My Neuro Survey

2024-25 technical report

Research

Introduction and background

1. Introduction

In the UK, at least 1 in 6 people live with a neurological condition. These conditions bring a wide range of physical, emotional, and cognitive challenges, often resulting in significant impacts on daily life, mental health, and financial security. For these individuals, accessing the right treatment, care, and support is essential but often challenging. Understanding their experiences is vital to improving the healthcare, social support, and policy frameworks that aim to support them.

The Neurological Alliance (England), the Neurological Alliance of Scotland, Northern Ireland Neurological Charities Alliance (niNCA) and the Wales Neurological Alliance work to ensure public policy reflects the realities of living with a neurological condition, so that everyone can access the treatment, care, and support they need. This report details the findings from the fifth iteration of My Neuro Survey, set up in 2014 by the Neurological Alliance (England) to gather data to help understand the experiences of people affected by neurological condition(s) in the UK.

My Neuro Survey 2024/25 is the second iteration of the survey that has considered the views of children and young people living with neurological conditions through a separate survey for children. In addition, this year a survey was developed for the carers of people with neurological conditions to share their experiences too.

My Neuro Survey aims to provide valuable insights into the lives of people with neurological conditions and the effectiveness of current services in 2024/25. In order to do so, the survey gathered information on a number of different topics, including diagnosis, treatment, day-to-day life, hospital care, mental health, financial support, social care access, and more. My Neuro Survey is the only survey to gather this information across such a wide range of neurological conditions, making it valuable in understanding the impact of living with different neurological disorders and indeed how well services are working to alleviate these impacts.

This year, the survey methodology was developed alongside research agency Revealing Reality with support from a steering group of The Neurological Alliance's member organisations and the Wales Neurological Alliance, Neurological Alliance of Scotland, the Northern Ireland Neurological Charities Alliance (niNCA).

In all, My Neuro Survey 2024/25 brings light to the thoughts and experiences of over 10,000 individuals with neurological conditions and their carers. Of these, 8,691 were adults with neurological conditions (including 7,834 adults self-reporting and 857 carers reporting on behalf of adults with neurological conditions), 402 were children and young people with neurological conditions (including 151 children and young people self-reporting and 251 carers reporting on behalf of children and young people with neurological conditions), and 1,249 were carers of people with neurological conditions.

This technical report has been written by Revealing Reality and describes the background and rationale for the survey, its methodology, and the findings from the survey. The results will be broken down by demographic information and condition characteristics, including the type of neurological condition and severity of condition.

2.1 Background

- My Neuro Survey 2024/25 is the fifth iteration of the My Neuro Patient Experience Survey. It collects insights into the lives of people living with neurological conditions, covering their day-to-day experiences and interactions with healthcare and other services. The Neurological Alliance partnered with research agency Revealing Reality for this iteration of My Neuro Survey

- This year was the first year where responses were obtained from those across the UK and the Republic of Ireland. While the first three iterations focused on England only, the 2021/22 survey expanded to the whole UK, and this year sees the addition of the Republic of Ireland. Data from the Republic of Ireland has been written up and reported separately.
- As in 2021/22, responses were gathered both online and through neurology, physiotherapy, and rehabilitation clinics (please see below for more details on dissemination). This is also the second iteration that children. and young people have been included via a tailored version of the survey, with questions designed to be easily understood by children.
- This is the first year that a separate survey has additionally been developed to capture the perspectives of carers supporting someone with a neurological condition.
- The survey was open for four months, from 22 July 2024 to 15 November 2024, in total capturing the experiences of 10,342 individuals with neurological conditions and their carers.

2.2 Objectives

This year, the survey had 3 main objectives:

- Collect data to understand the experiences of those affected by neurological conditions in the UK.
- Be accessible and inclusive through the design of accessible, robust surveys, using effective dissemination routes to enable participation from a diverse range of people, including using co-design.
- Support advocacy, influencing, and service improvement through working in close collaboration with the Neurological Alliance and their stakeholders to ensure the surveys reflect the Neurological Alliances' key priorities.

2.3 Methodology

Three versions of the survey were designed. These were designed for adults with neurological conditions, children and young people with neurological conditions, and carers of people affected by neurological conditions.

A new carers survey was introduced, inviting those providing paid or unpaid support to someone with a neurological condition to share their perspectives. A carer was defined as *someone providing paid or unpaid support and assistance to someone who cannot manage all aspects of their daily life due to a neurological condition*. This definition, included in the survey itself, ensured that unpaid carers, such as family members, felt included and able to participate.

Clinic Engagement

To maximise engagement, promotional materials and a briefing webinar were provided to clinics and members in the lead-up to the survey. These included posters for clinics, along with tailored information packs for members and clinics. These packs contained pre-written content for social media captions, graphics, emails, and newsletters to help spread awareness and encourage survey participation. Each clinic was also provided with QR codes linked directly to the survey, which were included on promotional materials alongside a standard web link (URL) for those preferring to complete the survey online. For individuals unable to complete the survey themselves, Revealing Reality operated a survey helpline, allowing respondents to participate over the phone. A telephone interpreter service was also made available to support those completing the survey in other languages, although this was not requested by any participants.

A methodology combining online and in-clinic engagement, helped ensure a broad response, reflecting the experiences of people with neurological conditions and their carers across the UK and Ireland.

2.4 Survey Design

The 2024/25 My Neuro Survey questions were developed through a collaborative process, building on previous iterations of the survey. This included the addition of more child-friendly language to the children and young people's survey and the creation of a new, separate survey for carers.

During the design of the surveys, The Neurological Alliance and Revealing Reality collaborated closely with a project steering group and specific working group on survey development, each of which included representatives from The Neurological Alliance member organisations, people affected by neurological conditions, healthcare professionals and covered a variety of neurological conditions. These representatives ensured the questionnaire addressed the needs and experiences of those with a wide range of neurological conditions. Members represented all four UK nations – England, Scotland, Wales, and Northern Ireland – and partner alliances, including the Wales Neurological Alliance, Neurological Alliance of Scotland, and Northern Ireland Neurological Charities Alliance (niNCA).

Cognitive testing was carried out with five individuals, including adults and children with neurological conditions. This process ensured the survey questions were accessible, clear, and effective in capturing the required information. Participants completed the draft questionnaire and provided detailed feedback on each question, including its wording, response options, layout, and length. The process was iterative, with changes made after each session when it was considered beneficial to improve the survey's clarity or effectiveness. This allowed subsequent sessions to focus on other aspects, avoiding repetitive feedback and ensuring comprehensive refinement. The participants' input was invaluable and greatly appreciated. Following these sessions, a report was shared with The Neurological Alliance and the project steering group. Revisions were made based on the findings, and the updated questionnaire was tested again to ensure it met the required standards.

The design process took place between April and June 2024 and involved drafting, reviewing, testing, and revising the questions. Revealing Reality worked closely with The Neurological Alliance to finalise the question set, ensuring it reflected the feedback and expertise of the steering group, and the insight gathered from the focus groups and cognitive testing interviews.

2.5 Sampling and Dissemination

My Neuro Survey 2024-25 was distributed across the UK through various channels to ensure it reached a wide and diverse group of respondents. The survey was promoted by The Neurological Alliance and its partner organisations, including the Wales Neurological Alliance, Neurological Alliance of Scotland, and the Northern Ireland Neurological Charities Alliance (niNCA). The dissemination approach ensured broad accessibility and aimed to capture the experiences of individuals living with neurological conditions, their carers, and children and young people affected by these conditions.

Online Distribution

Each clinic and participating organisation was given a unique link to the survey allowing members and clinics to track uptake from their networks.

Paper-Based Surveys

Paper versions of the survey were distributed in clinics across the UK. These paper surveys were accessible to all individuals who used the clinics, and were handed out without targeting specific patients, ensuring a random sample.

Individuals who were unable to complete the survey online or in person had the option to complete it by phone with the Revealing Reality team or were able to request a paper survey via email or phone from The Neurological Alliance. This option was available with a prepaid return envelope, ensuring that individuals with limited access to digital devices could still participate.

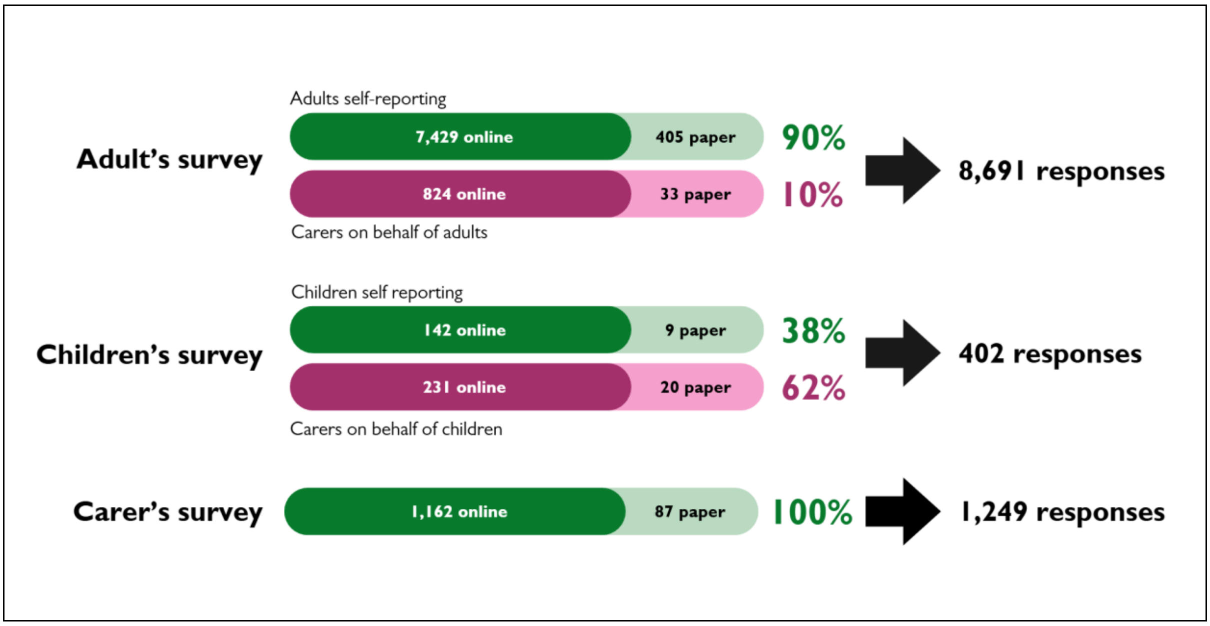
2.6 Data Collection

The data was collected through a combination of direct responses from individuals with neurological conditions and responses from carers completing the survey on behalf of those they care for, ensuring representation of those who may not be able to answer on their own behalf. These data points were merged where equivalent questions were asked.

It is important to note that not all questions given to adults were included in the section for carers responding on behalf of someone they support, as some questions would be difficult or inappropriate for carers to answer on behalf of another person. Caution was also taken regarding potential data accuracy due to the challenges of reporting on someone else's experiences.

2.7 Response Rates

In total, this iteration of My Neuro Survey received over 9,000 individual survey responses, representing the experiences of 10,342 individuals. These were received via each of the surveys as follows:



2.8 Project Timeline

Key dates for the project timeline were as follows:

1. Project scoping (April 2024): *Aligning priorities for changes to survey design, data collection processes, and reporting*

2. Survey development and testing (May to June 2024): *Evolving the research materials to achieve agreed goals*

This stage included:

1. Initial development of survey questions
2. Cognitive testing
3. Focus groups
4. Final amends to the surveys

3. Survey send-out (July to November 2024): *Online, paper, face-to-face, telephone, and in-post surveys were sent out*

Both online and in-clinic paper surveys were live between 22nd July 2024 and 15th November 2024. Paper survey returns were accepted up to a month after the survey close date, to ensure that these responses were not missed in analysis.

4. Data processing (December 2024 to March 2025): *Data cleaning, quality checks, and analysis*

Data cleaning took place between December 2024 to February 2025. Survey responses were merged across the different survey links provided to clinics and members, with the Welsh surveys translated back into English and merged, too. Questions where carers had answered on behalf of those with neurological conditions were duplicated such that they could be analysed with responses to the adults' and children's survey. The data was then cleaned in preparation for analysis.

Analysis took place between February to March 2024, and was carried out using Q Research Software, a statistical analysis software.

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3. About this technical report

This report provides charts and descriptions for all the questions in My Neuro Survey 2024-25. These are given at a total sample level. The structure of the report is as follows:

4.1. Results from the adults' survey and carers answering on behalf of adults with neurological conditions

4.2. Results from the children's survey and matched questions where carers answered on behalf of children and young people with neurological conditions

4.3. Results from the carers' survey

Note - throughout this report, most question wording appears exactly as it was presented in the survey, though some questions have been simplified or paraphrased slightly to improve the readability of the document.

For a full copy of the survey please contact The Neurological Alliance at info@neural.org.uk.

Results

4.1 Results from the adults' survey and carers answering on behalf of adults with neurological conditions

Q – Which of the following best describes you?

The majority of respondents (90%) filled in the survey themselves as an adult with a neurological condition. 10% of responses came from a carer who completed the survey on behalf of an adult with a neurological condition.

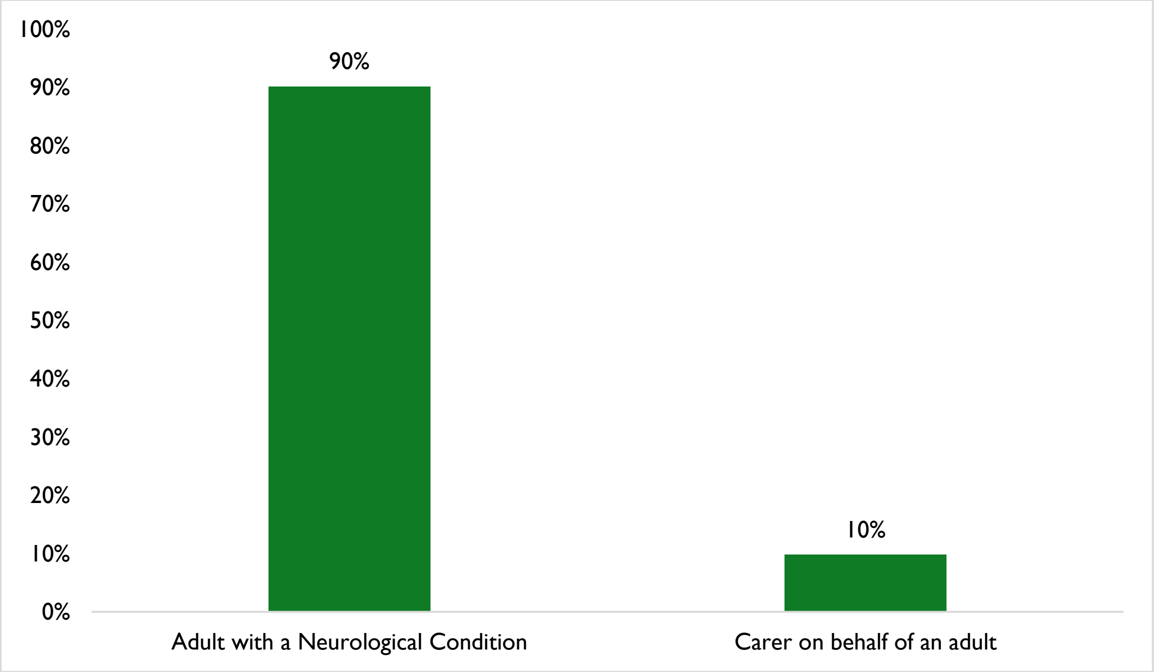

Figure 1. base n = 8688

Q – Please tell us which neurological condition(s) you have:

The five most commonly reported among adult respondents and their carers were[1]:

1. Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) – 16%
2. Multiple Sclerosis (MS) – 13%
3. Migraine – 10%
4. Fibromyalgia – 9%
5. Functional Neurological Disorder (FND) – 9%

Condition	%
Acoustic Neuroma	0%
Acquired Brain Injury	3%
Alzheimer's Disease	0%
Ataxia	1%
Autism	3%
Autoimmune Encephalitis	0%
Awaiting diagnosis	6%
Batten Disease	0%
Behçet's	0%
Brain Aneurysm	1%
Brain Tumour	1%
Carpal Tunnel Syndrome	2%
Cavernoma	1%
Cerebral Palsy	1%
Cerebrospinal Fluid (CSF) Leak	0%
Charcot-Marie-Tooth Disease	1%

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[1] Note that respondents were able to report multiple neurological conditions, if applicable.

Condition	%
Chiari Malformation	1%
Chronic Headache	3%
Chronic Inflammatory Demyelinating Polyneuropathy	1%
Cluster Headache	1%
Congenital Hemiplegia	0%
Corticobasal Degeneration (CBD)	1%
Dementia	1%
Down’s Syndrome	0%
Dravet Syndrome	0%
Dystonia	8%
Encephalitis/Autoimmune Encephalitis	0%
Epilepsy	8%
Essential Tremor	4%
Familial Dysautonomia	0%
Fibromyalgia	9%
Foetal Alcohol Spectrum Disorder	0%
Functional Neurological Disorder (FND)	9%
Guillain-Barre Syndrome	2%
Hemifacial Spasm	0%
Hereditary Spastic Paraplegia	0%
Huntington's Disease	1%
Hydrocephalus	3%
Idiopathic Intracranial Hypertension	1%

Condition	%
Lennox Gasteut Syndrome	0%
Long Covid Related Neurological Symptoms	2%
Meningitis	0%
Migraine	10%
Motor Neurone Disease (MND)	1%
Multifocal Motor Neuropathy	0%
Multiple Sclerosis (MS)	13%
Multiple System Atrophy (MSA)	1%
Muscular Dystrophy	1%
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	16%
Myasthenia	2%
Narcolepsy	0%
Neurofibromatosis	0%
Neuromyelitis Optica	0%
Parkinson's Disease	8%
Periodic Limb Movement Disorder Of Sleep (Plmd)	0%
Peripheral Neuropathy	3%
Pernicious Anemia	2%
POEMS (Polyneuropathy, Organomegaly, Endocrinopathy, M-Protein, and Skin Changes)	0%
Poliomyelitis/Post-Polio Syndrome	1%
Prefer not to say	0%
Progressive Supranuclear Palsy (PSP)	3%

Condition	%
Restless Legs Syndrome (Rls)	3%
Rett's Syndrome	0%
Ring 20	0%
Spina Bifida	2%
Spinal Muscular Atrophy	0%
Spinal Tumour	0%
Spondylosis	2%
Stroke / Tia	3%
Vasculitis	0%
Other (please specify)	8%

Figure 2. base n = 8618

Q – How long have you had a formal diagnosis for your condition(s)?

How long respondents had been diagnosed varied, both across individuals and across different conditions. For the five most commonly reported conditions:

- **ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)** respondents showed a skew toward longer-term diagnosis, with half (50%) reporting a diagnosis over 10 years ago, 18% between 6-10 years ago, and 8% between 4-5 years ago. Only 3% were diagnosed between 6-11 months ago and 4% less than 6 months ago.

- **Multiple Sclerosis (MS)** showed similar patterns to ME/CFS. Half (50%) reported a diagnosis more than 10 years ago. 18% had been diagnosed between 6-10 years ago, and 11% between 4-5 years. Smaller numbers were diagnosed more recently, with only 2% between 6-11 months ago and 3% less than 6 months ago.

- **Migraine** similarly showed a longer overall diagnostic history, with 52% of respondents indicating they were diagnosed more than 10 years ago. 16% were diagnosed 6-10 years ago, and 10% between 4-5 years ago. Shorter-term diagnoses were less common, with just 2% reporting diagnosis within the last 6 months. 5% indicated they had had the condition “since birth or early childhood”.

- **Fibromyalgia** respondents reported a slightly broader range in time since diagnosis. Over a third (36%) reported having received their diagnosis more than 10 years ago (but not since birth/childhood), while 25% had been diagnosed between 6-10 years ago. A further 15% received a diagnosis 4-5 years ago, and 15% between 1-3 years ago. Smaller proportions were diagnosed more recently, with 4% between 6-11 months and 2% less than 6 months ago. Only 3% preferred not to say.

- **FND (Functional Neurological Disorder)** respondents were more likely to have received a diagnosis in the past few years. The largest proportion (35%) received a diagnosis between 1-3 years ago, followed by 16% between 4-5 years ago and 16% between 6-10 years ago. Just 8% had had their diagnosis for more than 10 years, while 12% were diagnosed between 6-11 months ago and 11% less than 6 months ago.

Row %	I’m waiting for a formal diagnosis	Less than 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	Between 6-10 years	More than 10 years ago, but not since birth / childhood	Since birth or early childhood	Prefer not to say
Acoustic Neuroma	0%	0%	14%	28%	7%	14%	28%	10%	0%
Acquired Brain Injury	0%	4%	4%	18%	8%	19%	43%	5%	1%
Alzheimer’s Disease	17%	0%	0%	17%	17%	17%	0%	17%	17%
Ataxia	0%	5%	4%	19%	11%	18%	40%	2%	1%
Autism	0%	6%	8%	26%	8%	18%	16%	17%	3%

Row %	I'm waiting for a formal diagnosis	Less than 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	Between 6-10 years	More than 10 years ago, but not since birth / childhood	Since birth or early childhood	Prefer not to say
Autoimmune Encephalitis	8%	8%	15%	31%	31%	0%	0%	8%	0%
Batten Disease	0%	0%	0%	0%	0%	0%	0%	100%	0%
Behçet's	0%	5%	3%	19%	11%	19%	41%	0%	3%
Brain Tumour	0%	8%	8%	24%	14%	15%	29%	1%	2%
Brain Aneurysm	0%	6%	4%	19%	15%	19%	34%	4%	0%
Carpal Tunnel Syndrome	0%	8%	8%	11%	12%	21%	39%	0%	0%
Cavernoma	0%	3%	8%	28%	20%	13%	25%	2%	2%
Cerebral Palsy	1%	2%	1%	5%	0%	0%	6%	83%	2%
Charcot-Marie-Tooth Disease	5%	1%	3%	5%	13%	6%	60%	8%	0%
Chiari Malformation	2%	5%	4%	20%	11%	18%	23%	17%	0%
Chronic Headache	2%	3%	3%	17%	11%	23%	38%	3%	0%
Chronic Inflammatory Demyelinating Polyneuropathy	0%	6%	5%	31%	12%	21%	25%	0%	1%
Cluster Headache	3%	2%	2%	14%	13%	27%	36%	2%	0%
Corticobasal Degeneration (CBD)	0%	5%	5%	55%	25%	5%	5%	0%	0%
Congenital Hemiplegia	0%	0%	0%	0%	0%	50%	25%	25%	0%
Cerebrospinal Fluid (CSF) Leak	5%	10%	2%	46%	7%	7%	22%	0%	0%
Dementia	0%	0%	21%	29%	14%	14%	21%	0%	0%
Dravet Syndrome									
Down's Syndrome	0%	0%	0%	0%	0%	0%	0%	100%	0%

Row %	I'm waiting for a formal diagnosis	Less than 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	Between 6-10 years	More than 10 years ago, but not since birth / childhood	Since birth or early childhood	Prefer not to say
Dystonia	1%	2%	3%	13%	11%	15%	52%	2%	0%
Encephalitis/ Autoimmune Encephalitis	3%	7%	14%	10%	10%	3%	45%	3%	3%
Epilepsy	1%	2%	2%	10%	7%	13%	51%	13%	0%
Essential Tremor	7%	3%	4%	16%	11%	17%	38%	4%	0%
Familial Dysautonomia	0%	0%	0%	14%	29%	29%	29%	0%	0%
Foetal Alcohol Spectrum Disorder	0%	0%	0%	0%	0%	0%	100%	0%	0%
Fibromyalgia	3%	2%	4%	15%	15%	25%	36%	0%	0%
Functional Neurological Disorder (FND)	2%	11%	12%	35%	16%	16%	8%	0%	0%
Guillain-Barre Syndrome	1%	10%	9%	23%	17%	18%	22%	0%	0%
Hemifacial Spasm	6%	3%	3%	16%	16%	19%	35%	0%	0%
Hereditary Spastic Paraplegia	0%	9%	0%	18%	0%	27%	45%	0%	0%
Huntington's Disease	0%	9%	9%	9%	32%	5%	32%	0%	5%
Hydrocephalus	0%	3%	3%	15%	4%	11%	19%	45%	0%
Idiopathic Intracranial Hypertension	3%	7%	8%	35%	10%	10%	25%	1%	0%
Lennox Gasteut Syndrome	0%	100%	0%	0%	0%	0%	0%	0%	0%
Long Covid Related Neurological Symptoms	10%	4%	7%	60%	16%	0%	1%	0%	2%
Meningitis	0%	10%	0%	10%	10%	5%	30%	35%	0%
Migraine	1%	2%	2%	12%	10%	16%	52%	5%	0%

Row %	I'm waiting for a formal diagnosis	Less than 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	Between 6-10 years	More than 10 years ago, but not since birth / childhood	Since birth or early childhood	Prefer not to say
Motor Neurone Disease (MND)	3%	16%	16%	32%	16%	11%	8%	0%	0%
Multifocal Motor Neuropathy	0%	0%	8%	8%	8%	31%	46%	0%	0%
Multiple Sclerosis (MS)	2%	3%	2%	14%	11%	18%	50%	0%	0%
Multiple System Atrophy (MSA)	6%	10%	14%	38%	19%	9%	5%	0%	0%
Muscular Dystrophy	0%	4%	2%	0%	2%	9%	56%	27%	0%
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	2%	4%	3%	14%	8%	18%	50%	0%	0%
Myasthenia	1%	3%	3%	23%	16%	21%	34%	0%	0%
Narcolepsy	13%	13%	0%	38%	13%	13%	13%	0%	0%
Neurofibromatosis	9%	0%	0%	3%	3%	6%	36%	39%	3%
Neuromyelitis Optica	6%	0%	13%	13%	31%	0%	31%	6%	0%
Parkinson's Disease	1%	4%	4%	29%	16%	26%	19%	0%	0%
Peripheral Neuropathy	6%	5%	3%	18%	17%	21%	29%	1%	0%
Periodic Limb Movement Disorder Of Sleep (Plmd)	4%	4%	0%	16%	12%	28%	28%	4%	4%
Pernicious Anemia	4%	2%	2%	11%	6%	26%	47%	1%	1%
Poliomyelitis/Post-Polio Syndrome	5%	0%	4%	10%	5%	5%	31%	41%	0%
POEMS (Polyneuropathy, Organomegaly, Endocrinopathy, M-	0%	0%	0%	0%	0%	0%	33%	33%	33%

Row %	I'm waiting for a formal diagnosis	Less than 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	Between 6-10 years	More than 10 years ago, but not since birth / childhood	Since birth or early childhood	Prefer not to say
Protein, and Skin Changes)									
Progressive Supranuclear Palsy (PSP)	2%	9%	19%	44%	14%	9%	1%	2%	0%
Restless Legs Syndrome (Rls)	14%	1%	4%	10%	13%	17%	36%	4%	2%
Rett's Syndrome	0%	0%	0%	0%	0%	0%	0%	100%	0%
Ring 20	0%	0%	0%	0%	0%	0%	0%	100%	0%
Spina Bifida	0%	1%	0%	3%	2%	0%	6%	88%	0%
Spinal Muscular Atrophy	0%	8%	0%	17%	8%	8%	42%	17%	0%
Spinal Tumour	0%	0%	0%	36%	18%	9%	18%	18%	0%
Spondylosis	1%	3%	2%	13%	11%	26%	38%	5%	1%
Stroke / Tia	1%	5%	6%	31%	14%	21%	21%	2%	1%
Vasculitis	7%	3%	10%	24%	14%	10%	24%	3%	3%

Figure 3. base n = from 0 to 1378

Q – How long did it take to receive a formal diagnosis after you first experienced symptoms?

