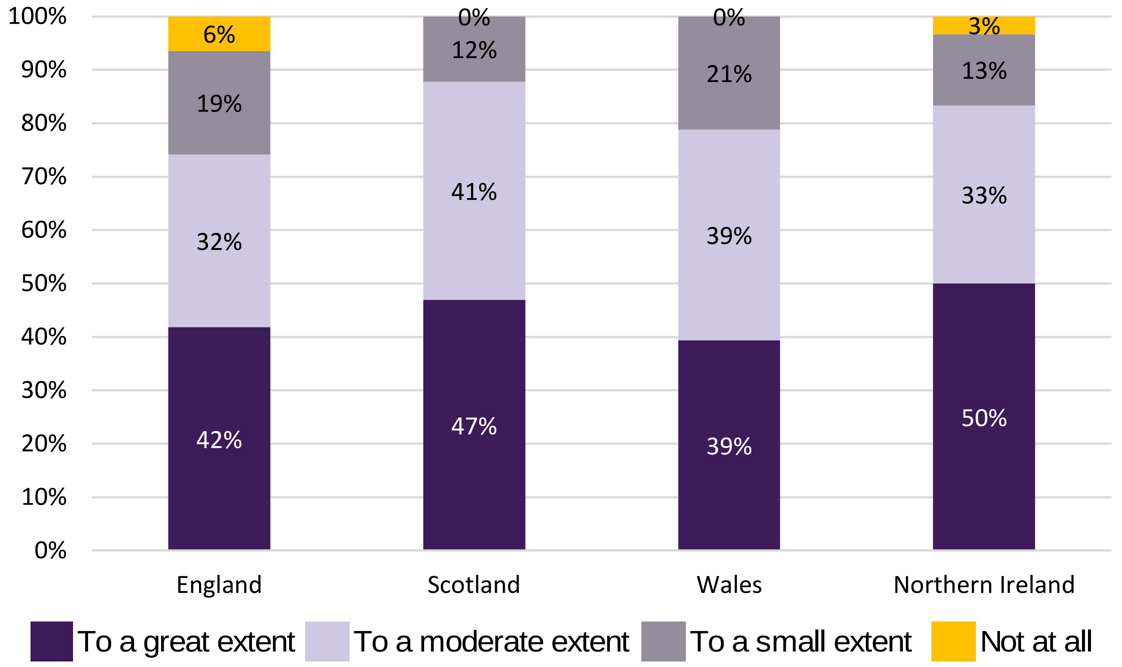


Based on responses for: England – 410, Scotland – 46, Wales – 30, Northern Ireland – 28

Fig 223. Change to mental health needs due to Covid-19 – paediatric respondents by nation

Overall impact

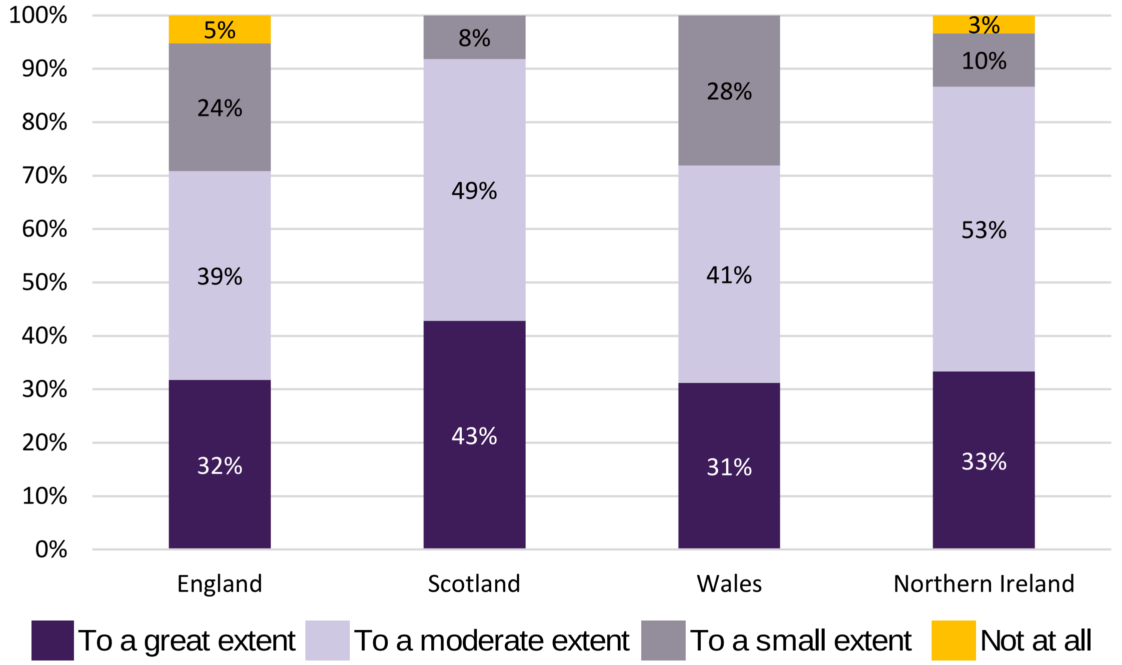
Q8. To what extent overall does your neurological condition(s) impact your day to day activities?



Based on responses for: England – 464, Scotland – 49, Wales – 33, Northern Ireland – 30

Fig 224. Overall impact of neurological conditions on day today activities – paediatric respondents by nation

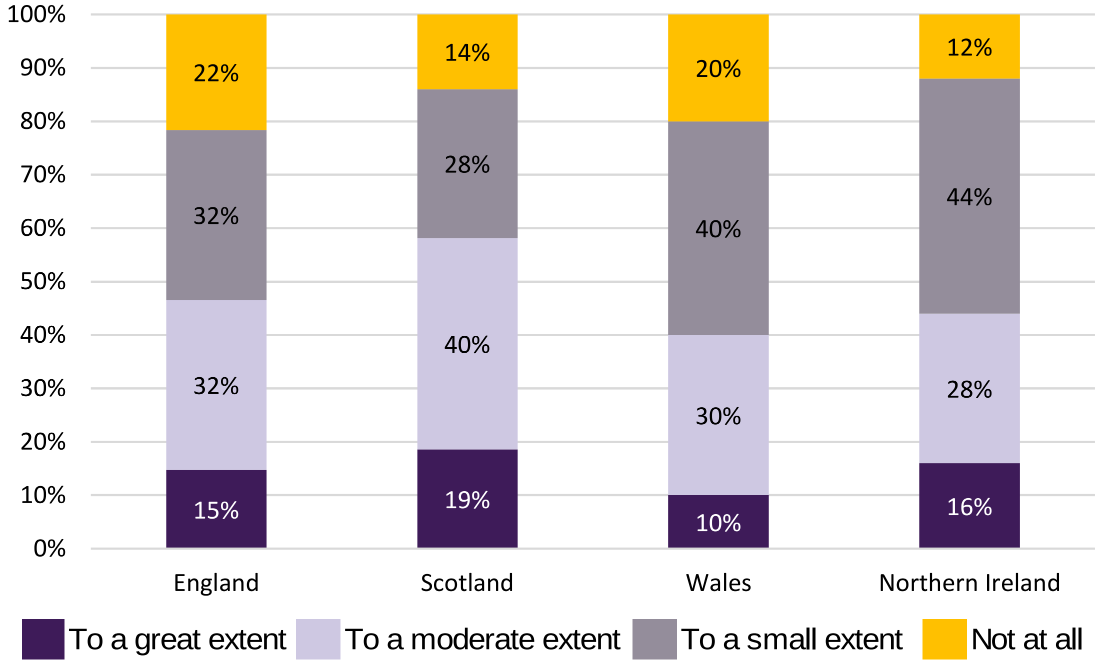
Q9. To what extent overall does your neurological condition(s) impact your quality of life?



Based on responses for: England – 463, Scotland – 49, Wales – 32, Northern Ireland – 30

Fig 225. Impact of neurological conditions on quality of life – paediatric respondents by nation

Q10. To what extent overall does your neurological condition(s) cause you pain?

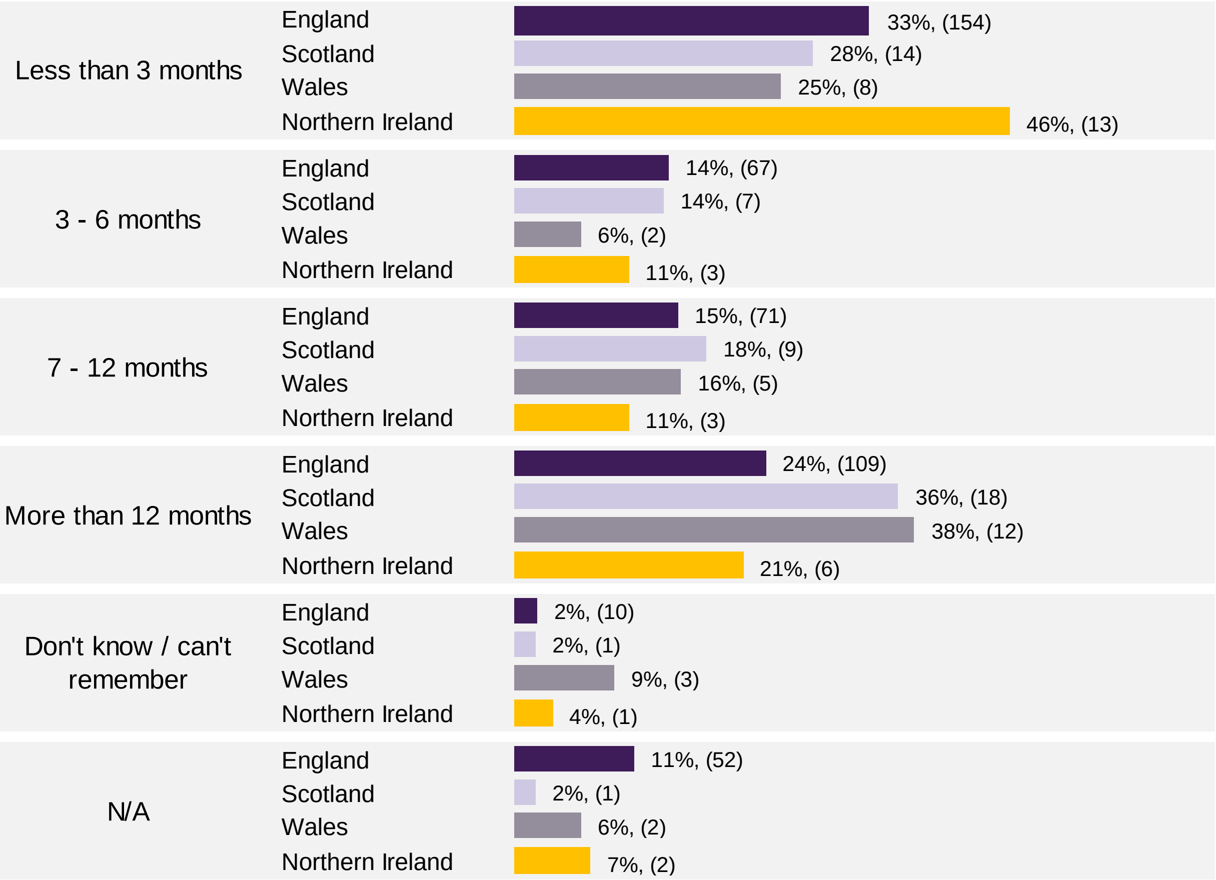


Based on responses for: England – 421, Scotland – 43, Wales – 30, Northern Ireland – 25

Fig 226. Pain caused by neurological conditions – paediatric respondents by nation

Before diagnosis

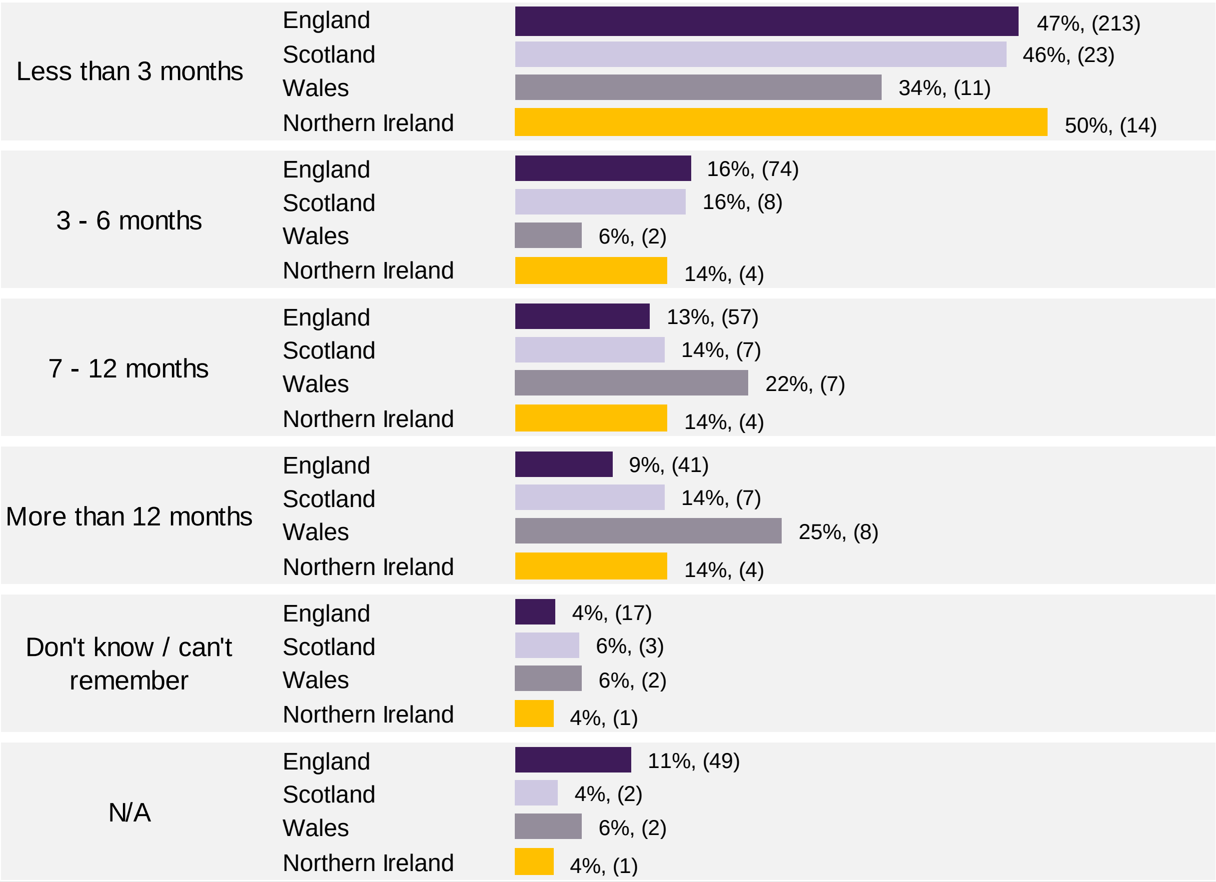
Q11a How long were you waiting between: First experiencing symptoms to getting a diagnosis?



Based on responses for: England – 463, Scotland – 50, Wales – 32, Northern Ireland – 28

Fig 227. Waiting for a diagnosis – paediatric respondents by nation

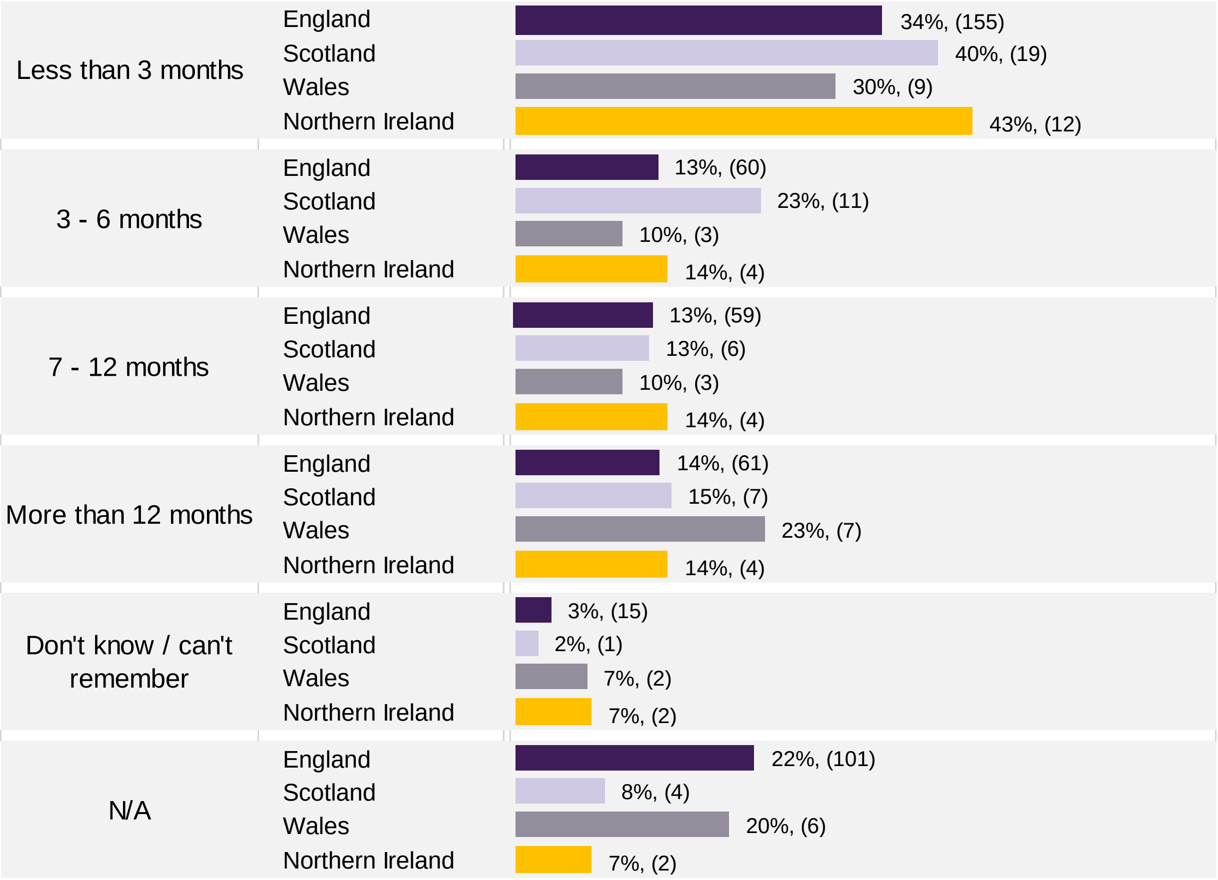
Q11b How long were you waiting between: First seeing a GP (or having an emergency admission) to seeing a hospital based paediatrician?