The five conditions that had the highest proportion of adults where it took more than five years to receive a diagnosis (where base n>29) were:

1. Bechet's Disease – 49%
2. Autism – 44%
3. Charcot-Marie-Tooth Disease – 44%
4. Pernicious Anemia – 40%
5. Spondylosis – 38%

The five conditions that had the highest proportion of adults still waiting for a formal diagnosis (where base n>29) were:

1. Autism (28%)
2. Restless Legs Syndrome (22%)
3. Long Covid Related Neurological Symptoms (18%)
4. Vasculitis (16%)
5. Acoustic Neuroma (16%)

Row %	I'm waiting for a formal diagnosis	Within 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	More than 5 years	Prefer not to say
Acoustic Neuroma	16%	38%	16%	13%	3%	13%	3%
Acquired Brain Injury	6%	57%	6%	11%	1%	15%	3%
Alzheimer's Disease	44%	11%	11%	0%	11%	0%	22%
Ataxia	13%	17%	11%	25%	13%	19%	2%
Autism	28%	6%	4%	12%	3%	44%	3%
Autoimmune Encephalitis	31%	31%	23%	8%	0%	8%	0%
Batten Disease	33%	33%	0%	0%	0%	17%	17%
Behçet's	5%	11%	3%	16%	16%	49%	0%
Brain Tumour	3%	48%	14%	18%	5%	9%	3%
Brain Aneurysm	4%	63%	13%	5%	4%	11%	2%
Carpal Tunnel Syndrome	7%	26%	21%	27%	7%	11%	2%
Cavernoma	3%	52%	8%	15%	0%	17%	6%

Row %	I'm waiting for a formal diagnosis	Within 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	More than 5 years	Prefer not to say
Cerebral Palsy	3%	26%	12%	34%	3%	15%	7%
Charcot-Marie-Tooth Disease	7%	18%	4%	17%	7%	44%	3%
Chiari Malformation	4%	33%	5%	14%	4%	35%	6%
Chronic Headache	5%	12%	11%	25%	13%	32%	2%
Chronic Inflammatory Demyelinating Polyneuropathy	3%	38%	23%	19%	4%	13%	0%
Cluster Headache	11%	18%	9%	29%	7%	25%	1%
Corticobasal Degeneration (CBD)	13%	0%	13%	61%	4%	9%	0%
Congenital Hemiplegia	29%	14%	0%	29%	14%	14%	0%
Cerebrospinal Fluid (CSF) Leak	9%	47%	7%	21%	2%	14%	0%
Dementia	20%	20%	20%	20%	7%	13%	0%
Dravet Syndrome	50%	0%	0%	25%	0%	0%	25%
Down's Syndrome	50%	25%	0%	25%	0%	0%	0%
Dystonia	2%	17%	16%	32%	8%	24%	1%
Encephalitis/Autoimmune Encephalitis	10%	52%	10%	16%	0%	10%	3%
Epilepsy	1%	42%	16%	23%	4%	10%	3%
Essential Tremor	9%	19%	11%	21%	7%	32%	1%
Familial Dysautonomia	20%	10%	10%	20%	0%	40%	0%
Foetal Alcohol Spectrum Disorder	33%	0%	0%	33%	17%	17%	0%

Row %	I'm waiting for a formal diagnosis	Within 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	More than 5 years	Prefer not to say
Fibromyalgia	4%	10%	10%	33%	11%	31%	0%
Functional Neurological Disorder (FND)	3%	24%	14%	30%	8%	20%	1%
Guillain-Barre Syndrome	2%	92%	1%	3%	1%	1%	0%
Hemifacial Spasm	15%	27%	12%	30%	9%	6%	0%
Hereditary Spastic Paraplegia	23%	8%	8%	15%	8%	38%	0%
Huntington's Disease	8%	21%	21%	13%	4%	17%	17%
Hydrocephalus	1%	63%	8%	13%	3%	8%	4%
Idiopathic Intracranial Hypertension	4%	51%	15%	15%	3%	11%	0%
Lennox Gasteut Syndrome	50%	50%	0%	0%	0%	0%	0%
Long Covid Related Neurological Symptoms	18%	20%	23%	34%	3%	2%	2%
Meningitis	9%	59%	0%	9%	9%	14%	0%
Migraine	3%	28%	11%	23%	8%	26%	1%
Motor Neurone Disease (MND)	7%	24%	17%	34%	7%	7%	2%
Multifocal Motor Neuropathy	11%	17%	17%	33%	6%	17%	0%
Multiple Sclerosis (MS)	1%	26%	19%	27%	7%	20%	0%
Multiple System Atrophy (MSA)	8%	13%	12%	45%	9%	12%	1%
Muscular Dystrophy	4%	28%	13%	26%	2%	23%	4%

Row %	I'm waiting for a formal diagnosis	Within 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	More than 5 years	Prefer not to say
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	2%	9%	17%	37%	9%	27%	0%
Myasthenia	3%	58%	18%	13%	1%	7%	0%
Narcolepsy	25%	17%	17%	33%	0%	8%	0%
Neurofibromatosis	14%	36%	3%	19%	0%	19%	8%
Neuromyelitis Optica	14%	36%	14%	21%	14%	0%	0%
Parkinson's Disease	2%	32%	24%	30%	5%	7%	0%
Peripheral Neuropathy	10%	17%	11%	30%	9%	21%	1%
Periodic Limb Movement Disorder Of Sleep (Plmd)	14%	11%	11%	14%	18%	25%	7%
Pernicious Anemia	5%	20%	7%	19%	8%	40%	1%
Poliomyelitis/Post-Polio Syndrome	9%	42%	7%	14%	5%	20%	2%
POEMS (Polyneuropathy, Organomegaly, Endocrinopathy, M-Protein, and Skin Changes)	40%	20%	0%	0%	0%	20%	20%
Progressive Supranuclear Palsy (PSP)	6%	9%	21%	40%	19%	5%	0%
Restless Legs Syndrome (Rls)	22%	15%	8%	22%	6%	24%	3%
Rett's Syndrome	50%	25%	0%	0%	0%	25%	0%
Ring 20	33%	33%	0%	0%	0%	33%	0%
Spina Bifida	2%	73%	3%	4%	3%	10%	6%

Row %	I'm waiting for a formal diagnosis	Within 6 months	Between 6-11 months	Between 1-3 years	Between 4-5 years	More than 5 years	Prefer not to say
Spinal Muscular Atrophy	14%	29%	7%	14%	7%	29%	0%
Spinal Tumour	13%	27%	20%	13%	13%	13%	0%
Spondylosis	2%	12%	7%	24%	14%	38%	2%
Stroke / Tia	1%	72%	7%	9%	3%	8%	1%
Vasculitis	16%	23%	6%	16%	10%	26%	3%

Figure 4. base n = from 2 to 1375

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Bladder and bowel symptoms)

Nearly one-third (32%) of respondents reported no impact on bladder and bowel symptoms. Around one-third reported experiencing symptoms 'A little' (20%) or 'Somewhat' (16%). Those impacted 'Quite a lot' or 'Very much' accounted for just under a third combined, while 2% were unsure or preferred not to say.

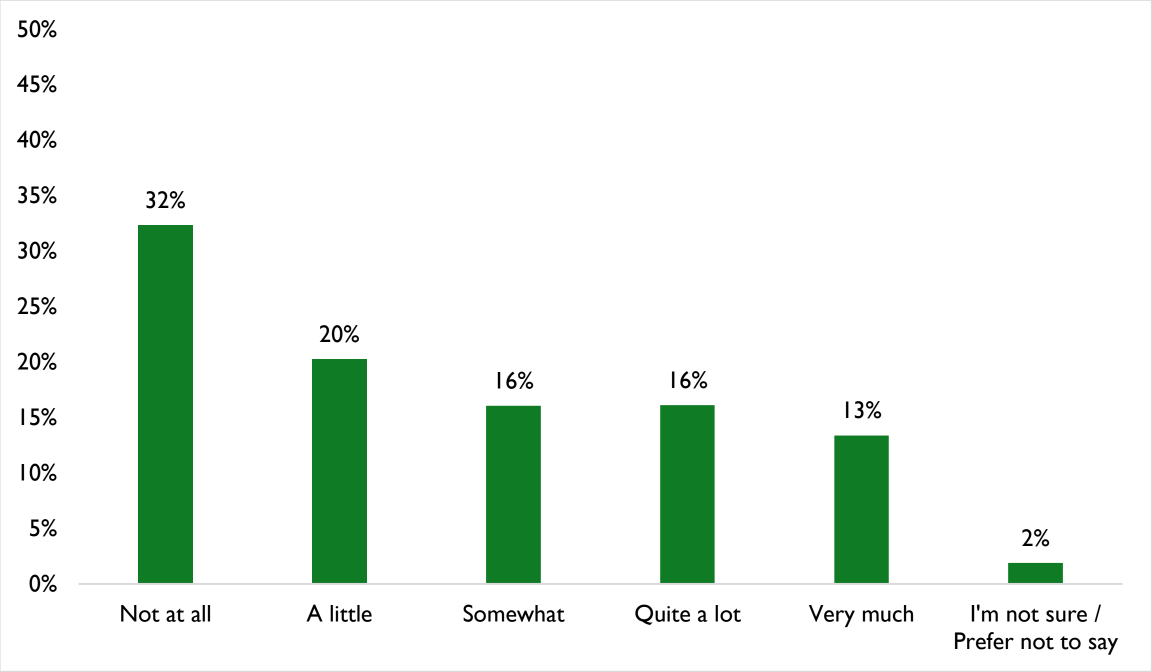

Figure 5. base n = 8498

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Breathing difficulties)

The majority (53%) reported no breathing difficulties. However, 22% were impacted 'A little', 13% 'Somewhat', and a smaller proportion (12%) reported more significant impacts ('Quite a lot' or 'Very much'). 1% were unsure or preferred not to answer.

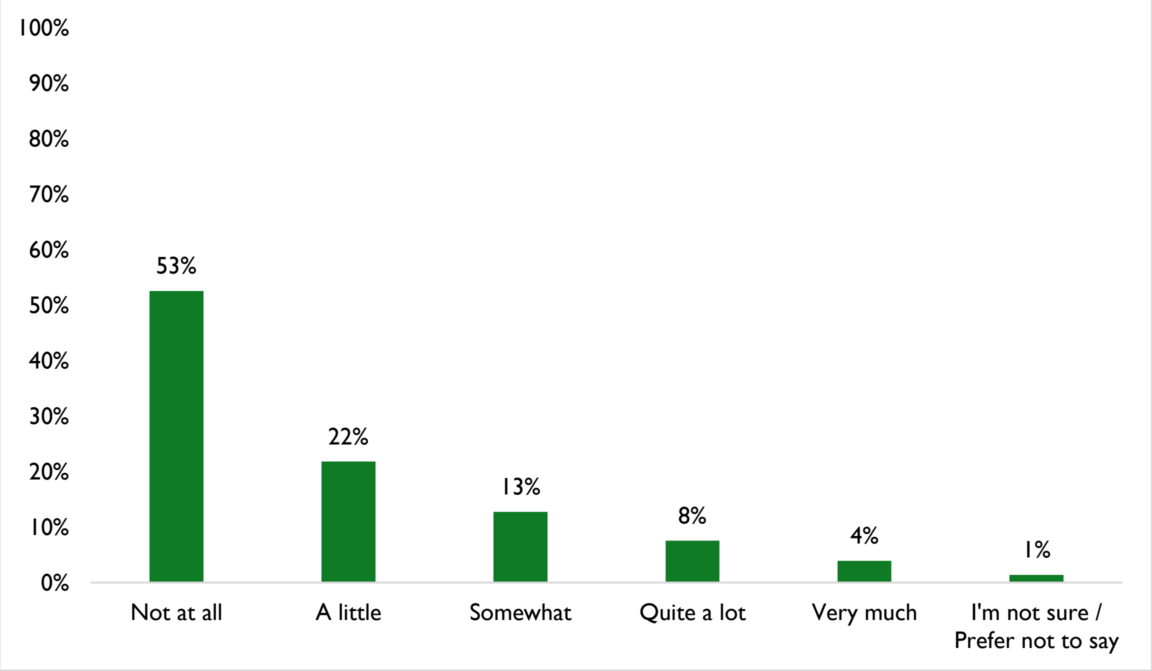

Figure 6. base n = 8470

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Communication)

Over a third (35%) reported no difficulties with communication. However, 26% experienced 'A little' impact, 17% reported being 'Somewhat' affected, and one in five indicated more significant impacts ('Quite a lot' or 'Very much'). 1% were unsure or preferred not to say.

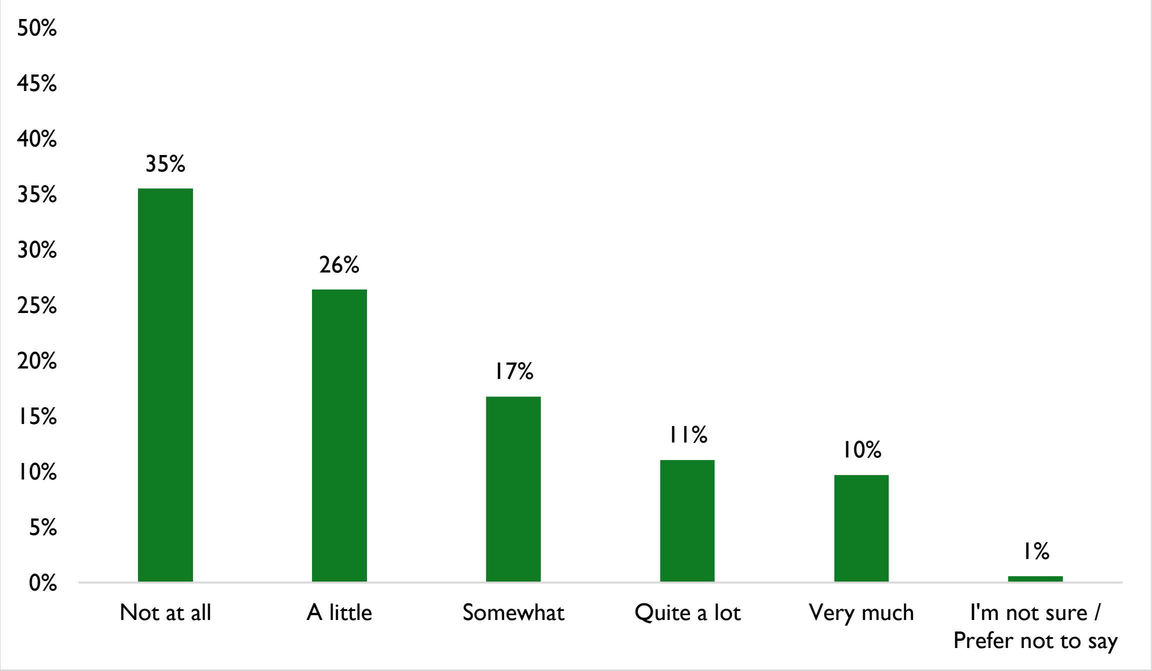

Figure 7. base n = 8488

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Eating and drinking)

40% of respondents reported no impact of their neurological condition on eating and drinking. 26% reported a little impact, 17% somewhat, 9% quite a lot, and 7% very much. Only 1% were unsure or preferred not to say.

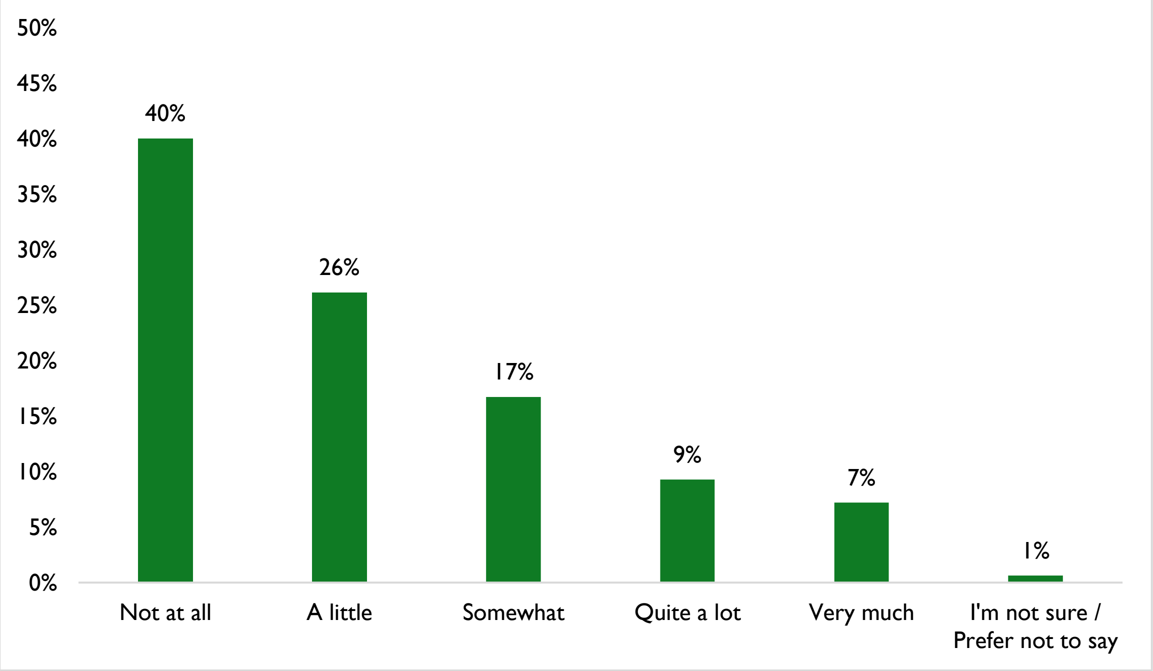

Figure 8. base n = 8481

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Fatigue)

Fatigue significantly affected respondents, with nearly half (45%) experiencing it 'Very much' and another 22% 'Quite a lot'. Smaller groups reported lower levels of impact ('Somewhat', 14%; 'A little', 11%), while only 6% had no fatigue impact. 1% were unsure or preferred not to say.

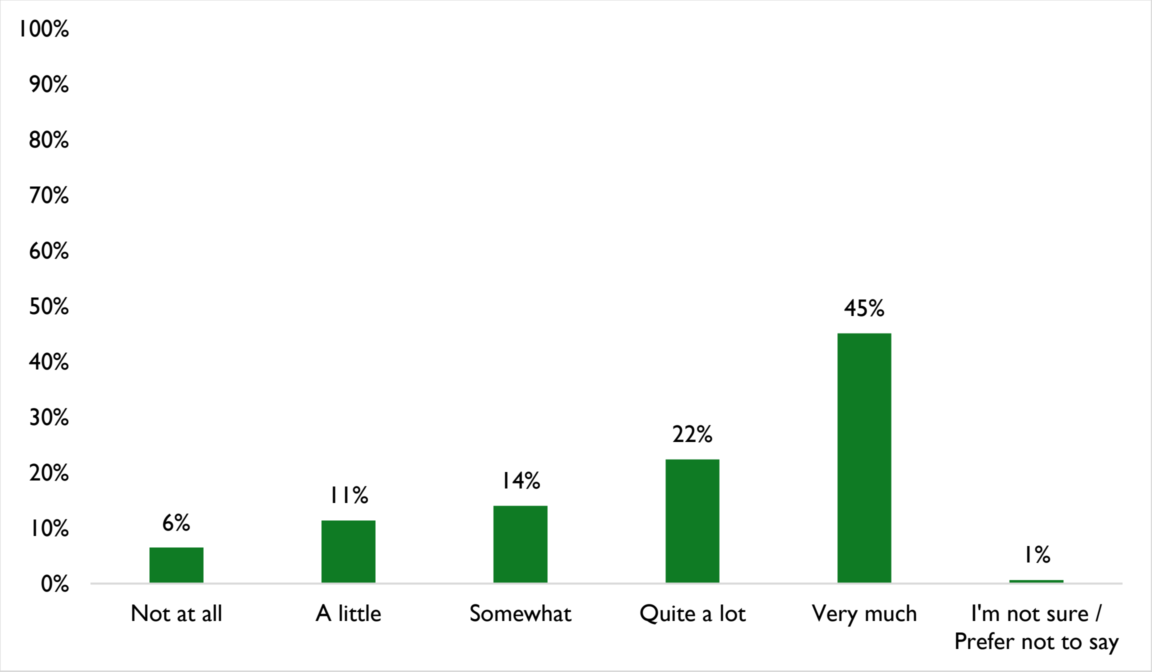

Figure 9. base n = 8538

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Hearing)

A majority of respondents (58%) reported no impact of their neurological condition on hearing. 17% reported a little impact, 12% somewhat, 6% quite a lot, and 4% very much. Only 2% were unsure or preferred not to say.

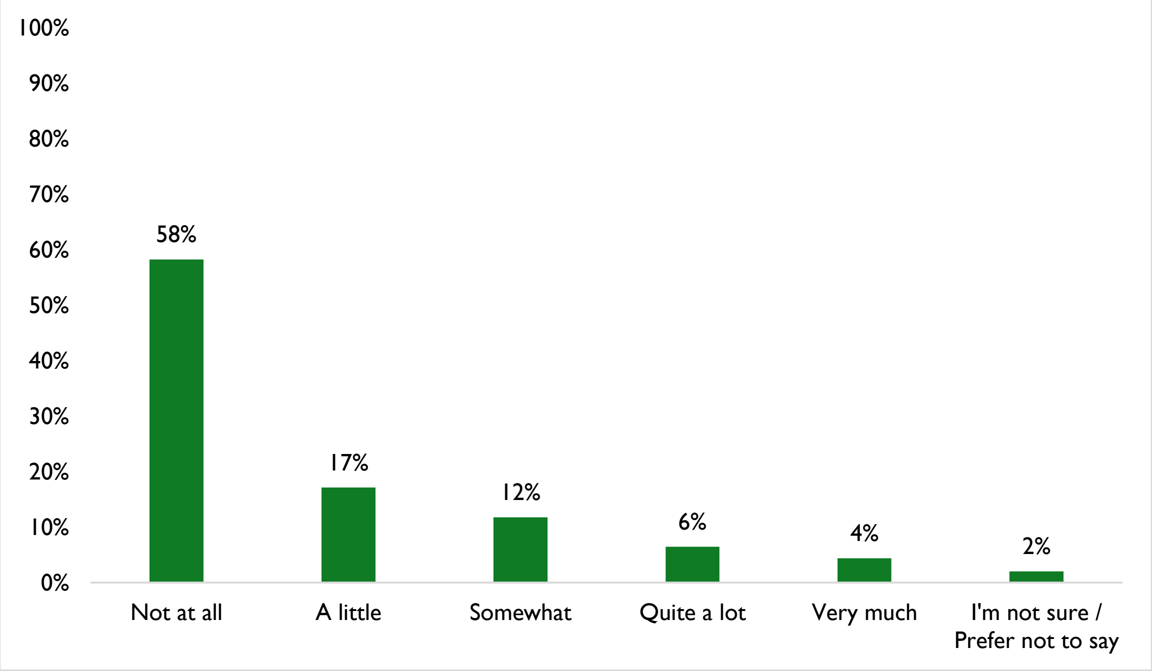

Figure 30. base n = 8474

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Mood and mental health issues)

Mood and mental health issues often impacted respondents, with 23% experiencing them 'Very much' and 19% 'Quite a lot'. A further two in five reported minimal ('A little', 22%) to moderate ('Somewhat', 20%) impact, while only 15% had no impact. 1% were unsure or preferred not to say.

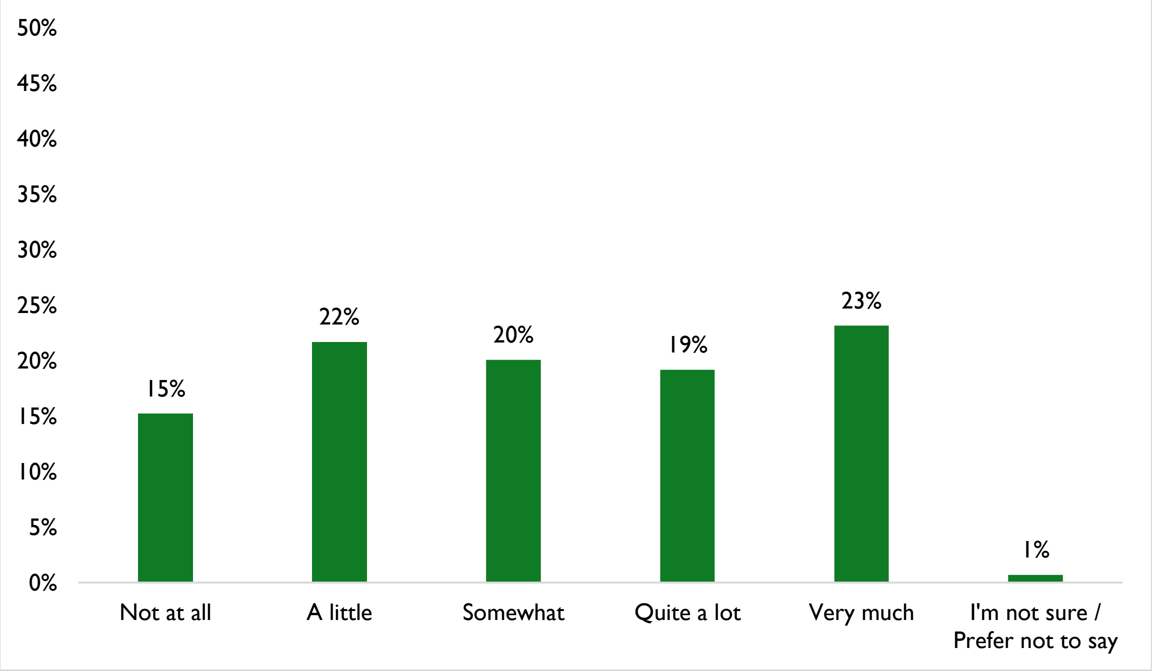

Figure 4. base n = 8527

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Movement)

Movement difficulties were commonly reported, with 36% affected 'Very much' and 24% 'Quite a lot'. Lesser impacts were reported by smaller groups ('Somewhat', 18%; 'A little', 13%). Only 9% had no impact. Less than 1% were unsure or preferred not to say.

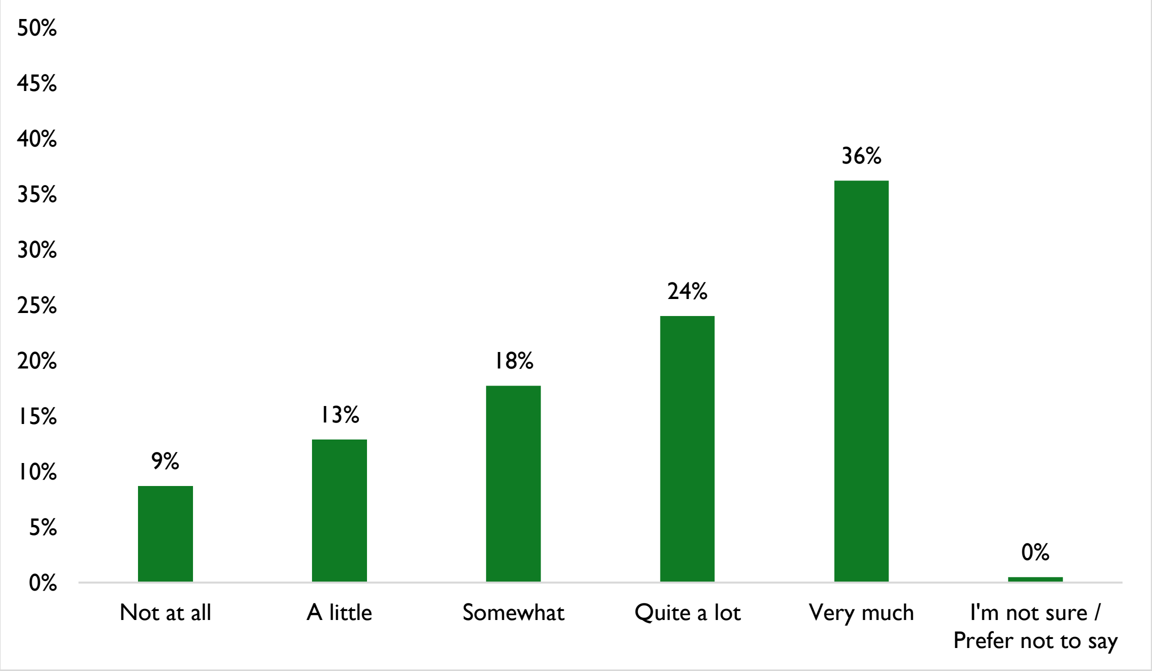

Figure 5. base n = 8555

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Pain)

Pain often affected respondents, with over a quarter (28%) experiencing it 'Very much' and 20% 'Quite a lot'. Lower levels of impact were experienced by respondents reporting 'Somewhat' (17%), 'A little' (17%), and 'Not at all' (18%). Only 1% were unsure or preferred not to say.

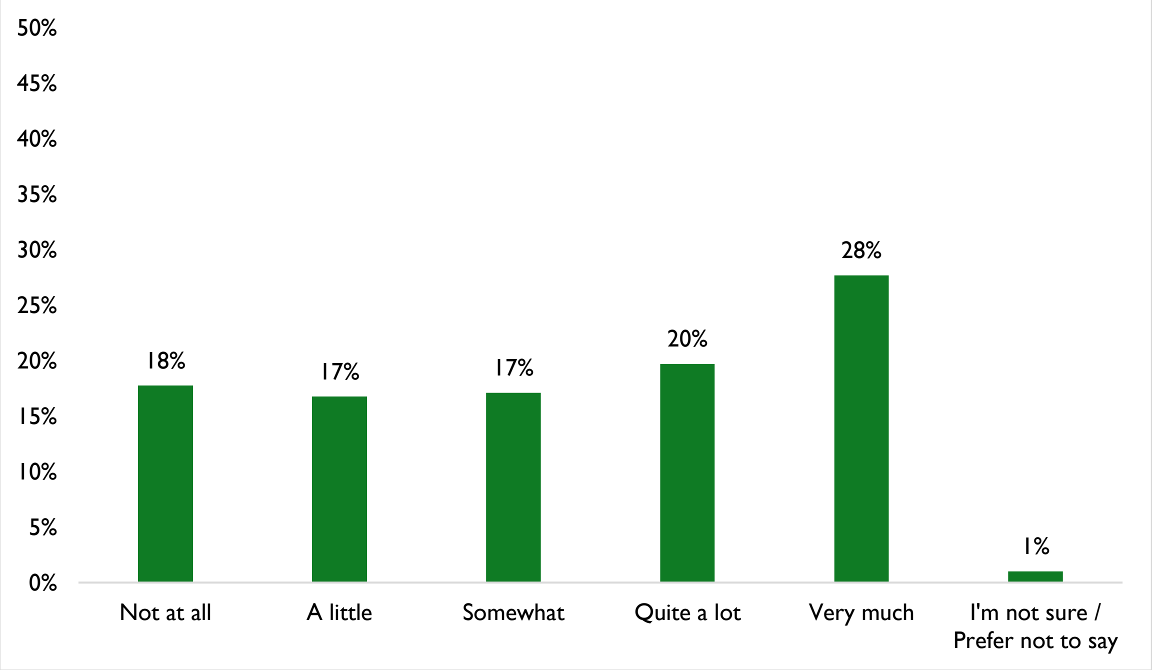

Figure 6. base n = 8535

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Seizures)

The majority (80%) of the sample reported no seizures. Smaller proportions experienced minimal ('A little', 6%) to significant impacts ('Somewhat', 4%; 'Quite a lot', 4%; 'Very much', 5%). 2% were unsure or preferred not to say.

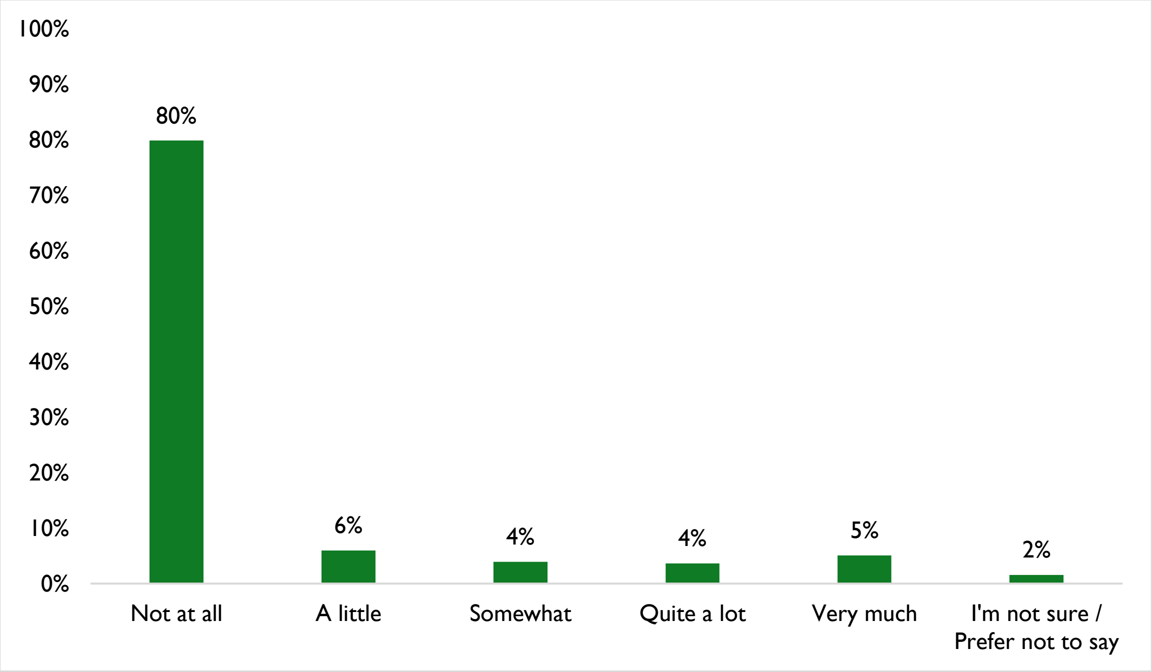

Figure 7. base n = 8469

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Sensation)

Responses for sensation impacts were relatively evenly distributed. 'Not at all' was reported by 22%, while the other responses ranged from 18%-20% each for impacts ranging from 'A little' to 'Very much'. 2% were unsure or preferred not to say.

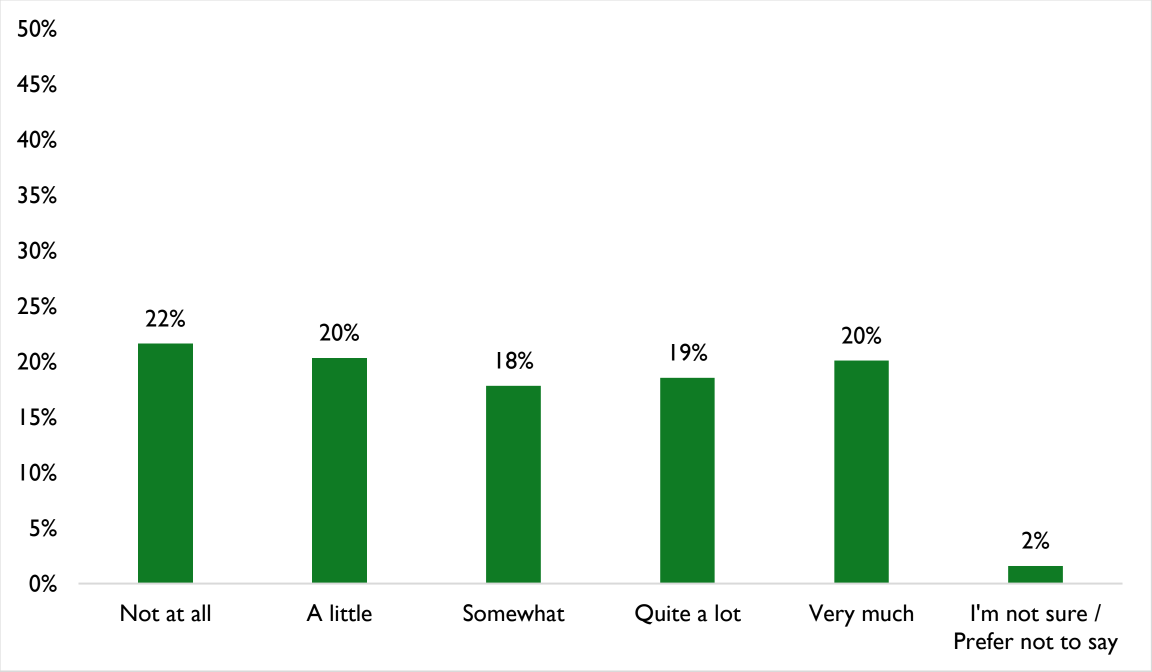

Figure 8. base n = 8507

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Sexual function)

A third of respondents (34%) indicated no impact on sexual function. Those significantly impacted ('Very much', 14%; 'Quite a lot', 9%) combined to 23%, with smaller groups reporting moderate ('Somewhat', 12%) to minimal ('A little', 13%) impacts. 18% were unsure or preferred not to say.

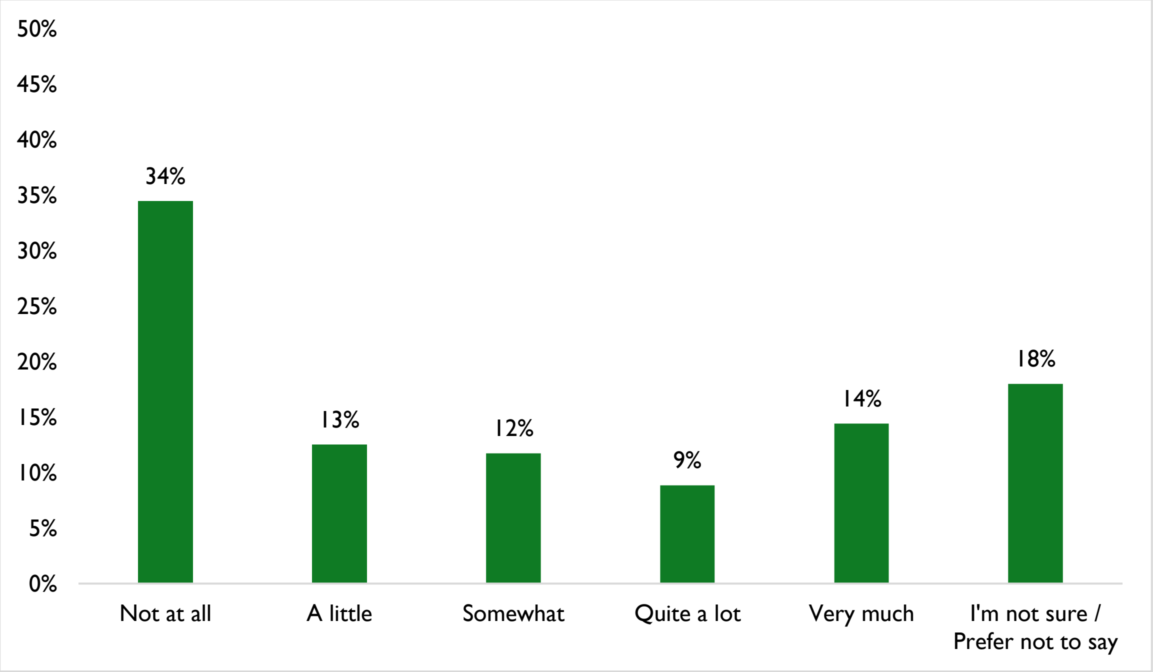

Figure 96. base n = 8475

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Sleep)

Sleep issues were common, with 30% affected 'Very much' and 22% 'Quite a lot'. Moderate ('Somewhat', 18%) and minimal ('A little', 15%) impacts were also reported, while only 13% reported no impact. 1% were unsure or preferred not to say.

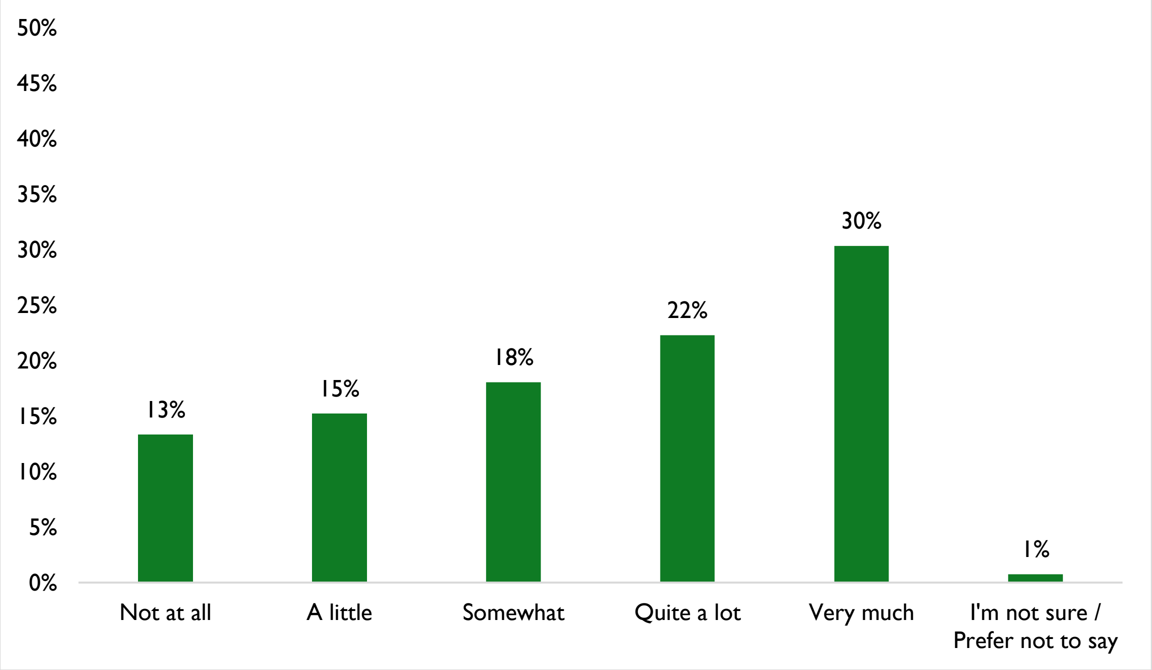

Figure 107. base n = 8531

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Thinking and memory)

Thinking and memory were significantly impacted, with 27% affected 'Very much' and 21% 'Quite a lot'. Moderate and minimal impacts were experienced by equal proportions ('Somewhat', 18%; 'A little', 18%). Only 16% had no impact, with 1% unsure or preferring not to say.

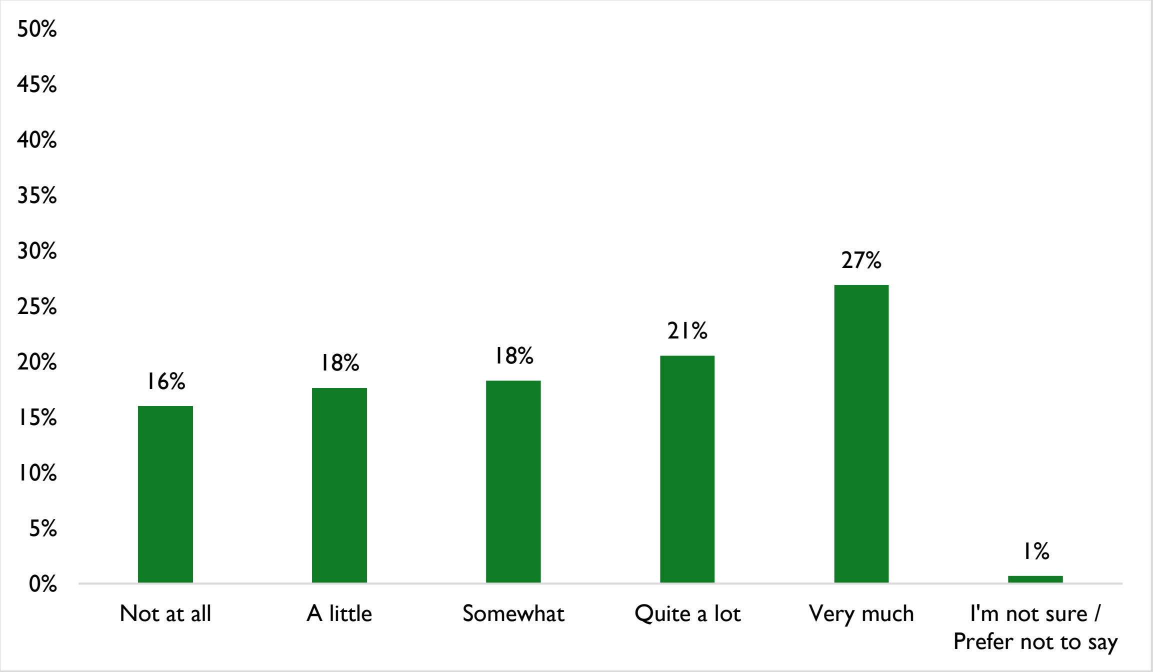

Figure 118. base n = 8522

Q – Which, if any, of the following ways does your neurological condition(s) impact your health? (Vision)

Vision issues were reported by fewer respondents, with 38% experiencing no impact. Minimal ('A little', 24%) and moderate ('Somewhat', 17%) impacts were common, while significant impacts ('Quite a lot', 11%; 'Very much', 8%) were less frequent. 2% were unsure or preferred not to say.

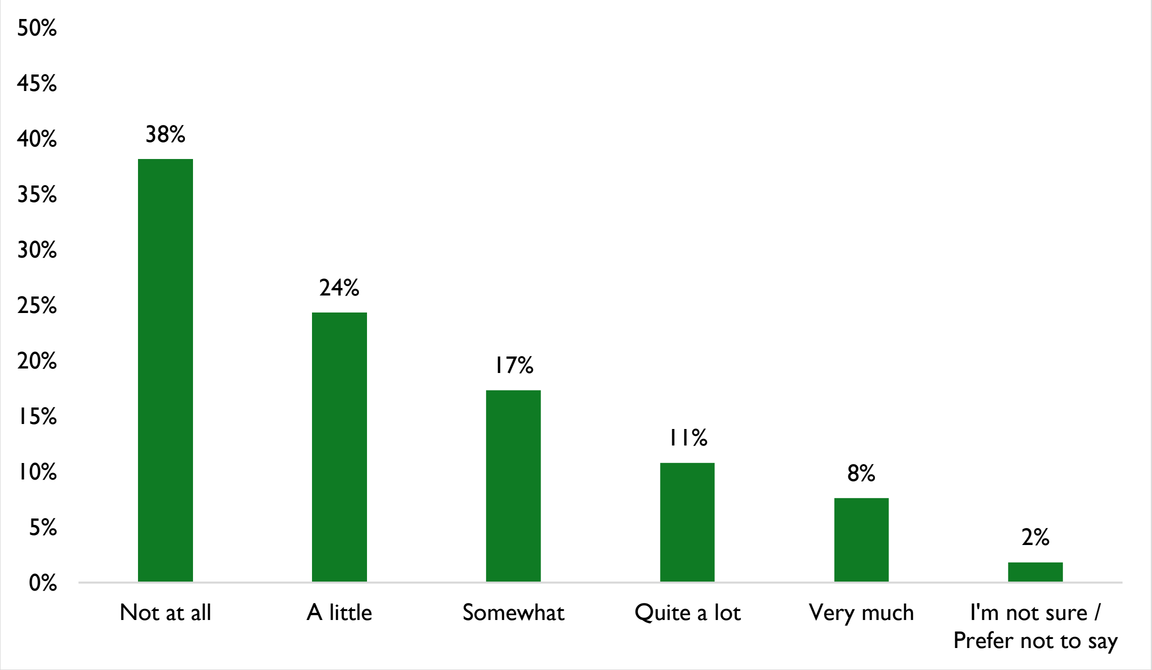

Figure 1912. base n = 8518

Q – Do you have any other health condition(s) in addition to your neurological condition(s)?

Many respondents reported having additional health conditions, with physical conditions (45%) and mental health conditions (36%) being most common. Around 21% had no other conditions, while sensory (22%), cognitive (9%), and other conditions (22%) were also reported. 2% preferred not to say.

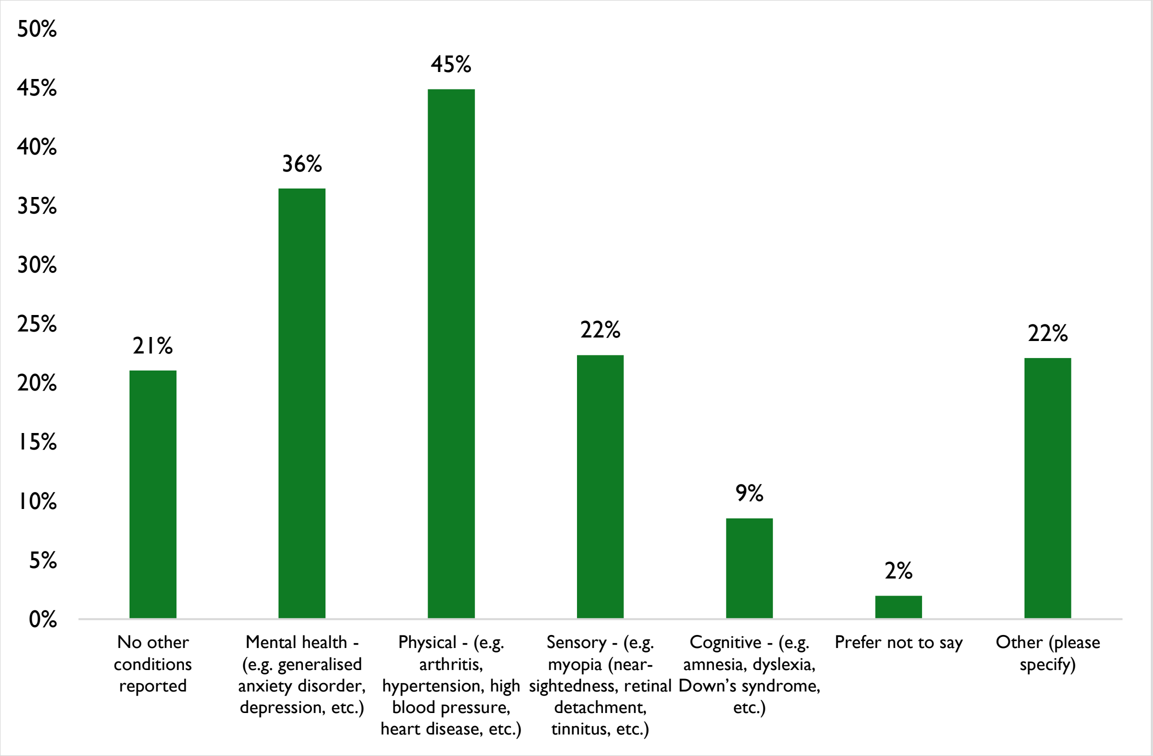

Figure 20. base n = 7834

Q – What is your age?

Most respondents were aged between 45-74, with the highest proportion being 55-64 years old (25%). Smaller groups included 65-74 years (19%), 45-54 years (20%), and 35-44 years (13%). Younger (18-34 years) and older respondents (75+) accounted for smaller proportions (3%-12%).

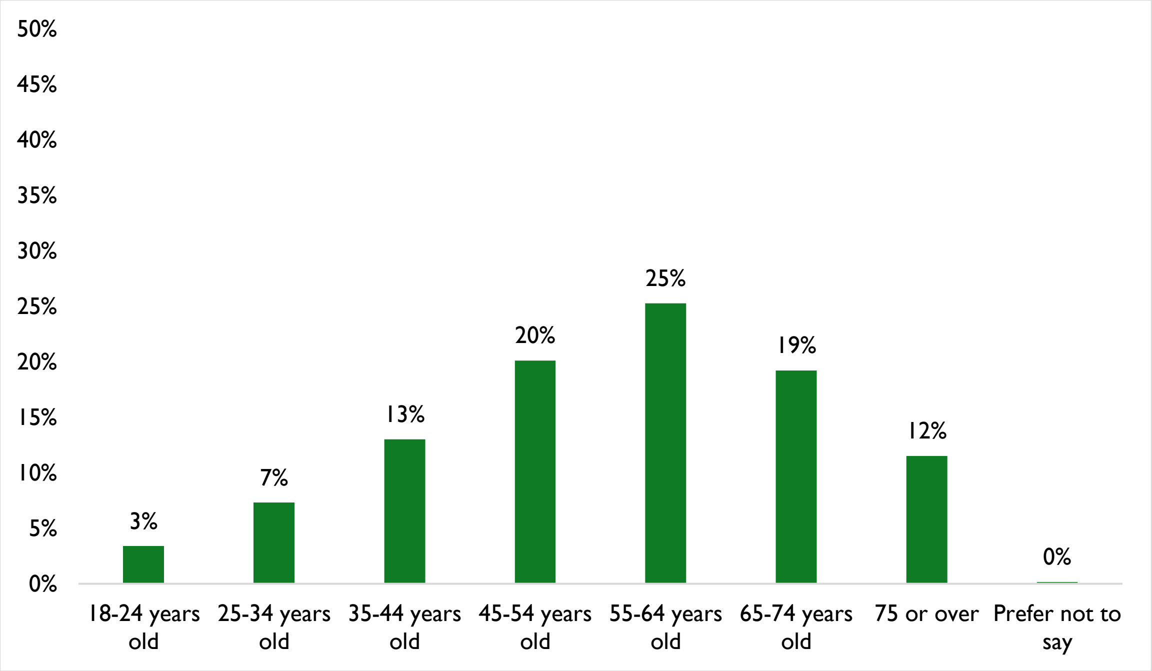

Figure 13. base n = 8636

Q – Which of the following describes how you think of yourself? [Gender]

The majority of respondents identified as female (68%), with approximately one-third (31%) identifying as male. Only 1% identified as 'Other'.

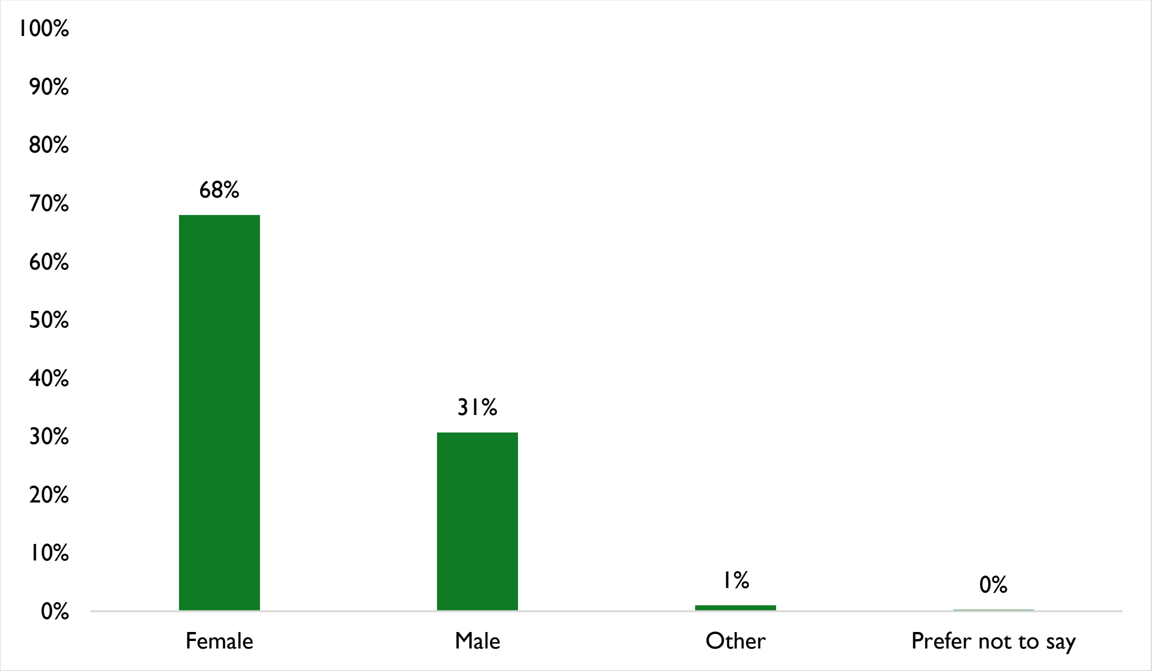

Figure 14. base n = 8634

Q – What is your ethnic group?

A large majority (95%) of respondents identified as White. Small proportions identified as Asian or Asian British (1%), Black or Black British (1%), and Mixed or multiple ethnic groups (1%). Other ethnic groups and those preferring to self-describe accounted for less than 1% each.

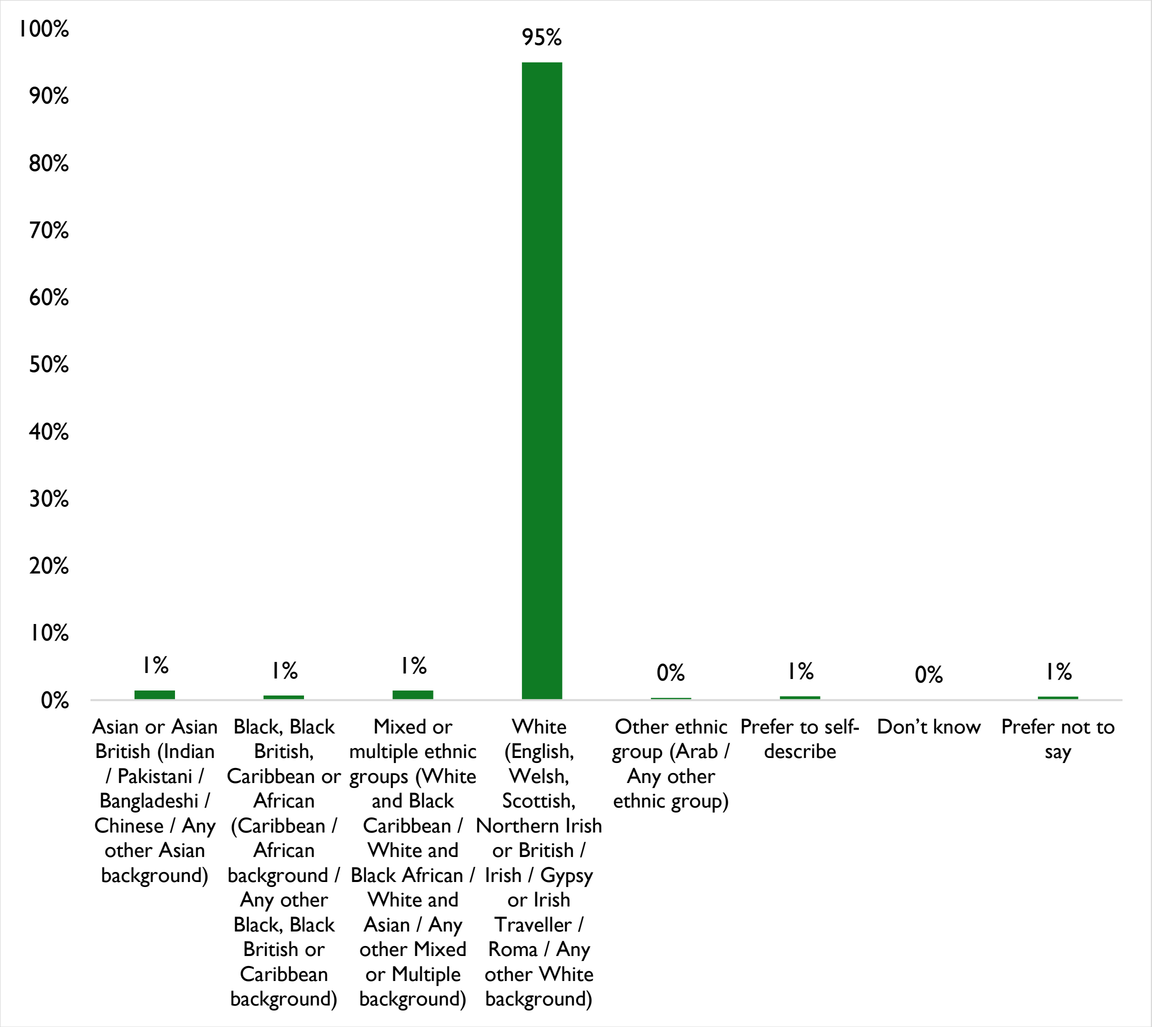

Figure 153. base n = 8633

Q – What is your postcode? [CODED]

The Local Health Commissioners where most responses were received were:

1. Gloucestershire (8%)
2. Hampshire and Isle of Wight (7%)
3. North East and North Cumbria (4%)
4. Cheshire and Merseyside (3%)
5. Humber and North Yorkshire (3%)

Local Health Commissioner	%
Aneurin Bevan University Health Board	1%
Ayrshire and Arran	1%
Betsi Cadwaladr University Health Board	2%
Borders	0%
Cardiff and Vale University Health Board	1%
Cwm Taf Morgannwg University Health Board	1%
Dumfries and Galloway	0%
Eastern Health Board	2%
Fife	1%
Forth Valley	1%
Grampian	1%
Greater Glasgow and Clyde	2%
Highland	1%
Hywel Dda University Health Board	1%
Lanarkshire	1%
Lothian	2%
NHS BATH AND NORTH EAST SOMERSET, SWINDON AND WILTSHIRE INTEGRATED CARE BOARD	2%

Local Health Commissioner	%
NHS BEDFORDSHIRE, LUTON AND MILTON KEYNES INTEGRATED CARE BOARD	1%
NHS BIRMINGHAM AND SOLIHULL INTEGRATED CARE BOARD	1%
NHS BLACK COUNTRY INTEGRATED CARE BOARD	1%
NHS BRISTOL, NORTH SOMERSET AND SOUTH GLOUCESTERSHIRE INTEGRATED CARE BOARD	1%
NHS BUCKINGHAMSHIRE, OXFORDSHIRE AND BERKSHIRE WEST INTEGRATED CARE BOARD	3%
NHS CAMBRIDGESHIRE AND PETERBOROUGH INTEGRATED CARE BOARD	1%
NHS CHESHIRE AND MERSEYSIDE INTEGRATED CARE BOARD	3%
NHS CORNWALL AND THE ISLES OF SCILLY INTEGRATED CARE BOARD	1%
NHS COVENTRY AND WARWICKSHIRE INTEGRATED CARE BOARD	1%
NHS DERBY AND DERBYSHIRE INTEGRATED CARE BOARD	2%
NHS DEVON INTEGRATED CARE BOARD	2%
NHS DORSET INTEGRATED CARE BOARD	2%
NHS FRIMLEY INTEGRATED CARE BOARD	1%
NHS GLOUCESTERSHIRE INTEGRATED CARE BOARD	8%
NHS GREATER MANCHESTER INTEGRATED CARE BOARD	2%
NHS HAMPSHIRE AND ISLE OF WIGHT INTEGRATED CARE BOARD	7%
NHS HEREFORDSHIRE AND WORCESTERSHIRE INTEGRATED CARE BOARD	2%
NHS HERTFORDSHIRE AND WEST ESSEX INTEGRATED CARE BOARD	2%
NHS HUMBER AND NORTH YORKSHIRE INTEGRATED CARE BOARD	3%

Local Health Commissioner	%
NHS KENT AND MEDWAY INTEGRATED CARE BOARD	2%
NHS LANCASHIRE AND SOUTH CUMBRIA INTEGRATED CARE BOARD	2%
NHS LEICESTER, LEICESTERSHIRE AND RUTLAND INTEGRATED CARE BOARD	1%
NHS LINCOLNSHIRE INTEGRATED CARE BOARD	1%
NHS MID AND SOUTH ESSEX INTEGRATED CARE BOARD	1%
NHS NORFOLK AND WAVENEY INTEGRATED CARE BOARD	2%
NHS NORTH CENTRAL LONDON INTEGRATED CARE BOARD	1%
NHS NORTH EAST AND NORTH CUMBRIA INTEGRATED CARE BOARD	4%
NHS NORTH EAST LONDON INTEGRATED CARE BOARD	1%
NHS NORTH WEST LONDON INTEGRATED CARE BOARD	1%
NHS NORTHAMPTONSHIRE INTEGRATED CARE BOARD	1%
NHS NOTTINGHAM AND NOTTINGHAMSHIRE INTEGRATED CARE BOARD	1%
NHS SHROPSHIRE, TELFORD AND WREKIN INTEGRATED CARE BOARD	1%
NHS SOMERSET INTEGRATED CARE BOARD	1%
NHS SOUTH EAST LONDON INTEGRATED CARE BOARD	2%
NHS SOUTH WEST LONDON INTEGRATED CARE BOARD	2%
NHS SOUTH YORKSHIRE INTEGRATED CARE BOARD	2%
NHS STAFFORDSHIRE AND STOKE-ON-TRENT INTEGRATED CARE BOARD	1%
NHS SUFFOLK AND NORTH EAST ESSEX INTEGRATED CARE BOARD	2%
NHS SURREY HEARTLANDS INTEGRATED CARE BOARD	1%

Local Health Commissioner	%
NHS SUSSEX INTEGRATED CARE BOARD	3%
NHS WEST YORKSHIRE INTEGRATED CARE BOARD	2%
Northern Health Board	1%
Orkney	0%
Powys Teaching Health Board	0%
Shetland	0%
Southern Health Board	1%
Swansea Bay University Health Board	1%
Tayside	1%
Western Health Board	0%
Western Isles	1%

Figure 164. base n = 7714

Q – What is your postcode? [CODED]

Most respondents were based in England (80%), with smaller proportions from Scotland (10%), Wales (6%), and Northern Ireland (3%).