Based on responses for: England – 451, Scotland – 50, Wales – 32, Northern Ireland – 28

Fig 228. First seeing a hospital based paediatrician – paediatric respondents by nation

Q11c How long were you waiting between: First seeing a paediatrician to seeing a neurologist?

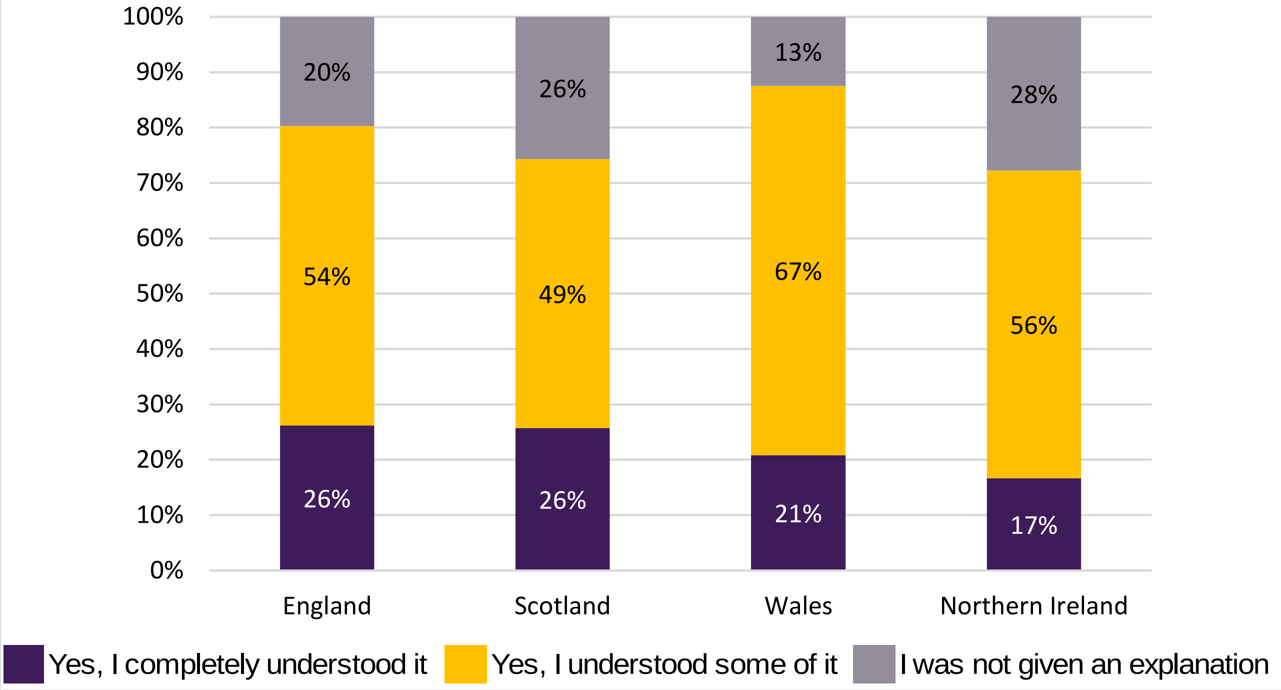


Based on responses for: England – 451, Scotland – 48, Wales – 30, Northern Ireland – 28

Fig 229. First seeing a neurologist – paediatric respondents by nation

Diagnosis

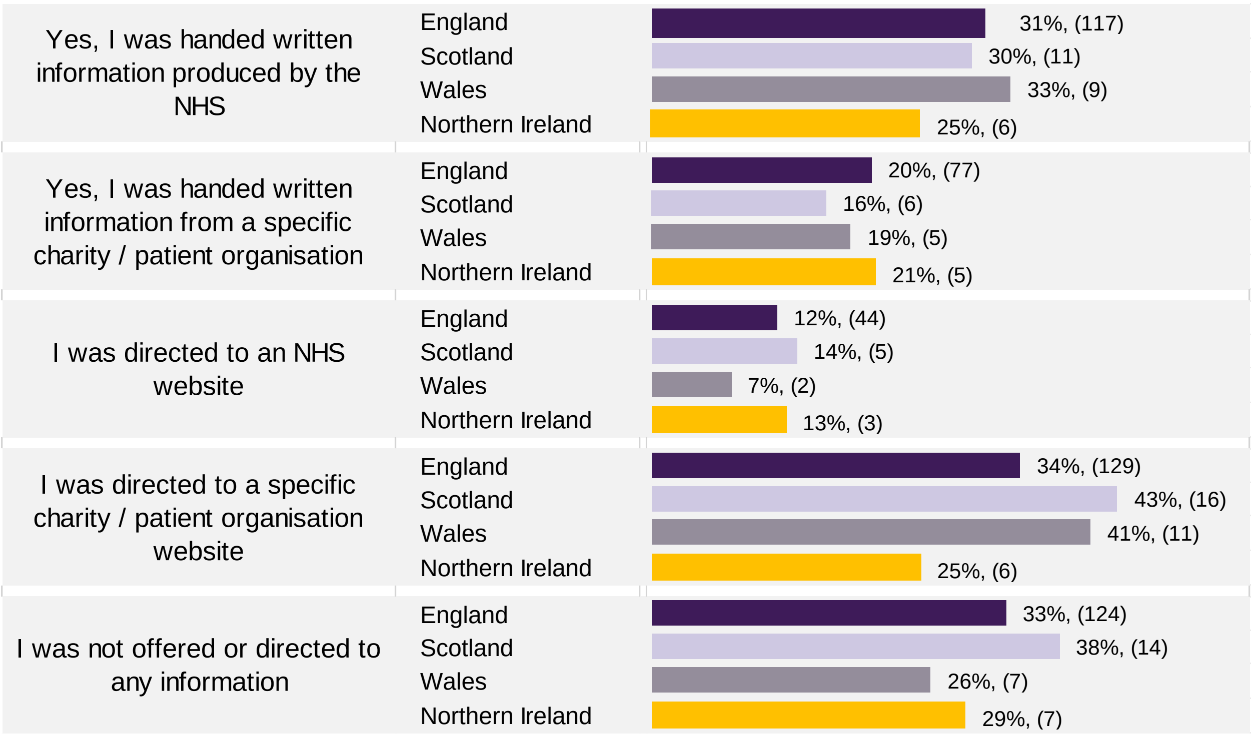
Q14 Did you understand the explanation given to you at your diagnosis / when you were first told about your condition?



Based on responses for: England – 340, Scotland – 35, Wales – 24, Northern Ireland – 18

Fig 230. Explanation of diagnosis – paediatric respondents by nation

Q15 When you were told you had a neurological condition, were you given written information about it? Please tick all that apply

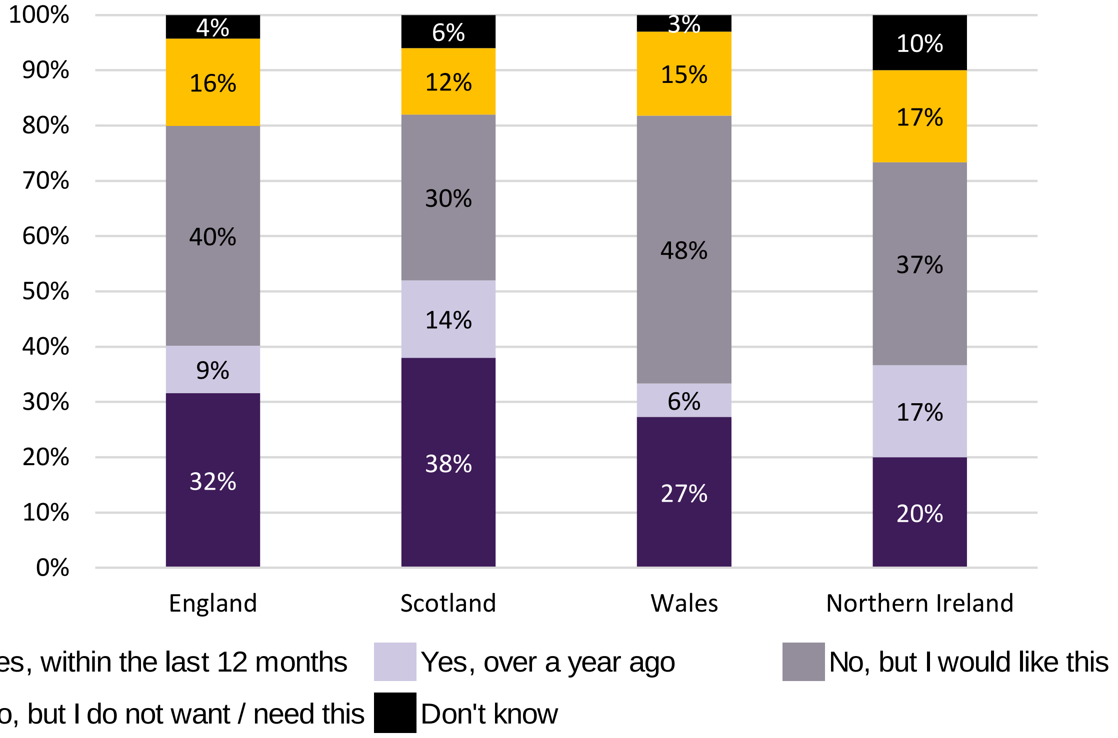


Based on responses for: England – 377, Scotland – 37, Wales – 27, Northern Ireland – 24

Fig 231. Written information – paediatric respondents by nation

Treatment and care

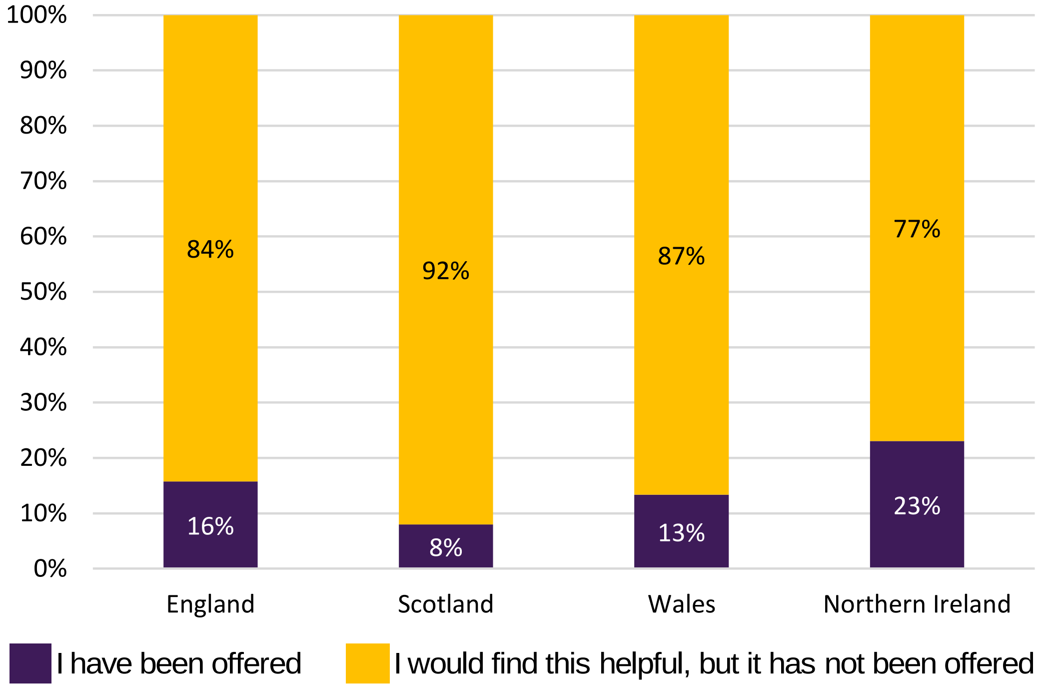
Q18 Have you had an appointment with a specialist nurse for your neurological condition(s)?



Based on responses for: England – 468, Scotland – 50, Wales – 33, Northern Ireland – 30

Fig 232. Access to Specialist Nurses – paediatric respondents by nation

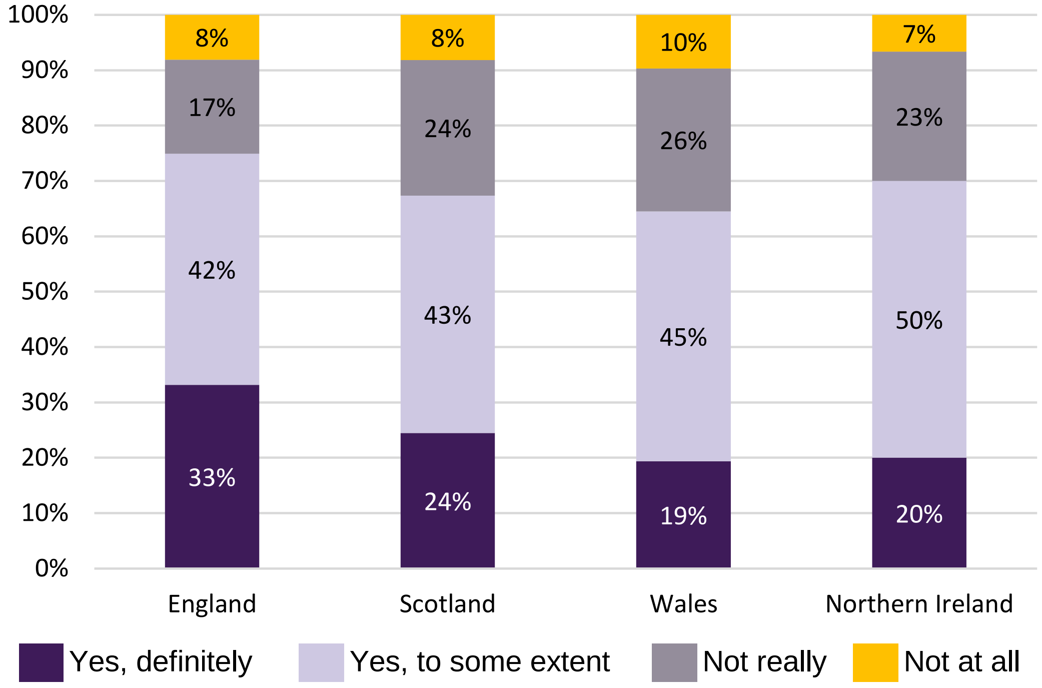
Q20 Do you have a named worker to support the transition process between paediatric and adult services?