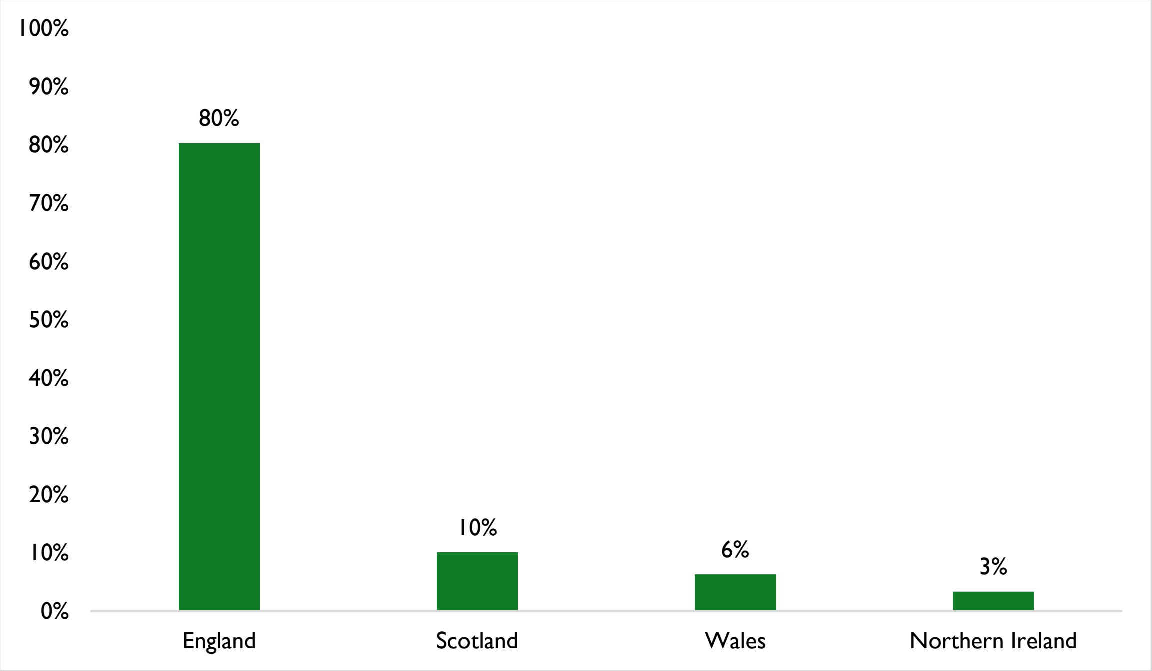

Figure 17. base n = 7714

Q – What is your highest level of education?

Respondents had diverse education levels, with the highest proportion holding a university degree (26%). Postgraduate qualifications were held by 18%, while GCSE or equivalent was the highest for 16%. Other qualifications (including A-level, Apprenticeships, and Diplomas) were less common.

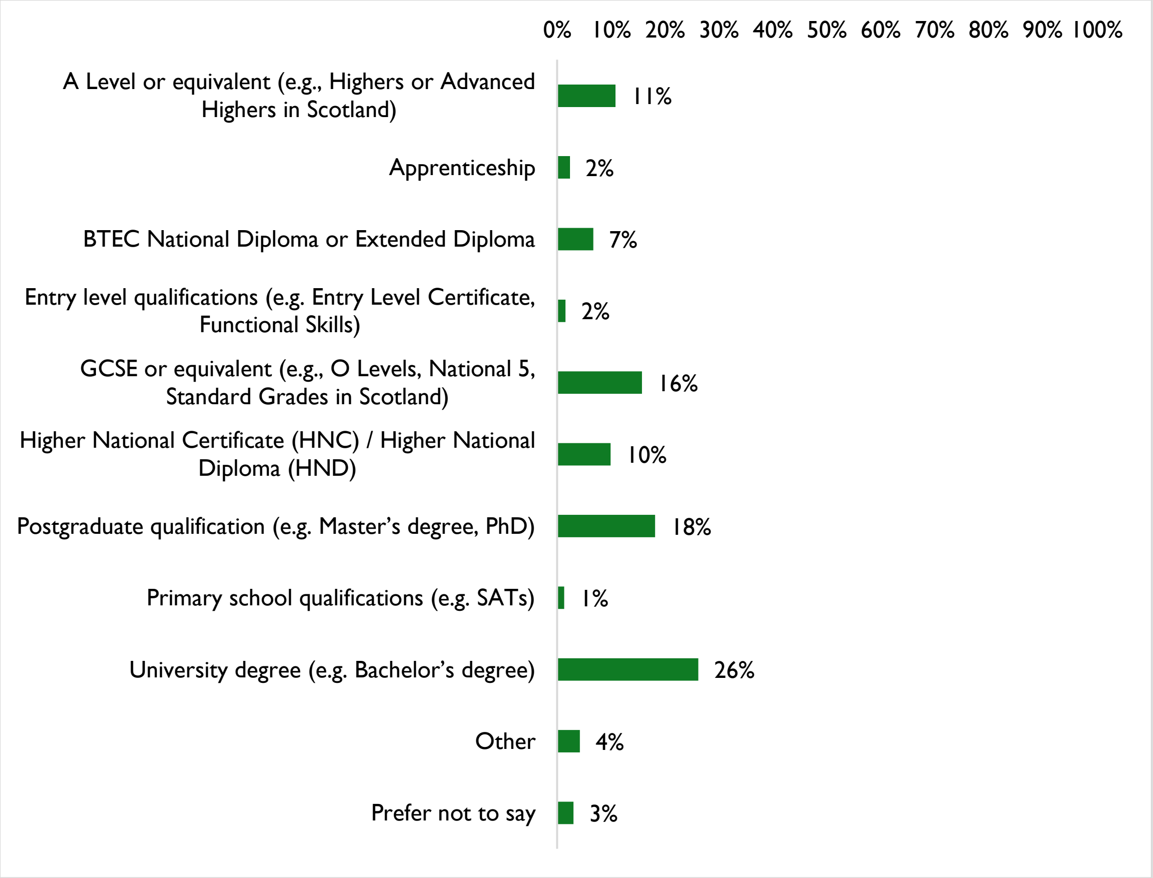

Figure 18. base n = 7746

Q – What is your current annual household income?

Nearly half of respondents had lower household incomes, with 25% earning less than £20,000, and 22% earning £20,000-£34,999. Smaller proportions earned higher incomes, while 19% preferred not to disclose their income.

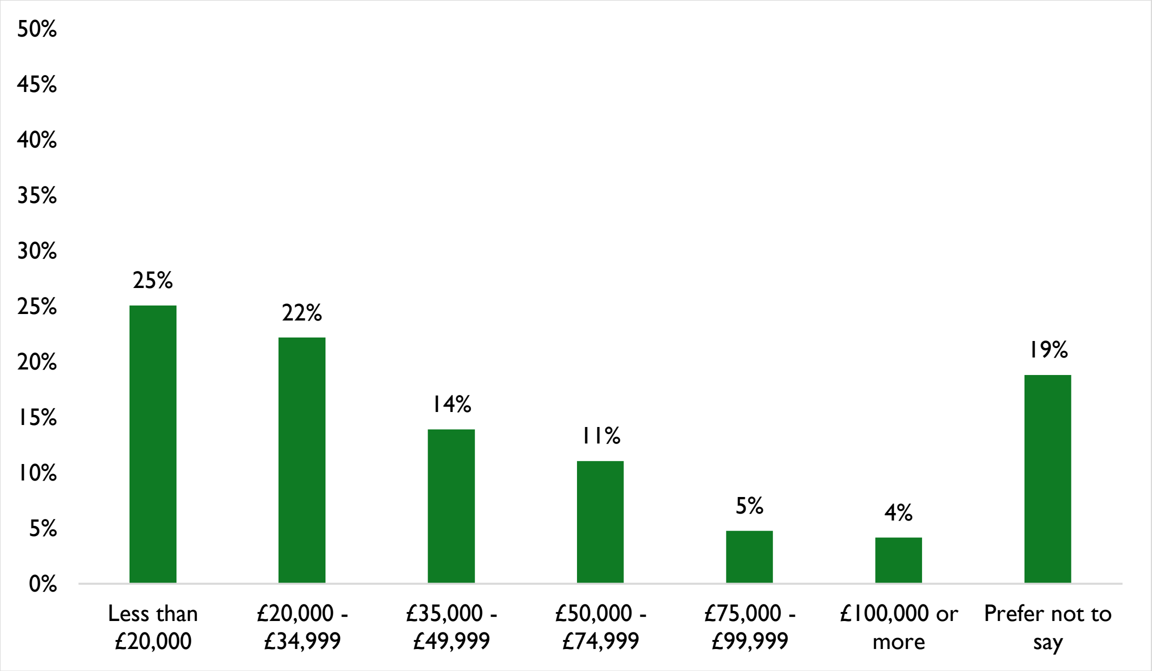

Figure 19. base n = 7767

Q – What is your current living situation?

Most respondents reported living with a spouse or significant other (62%), while 23% lived alone. Smaller groups lived with parents or relatives (11%), in supported accommodation (1%), or shared accommodation (less than 1%).

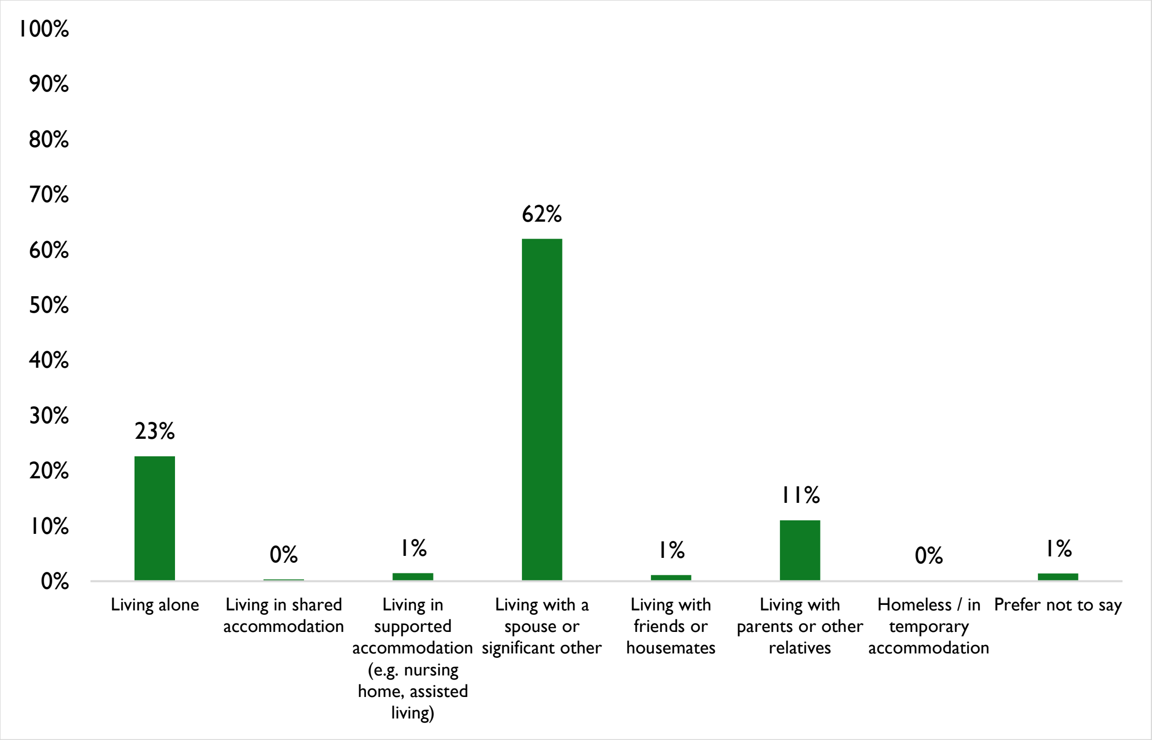

Figure 20. base n = 8636

Q – How does your neurological condition(s) affect your ability to do the following? (Complete daily tasks)

Nearly half (49%) reported significant difficulty ('Very much' 30%, 'Quite a lot' 19%) with daily tasks. Lesser impacts were reported by a further third ('Somewhat' 17%, 'A little' 18%), while 16% experienced no difficulty.

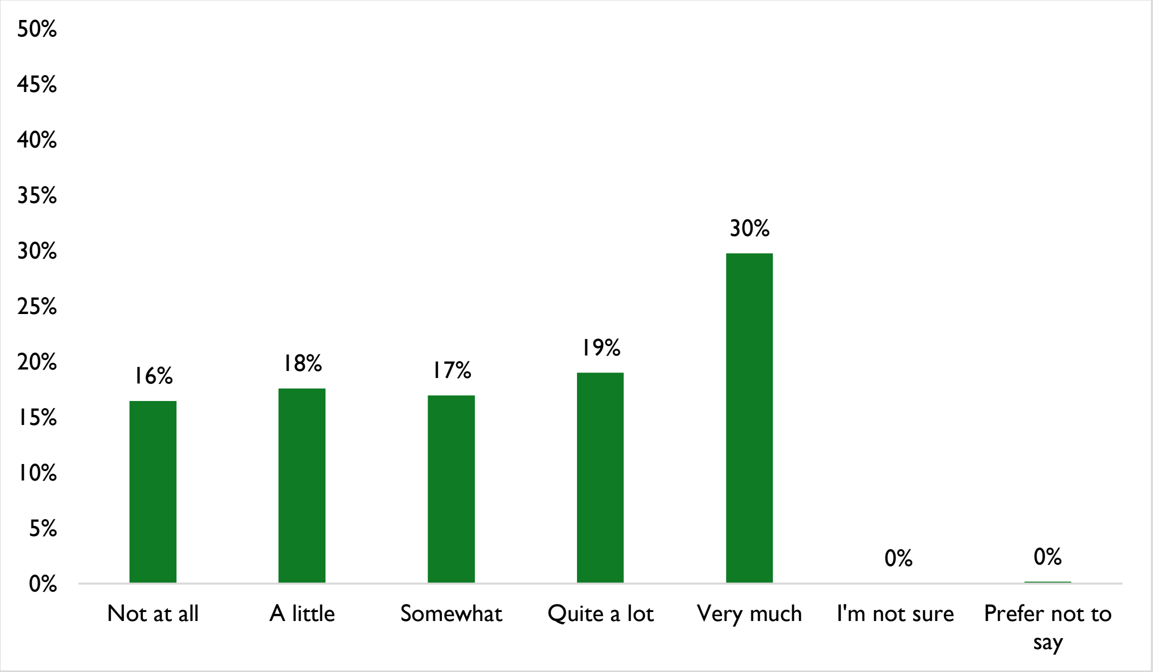

Figure 2921. base n = 8633

Q – How does your neurological condition(s) affect your ability to do the following? (Do fun things out and about)

A majority of respondents reported significant impacts ('Very much' 41%, 'Quite a lot' 20%) on their ability to participate in fun activities. Moderate ('Somewhat' 16%) to minimal ('A little' 14%) impacts were reported less frequently, with only 9% reporting no impact.

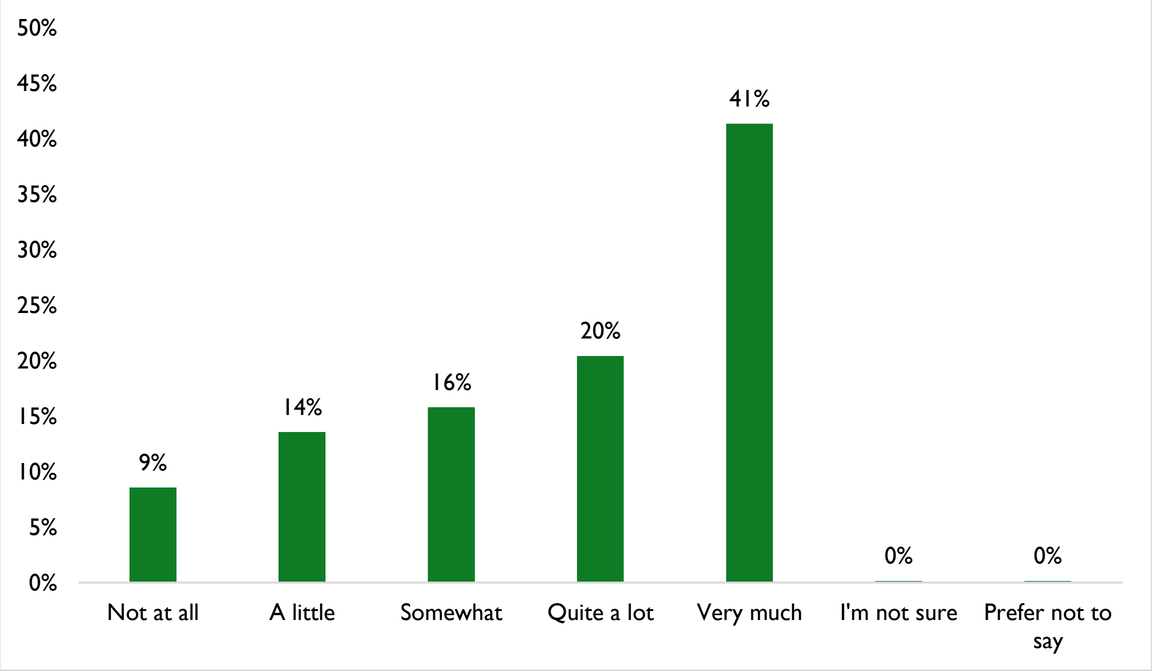

Figure 22. base n = 8626

Q – How does your neurological condition(s) affect your ability to do the following? (Socialise)

Socialising was significantly impacted for many respondents ('Very much' 36%, 'Quite a lot' 20%). Smaller proportions reported moderate ('Somewhat' 16%) or minimal impacts ('A little' 15%), while only 12% had no difficulty.

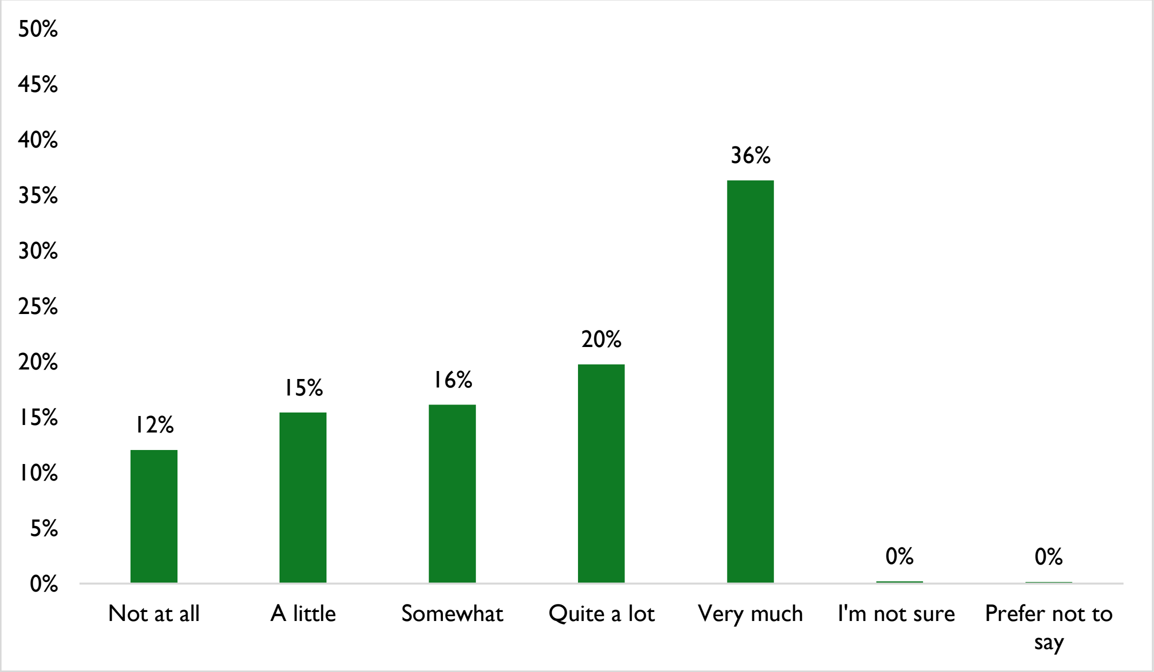

Figure 23. base n = 8607

Q – How does your neurological condition(s) affect your ability to do the following? (Be active)

Being physically active was significantly impacted, with over half (52%) experiencing 'Very much' difficulty and 15% 'Quite a lot'. Lesser impacts ('Somewhat' 12%, 'A little' 12%) were reported less frequently, and only 9% had no issues.

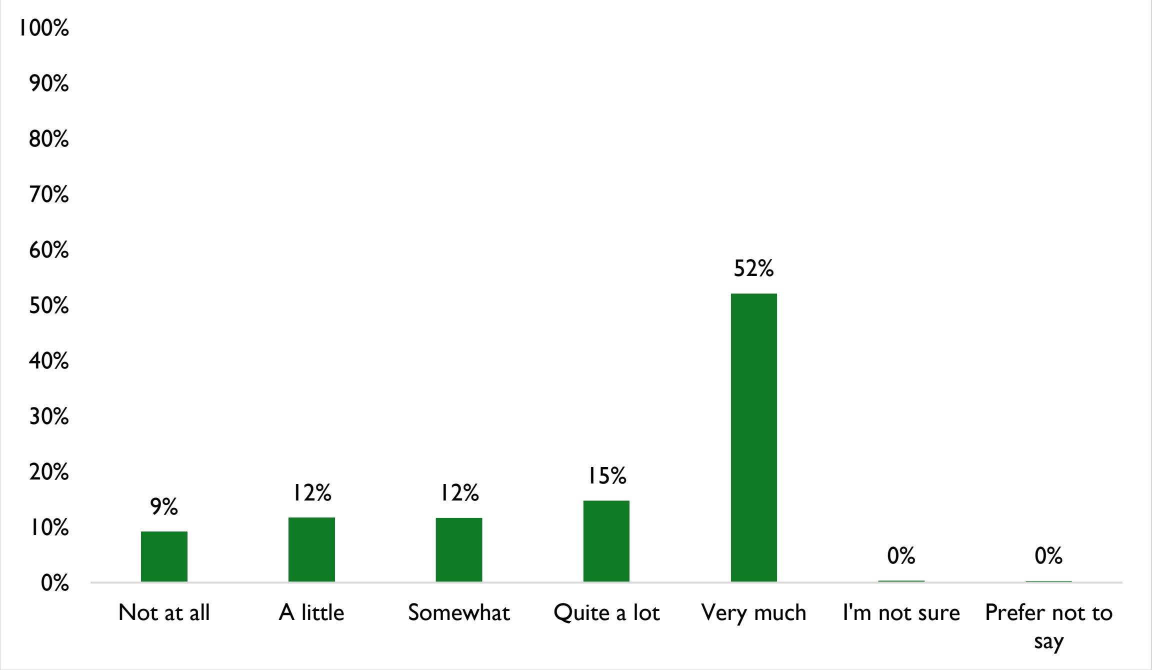

Figure 24. base n = 8609

Q – How does your neurological condition(s) affect your ability to do the following? (Maintain romantic relationships and intimacy)

Romantic relationships and intimacy posed significant difficulty for 29% ('Very much') and 11% ('Quite a lot') of respondents. Smaller proportions experienced moderate ('Somewhat' 13%) to minimal ('A little' 13%) impacts, with 21% reporting no impact. 13% were unsure or preferred not to say.

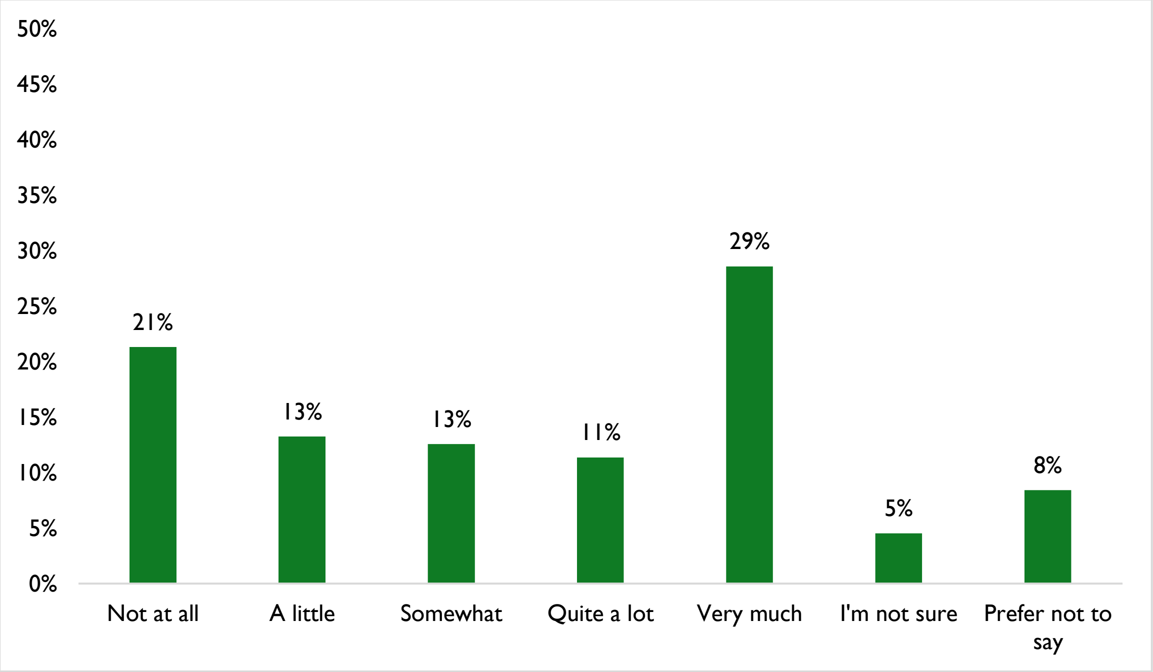

Figure 325. base n = 8591

Q – How does your neurological condition(s) affect your ability to do the following? (Maintain family relationships)

Respondents were fairly evenly split in their experiences. 22% said they are affected 'very much', and another 18% 'quite a lot'. An additional 36% experienced some or minor impact – 18% 'somewhat' and 18% 'a little'. 22% reported no difficulties, while 2% were unsure or preferred not to say.

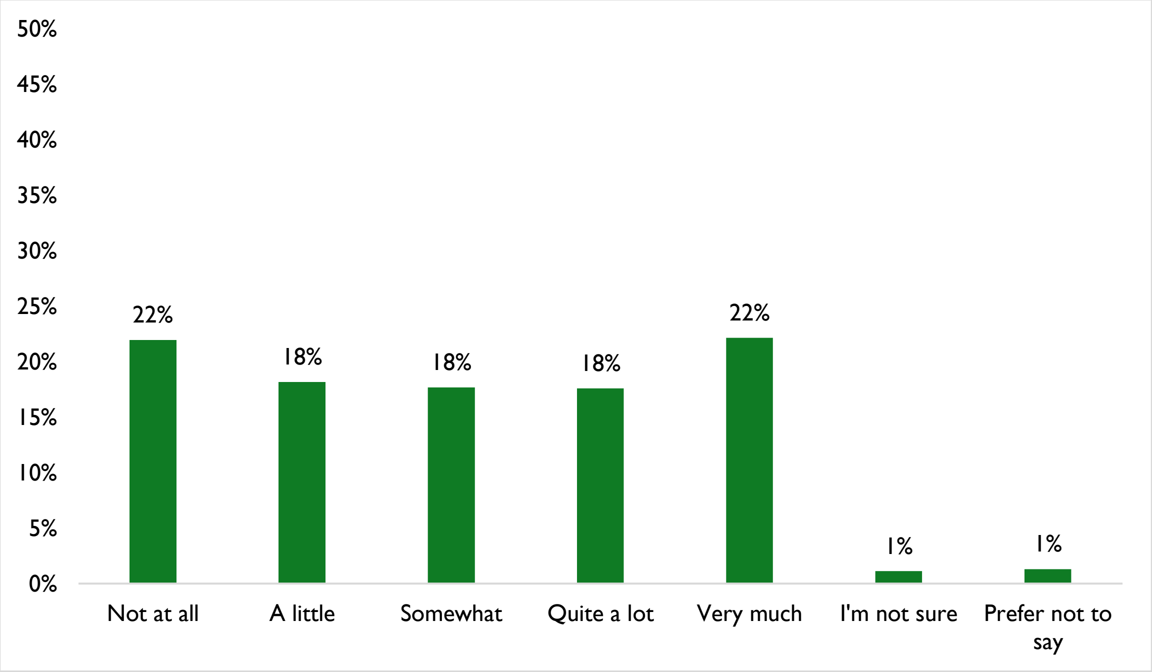

Figure 26. base n = 8612

Q – How does your neurological condition(s) affect your ability to do the following? (Manage financially)

One in five respondents (20%) said their neurological condition affects their ability to manage financially very much, and 12% said it impacts them quite a lot. A further 15% said it affects them somewhat and 17% said a little. A third (33%) reported that their condition does not at all affect their ability to manage financially. A small proportion (3%) were unsure or preferred not to say.

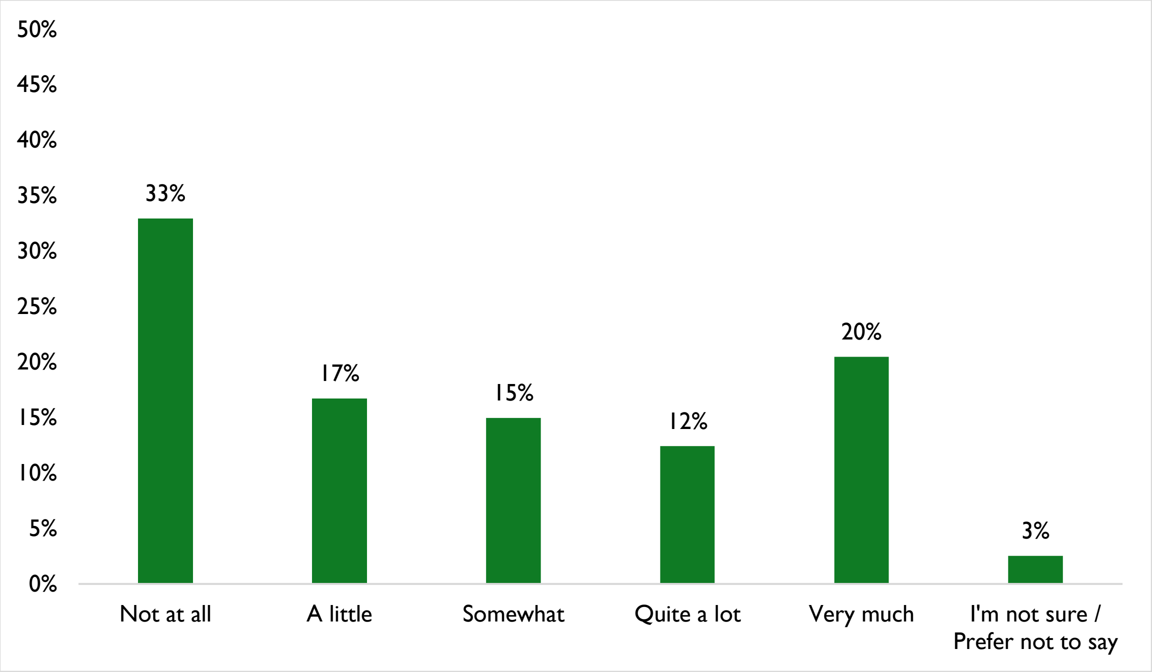

Figure 27. base n = 8619

Q – How does your neurological condition(s) affect your ability to do the following? (Work or study)

Just under half (45%) of respondents said they are 'very much' affected in their ability to work or study. 30% experienced some or moderate difficulty – 10% each for 'quite a lot', 'somewhat', and 'a little'. One in five (20%) reported no impact, while 5% were unsure or preferred not to answer.

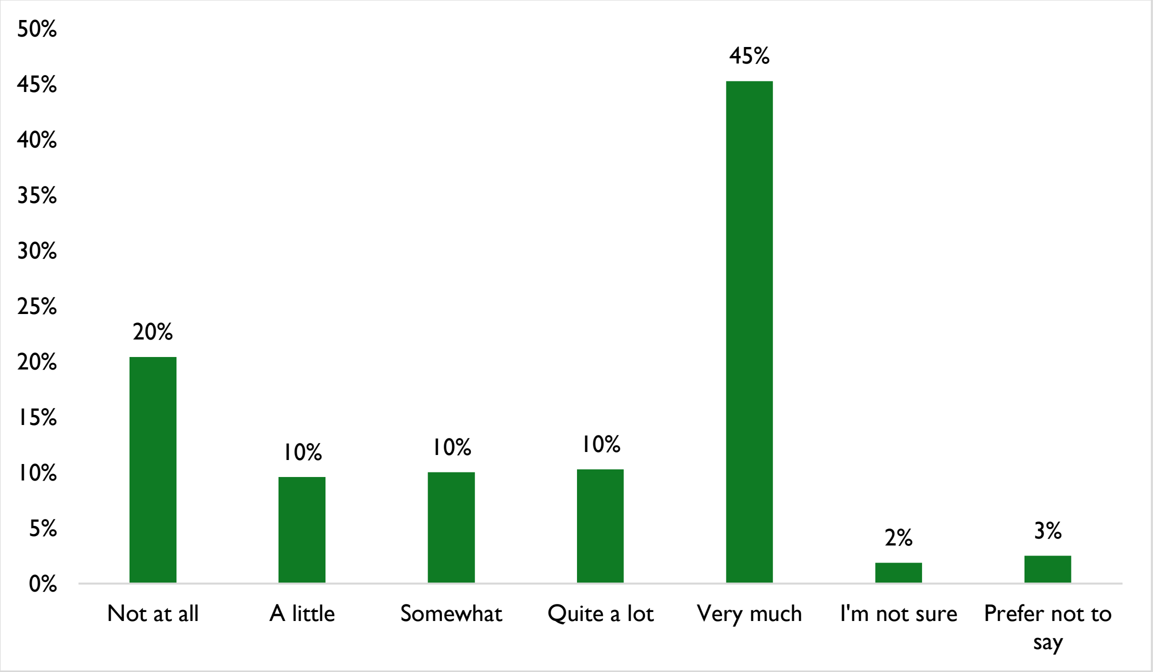

Figure 28. base n = 8598

Q – How do you feel most of the time about your own life?

Respondents varied in how they feel about their day-to-day life. 28% found every day challenging, and 30% said they regularly face challenges. A further 31% sometimes found it challenging. Only 11% said they feel confident and capable. 1% preferred not to say.

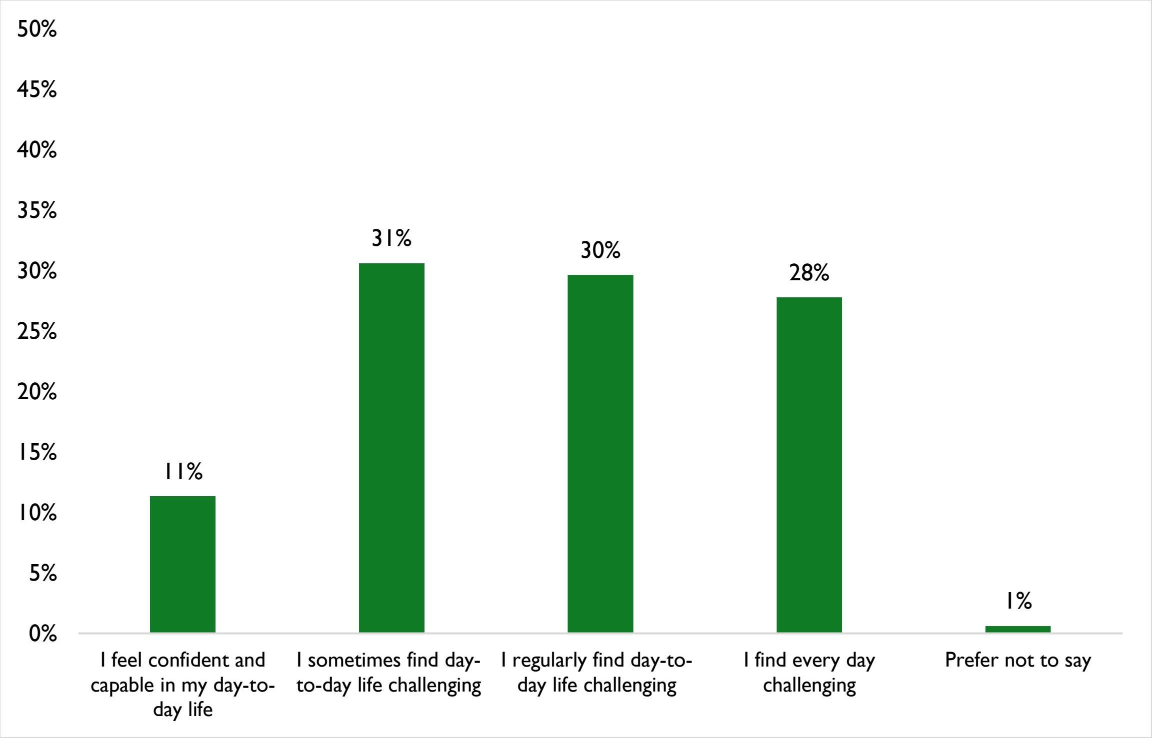

Figure 29. base n = 7776

Q – Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? I can afford the additional costs associated with treatments for my condition(s)

Only 5% of respondents strongly agreed they could afford additional treatment costs, and 23% agreed. However, 38% disagreed or strongly disagreed, indicating financial strain. 21% neither agreed nor disagreed, 11% said it was not applicable, and 2% preferred not to say.

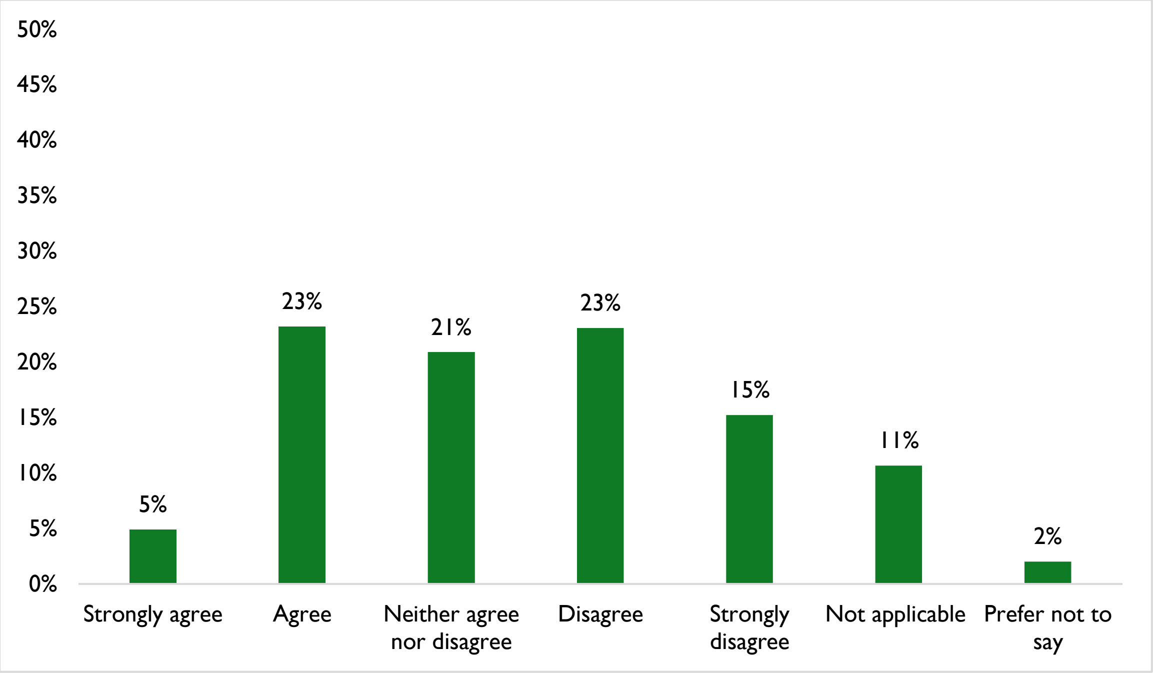

Figure 30. base n = 7759

Q – Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? I have reliable transportation or assistance to attend appointments

A majority of respondents agreed they have reliable transport or assistance to attend appointments – 17% 'strongly agree' and 45% 'agree'. However, one in five expressed disagreement (13% 'disagree', 8% 'strongly disagree'), while 11% neither agreed nor disagreed. An additional 5% said it was not applicable.

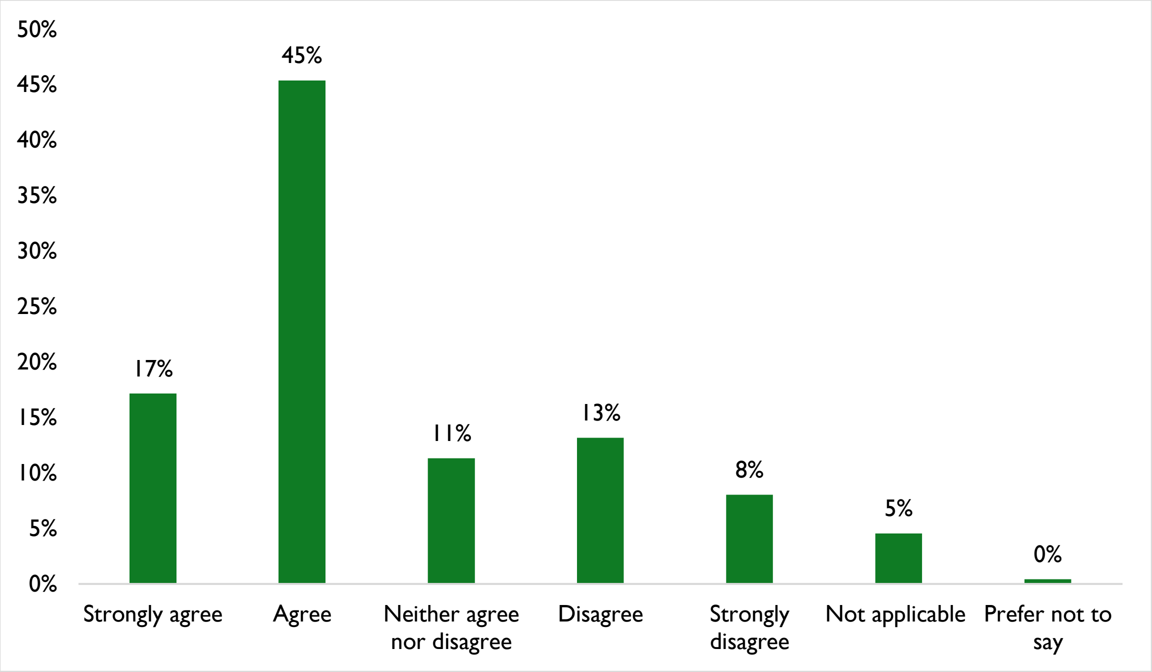

Figure 3931. base n = 7765

Q – Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? I can schedule appointments without conflicts with other commitments

Over half of respondents reported they can schedule appointments without conflicts – 12% 'strongly agree' and 43% 'agree'. However, just under a quarter reported difficulties (17% 'disagree', 6% 'strongly disagree'), and 18% neither agreed nor disagreed. 4% found this question not applicable, while 1% preferred not to say.

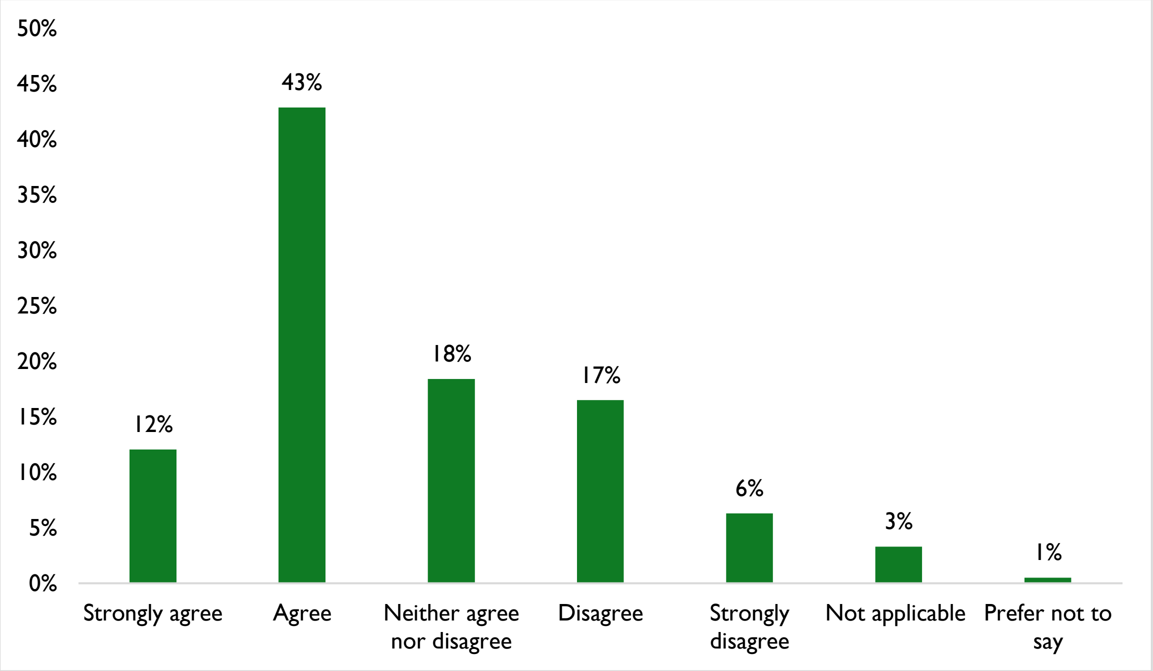

Figure 320. base n = 7755

Q – Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? I have someone to talk to about my mental health and well-being

Nearly half of respondents said they have someone to talk to about mental health – 10% 'strongly agree' and 34% 'agree'. Over a third did not – 22% 'disagree' and 14% 'strongly disagree'. 16% neither agreed nor disagreed, and 4% said it was not applicable.

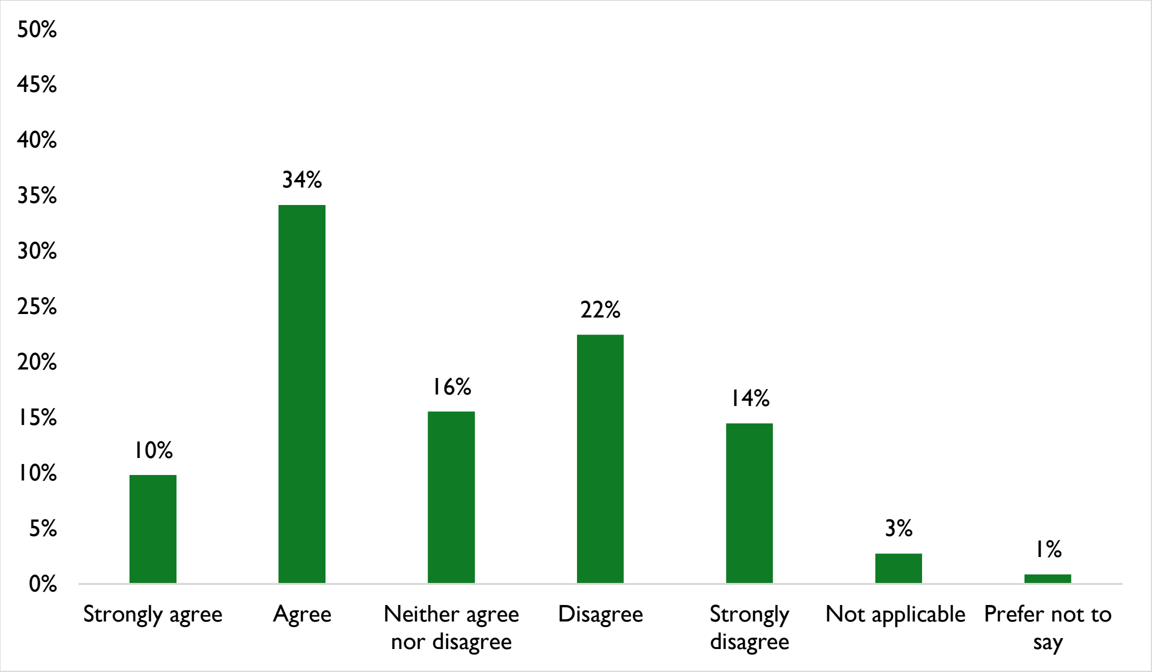

Figure 331. base n = 7758

Q – Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? I feel involved in decisions about my treatment, care, and support plan

Half of respondents felt involved in decisions about their treatment and care – 14% 'strongly agree' and 36% 'agree'. However, a quarter disagreed (15% 'disagree', 11% 'strongly disagree'), and 19% were neutral. 5% felt the question did not apply.

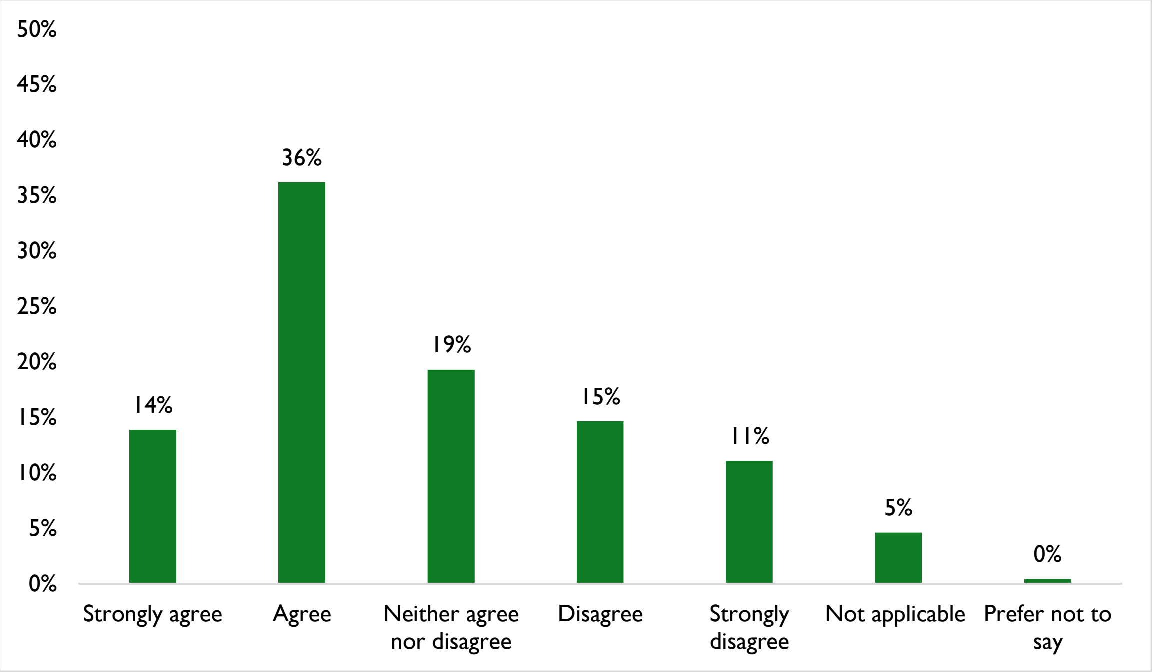

Figure 342. base n = 7751

Q – Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? I understand my condition(s) and treatment options available

Most respondents said they understand their condition and treatment options – 18% 'strongly agree' and 43% 'agree'. One in five expressed disagreement – 13% 'disagree' and 7% 'strongly disagree'. 16% neither agreed nor disagreed, while 2% found the question not applicable.

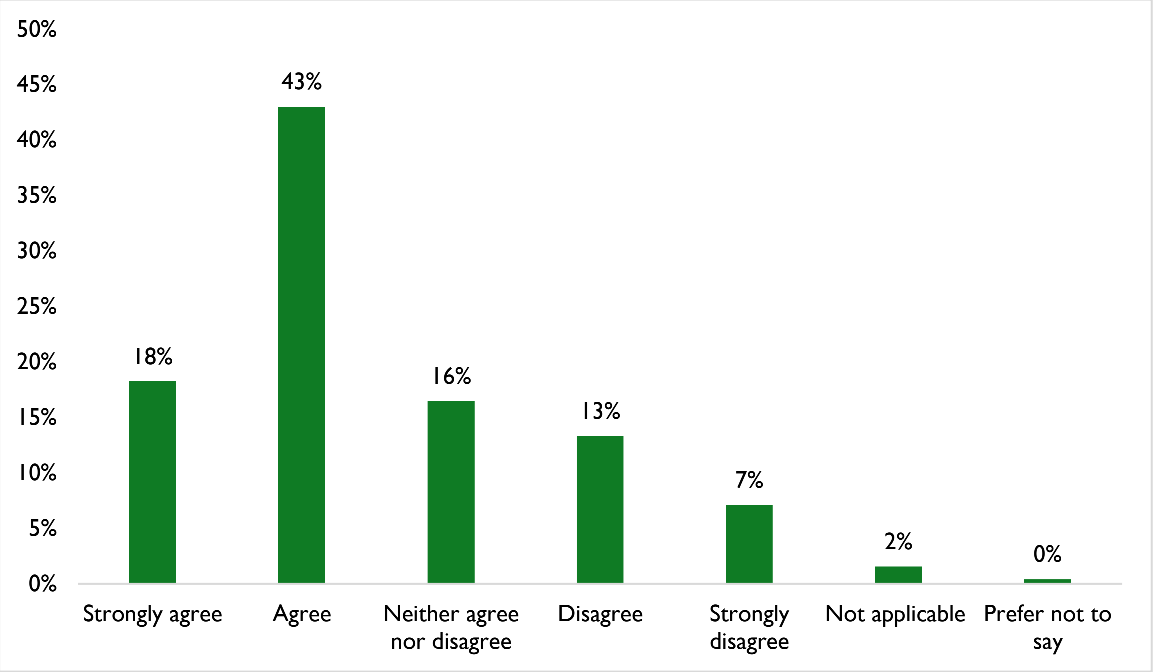

Figure 35. base n = 7754

Q – Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? I feel supported by the health system

Less than a third agreed they feel supported by the health system – 8% 'strongly agree' and 24% 'agree'. Just under half disagreed – 22% 'disagree' and 26% 'strongly disagree'. 19% neither agreed nor disagreed, and 1% marked not applicable.

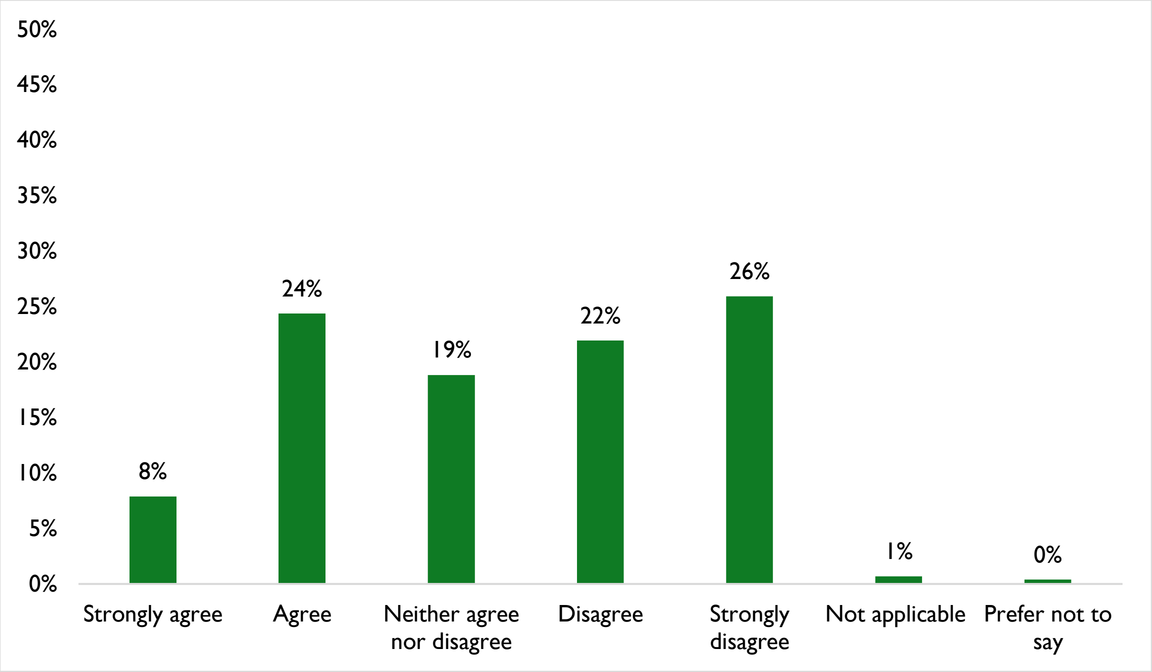

Figure 36. base n = 7762

Q – Thinking about your wider life, to what extent do you agree or disagree with the following statements regarding managing your condition(s)? My housing is suitable for my needs

Two thirds of respondents said their housing was suitable – 20% 'strongly agree' and 45% 'agree'. 19% reported that their housing was not suitable (12% 'disagree', 7% 'strongly disagree'), and 14% were neutral. 2% said it was not applicable.