Based on responses for: England – 216, Scotland – 25, Wales – 15, Northern Ireland – 13

Fig 233. Transition to adult services – paediatric respondents by nation

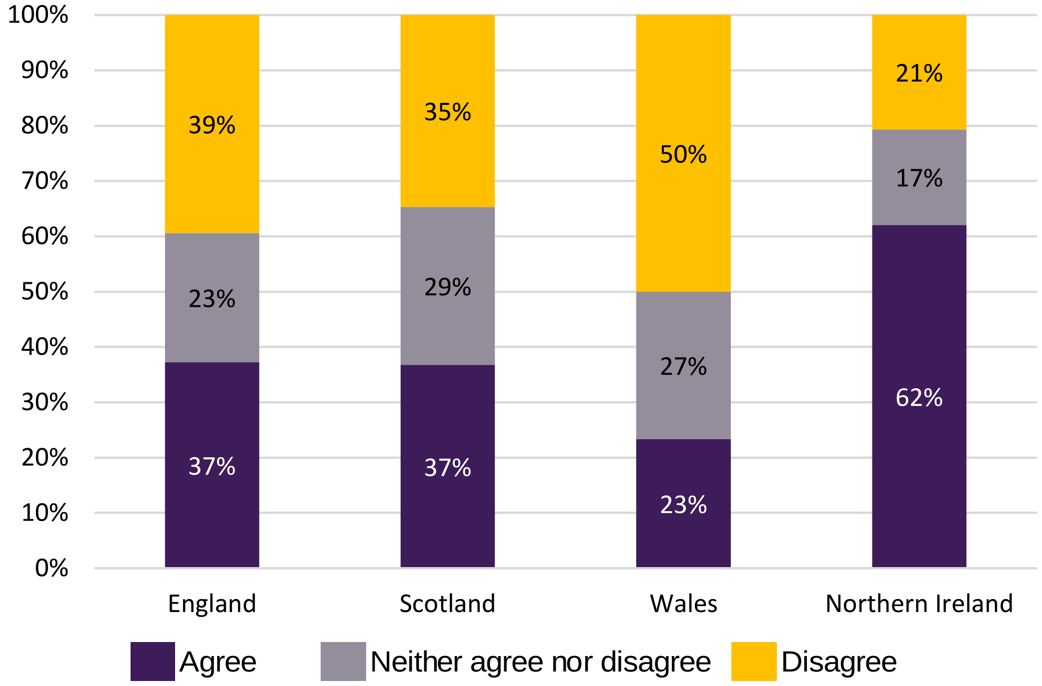
Q21 Do you feel fully involved in making choices about your health care?



Based on responses for: England – 458, Scotland – 49, Wales – 31, Northern Ireland – 30

Fig 234. Involvement in health care – paediatric respondents by nation

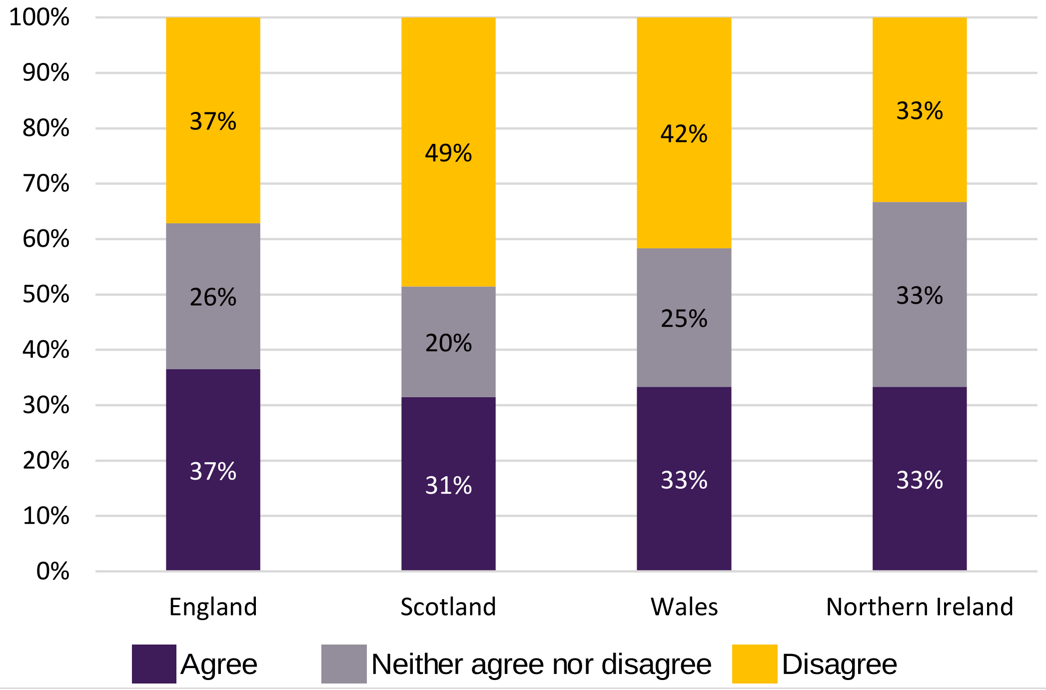
Q25b Information about my condition is effectively passed between the people that care for me (such as my specialists, GP, family carer)



Based on responses for: England – 454, Scotland – 49, Wales – 30, Northern Ireland – 29

Fig 235. Communication – paediatric respondents by nation

Q25c I got the care I needed at home after my hospital visit

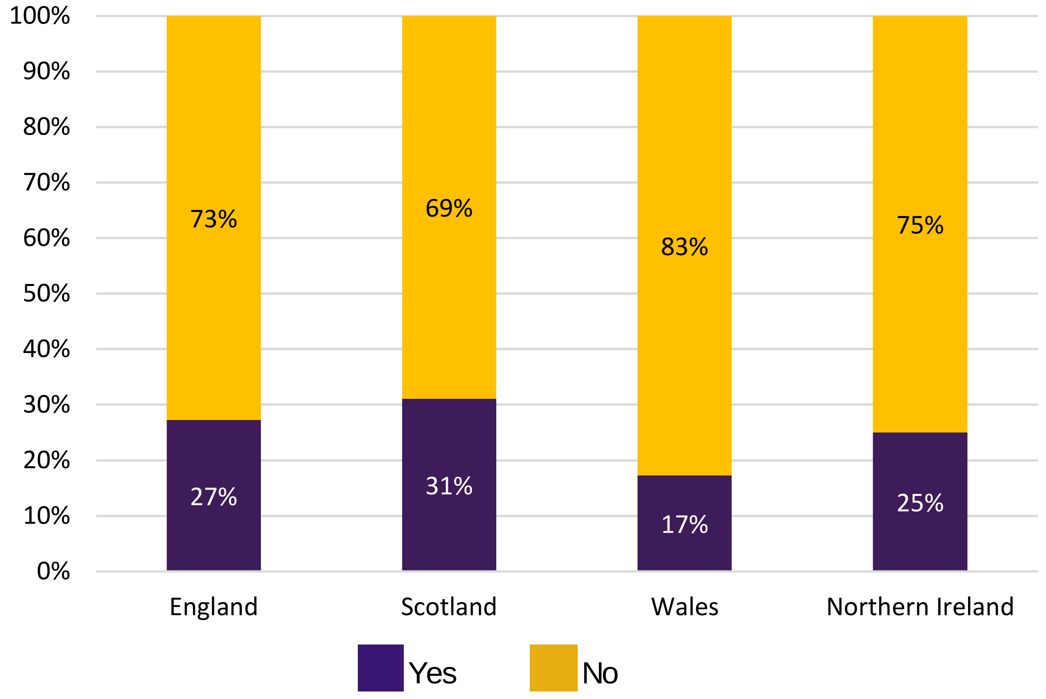


Based on responses for: England – 334, Scotland – 35, Wales – 24, Northern Ireland – 27

Fig 236. Care at home after hospital visit– paediatric respondents by nation

Support for condition

Q26 Within the last three years have you been offered a care and support plan to help you manage your neurological condition?

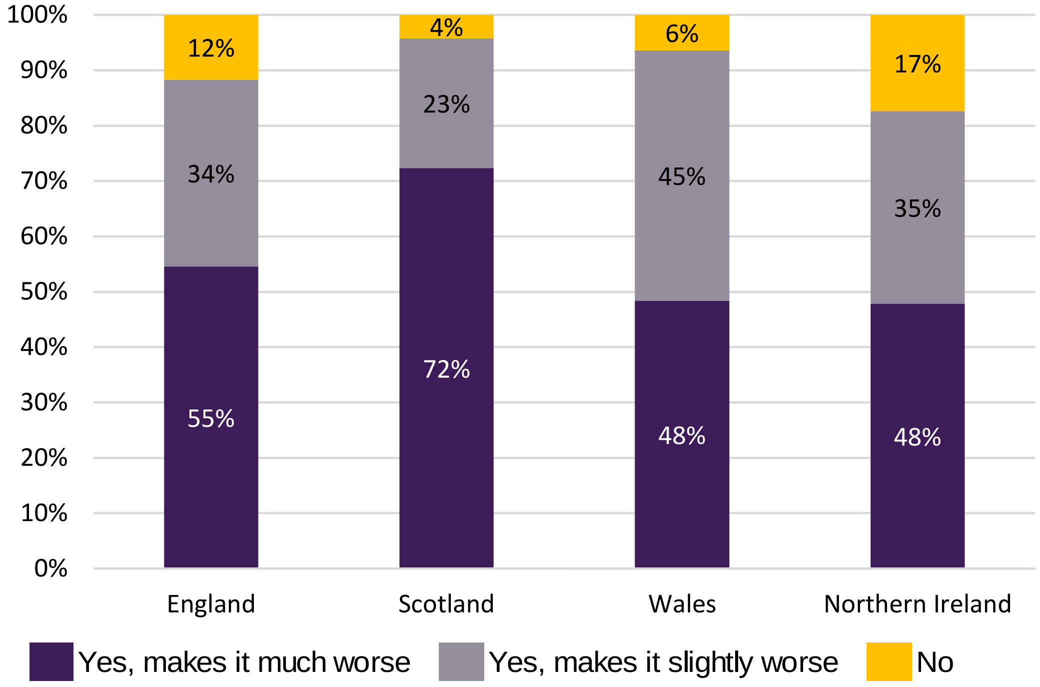


Based on responses for: England – 426, Scotland – 45, Wales – 29, Northern Ireland – 28

Fig 237. Offered a care plan – paediatric respondents by nation

Mental wellbeing

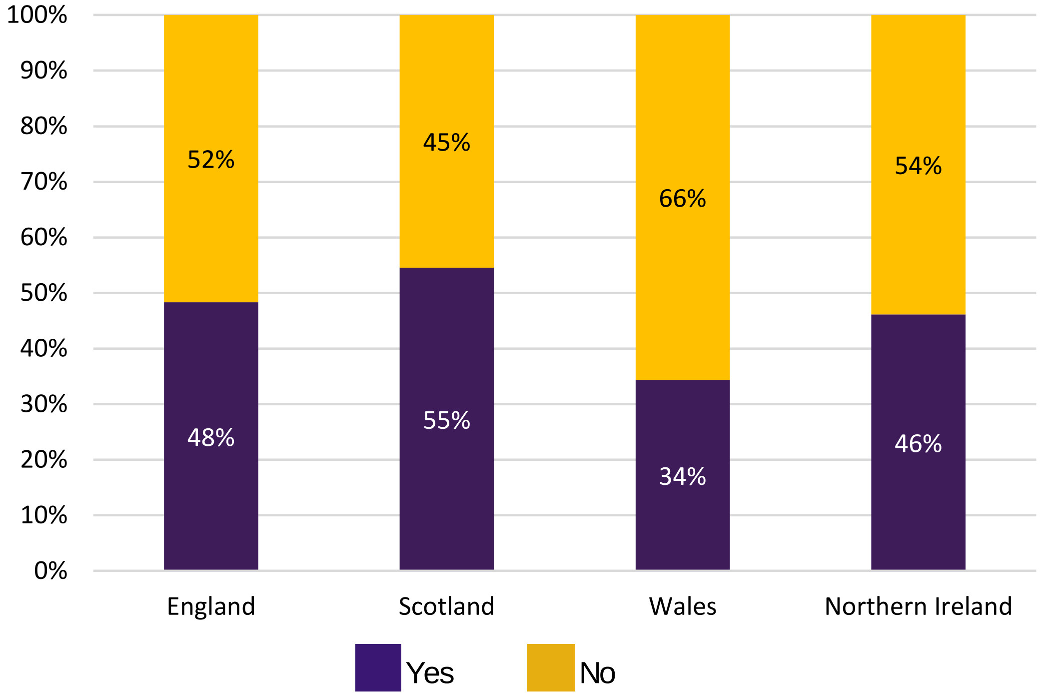
Q28 Does your neurological condition affect your mental wellbeing?



Based on responses for: England – 427, Scotland – 47, Wales – 31, Northern Ireland – 23

Fig 238. Mental wellbeing – paediatric respondents by nation

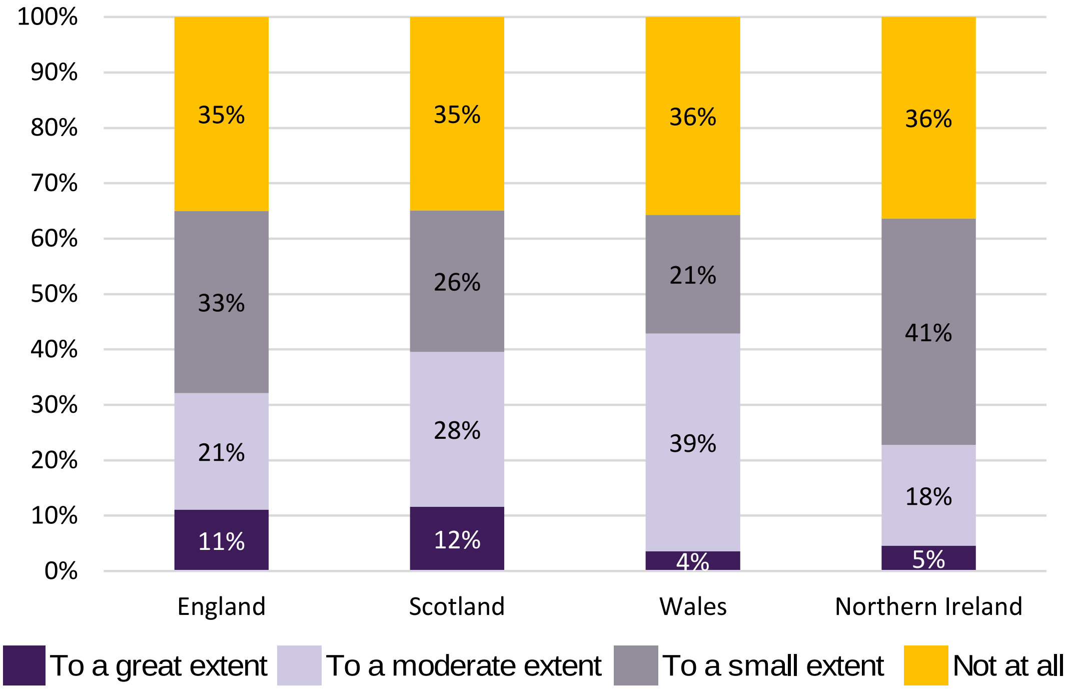
Q29 Have you been asked about your mental wellbeing by a health or social care professional within the last three years?



Based on responses for: England – 428, Scotland – 44, Wales – 32, Northern Ireland – 26

Fig 239. Mental wellbeing and healthcare professionals – paediatric respondents by nation

Q32 To what extent do you feel your mental wellbeing needs are being met?