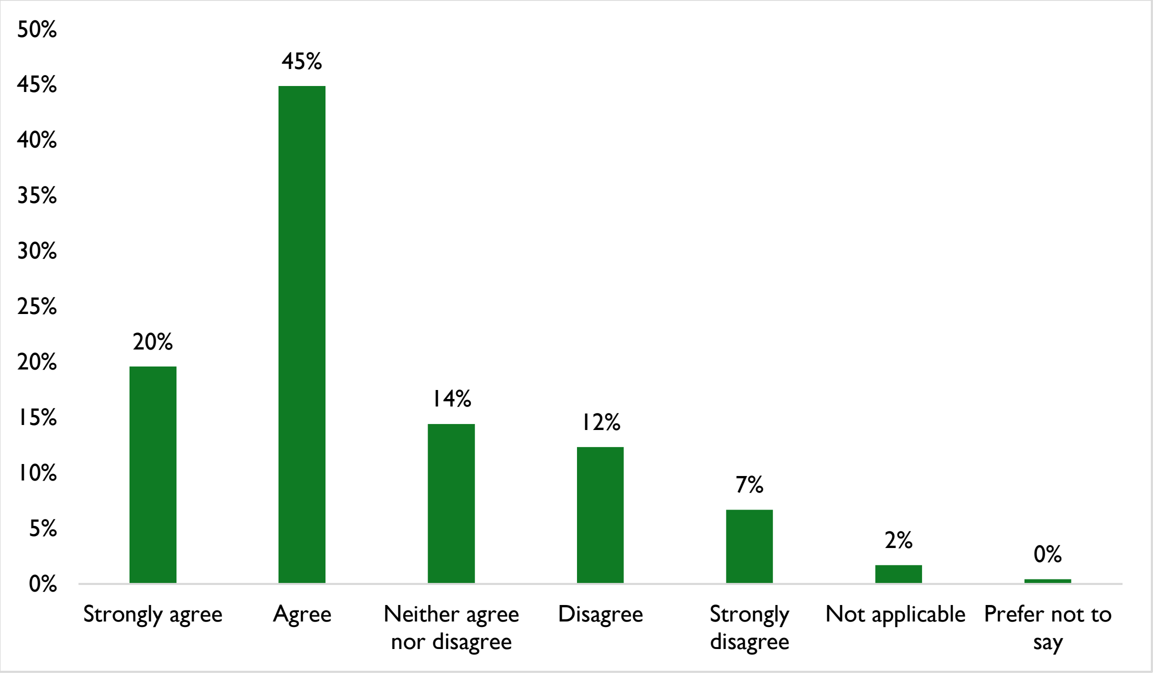

Figure 37. base n = 7765

Q – I have been discriminated against at work due to attitudes towards my neurological condition(s)

Over a quarter of respondents reported experiencing workplace discrimination – 14% 'strongly agree' and 14% 'agree'. A similar proportion disagreed (16% 'disagree', 14% 'strongly disagree'), and 11% were neutral. Notably, 30% indicated the question was not applicable.

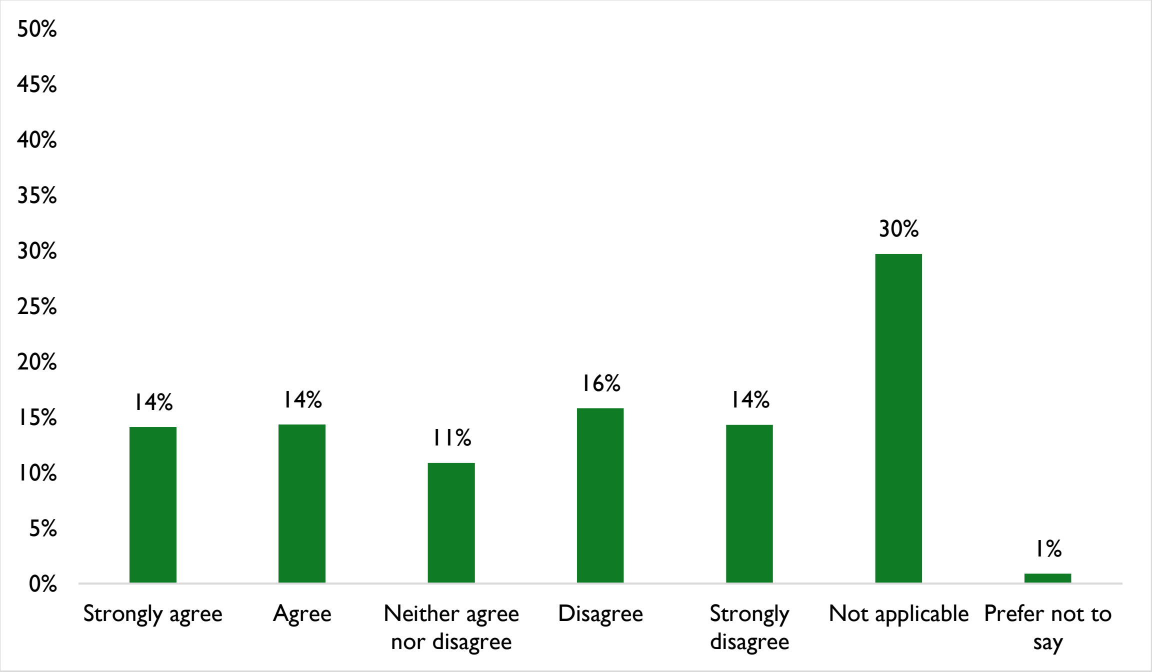

Figure 38. base n = 7747

Q – I have stopped working because of my neurological condition(s)

Almost half of respondents reported stopping work due to their condition – 33% 'strongly agree' and 16% 'agree'. A quarter disagreed (12% each for 'disagree' and 'strongly disagree'), and 7% were neutral. 19% said the question was not applicable.

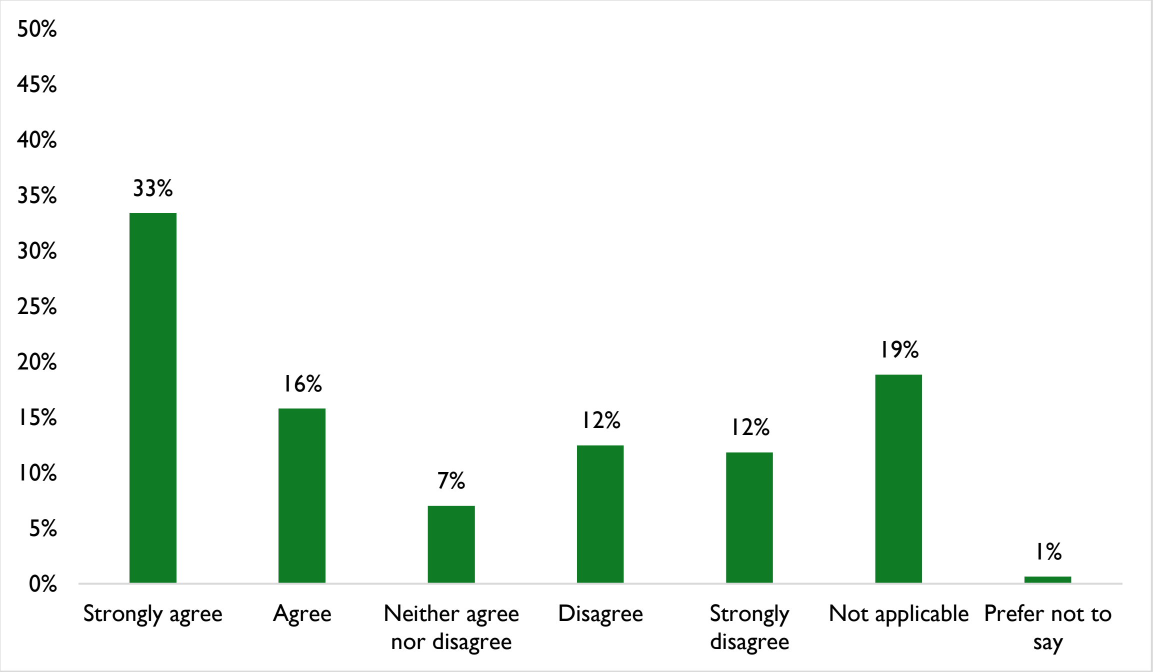

Figure 39. base n = 7749

Q – I have needed specific support in order to retain my employment

A majority of respondents (43%) said the question was not applicable. Of the rest, 28% agreed they needed specific support – 11% 'strongly agree' and 17% 'agree'. 18% disagreed (9% 'disagree', 8% 'strongly disagree'), and 11% were neutral.

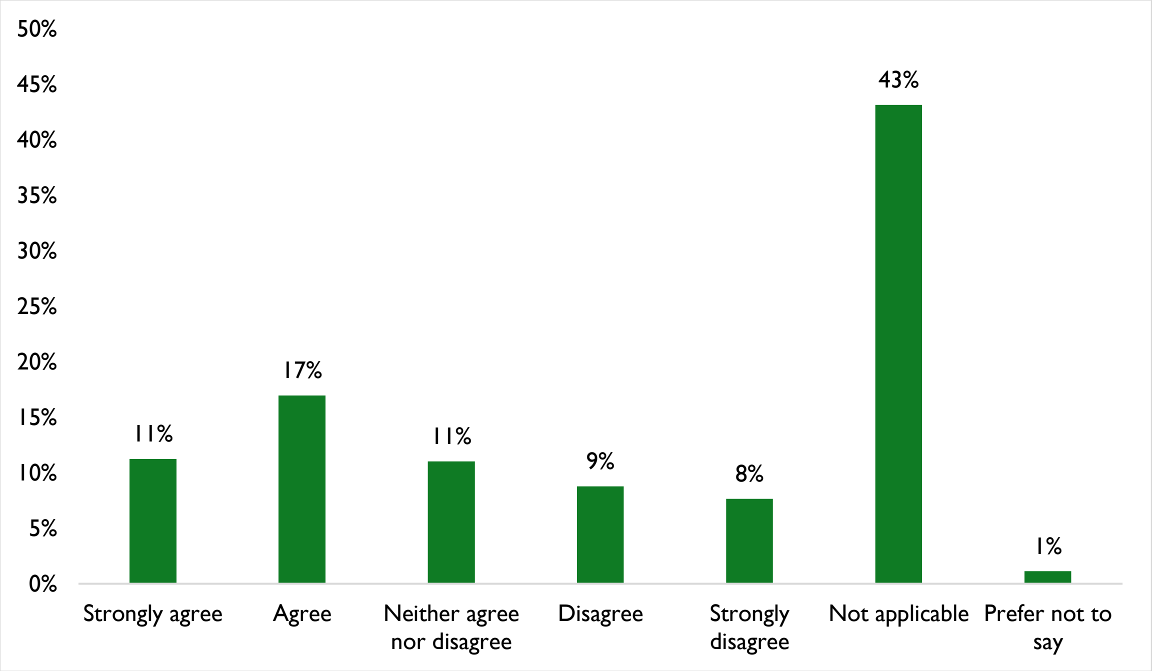

Figure 40. base n = 7742

Q – I have needed specific support in order to enter the workforce

Half of respondents (50%) said this question was not applicable. Among the remainder, 14% agreed they needed specific support to enter employment – 6% 'strongly agree' and 8% 'agree'. 24% disagreed (12% each for 'disagree' and 'strongly disagree'), and 12% were neutral.

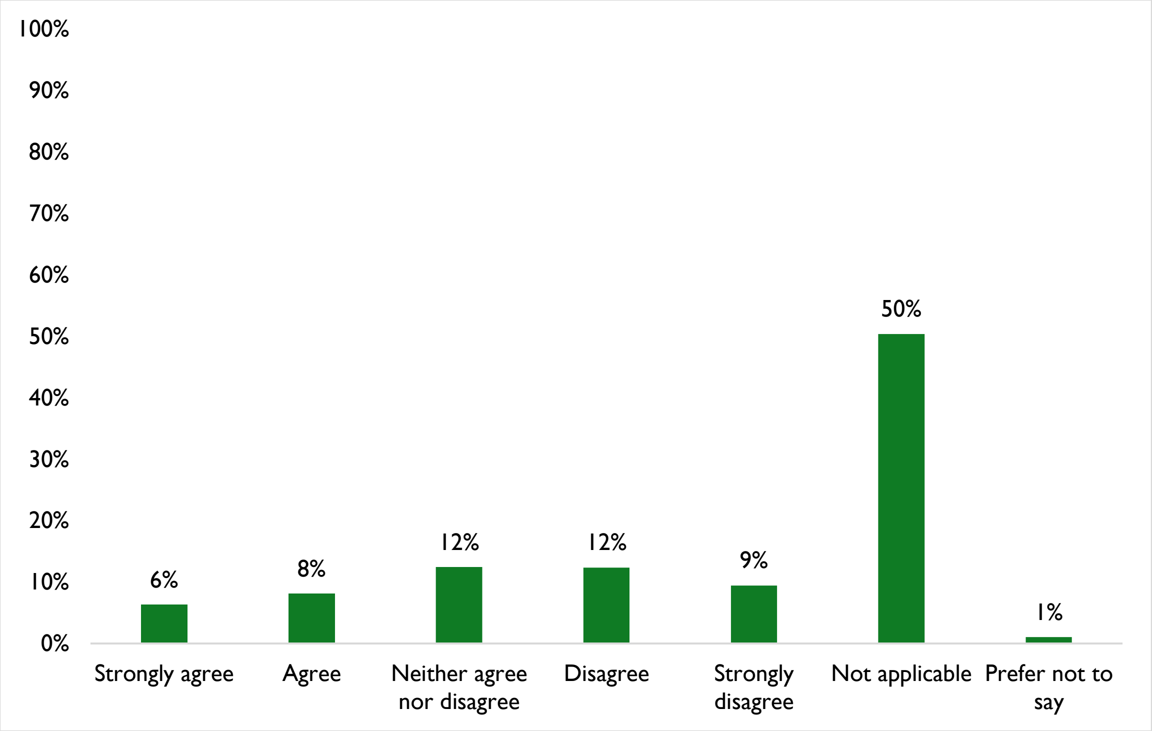

Figure 4941. base n = 7745

Q – I have had to leave a job because of my employer's actions/inaction

A total of 22% of respondents said they had left a job due to employer behaviour – 13% 'strongly agree' and 9% 'agree'. 32% disagreed (16% 'disagree' and 16% 'strongly disagree'), 8% were neutral, and 38% said the question was not applicable. 2% preferred not to say.

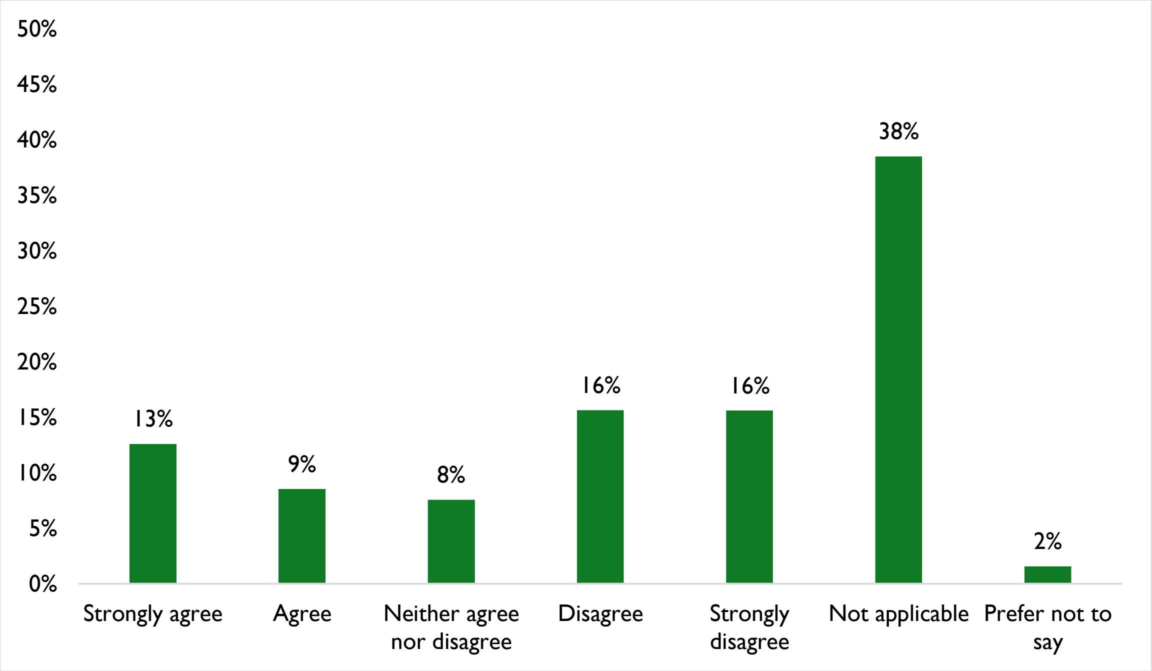

Figure 420. base n = 7738

Q – Which of the following types of support do you receive?

Most respondents reported receiving support from family or friends (78%), followed by financial support (45%) and support from state-funded professionals (41%). One in five (20%) reported receiving no support for their condition, while 18% paid for support themselves or through family. Support from charities was reported by 15%, and 5% said they don't need support. 1% preferred not to say and 3% selected 'Other'.

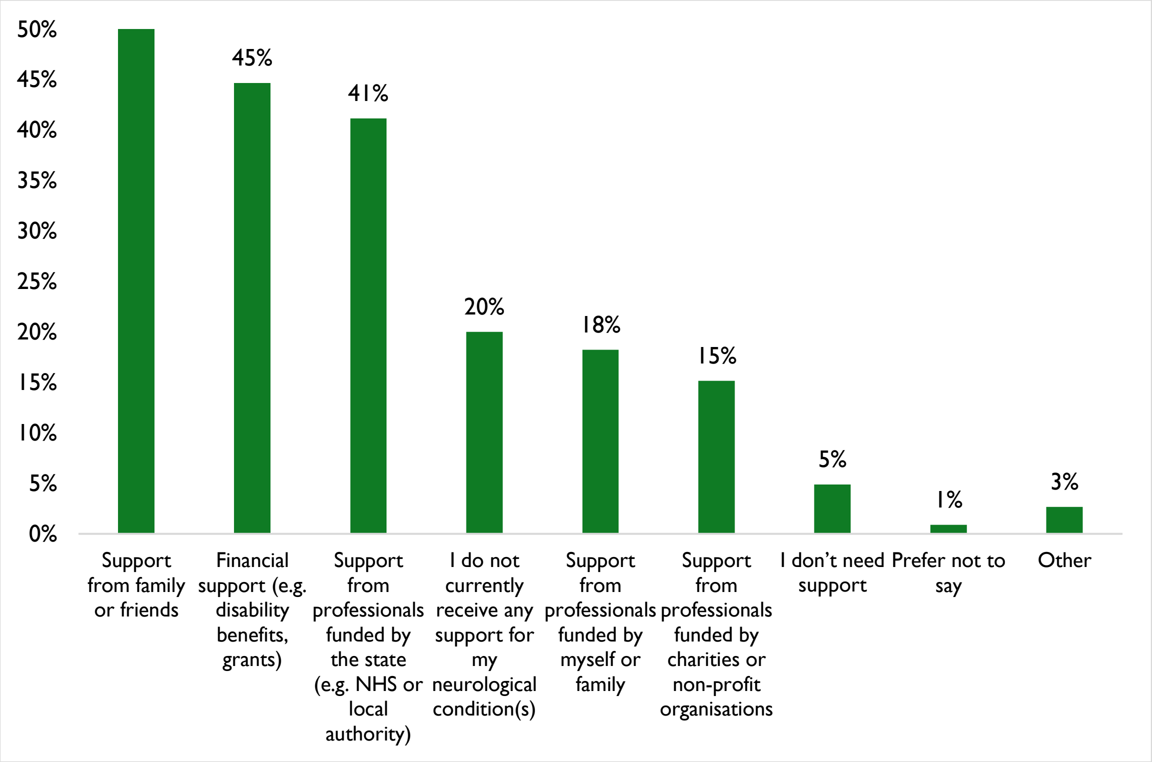

Figure 431. base n = 7766

Q – If you haven't received the support you need, what are the main reasons?

The most reported reason for not receiving support was lack of awareness (27%), followed by being denied support after asking (17%) and not knowing how to access it (16%). Other notable reasons included ineligibility (16%), being on a waiting list (11%), and unaffordability (12%). 18% said they did not need support, while 13% selected 'Other' and 9% preferred not to say.

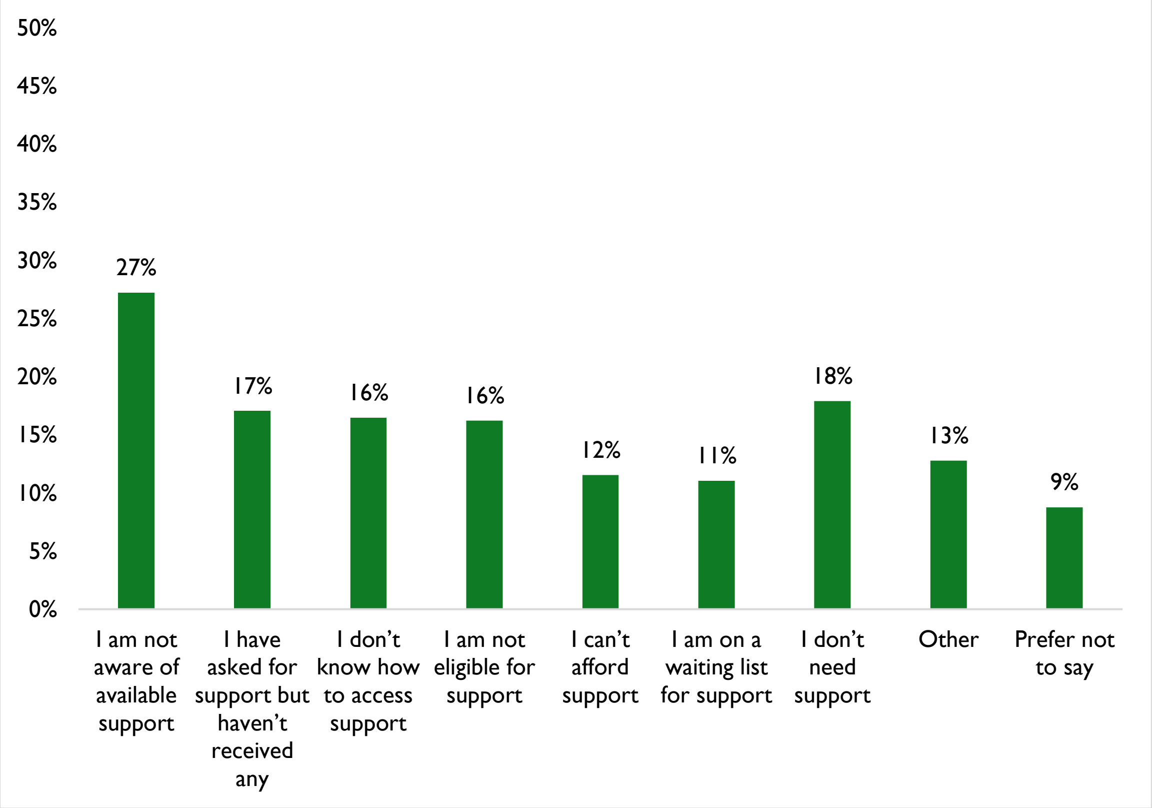

Figure 442. base n = 7834

Q – Would you be interested in taking part in research studies about your condition(s) to help others with neurological condition(s)?

A large majority (70%) of respondents said they would be interested in participating in research about their condition to help others. 19% were unsure, 10% said no, and 1% preferred not to say.

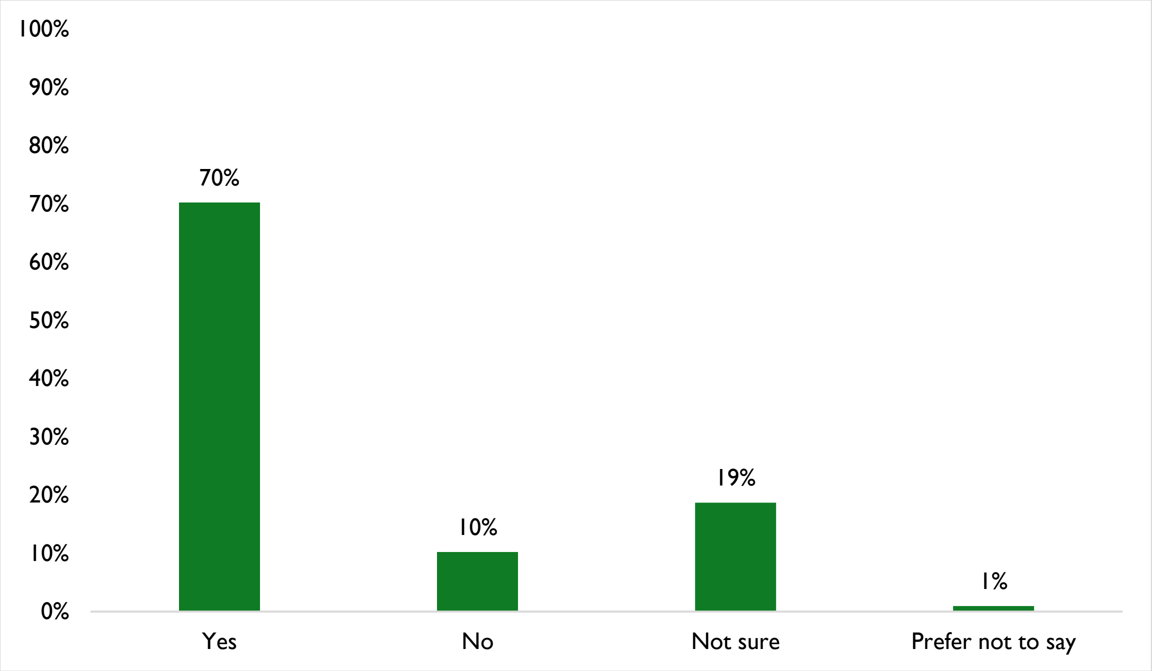

Figure 453. base n = 7765

Q – Have you already participated in research about your neurological condition(s)?

Over a quarter of respondents (27%) reported having already participated in research. A majority (62%) had not, while 10% were unsure.

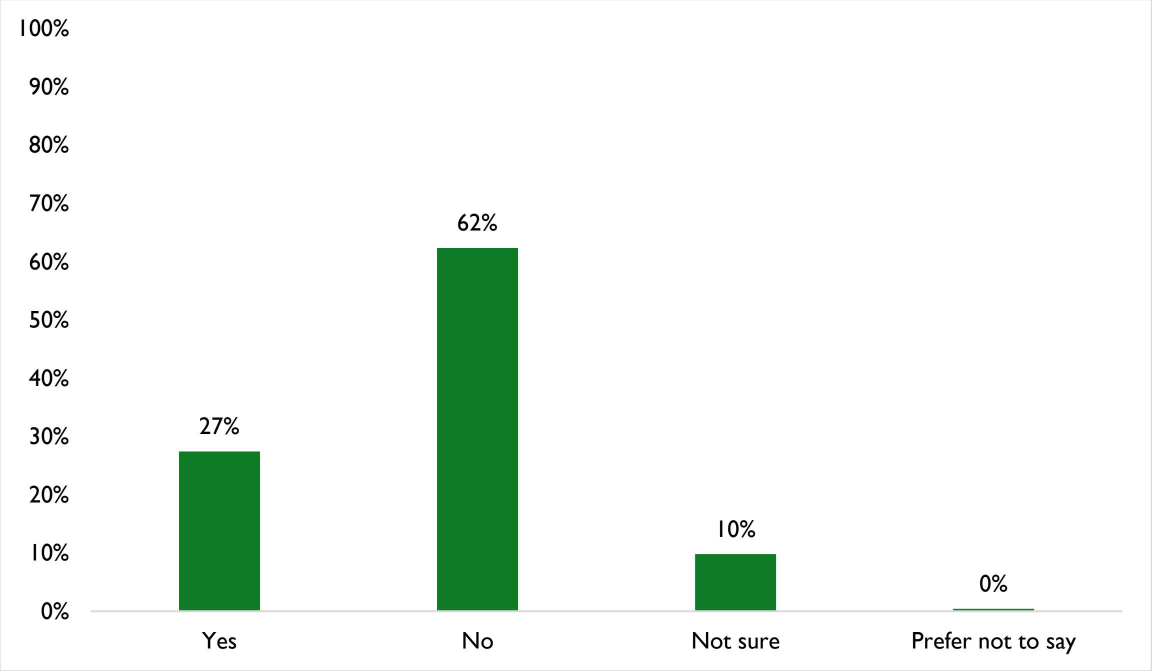

Figure 464. base n = 7767

Q – How many times in the past 12 months have you had a planned hospital visit due to your neurological condition?

Almost two-thirds of respondents had at least one planned hospital visit in the past year. The most common frequency was 1-2 times (38%), followed by no visits (35%). 16% had 3-5 visits, and 9% had six or more. 2% were unsure or preferred not to say.

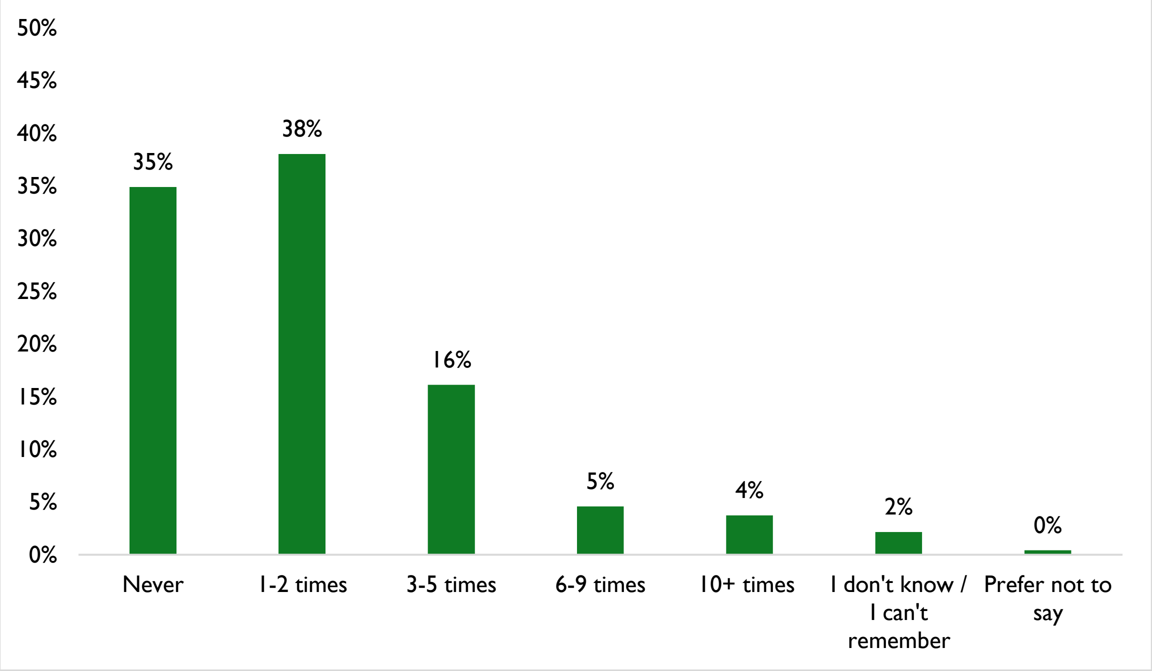

Figure 475. base n = 8615

Q – How many times in the past 12 months have you had an emergency hospital visit due to your neurological condition?

The majority (72%) had no emergency hospital visits in the past year. 19% had 1-2 emergency visits, and 6% had three or more. The remaining 3% did not know or preferred not to say.

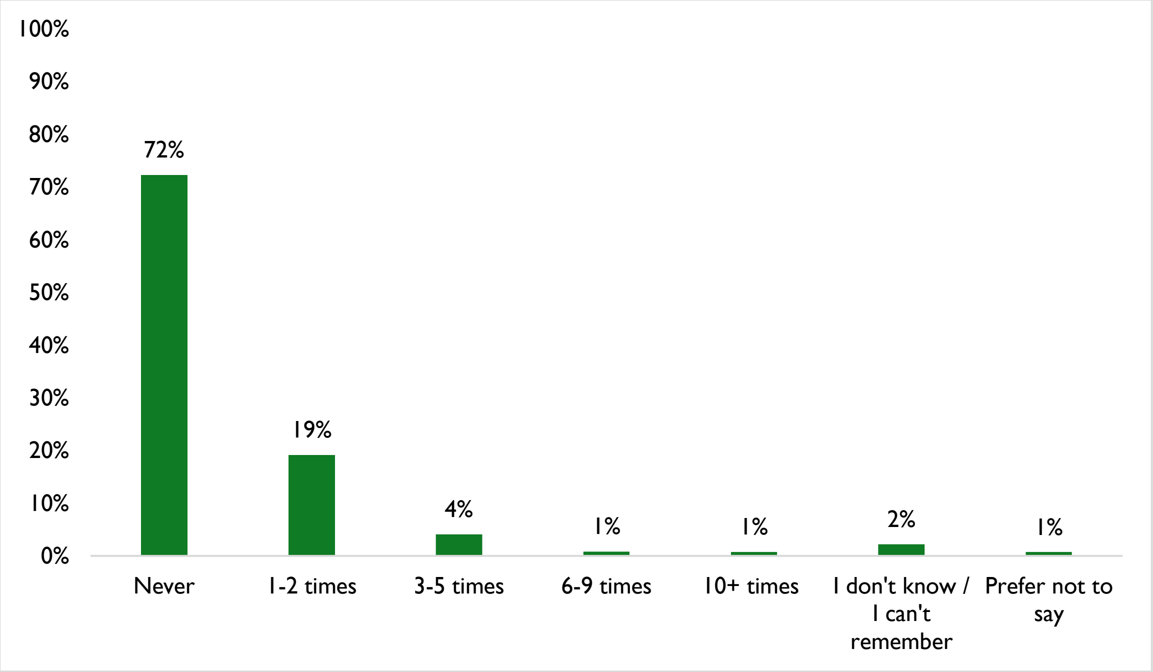

Figure 486. base n = 8570

Q – In the last 12 months, have you used any of the following services for your neurological condition(s)?

The five most commonly used services were:

- GP (used by 74% of respondents)
- Neurologist (59%)
- Scans (e.g., MRI, CT) (50%)
- Physiotherapy (38%)
- Specialist nurse (29%)

The least commonly used services were:

- End of life care (2%)
- Palliative care (2%)
- Respite care (2%)

Where individuals reported that a service was relevant, the five services most frequently reported as inaccessible were:

- Neuropsychiatry (69%)
- Respite care (66%)
- Inpatient neurorehabilitation (64%)
- Neuropsychology (61%)
- Personal assistant support (61%)

Where individuals reported they had received support from a service, the five services most frequently reported as meeting needs were:

- Scans (e.g., MRI, CT) (86%)
- Specialist nurse (83%)
- End of life care (82%)
- Home adaptations (78%)
- Community transport (77%)

Row %	**I/they had it and it met needs**	**I/they had it and it did not meet needs**	**I/they have not been able to access it**	**Not relevant**	**I don't know what this is**	**Prefer not to say**
Audiology	8%	3%	6%	76%	5%	2%
Care Planning	6%	3%	12%	62%	13%	2%
Community transport	5%	2%	11%	76%	5%	2%

Row %	**I/they had it and it met needs**	**I/they had it and it did not meet needs**	**I/they have not been able to access it**	**Not relevant**	**I don't know what this is**	**Prefer not to say**
Neurologist	42%	17%	22%	15%	2%	2%
Continence Supports	12%	5%	9%	66%	5%	3%
Counselling	12%	9%	23%	50%	2%	4%
Day Services	4%	1%	9%	73%	12%	2%
Dietician	7%	4%	17%	68%	2%	2%
End of Life Care	1%	0%	2%	93%	1%	2%
GP	44%	30%	7%	16%	0%	3%
Home adaptations	19%	5%	13%	57%	3%	3%
Inpatient Neurorehabilitation	2%	1%	9%	69%	17%	2%
Neuropsychiatry	2%	2%	12%	60%	22%	2%
Neuropsychology	4%	2%	13%	57%	22%	2%
Neurosurgery	5%	2%	5%	79%	8%	2%
Occupational Therapy	18%	9%	16%	50%	4%	2%
Orthotics	9%	4%	5%	65%	15%	2%
Outpatient Neurorehabilitation	5%	2%	12%	61%	18%	2%
Pain services	6%	9%	22%	53%	7%	2%
Palliative Care	1%	0%	2%	91%	3%	2%

Row %	**I/they had it and it met needs**	**I/they had it and it did not meet needs**	**I/they have not been able to access it**	**Not relevant**	**I don't know what this is**	**Prefer not to say**
Personal Assistant	4%	1%	11%	75%	7%	2%
Physiotherapy	22%	17%	17%	41%	2%	2%
Respiratory Services	7%	2%	5%	79%	4%	2%
Respite care	1%	1%	7%	85%	4%	2%
Scans (e.g. MRI, CT)	43%	7%	12%	35%	1%	2%
Social Worker	5%	4%	10%	76%	2%	2%
Specialist Nurse	24%	5%	14%	51%	4%	2%
Speech and language therapy	10%	3%	7%	76%	2%	2%
Spinal surgery	2%	1%	4%	89%	2%	2%
Supported living/residential care	2%	1%	5%	88%	3%	2%
Wheelchair Services	9%	4%	10%	72%	3%	2%

Figure 497. base n = from 761 to 8469

Q – Thinking about your neurological care you have waited for or are still waiting for, how long have you been waiting?

Adults most often reported that this was ‘not applicable’ to them. 11% of the sample reported that they had waited more than 2 years for the neurologist, with 8% reporting this about scans and 7% about pain services. 19% of adults reported they had waited less than 3 months for the GP, with 6% reporting this for scans and 5% for continence supports, physiotherapy, and neurologist.

Row %	Less than 3 months	3-6 months	7-11 months	1-2 years	More than 2 years	Still waiting	Not applicable	I don't know / I can't remember	Prefer not to say
Audiology	4%	3%	3%	4%	4%	17%	51%	12%	2%
Care Planning	2%	2%	2%	4%	5%	27%	41%	15%	3%
Community transport	2%	2%	1%	1%	2%	17%	55%	16%	3%
Neurologist	5%	5%	5%	13%	11%	20%	28%	11%	2%
Continence Supports	5%	5%	3%	4%	4%	20%	39%	14%	6%
Counselling	3%	4%	3%	5%	6%	26%	37%	13%	4%
Day Services	2%	1%	1%	2%	3%	17%	56%	14%	3%
Dietician	3%	2%	3%	3%	4%	24%	44%	15%	3%
End of Life Care	3%	0%	1%	1%	3%	13%	67%	9%	3%
GP	19%	6%	5%	4%	5%	12%	31%	13%	4%
Home adaptations	2%	2%	2%	4%	6%	24%	44%	12%	4%
Inpatient Neurorehabilitation	1%	1%	2%	3%	5%	20%	54%	12%	3%
Neuropsychiatry	2%	2%	2%	3%	5%	27%	44%	12%	3%
Neuropsychology	1%	3%	3%	3%	6%	29%	40%	12%	3%
Neurosurgery	1%	1%	3%	4%	6%	19%	55%	9%	2%
Occupational Therapy	4%	4%	3%	4%	5%	25%	39%	13%	3%

Row %	**Less than 3 months**	**3-6 months**	**7-11 months**	**1-2 years**	**More than 2 years**	**Still waiting**	**Not applicable**	**I don't know / I can't remember**	**Prefer not to say**
Orthotics	4%	3%	2%	4%	4%	16%	50%	14%	3%
Outpatient Neurorehabilitation	2%	2%	3%	3%	5%	26%	43%	13%	2%
Pain services	2%	2%	3%	5%	7%	29%	35%	14%	4%
Palliative Care	4%	1%	1%	1%	2%	15%	66%	8%	2%
Personal Assistant	1%	1%	1%	2%	4%	20%	52%	15%	4%
Physiotherapy	5%	5%	4%	5%	6%	27%	32%	13%	3%
Respiratory Services	3%	2%	3%	4%	4%	20%	51%	11%	2%
Respite care	2%	1%	1%	1%	5%	23%	53%	10%	5%
Scans (e.g. MRI, CT)	6%	5%	2%	6%	8%	23%	36%	11%	2%
Social Worker	2%	2%	1%	2%	6%	25%	44%	15%	3%
Specialist Nurse	3%	2%	3%	4%	6%	28%	38%	12%	3%
Speech and language therapy	4%	4%	3%	3%	5%	23%	44%	11%	3%
Spinal surgery	1%	2%	2%	4%	5%	20%	54%	8%	4%
Supported living / residential care	1%	1%	2%	1%	4%	19%	56%	12%	4%
Wheelchair Services	2%	1%	1%	3%	4%	25%	43%	15%	5%

Figure 58. base n = from 45 to 2045

Q – In the last 12 months, have you been offered or directed to any information about your neurological condition(s) by the following?

Respondents most frequently received information from their own research (39%), followed by neurologists (32%) and GPs (20%). Other sources included specialist nurses (20%), charities (23%), peer support groups (18%), and social media (16%). 27% said they had not received any information, while 1% preferred not to say and 4% selected 'Other'.

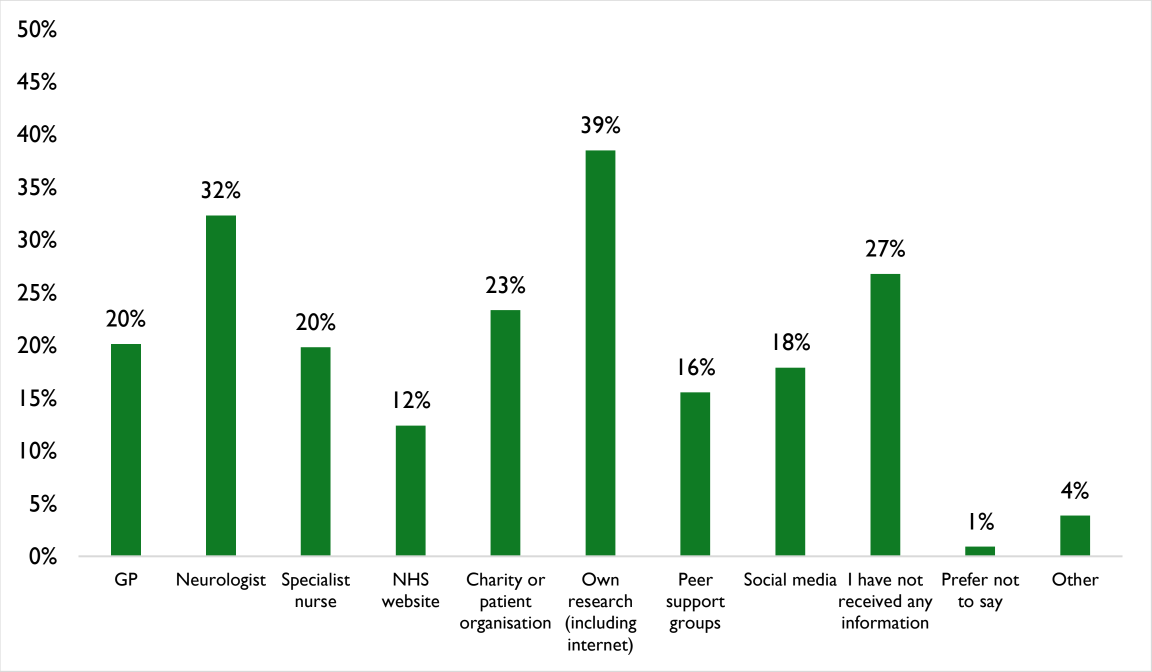

Figure 59. base n = 7725

Q – How helpful did you find the information from these sources?

Respondents generally found information helpful – 39% said it was 'helpful' and 18% 'very helpful'. 26% were neutral, while 8% found it unhelpful (4% each for 'unhelpful' and 'very unhelpful'). 9% preferred not to say.

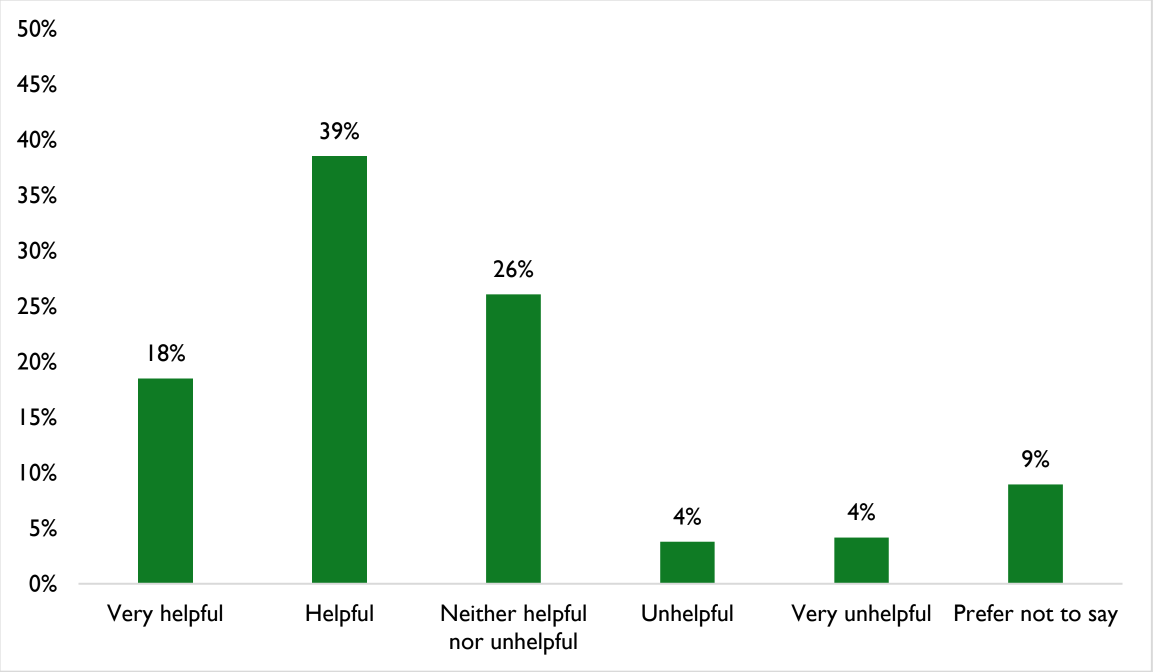

Figure 60. base n = 7685

Q – I feel comfortable talking to healthcare professionals and asking questions during appointments

Most respondents felt comfortable engaging with healthcare professionals – 29% 'strongly agree' and 42% 'agree'. Only 17% expressed discomfort (11% 'disagree', 6% 'strongly disagree'), while 10% were neutral. 1% said the question was not applicable.

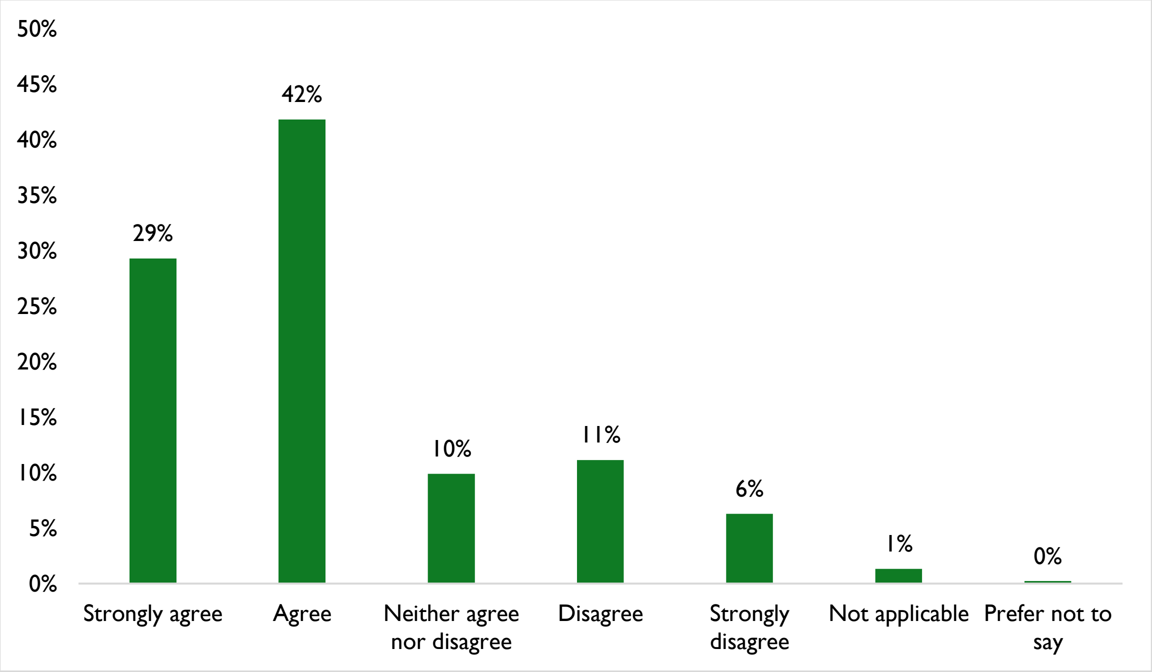

Figure 501. base n = 7755

Q – I have enough time during appointments to discuss all my concerns

Less than half of respondents (45%) felt they had enough time during appointments – 14% 'strongly agree' and 31% 'agree'. 39% disagreed – 24% 'disagree' and 15% 'strongly disagree'. 14% were neutral, and 3% said the question was not applicable.

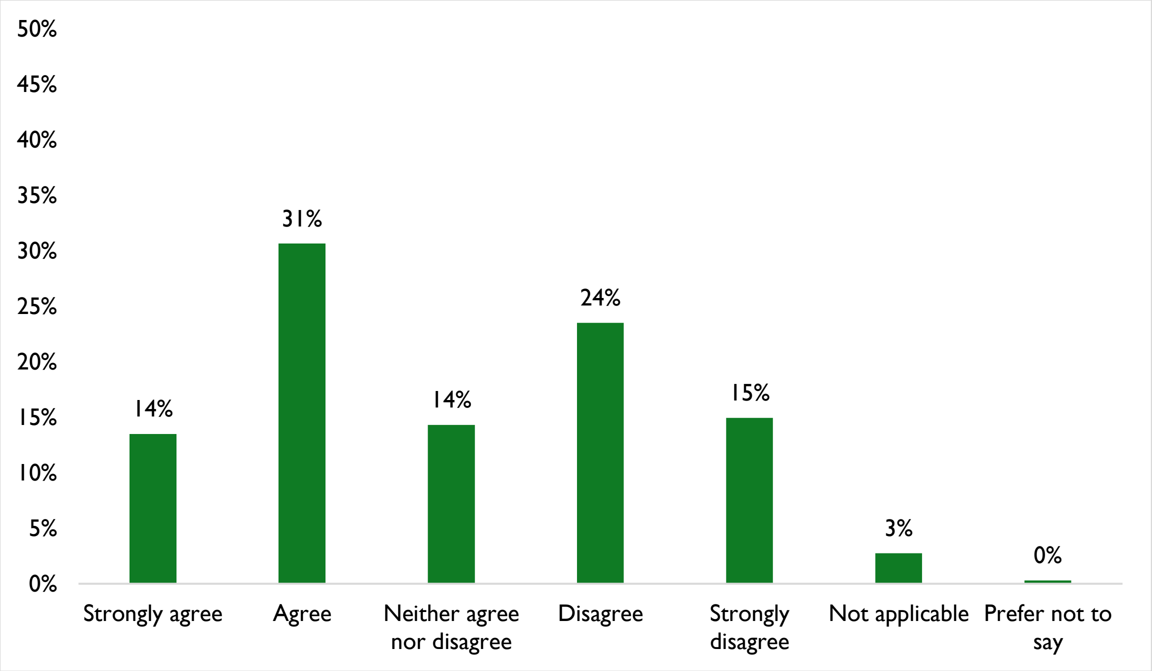

Figure 512. base n = 7747

Q – I feel like my preferences and priorities are considered when discussing treatment options

Just under half of respondents felt their preferences were considered – 13% 'strongly agree' and 34% 'agree'. 26% disagreed (16% 'disagree', 10% 'strongly disagree'), while 22% were neutral. 6% said the question was not applicable, and 1% preferred not to say.

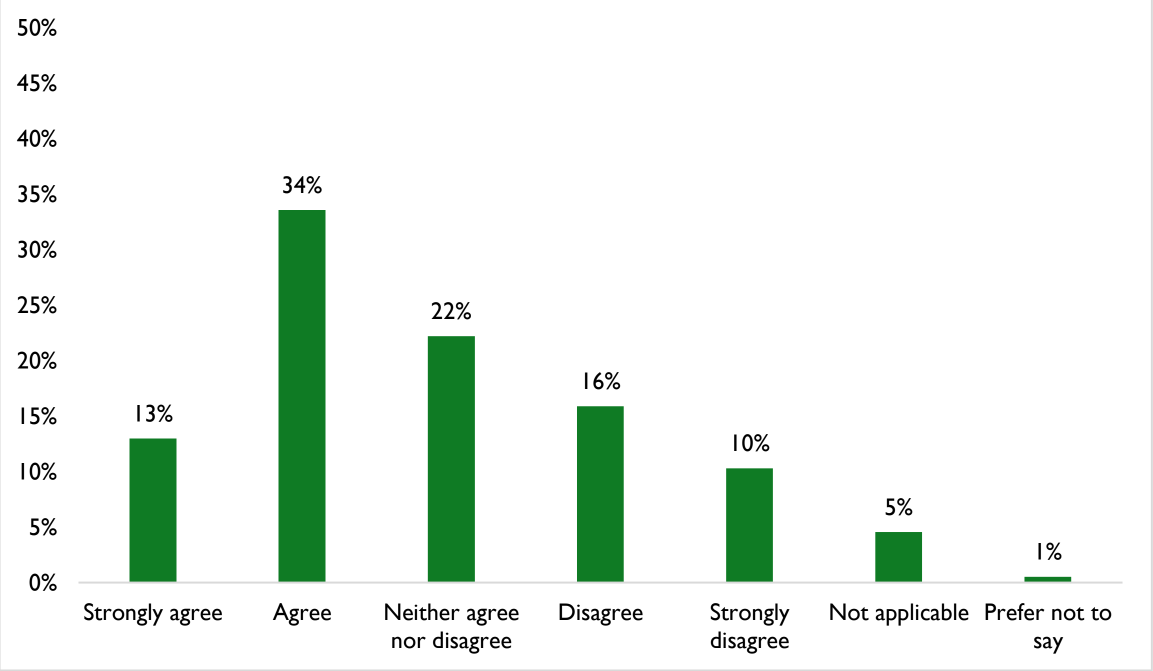

Figure 52. base n = 7739

Q – I am able to get follow-up appointments easily and when I need them

Fewer than one-third of respondents (28%) agreed they could access follow-up appointments when needed – 7% 'strongly agree' and 21% 'agree'. Nearly half (47%) expressed difficulty – 26% 'disagree' and 21% 'strongly disagree'. 20% were neutral, and 5% said it was not applicable.

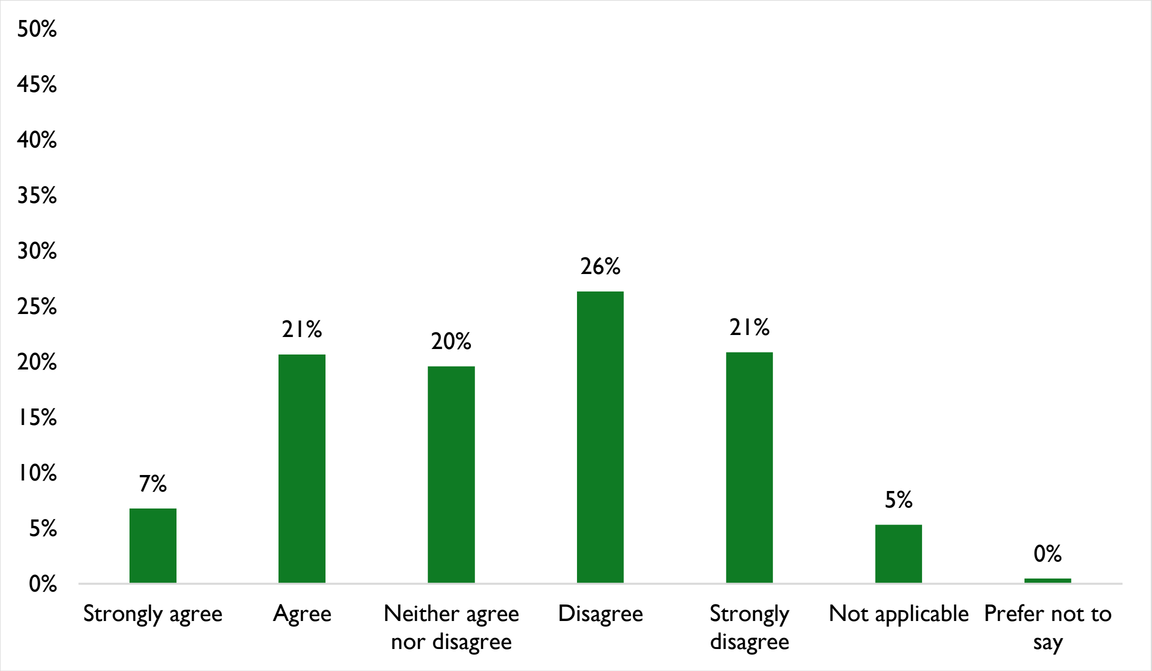

Figure 53. base n = 7730

Q – I know who to contact if I need support for my neurological condition(s) between appointments

Just under half (44%) said they knew who to contact between appointments – 13% 'strongly agree' and 31% 'agree'. A combined 41% did not – 20% 'disagree' and 21% 'strongly disagree'. 11% were neutral, and 3% said it was not applicable.

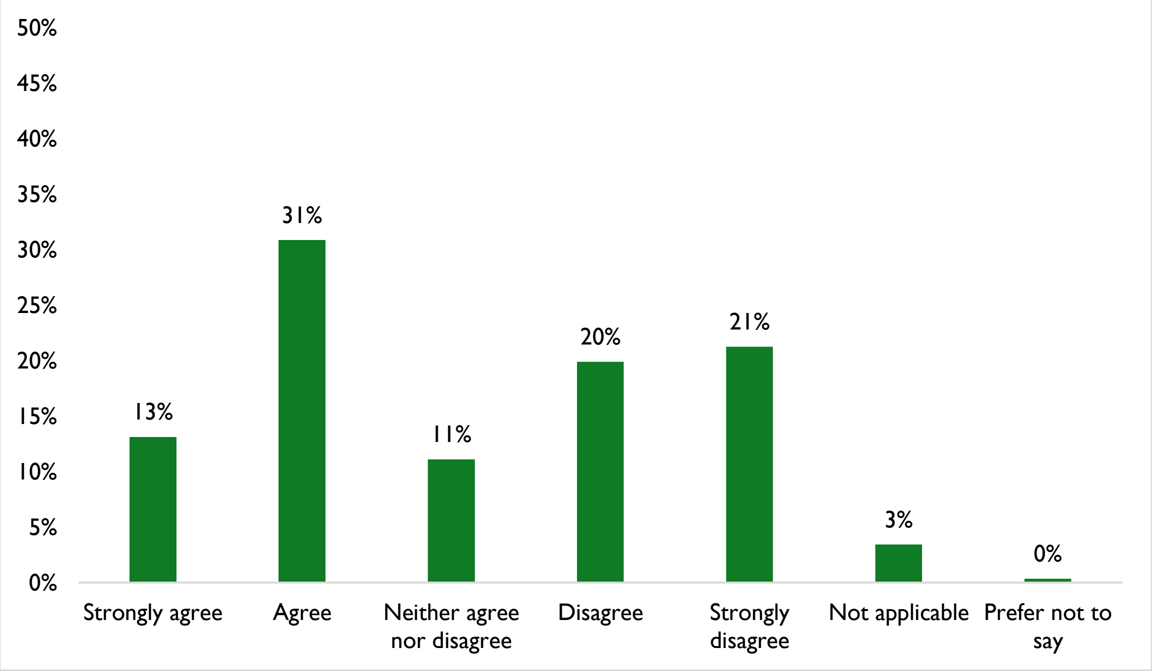

Figure 54. base n = 7742

Q – Healthcare professionals explain medical information clearly and in a way I can understand

Most respondents (58%) agreed that healthcare professionals explained things clearly – 15% 'strongly agree' and 43% 'agree'. 20% disagreed (12% 'disagree', 8% 'strongly disagree'), and 19% were neutral. 3% found the question not applicable.