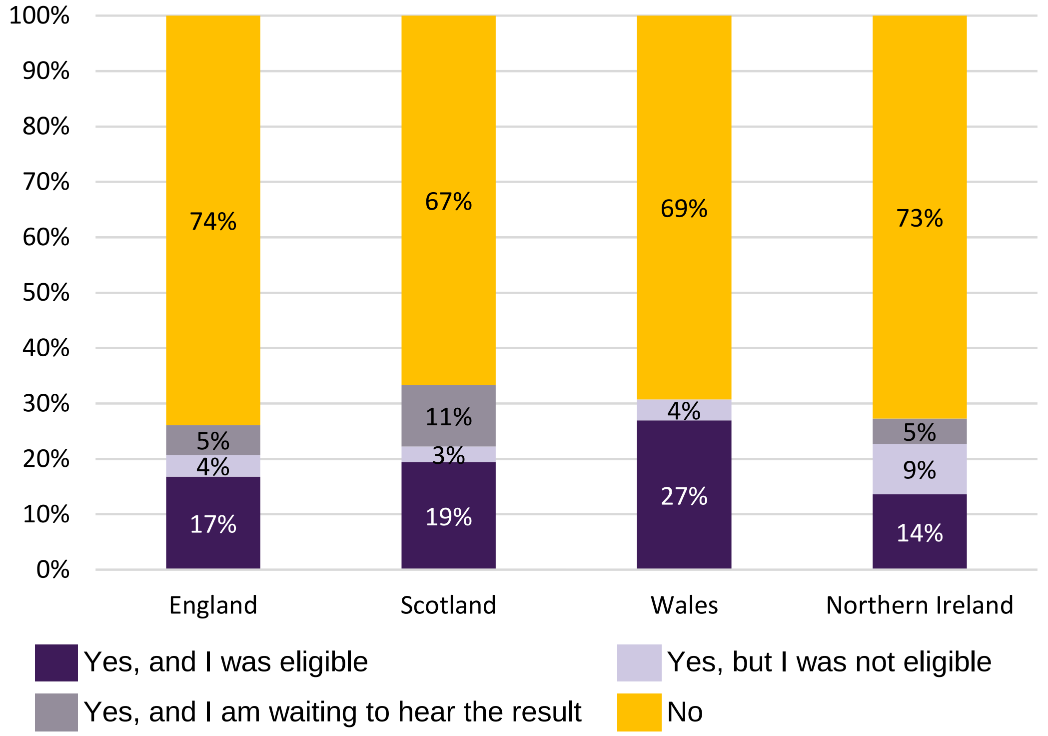


Based on responses for: England – 380, Scotland – 43, Wales – 28, Northern Ireland – 22

Fig 240. Meeting mental wellbeing needs – paediatric respondents by nation

Social care

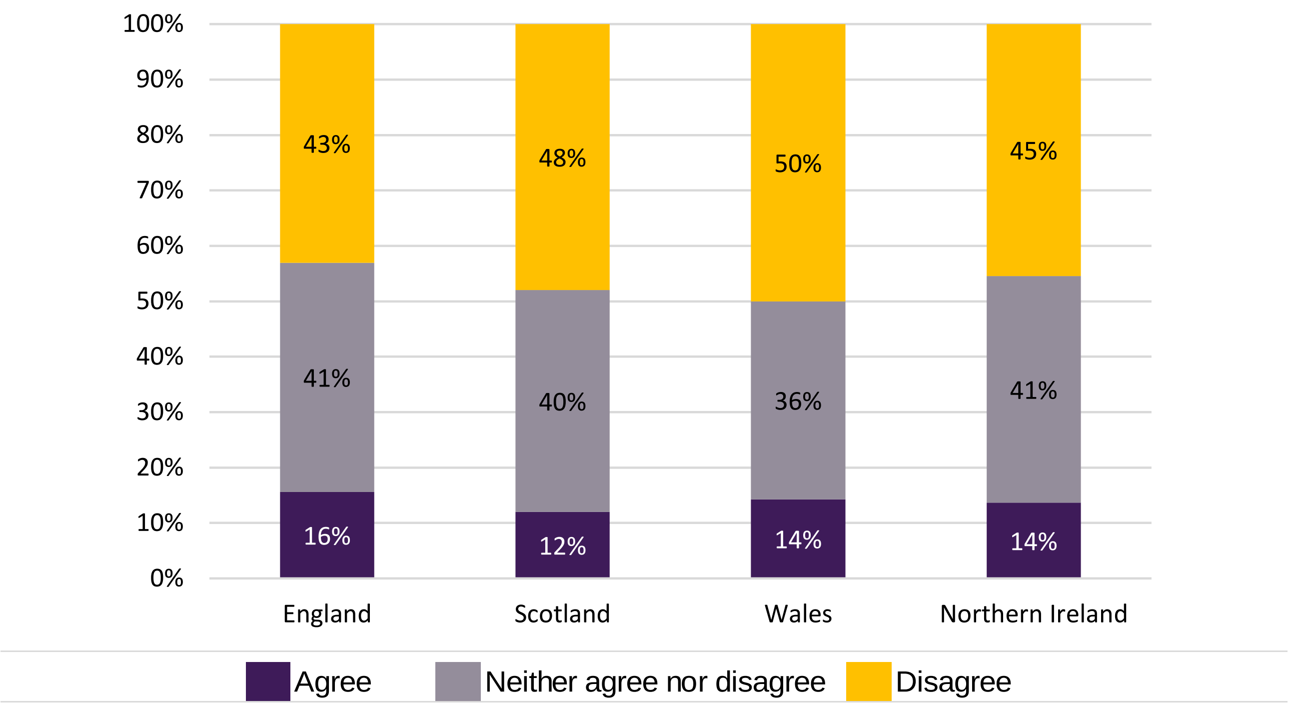
Q34 Has your local council assessed your care and support needs to see if you are eligible to receive funded care or support?



Based on responses for: England – 333, Scotland – 36, Wales – 26, Northern Ireland – 22

Fig 241. Assessments for funded care and support – paediatric respondents by nation

Q37a Overall, the social care I have received meets my needs

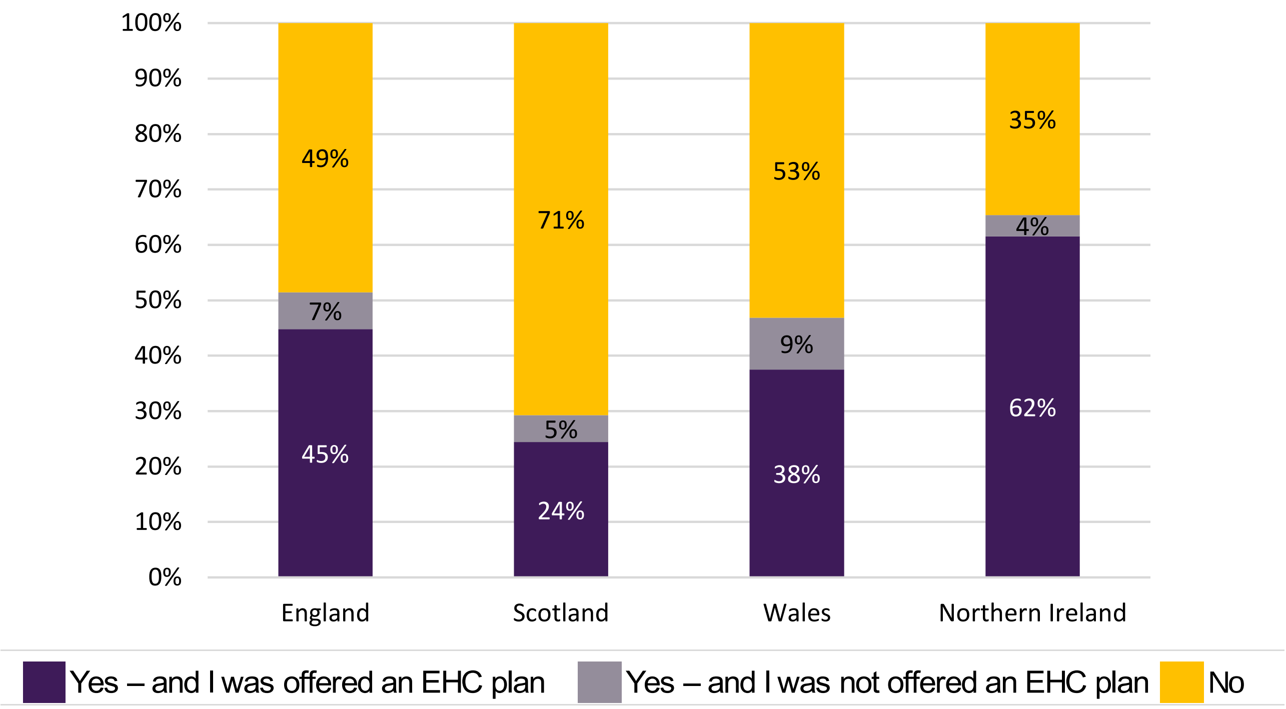


Based on responses for: England – 237, Scotland – 25, Wales – 14, Northern Ireland – 22

Fig 242. Overall views of social care – paediatric respondents by nation

Education and Welfare

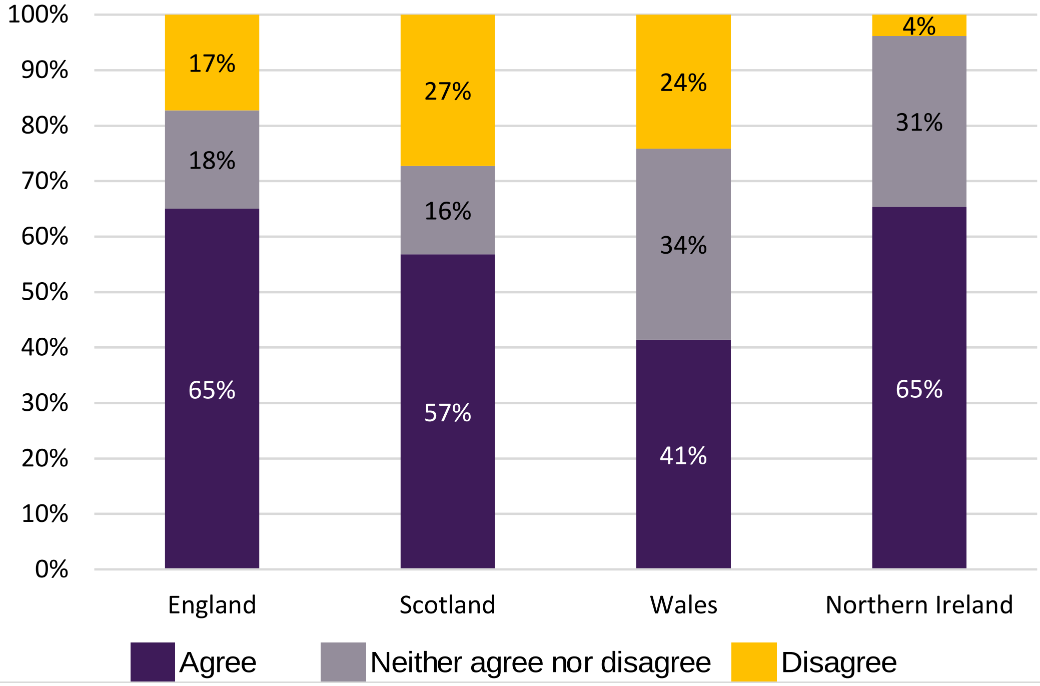
Q39 Have you been assessed for an education, health and care (EHC) plan?



Based on responses for: England – 453, Scotland – 41, Wales – 32, Northern Ireland – 26

Fig 243. EHC plans – paediatric respondents by nation

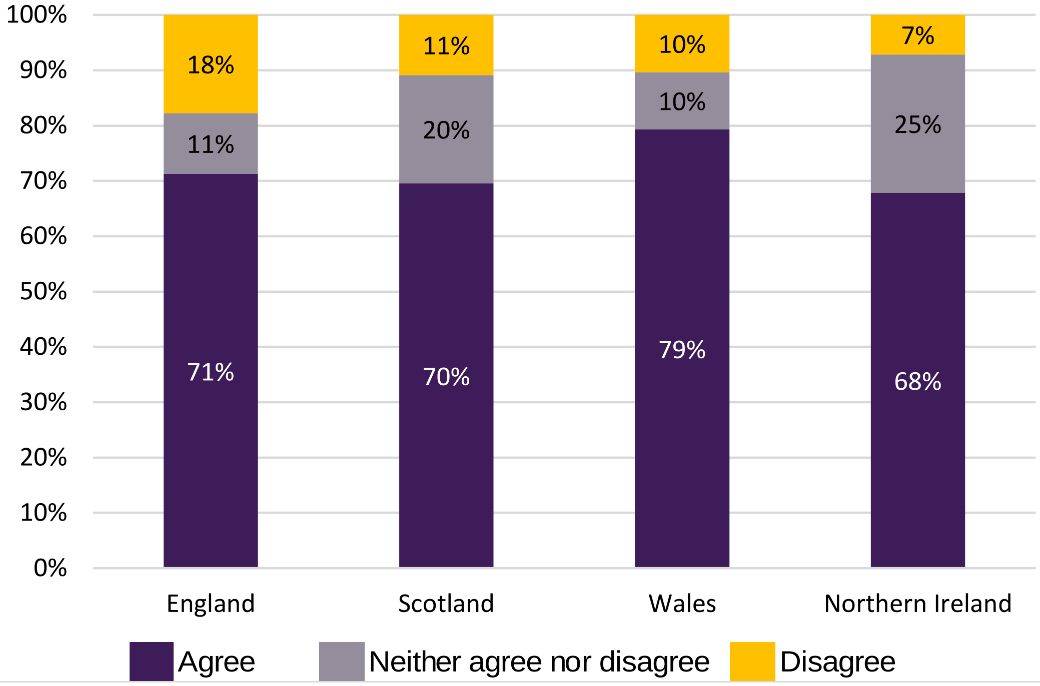
Q40a My school has made useful changes to help me to attend



Based on responses for: England – 406, Scotland – 44, Wales – 29, Northern Ireland – 26

Fig 244. School adaptations – paediatric respondents by nation

Q40b My attendance at school has been affected due to my neurological condition



Based on responses for: England – 428, Scotland – 46, Wales – 29, Northern Ireland – 28

Fig 245. School attendance – paediatric respondents by nation

7.3.2 Regional breakdowns

Due to the number of responses, there are limited ways the data can be further mapped to geographical areas. However, going forward we plan to publish the data relating to small number of England Integrated Boards (ICBs) where the numbers allow.

7.4 Age breakdowns

The following section illustrates how the results compare across the different age groups.

Due to some small numbers in this section, we are reporting on a reduced number of the key questions.

We have charted the top and bottom three scoring conditions for the following questions:

COVID-19

Q3a Experienced delays with a routine appointment with your neurologist

Q6 Change in mental health needs due to COVID-19

Overall impact

Q8 Impact on day to day activities

Q9 Impact on quality of life

Before diagnosis

Q11a Time between symptoms and diagnosis

Q11b Time between first GP and seeing a hospital based paediatrician

Q11c Time between first seeing a paediatrician to seeing a neurologist

Diagnosis

Q15 Were you given written information?

Treatment and care

Q18 Access to a specialist nurse

Q21 Involvement in choices about healthcare

Q25b Information about condition is effectively shared

Support for condition

Q26 Have been offered a care plan

Mental wellbeing

Q29 Have they been asked about their mental wellbeing by HCP in last 3 years

Education and Welfare

Q40 School has made useful changes to help them attend

Q41 Attendance at school has been affected due to neurological condition

Number of responses to the paediatric questionnaire by age group

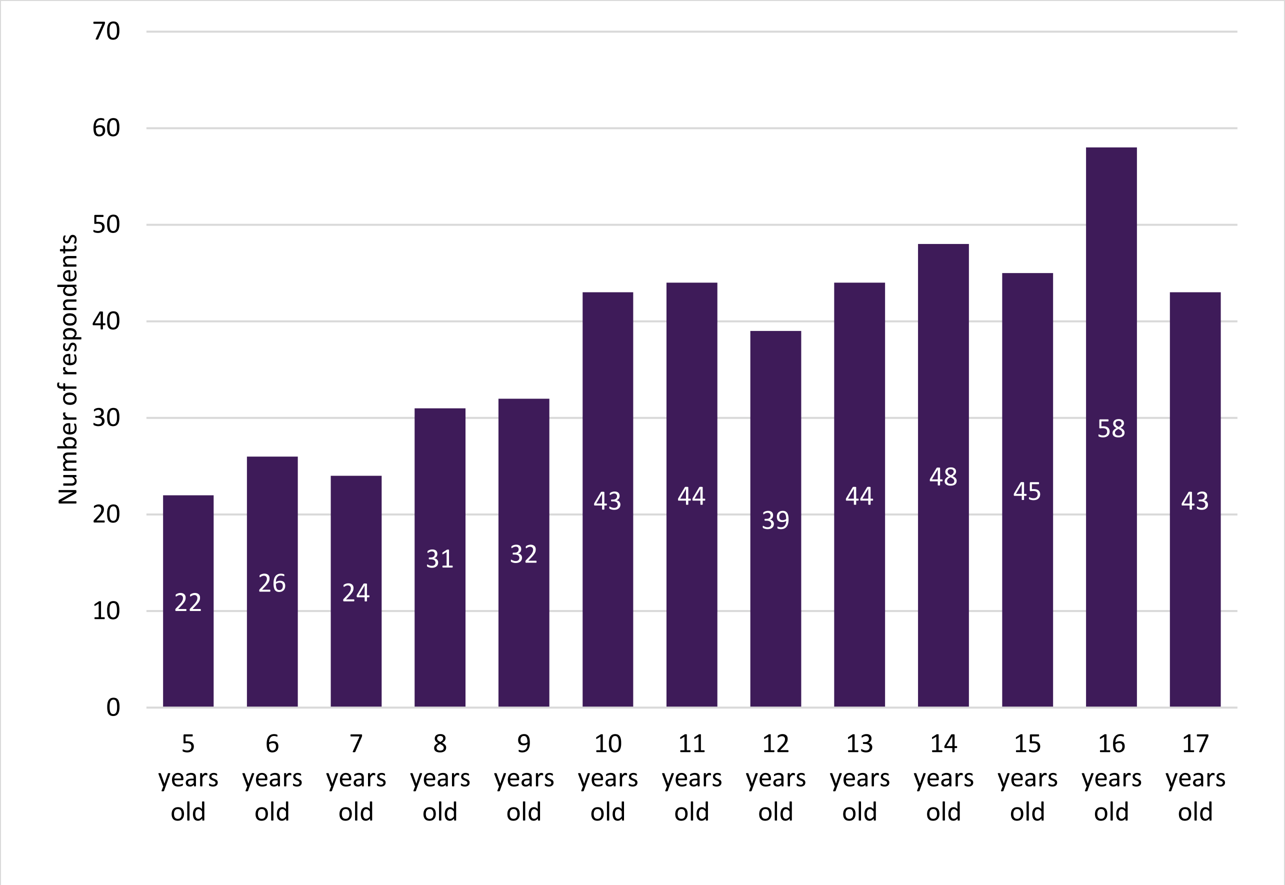
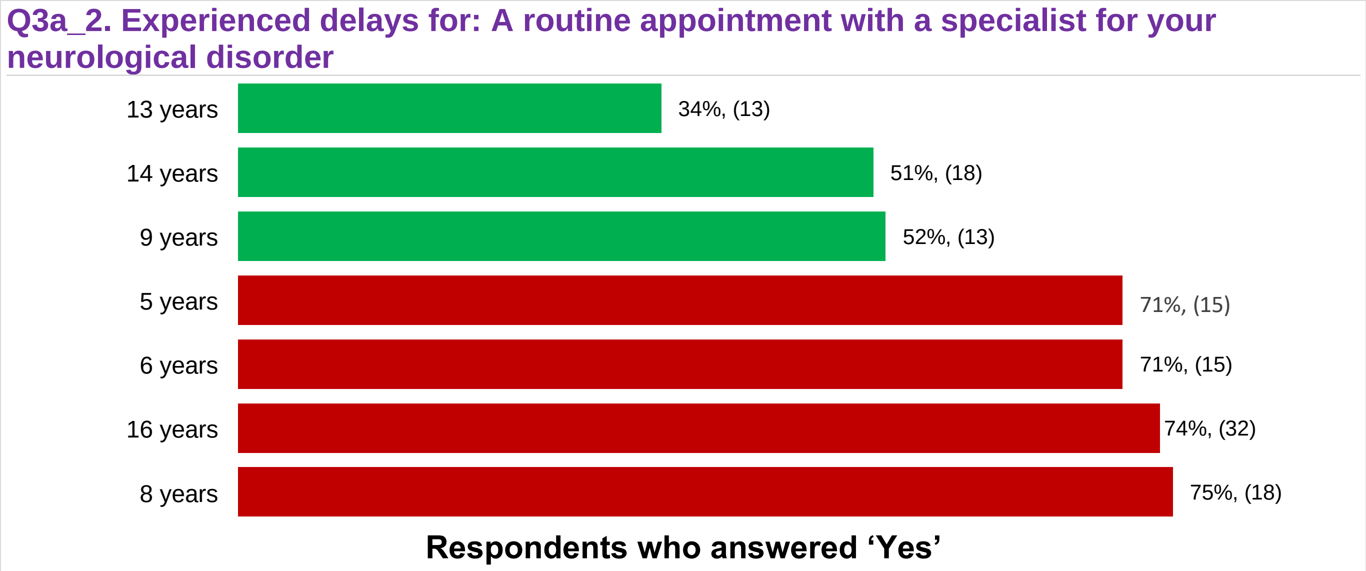


Fig 246. Age distribution – paediatric respondents

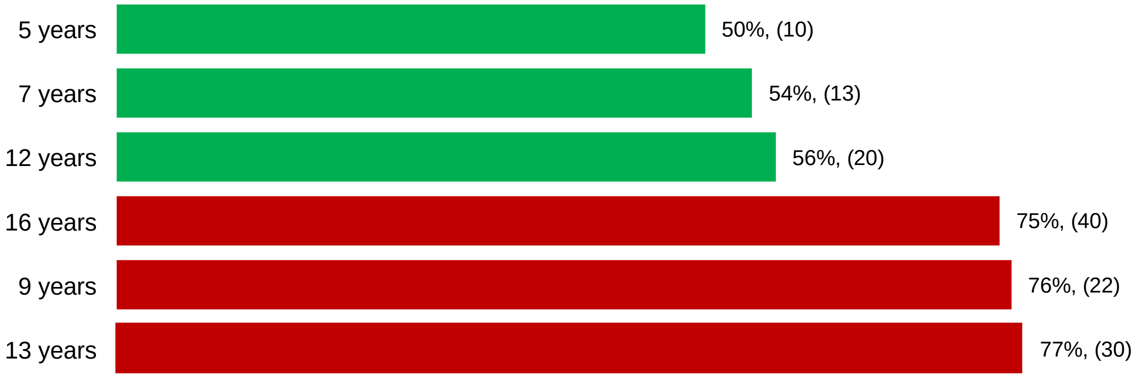
COVID-19



Based on responses for: 13 years – 38, 14 years – 35, 9 years – 25, 5 years – 21, 6 years - 21, 16 years – 43, 8 years – 24

Fig 247. Delays for a routine appointment with your specialist – paediatric respondents by age

Q6 Have you experienced a change in your mental health or behaviour during the pandemic?



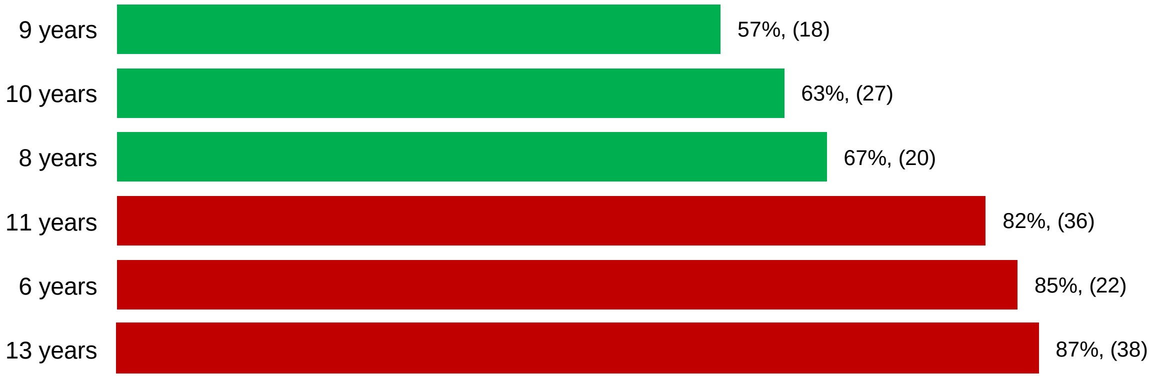
Respondents who answered ‘Yes, my mental health has worsened’

Based on responses for: 5 years – 20, 7 years – 24, 12 years – 36, 16 years – 53, 9 years - 29, 13 years – 39

Fig 248. Change to mental health needs due to Covid-19 – paediatric respondents by age

Overall impact

Q8. To what extent overall does your neurological condition(s) impact your day to day activities?

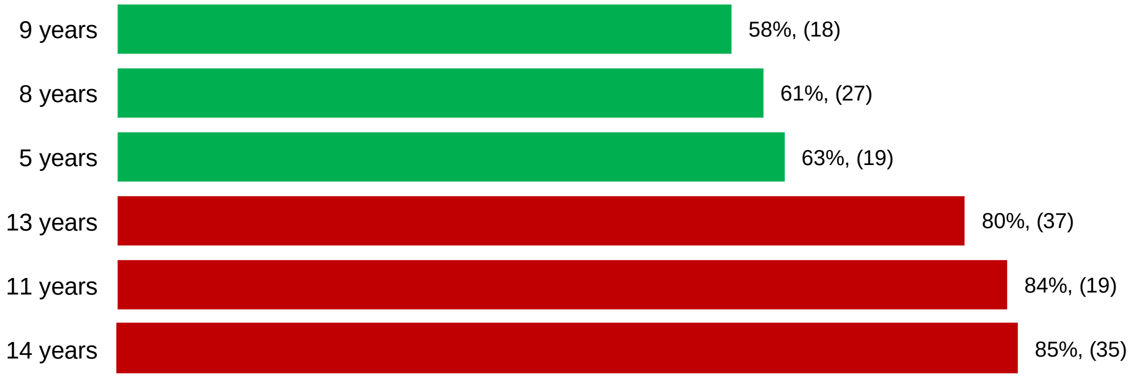


Respondents who answered ‘To a great extent/To a moderate extent’

Based on responses for: 9 years – 32, 10 years – 43, 8 years – 30, 11 years – 44, 6 years - 26, 13 years – 44

Fig 249. Change to mental health needs due to Covid-19 – paediatric respondents by age

Q9. To what extent overall does your neurological condition(s) impact your quality of life?



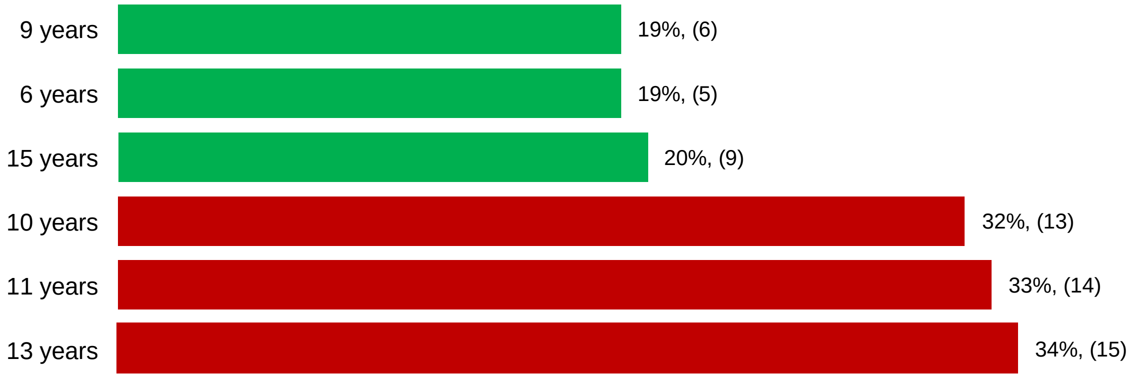
Respondents who answered 'Yes, my mental health has worsened'

Based on responses for: 5 years – 20, 7 years – 24, 12 years – 36, 16 years – 53, 9 years - 29, 13 years – 39

Fig 250. Impact of neurological conditions on quality of life – paediatric respondents by age

Before diagnosis

Q11a How long were you waiting between: First experiencing symptoms to getting a diagnosis?

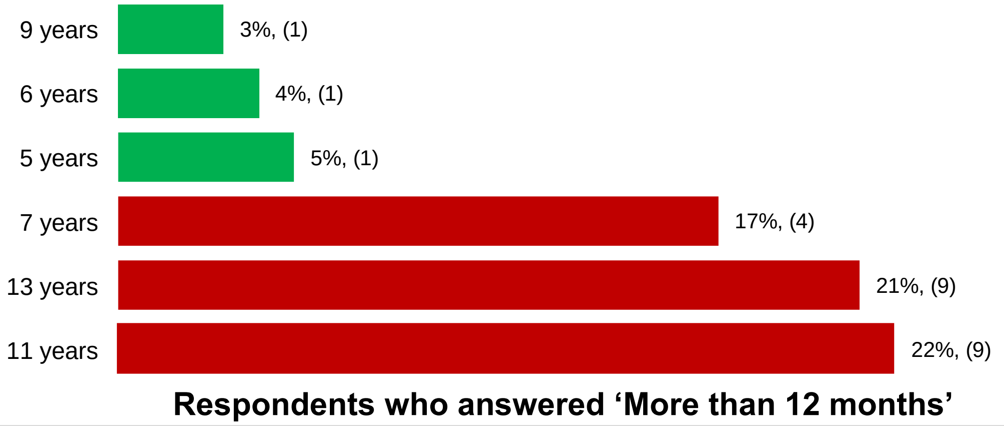


Respondents who answered 'More than 12 months'

Based on responses for: 9 years – 32, 6 years – 25, 15 years – 45, 10 years – 41, 11 years - 42, 13 years – 44

Fig 251. Waiting for a diagnosis – paediatric respondents by age

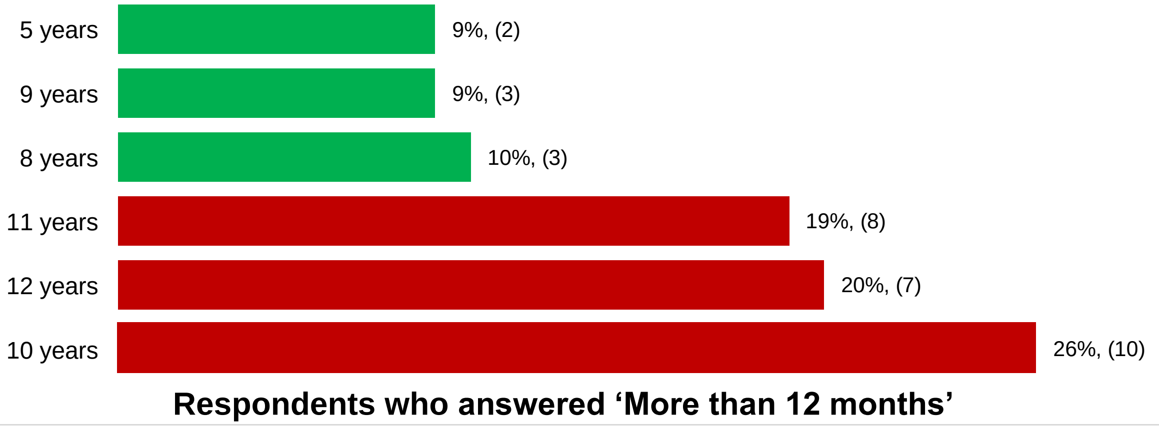
Q11b How long were you waiting between: First seeing a GP (or having an emergency admission) to seeing a hospital based paediatrician?



Based on responses for: 9 years – 32, 6 years – 26, 5 years – 22, 7 years – 23, 13 years - 42, 11 years – 41

Fig 252. First seeing a hospital based paediatrician – paediatric respondents by age

Q11c How long were you waiting between: First seeing a paediatrician to seeing a neurologist?

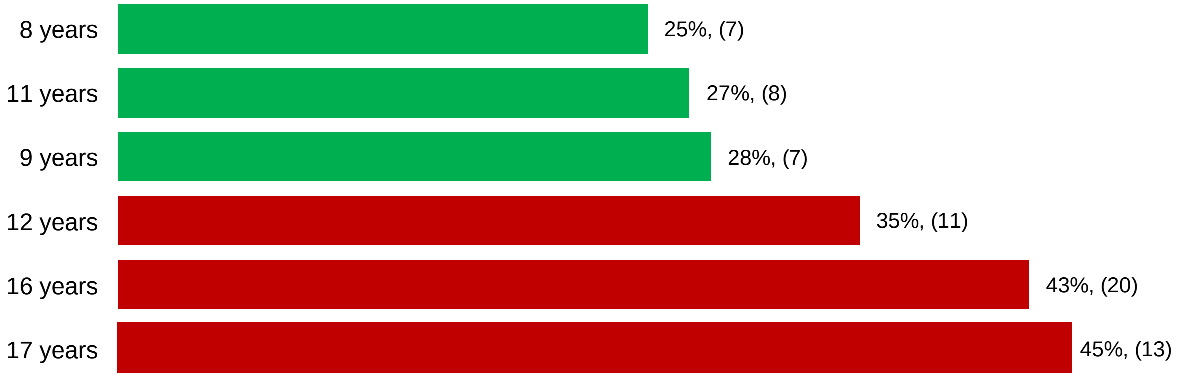


Based on responses for: 5 years – 22, 9 years – 32, 8 years – 30, 11 years – 42, 12 years - 35, 10 years – 39

Fig 253. First seeing a neurologist – paediatric respondents by age

Diagnosis

Q15 When you were told you had a neurological condition, were you given written information about it?



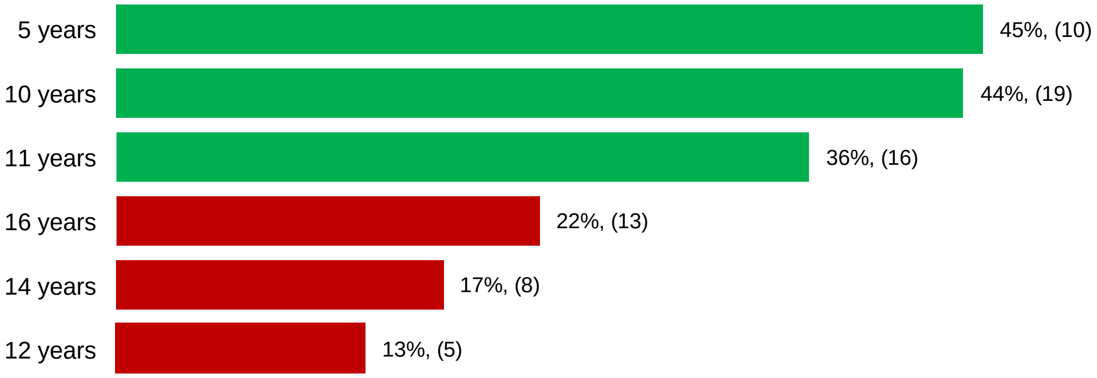
Respondents who answered ‘I was not offered or directed to any information’

Based on responses for: 8 years – 28, 11 years – 30, 9 years – 25, 12 years – 31, 16 years - 47, 17 years – 29

Fig 254. Written information – paediatric respondents by age

Treatment and care

Q18 Have you had an appointment with a specialist nurse for your neurological condition(s)?

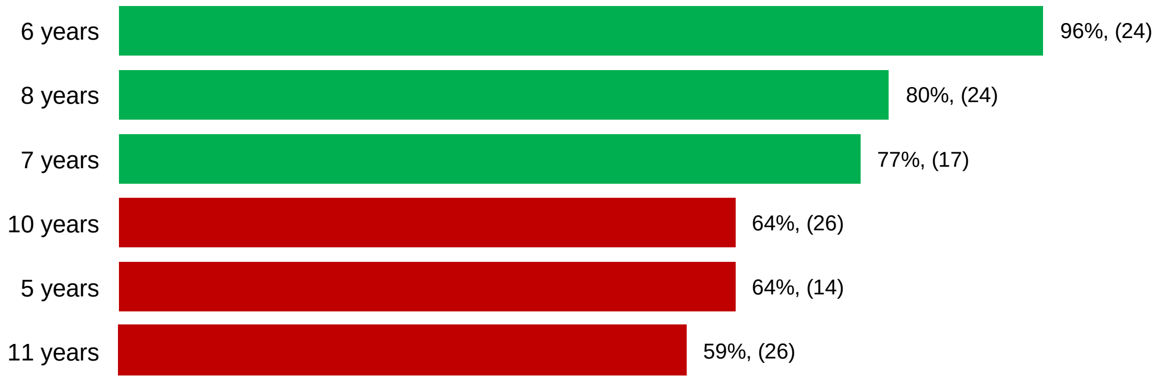


Respondents who answered ‘Yes, within the last 12 months’

Based on responses for: 5 years – 22, 10 years – 43, 11 years – 44, 16 years – 58, 14 years - 48, 12 years – 39

Fig 255. Access to Specialist Nurses – paediatric respondents by age

Q21 Do you feel fully involved in making choices about your health care?

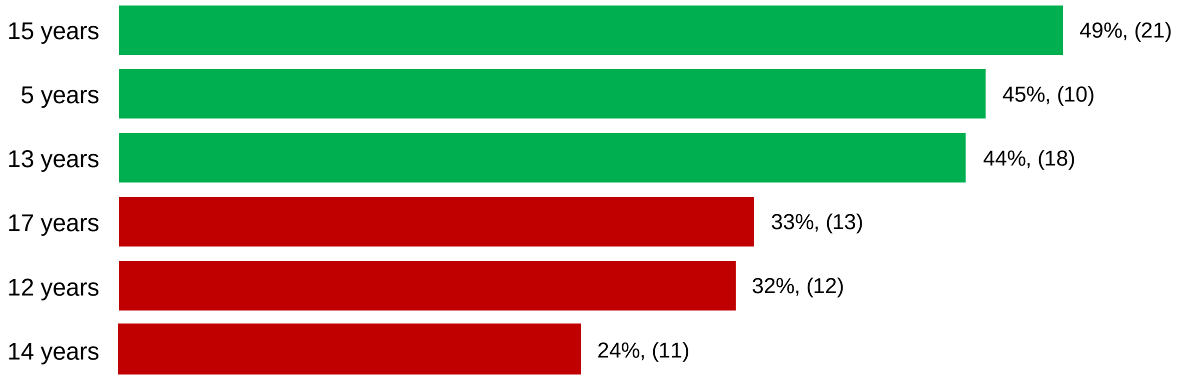


Respondents who answered ‘Yes, definitely/Yes to some extent’

Based on responses for: 6 years – 25, 8 years – 30, 7 years – 22, 10 years – 42, 5 years - 22, 11 years – 44

Fig 256. Involvement in health care – paediatric respondents by age

Q25b Information about my condition is effectively passed between the people that care for me (such as my specialists, GP, family carer)



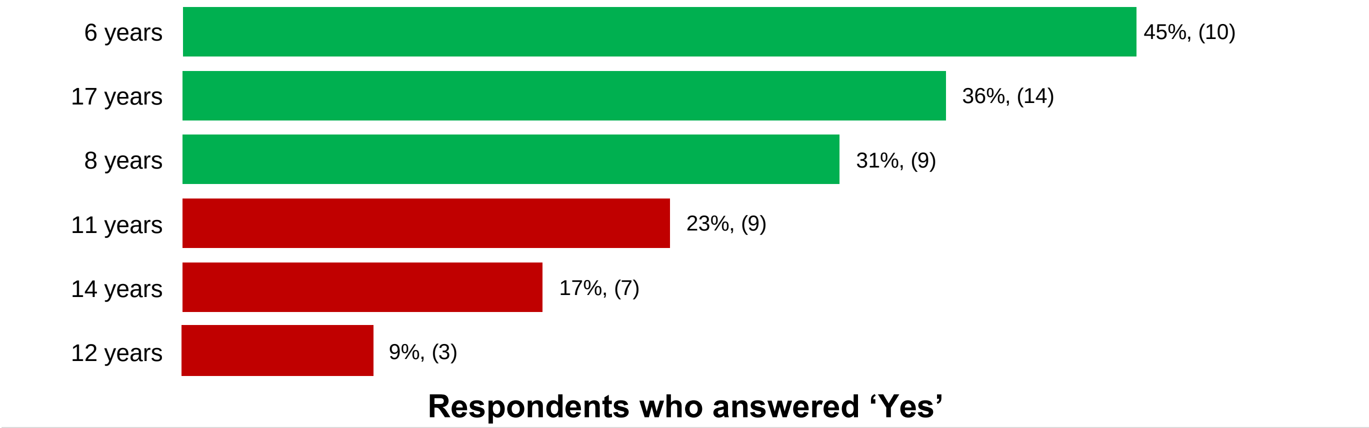
Respondents who answered ‘Agree’

Based on responses for: 6 years – 26, 8 years – 30, 7 years – 23, 10 years – 42, 5 years - 22, 11 years – 43

Fig 257. Communication – paediatric respondents by age

Support for condition

Q26 Within the last three years have you been offered a care and support plan to help you manage your neurological condition?

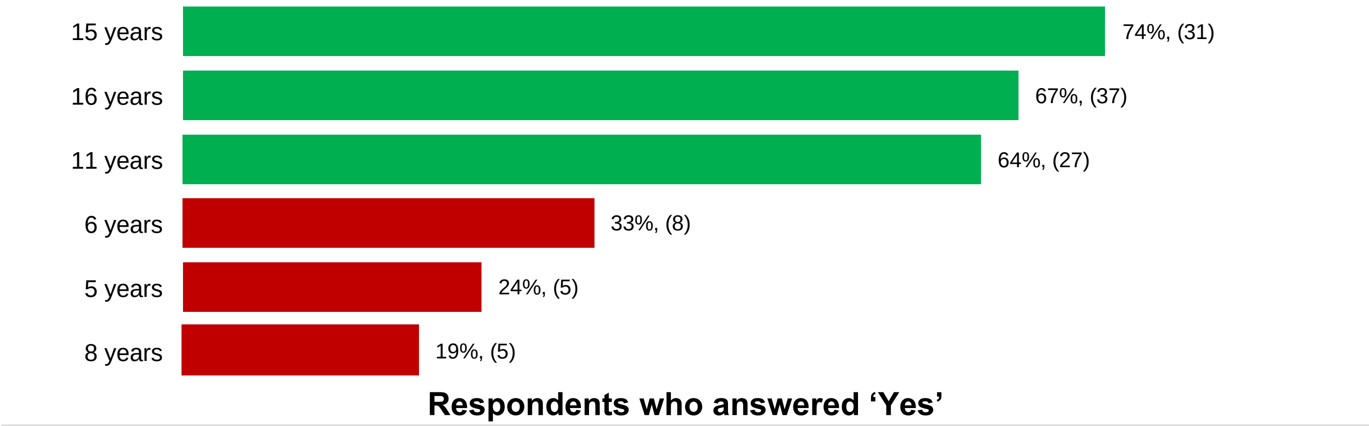


Based on responses for: 6 years – 22, 17 years – 39, 8 years – 29, 11 years – 40, 14 years - 41, 12 years – 35

Fig 258. Offered a care plan – paediatric respondents by age

Mental wellbeing

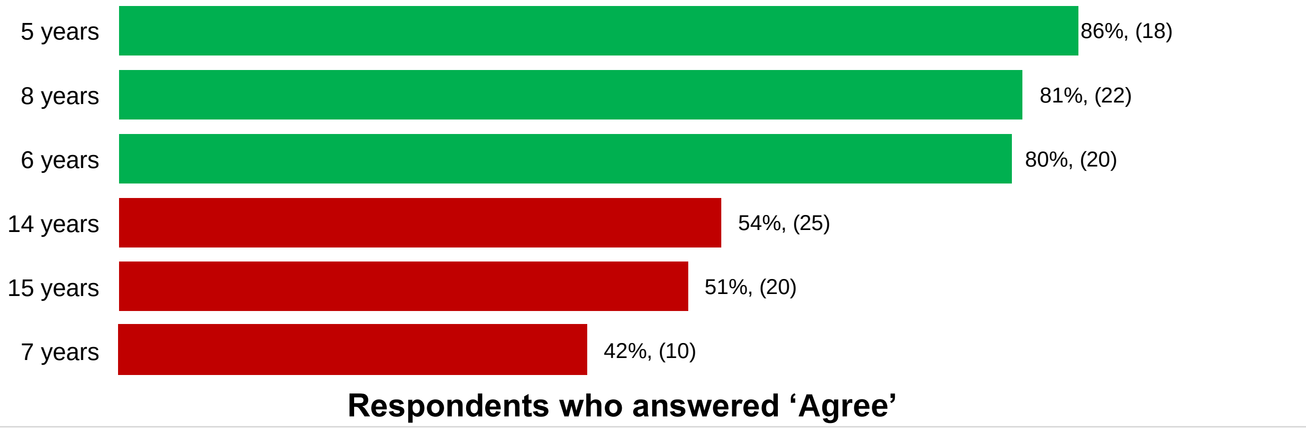
Q29 Have you been asked about your mental wellbeing by a health or social care professional within the last three years?



Based on responses for: 15 years – 42, 16 years – 55, 11 years – 42, 6 years – 24, 5 years - 21, 8 years – 26

Fig 259. Mental wellbeing and healthcare professionals – paediatric respondents by age

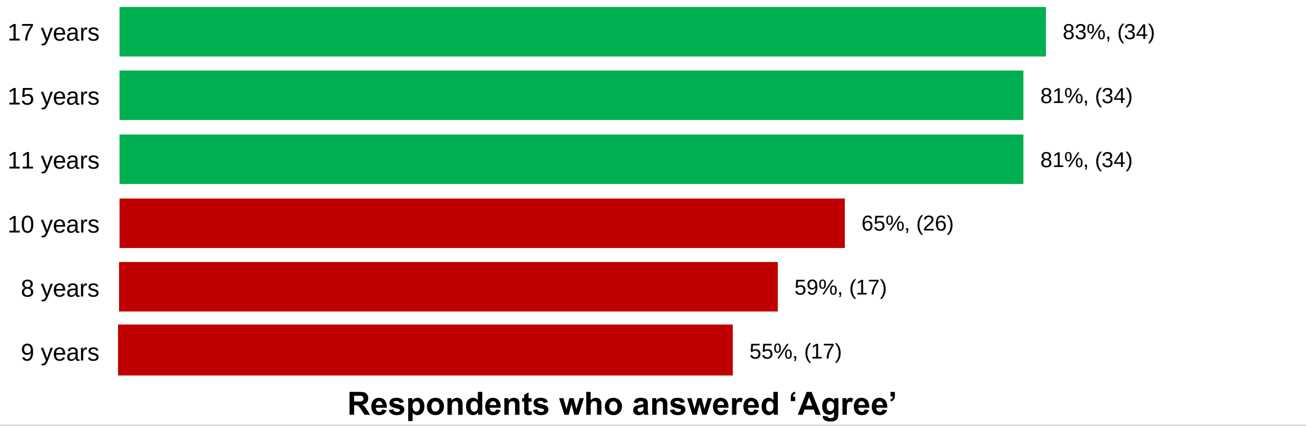
Q40a My school has made useful changes to help me to attend



Based on responses for: 5 years – 21, 8 years – 27, 6 years – 25, 14 years – 46, 15 years - 39, 7 years – 24

Fig 250. School adaptations – paediatric respondents by age

Q40b My attendance at school has been affected due to my neurological condition



Based on responses for: 17 years – 41, 15 years – 42, 11 years – 42, 10 years – 40, 8 years - 29, 9 years – 31

Fig 261. School attendance – paediatric respondents by age

7.5 Gender breakdowns

7.5.1 Comparisons between male and female respondents

Slightly more respondents to the paediatric survey were female, 309 compared to 393. There were very few significant differences between male and female children/young people.

A two-tailed t-test on proportions for significant differences has been carried out on the key questions. Where differences are reported, there is a significant difference level of at least 95%.

COVID-19

Male respondents were **less likely** to experience delays with a first neurologist appointment - 65% v 52%

Overall impact

Female respondents were more likely to say that their neurological condition causes them pain to a great/moderate extent - 58% v 36%

Before diagnosis

There were no significant differences with the key questions in this section.

Diagnosis

There were no significant differences with the key questions in this section.

Treatment and care

There were no significant differences with the key questions in this section.

Support for condition

There were no significant differences with the key questions in this section.

Mental wellbeing

Female respondents were more likely to say they had been referred or directed to support for mental wellbeing by HCP in last 3 years - 44% vs 32%

Social care

There were no significant differences with the key questions in this section.

Education and Welfare

Male respondents were more likely to say that they **have** been assessed for an education, health and care plan - 56% vs 45%

Female respondents were more likely to agree that their attendance at school has been affected due to their neurological condition - 75% vs 66%

8. Further cross-tabulation of the data

The most needed crosstabs have been presented in this report. However, there are many ways in which the data can be cut and analysed. This is especially true as there was a high response rate, and so multiple crosstabs could be used where more than one variable is selected. The data for the entire survey will be available on Quality Health/IQVIA’s online analysis tool, SOLAR, to allow for further interrogation of the data. The Neurological Alliance, and a select number of partner organisations working within neurology, will have access to this tool and be able to cut the data in any number of ways.

9. Comments and analysis

This section of the report presents an overview of the free text comments received from people who completed the survey.

Respondents were invited to make comments at two points within the questionnaire:

Q5 (adult only). If you would like to tell us more about access to remote appointments especially due to Covid-19, please use this box.

Q7 (paediatric only). If you would like to tell us more about access to appointments by phone or video conference, please use this box.

Q43. If you have any other comments about your neurological condition, your care and treatment, or this survey, please use the box below.

For Q5 and Q7, every comment has been typed up and “sanitised” (removing any patient identifiable data and removing any staff names or details).

Q43 contained the following disclaimer: Please note that the comments you provide will be looked at in full by the Neurological Alliance and researchers analysing the data. We will remove any information that could identify you before publishing any of your feedback.

This report presents a thematic analysis of a randomised sample of these comments.

While this report only illustrates a top level of the comments, The Neurological Alliance has been given a file containing both the sanitised (Q5) and verbatim comments (Q43) in order to allow more in-depth analysis.

9.1 Approach to analysis

Comments were read in full by an analyst and an appropriate code applied to each one. Quality Health has categorised the comments in two ways:

By the sentiment of the comment, i.e., whether it is positive, negative, mixed or neutral.

By the theme which it addresses.

Many of the comments were coded more than once. For example, if an individual talked about their diagnosis, ongoing treatment and employment these were coded separately.

9.2 Thematic analysis

9.2.1 Adult comments – Question 5

There were 2,463 comments received in total. Due to the high number received, a thematic analysis has been carried out on a random selection of 100 comments. As people sometimes addressed more than one aspect of their care, of the 100 individual free text comments analysed, 179 ‘sub comments’ were identified.

The comments were themed and analysed by whether they were positive or negative, mixed or neutral / suggestion.

Themes	**Positive**	**Negative**	**Mixed**	**Neutral/ Suggestion**	**Totals**
Remote appointments	23	29	23	1	**76**
Access appointments to Specialist(s)	-	11	6	1	**18**
Diagnosis	2	8	6	-	**16**
Face to face appointments	3	-	10	-	**13**
Access appointments to GP(s)	1	5	4	2	**12**
Not travelling to appointments	7	-	4	-	**11**
Delays and cancelled appointments	1	6	2	-	**9**
Treatment and Care	-	-	3	5	**8**
Mental Wellbeing	1	1	-	-	**2**
Other	-	9	4	1	**14**
Total %	**21%**	**40%**	**36%**	**3%**	

Fig 262. Q5 Theme and sentiment of comments table – adult respondents

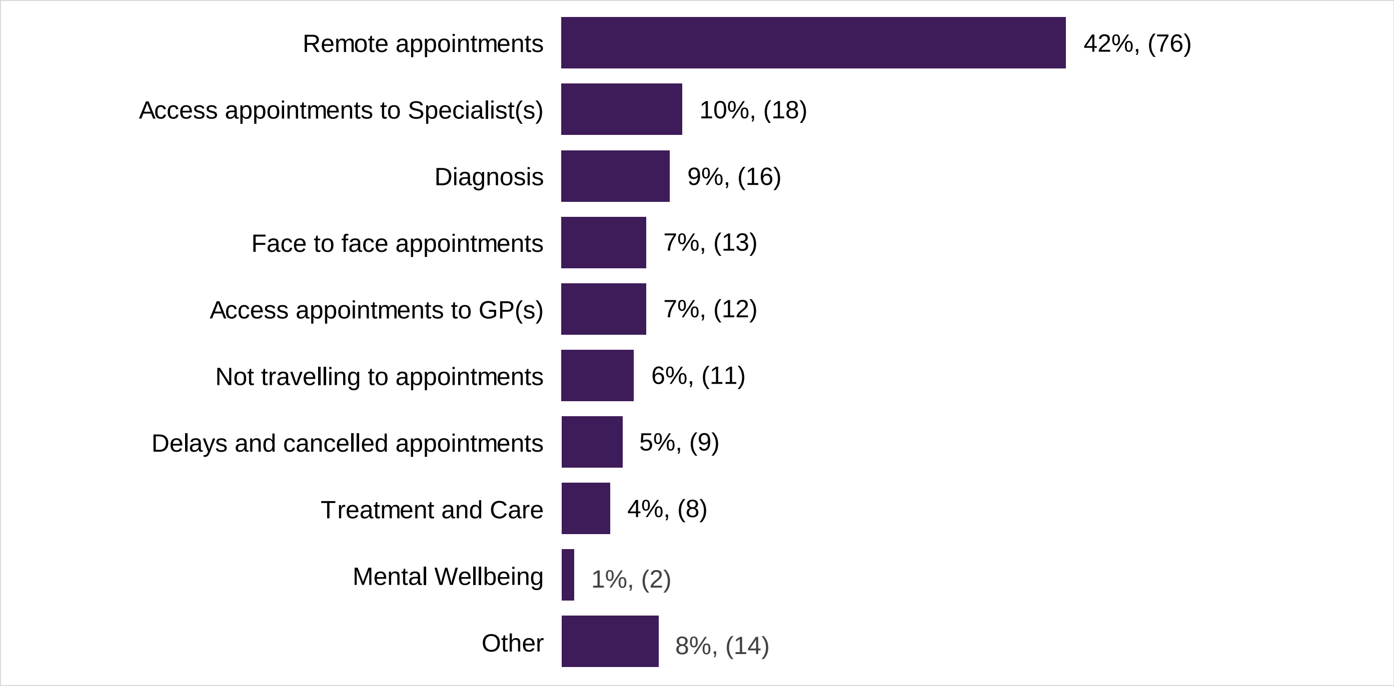


Fig 263. Q5 Theme of comments table – adult respondents

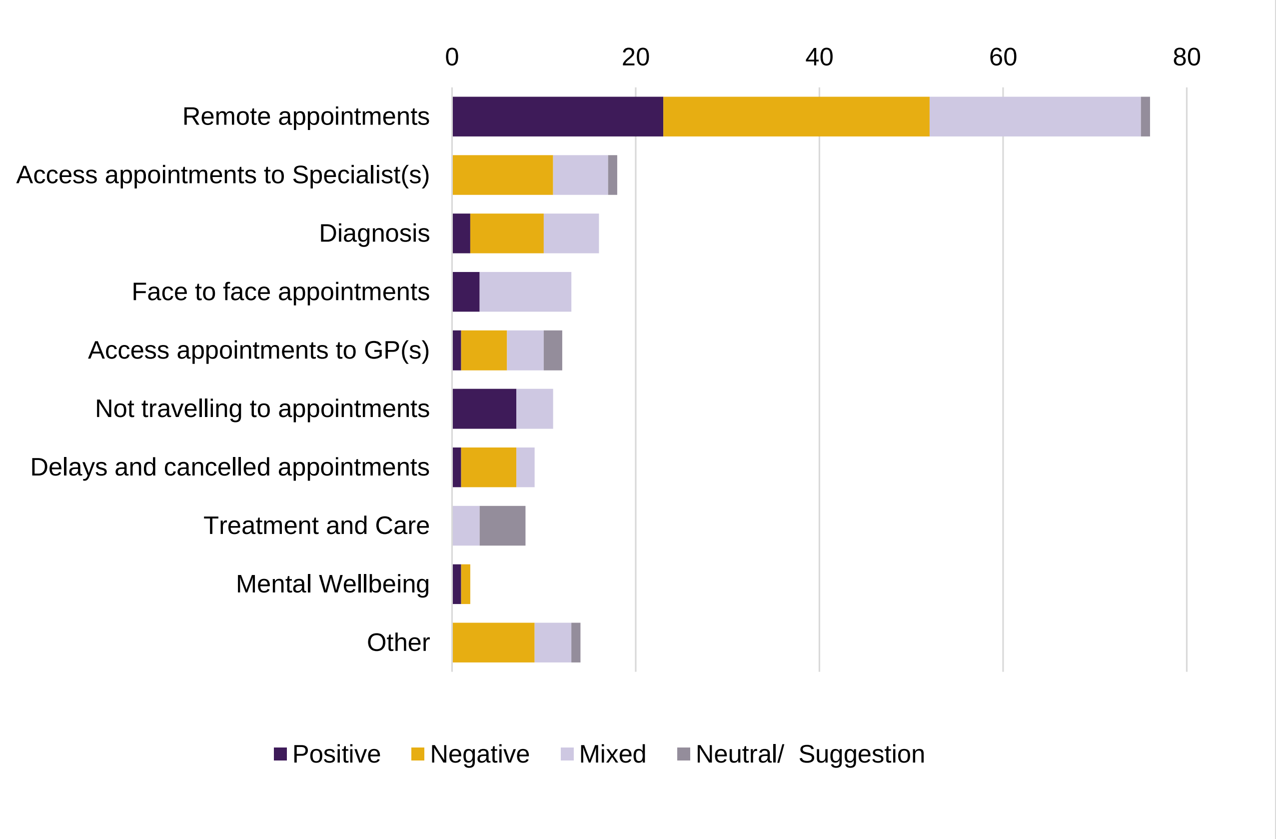


Fig 264. Q5 Sentiment of comments table – adult respondents

Summary

Adult respondents seemed to have more positive comments about remote appointments compared to people responding to the paediatric survey. A number of people liked them as they didn't have to leave the house, they were less tiring and easy to attend. There was mention that some did not like being 'forced to attend face to face'. There seemed to be more openness to a combination approach of some appointments being remote and some in person.

There was criticism that remote appointments were not suitable for where physical examinations were needed or physiotherapy needed to take place. There was also mention that when talking about mental health that people didn't want this to be carried out remotely.

Some people also felt that remote appointments felt 'hurried', time limited and 'impersonal'.

9.2.2 Adult comments – Question 43

There were 3,278 comments received in total. Due to the high number received, a thematic analysis has been carried out on a random selection of 500 comments. Due to people addressing more than one aspect of their care, of the 500 individual free text comments analysed, 924 'sub comments' were identified.

The comments were themed and analysed by whether they were positive or negative, mixed or neutral / suggestion.

Themes	Positive	Negative	Mixed	Neutral/ Suggestion	Totals
Treatment and care	51	362	40	3	**456**
Support for your condition(s)	5	70	5	1	**81**
Before diagnosis of your neurological condition(s)	1	60	6	1	**68**
Your care during Covid -19	2	48	3	1	**54**
Social Care	-	33	1	1	**35**
Mental Wellbeing	-	30	2	-	**32**
Information about your neurological condition	-	21	4	-	**25**
Employment and Welfare	-	22	-	2	**24**
Finding out about your neurological condition(s)	-	9	-	-	**9**
Other	1	100	10	29	**140**
Total %	**6%**	**82%**	**8%**	**4%**	

Fig 265. Q43 Theme and sentiment of comments table – adult respondents

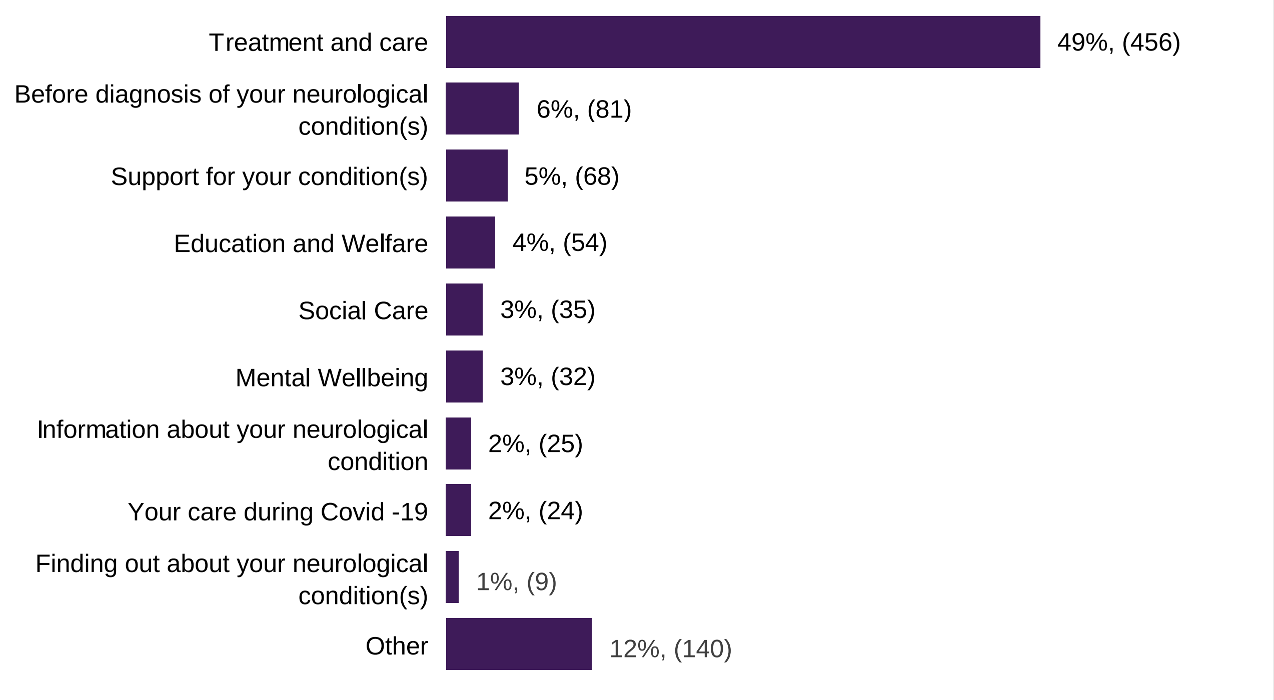


Fig 266. Q43 Theme of comments chart – adult respondents

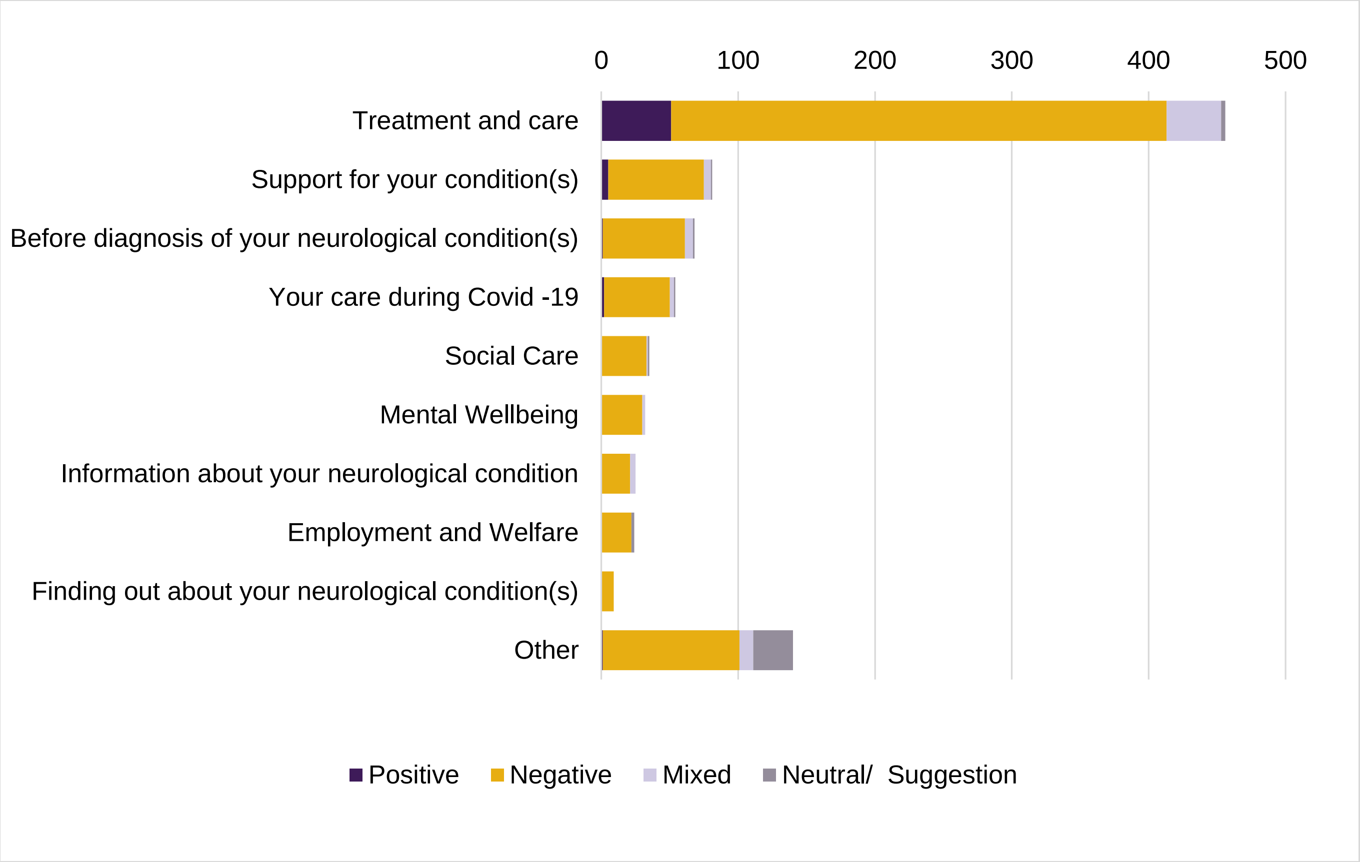


Fig 267. Q43 Sentiment of themes chart – adult respondents

Summary

Many people used this opportunity to tell their specific (and detailed) stories of their own experiences of care.

These descriptions often included an explanation of medications they were taking, including their opinions of these, their response to them and the side effects experienced.

A reoccurring theme amongst the comments was people receiving a diagnosis and then feeling ‘nothing was done’, that there was ‘no further care’ or that they should ‘just get on with their life’.

There were multiple uses of the words ‘abandoned’, ‘ignored’ and ‘unsupported’ alongside criticism of the lack of information and guidance provided.

There were a number of people who mentioned wanting physiotherapy or a Blue Badge but having difficulties obtaining them.

Analysing these comments it is perhaps not surprising that there were a noticeable amount that spoke about the need to pay and ‘go private’ to get an accurate diagnosis or to be seen by a neurologist for the correct treatment and care.

9.2.3 Paediatric comments – Question 7

There were 161 comments received in total and analysis has been carried out on 100 of these. As people sometimes addressed more than one aspect of their care, of the 100 individual free text comments analysed, 159 ‘sub comments’ were identified.

The comments were themed and analysed by whether they were positive or negative, mixed or neutral / suggestion.

Themes	Positive	Negative	Mixed	Neutral/ Suggestion	Totals
Remote appointments	12	33	6	7	**58**
Access appointments to Specialist(s)	2	16	2	-	**20**
Face to face appointments	7	3	3	5	**18**
Mental Wellbeing	-	15	-	-	**15**
Diagnosis	-	7	1	-	**8**
Treatment and Care	4	3	1	-	**8**
Access appointments to GP(s)	2	2	-	-	**4**
Delays and cancelled appointments	2	2	-	-	**4**
Self-funding treatments	-	3	-	-	**3**
Other	-	17	3	1	**21**
Total %	**18%**	**64%**	**10%**	**8%**	

Fig 268. Q43 Theme and sentiment of comments table – paediatric respondents

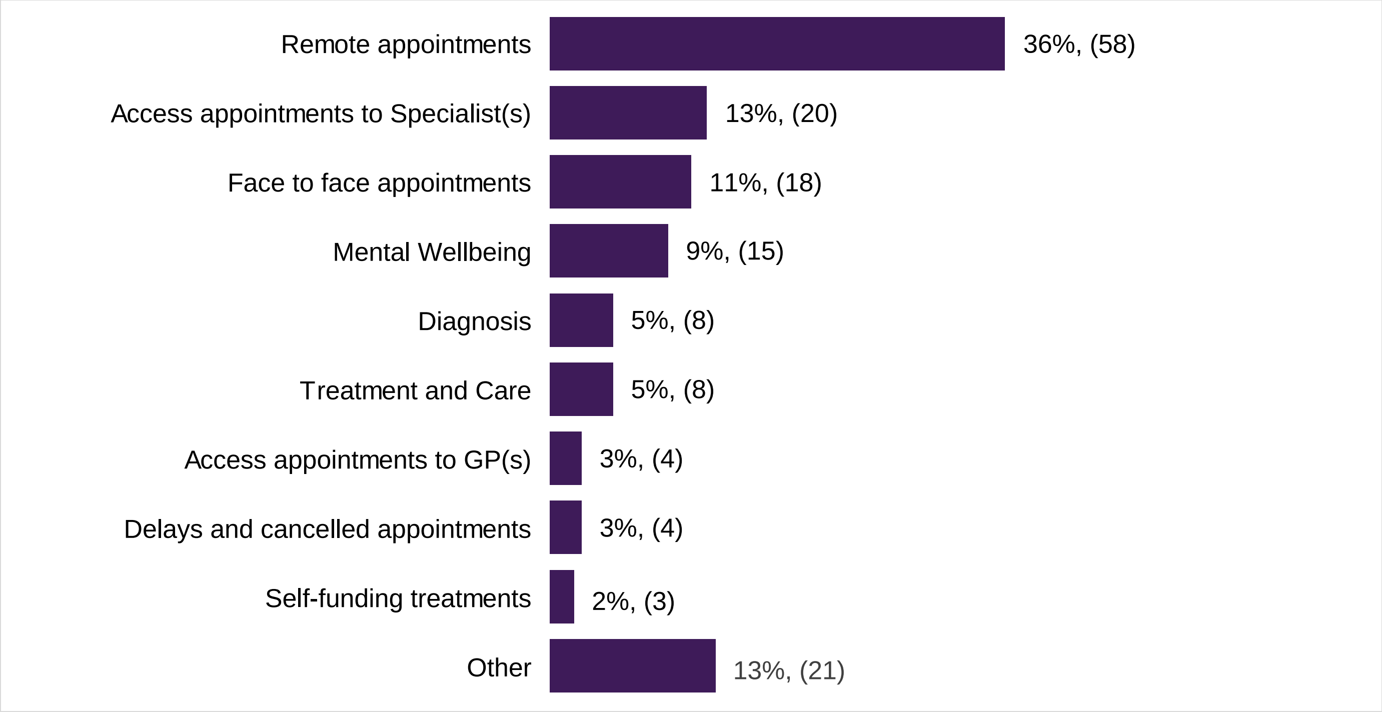


Fig 269. Q7 Theme of comments chart – paediatric respondents

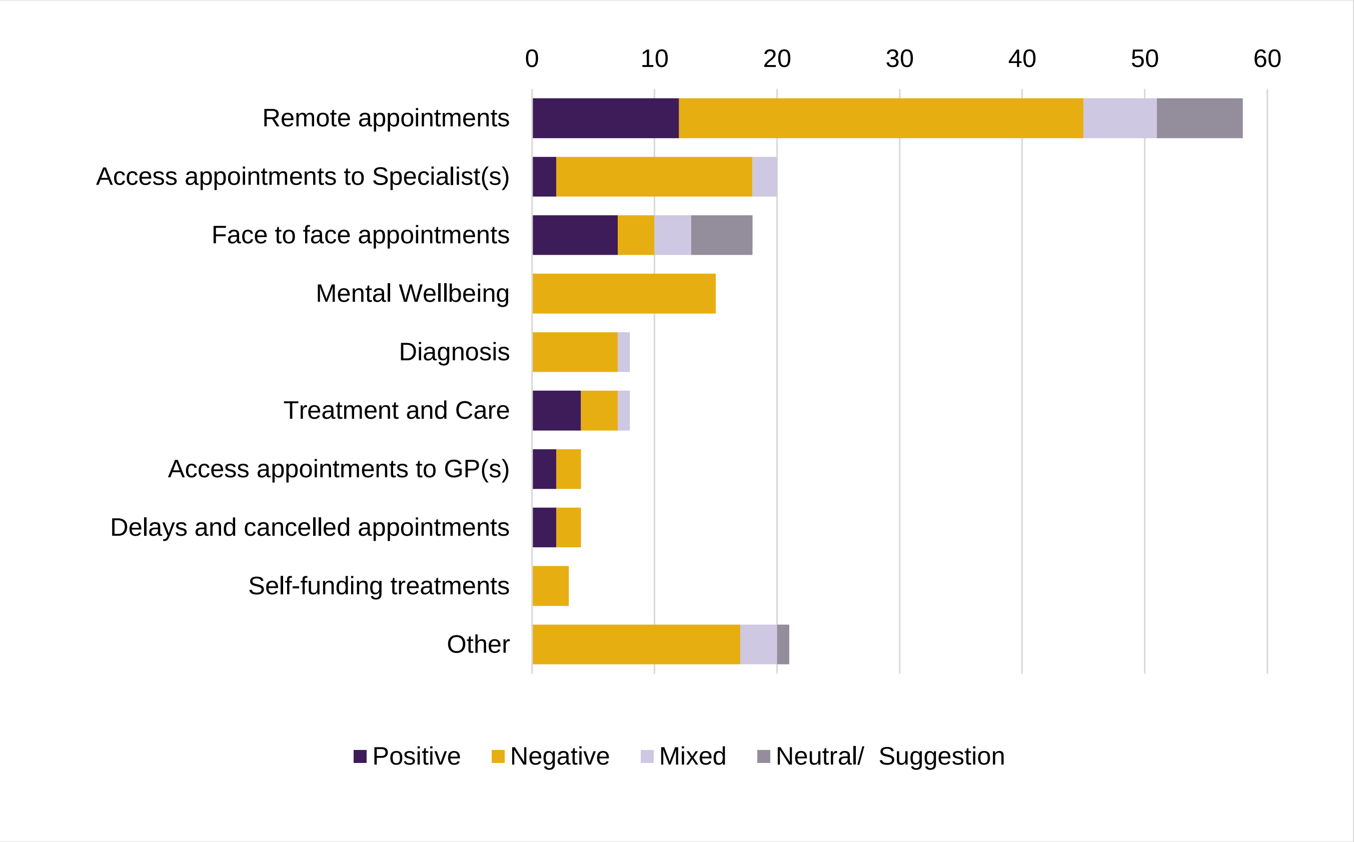


Fig 270. Q7 Sentiment of themes chart – paediatric respondents

Summary

While some people preferred remote appointments and found them ‘reliable’ and less ‘hassle’, many people reported difficulties with them.

Some parents said their child was uncomfortable, or anxious on video calls and struggled to talk, while others said there were difficulties to ‘keep the attention span’ or they had to set up a space to make the child feel comfortable.

There were people who had issues setting up the technology such as webcams, or were not confident using it. There was also the mention that not everyone could afford the equipment to have a video call.

It was mentioned that remote appointments were not as connected or effective as an in-person appointments, and they had concerns that things would be missed as a physical examination was needed.

9.2.4 Paediatric comments – Question 43

There were 228 comments received in total. Due to people addressing more than one aspect of their care, of the 228 individual free text comments analysed, 430 ‘sub comments’ were identified.

The comments were themed and analysed by whether they were positive or negative, mixed or neutral / suggestion.

Themes	**Positive**	**Negative**	**Mixed**	**Neutral/ Suggestion**	**Totals**
Treatment and care	11	171	20	-	**202**
Before diagnosis of your neurological condition(s)	2	43	2	-	**47**
Support for your condition(s)	1	41	2	-	**44**
Education and Welfare	-	38	4	2	**44**
Social Care	-	20	2	1	**23**
Mental Wellbeing	-	12	-	-	**12**
Information about your neurological condition	-	6	-	1	**7**
Your care during Covid -19	1	4	1	-	**6**
Finding out about your neurological condition(s)	-	2	-	-	**2**
Other	-	32	-	11	**43**
TOTALS	**4%**	**86%**	**7%**	**3%**	

Fig 271. Q43 Theme and sentiment of comments table – paediatric respondents

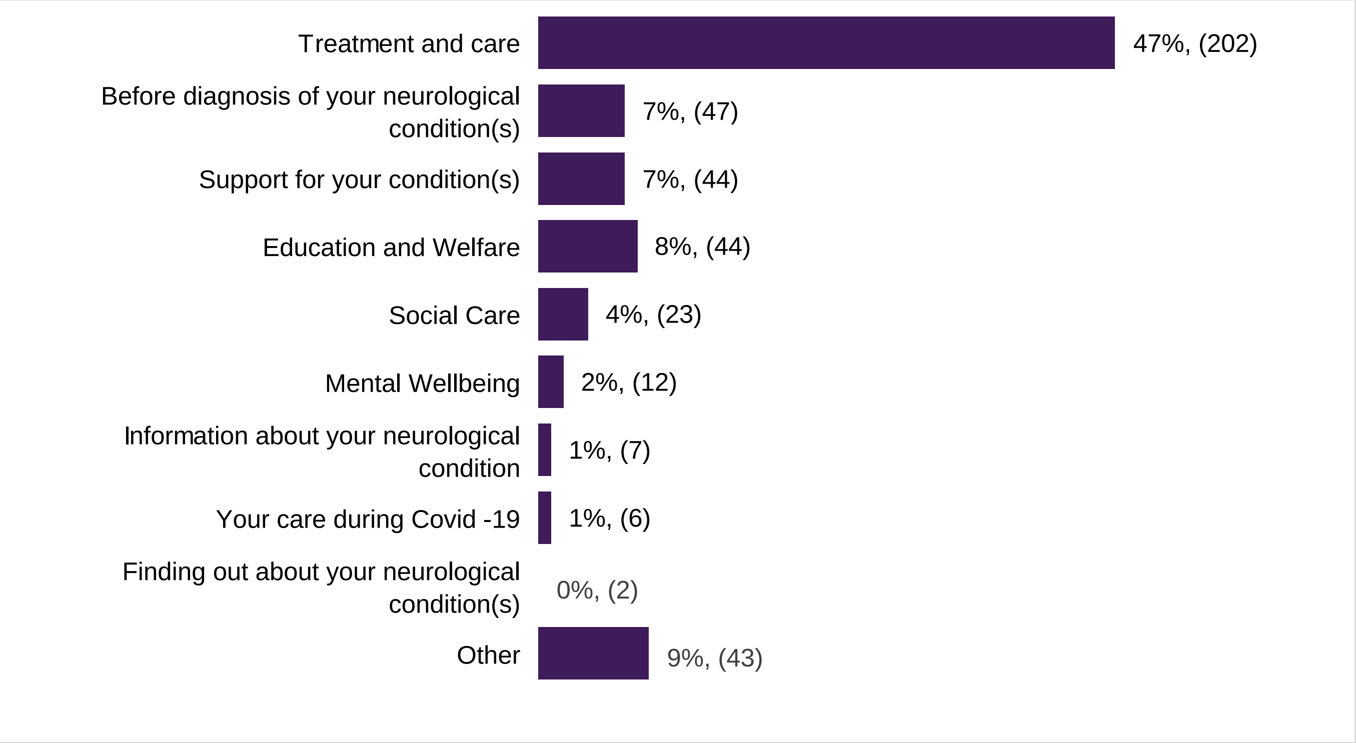


Fig 272. Q43 Theme of comments chart – paediatric respondents

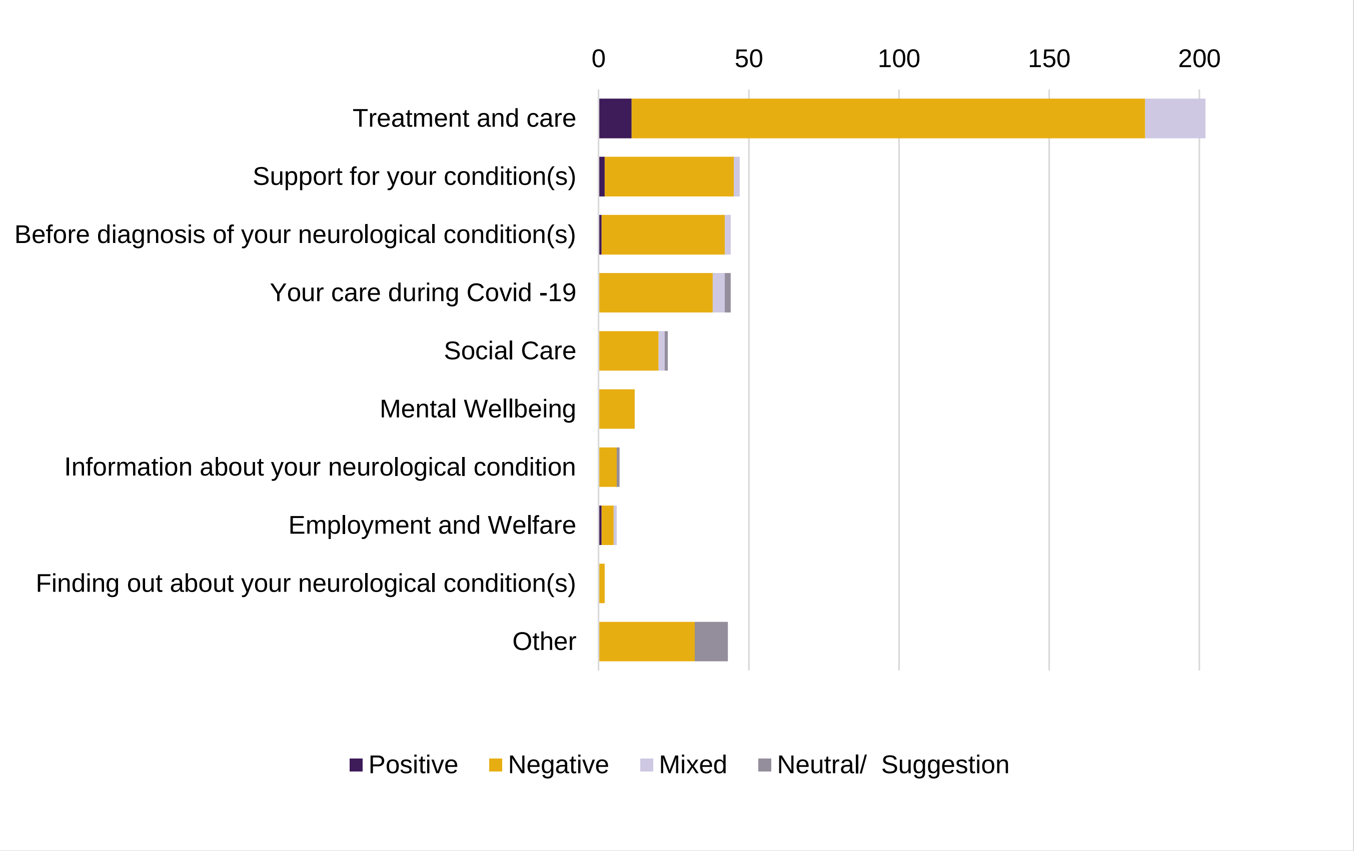


Fig 268. Q43 Sentiment of themes chart – paediatric respondents

Summary

As with the adult comments, the majority within the paediatric questionnaire were negative. Where there were positive comments these were often still mixed in with some negative care. Interestingly some positive responses seemed to acknowledge that they were ‘fortunate’ or ‘lucky’.

Criticism of CAMHS (Child and Adolescent Mental Health Services) was prevalent in many comments, with reference to long waiting lists, ‘nothing happening’ or even being it being ‘unfit for purpose’.

Many people expressed frustration with the healthcare systems relating to diagnosis and subsequent care; feeling that they are ‘going round in circles’ or being ‘bounced around services’. Respondents felt there was a lack of joined up services and often the parent was the one driving communication or ‘pushing’ for care. Furthermore, there was a shared sentiment that parents felt isolated and left to their own devices to care for their children.

School/ college were also frequently mentioned; relating to not being able to attend or being pressured to maintain attendance with difficult circumstances; not being equipped for people with a neurological condition, or feeling that staff needed to have appropriate training.

Similarly, to the adult comments there were several mentions of people seeking help from private healthcare either for a diagnosis or for treatment and care.

10. Conclusions and recommendations

Conclusions and recommendations are presented in a separate policy report authored by The Neurological Alliance at https://www.neural.org.uk/togetherforthe1in6/, alongside the individual policy reports for England, Scotland, Wales and Northern Ireland and data frequency tables.

11. Next steps

As in previous years, this project has been an invaluable piece of research and it is hoped that the data, its analysis and our interpretation of it will add to data and intelligence about neurological services in the whole of the UK, providing the voice and views of people who live with these conditions every day.

Moreover, it is hoped the recommendations identified in the UK and nation level policy reports 'Together for the 1 in 6' authored by neurological alliances will lead to improved practices for diagnosing, treating and supporting people affected by a neurological condition, which in turn will make an impact on outcomes and improved patient experience.

The survey and its findings have also identified important priorities and actions for The Neurological Alliance itself, in relation to work directly with its members (i.e. those organisations who support people with neurological conditions) and policy makers, and indirectly with patients themselves.

The priority therefore is for The Neurological Alliance to work with its members and wider stakeholders to call on the UK Government, Scottish Government, Welsh Government and Northern Ireland Executive to prioritise services for people with neurological conditions and establish a Neuro Taskforce. The Taskforce would bring together relevant Departments, health and social care bodies, professional bodies, people affected by neurological conditions and the voluntary sector to:

- Assess the current neuroscience workforce and set out plans to ensure it is fit for the future.

- Share approaches to common problems, such as addressing longstanding barriers to accessing mental, emotional and cognitive support, driving down waiting lists for elective care, improving the quality and analysis of health and care data and supporting transition between paediatric and adult neuroscience services.

- Assess the level of investment in research into the causes, impacts and possible cures of neurological conditions and set out plans to level up investment in areas that do not receive a fair share currently.