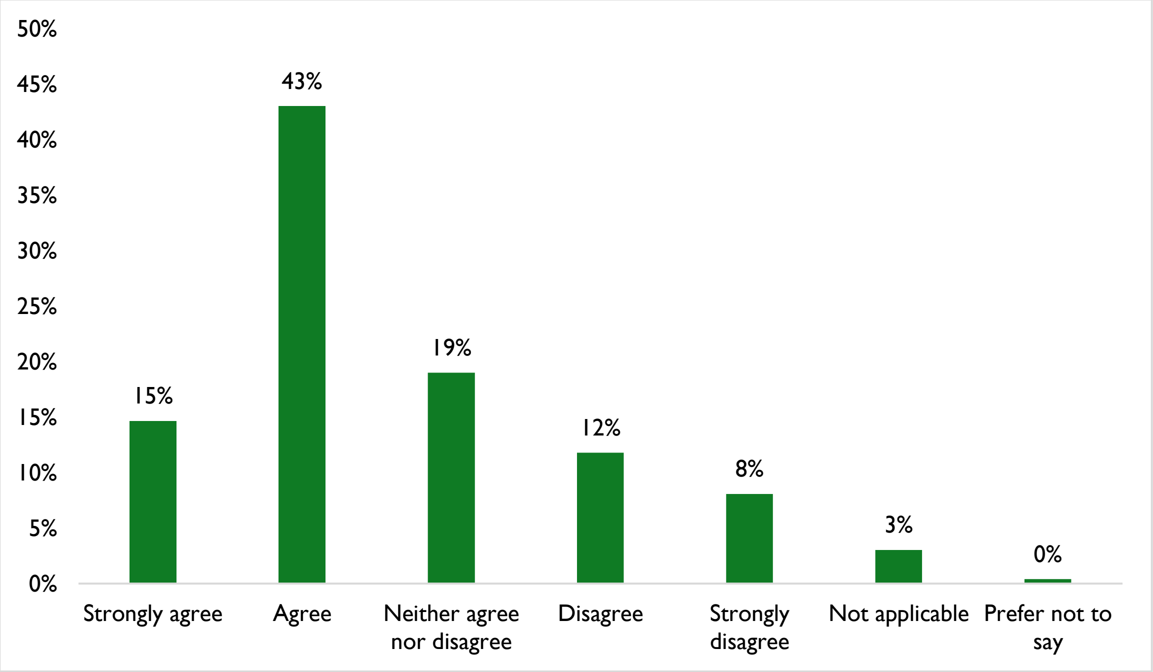

Figure 55. base n = 7741

Q – I feel comfortable to raise and discuss mental health concerns with my healthcare professional

Just under half (48%) felt comfortable discussing mental health – 12% 'strongly agree' and 36% 'agree'. 24% disagreed (15% 'disagree', 9% 'strongly disagree'), 18% were neutral, and 9% said it was not applicable. 1% preferred not to say.

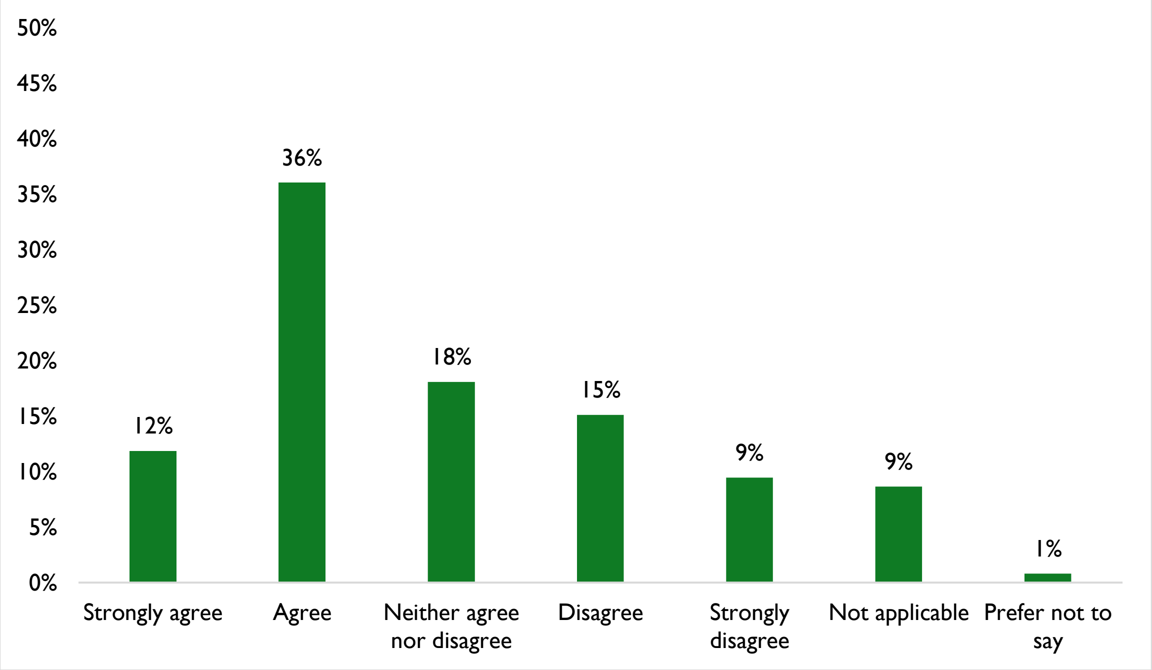

Figure 56. base n = 7738

Q – I have a consistent healthcare professional so I do not have to explain my condition(s) repeatedly to different people

Only just over a third of the sample said they had a consistent healthcare professional – 11% 'strongly agree' and 25% 'agree'. Just under half disagreed – 20% 'disagree' and 25% 'strongly disagree'. 13% were neutral, 5% said it was not applicable, and 1% preferred not to say.

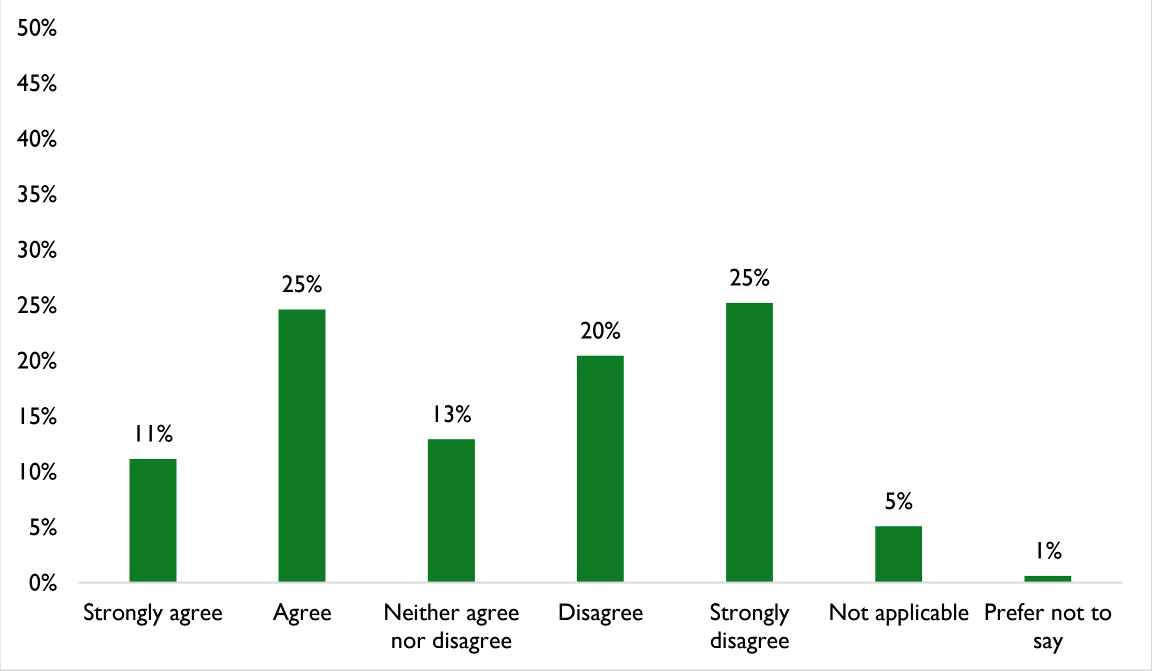

Figure 6857. base n = 7735

Q – I am happy with the format (e.g. face-to-face, phone call) of my appointments

Most respondents (58%) were satisfied with appointment formats – 14% 'strongly agree' and 44% 'agree'. 19% were neutral, while 19% were dissatisfied – 11% 'disagree' and 8% 'strongly disagree'. 4% marked not applicable.

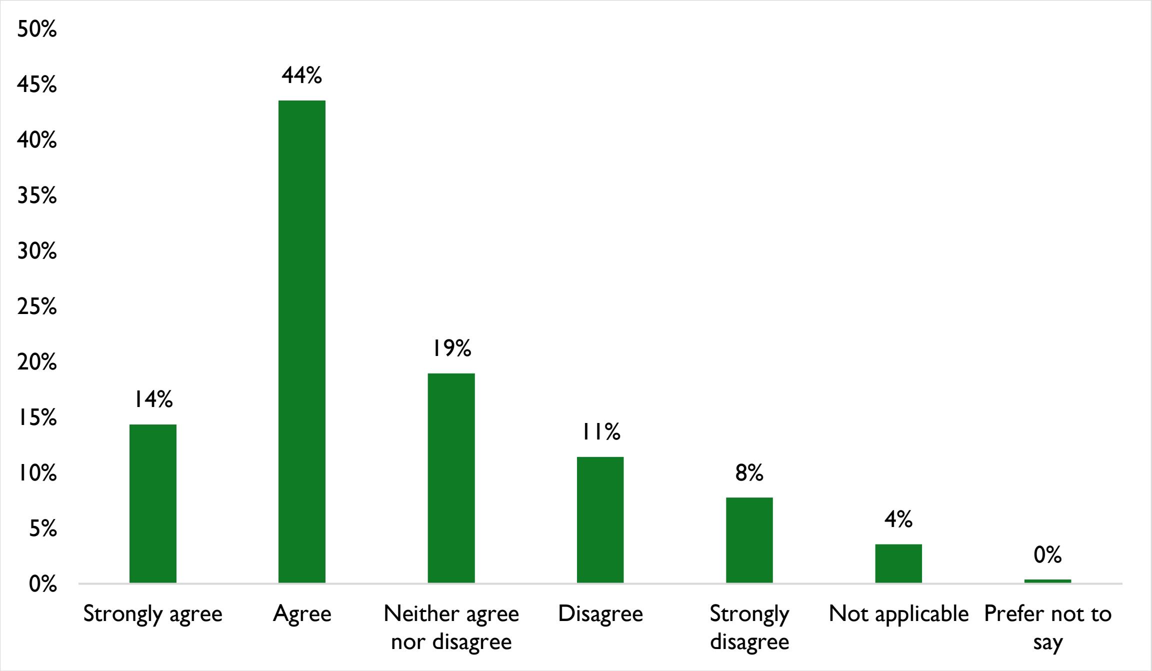

Figure 6958. base n = 7740

Q – My care from medical and healthcare services meets my needs

Only 35% agreed that their care from medical and healthcare services meets their needs – 7% 'strongly agree' and 28% 'agree'. A larger proportion (42%) disagreed – 23% 'disagree', 19% 'strongly disagree'. 20% were neutral and 2% said it was not applicable.

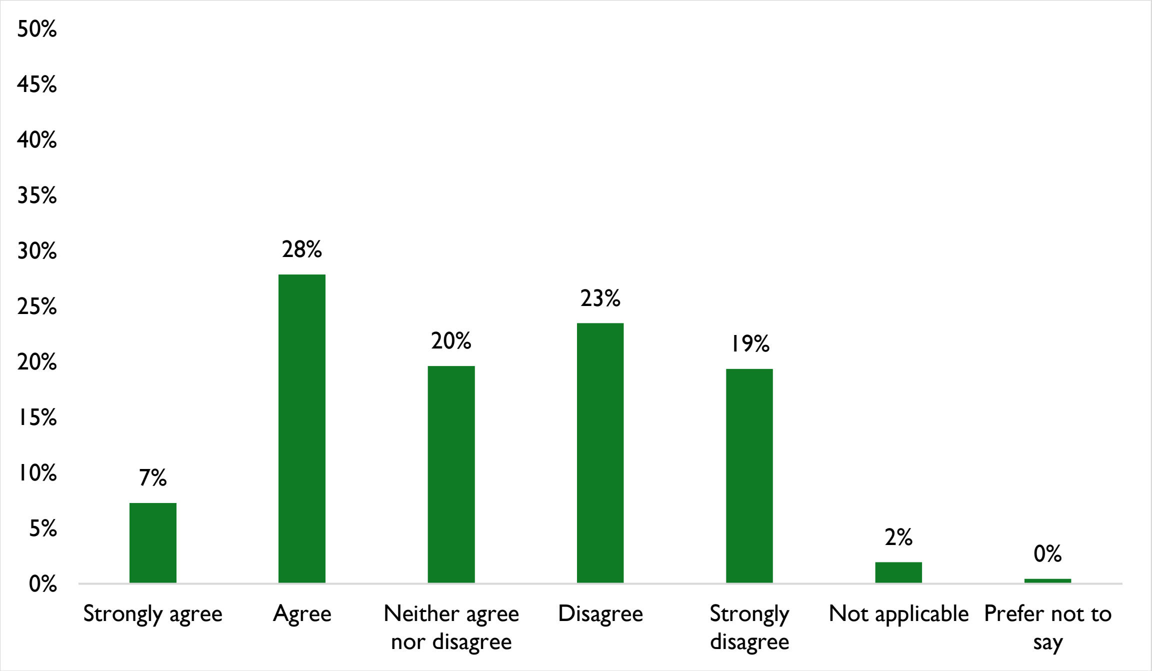

Figure 70. base n = 8613

Q – My care from government-provided personal and support services meets my needs

Only 15% of respondents agreed that government-provided support services meet their needs – 3% 'strongly agree' and 12% 'agree'. A similar proportion (20%) were neutral, while 39% disagreed – 20% 'disagree' and 19% 'strongly disagree'. 25% said the question was not applicable.

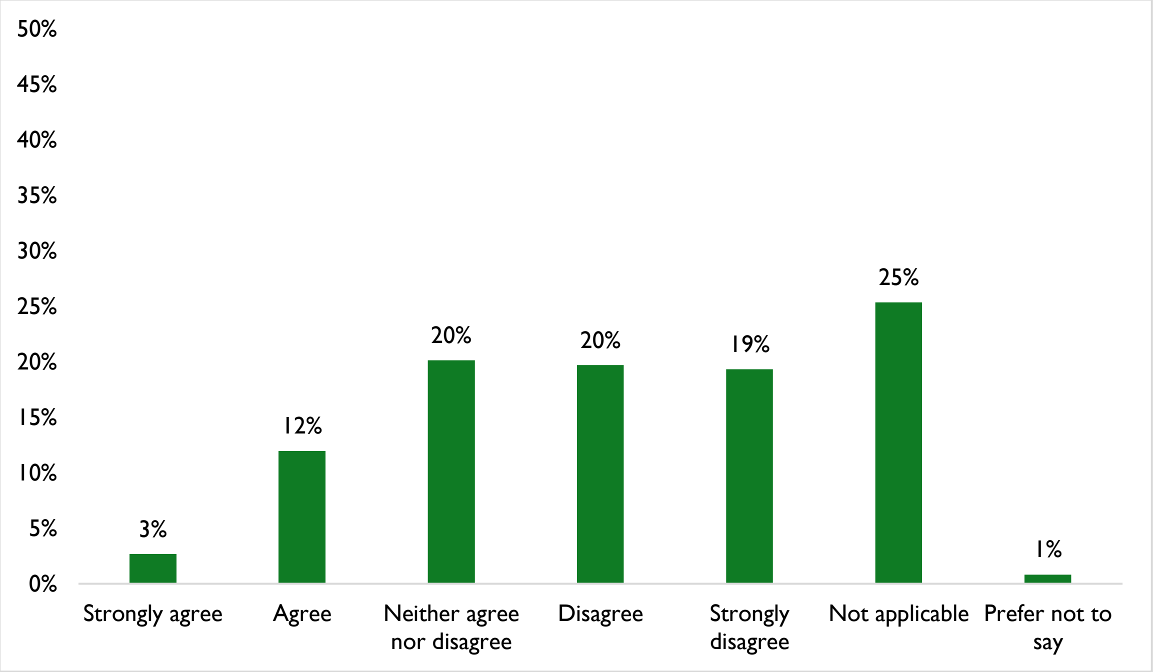

Figure 591. base n = 8555

Q – My care from mental health services meets my needs

Just 12% of respondents agreed that mental health services meet their needs – 2% 'strongly agree' and 10% 'agree'. A substantial 31% disagreed – 16% 'disagree' and 15% 'strongly disagree' – while 20% were neutral. 35% marked the question as not applicable.

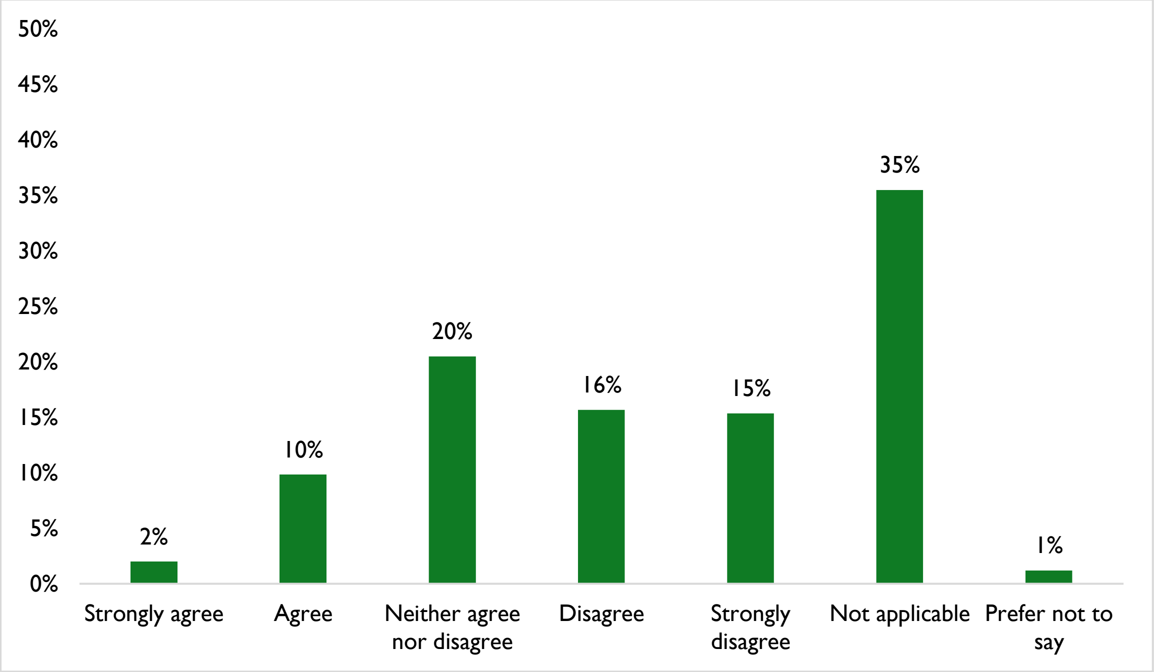

Figure 602. base n = 8555

Q – Overall, how happy do you feel with your experience with healthcare in the last 12 months?

Over a third of respondents (34%) were satisfied – 9% 'very happy' and 25% 'happy'. 28% were neutral, while 37% expressed dissatisfaction – 19% 'unhappy' and 18% 'very unhappy'. 1% preferred not to say.

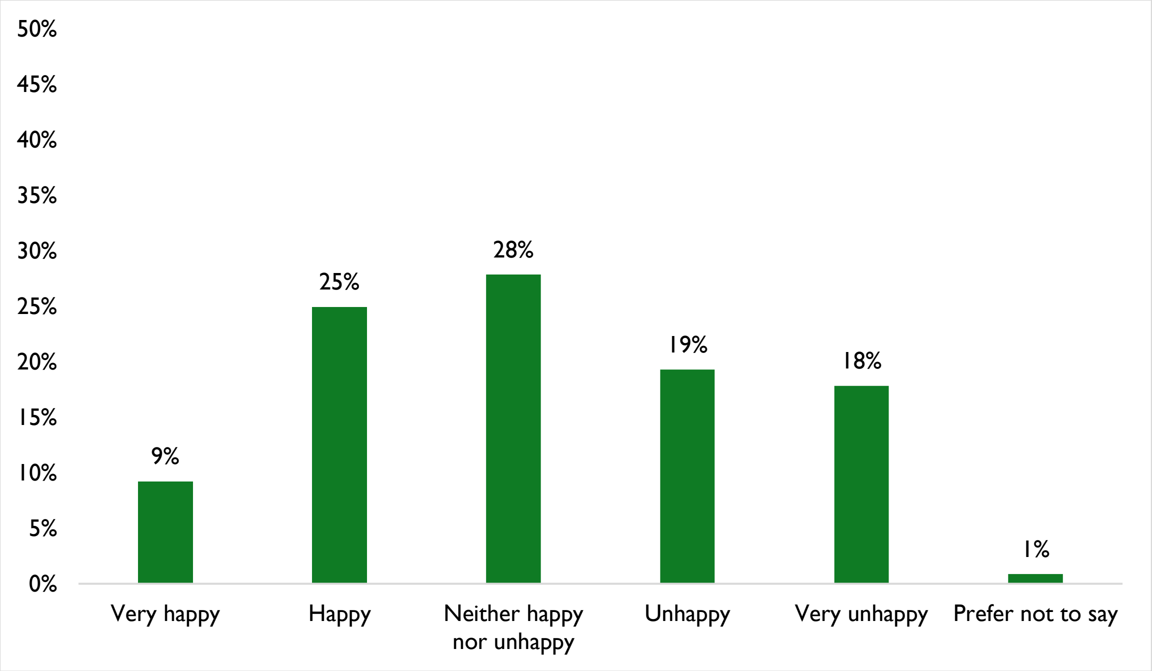

Figure 61. base n = 8595

Q – For each service, how much do you agree your care has improved in the last 12 months? Medical and health care (e.g. visits to doctors, hospital care, medication management

Only 23% felt their medical care had improved in the past year – 4% 'strongly agree' and 19% 'agree'. 38% disagreed – 22% 'disagree' and 16% 'strongly disagree'. 34% were neutral, and 5% said the question was not applicable.

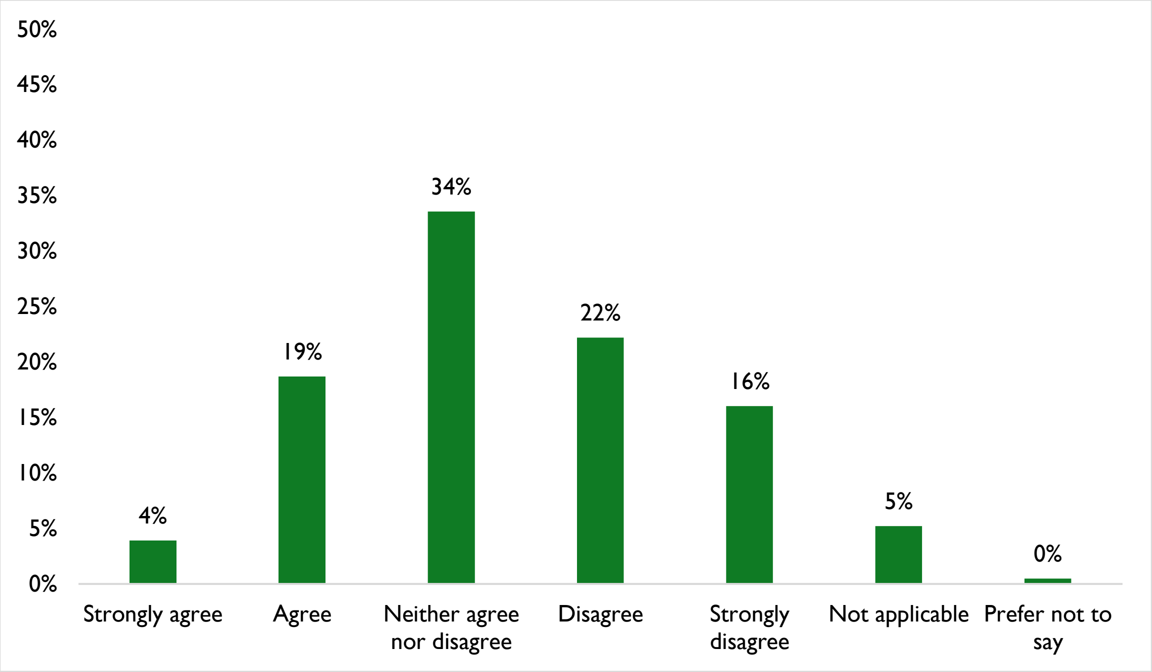

Figure 62. base n = 8585

Q – For each service, how much do you agree your care has improved in the last 12 months? Personal and support services (e.g. assistance with daily activities, in-home support, personal care)

Just 9% felt there had been improvement in personal and support services – 2% 'strongly agree' and 7% 'agree'. 25% disagreed, and 13% 'strongly disagreed'. 21% were neutral, while 43% said the question was not applicable.

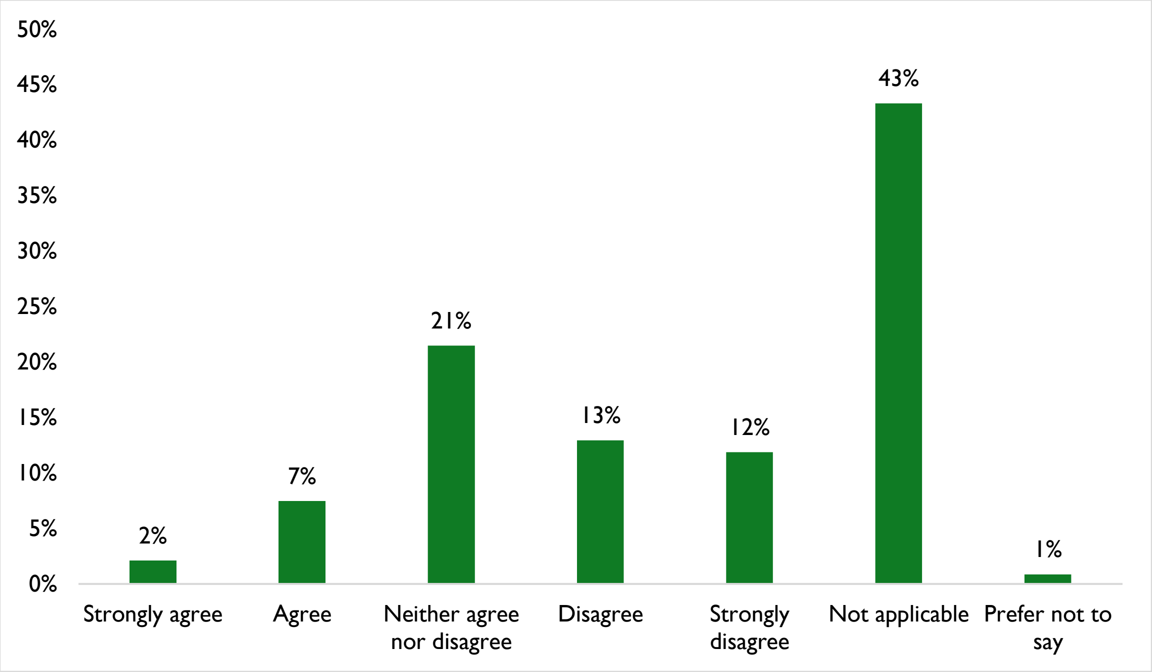

Figure 63. base n = 8557

Q – For each service, how much do you agree your care has improved in the last 12 months? Mental health services (e.g. counselling, psychiatric care, support groups)

Only 8% of respondents agreed that mental health services had improved – 1% 'strongly agree' and 7% 'agree'. 29% disagreed – 15% 'disagree', 14% 'strongly disagree' – while 21% were neutral. 41% said the question was not applicable.

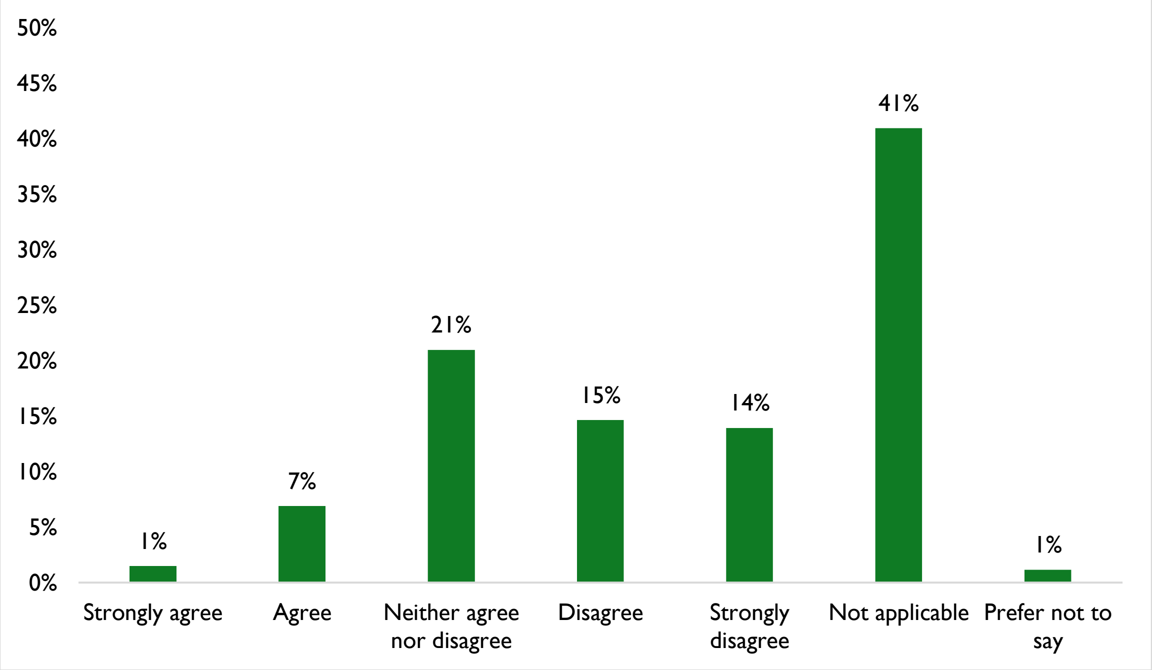

Figure 64. base n = 8545

4.2 Results from the children's survey and matched questions where carers answered on behalf of children and young people with neurological conditions

Q – Which of the following best describes you?

Most responses (62%) came from a carer completing the survey on behalf of a child with a neurological condition. Just over one-third (38%) of responses were from a child under 18 reporting about themselves.

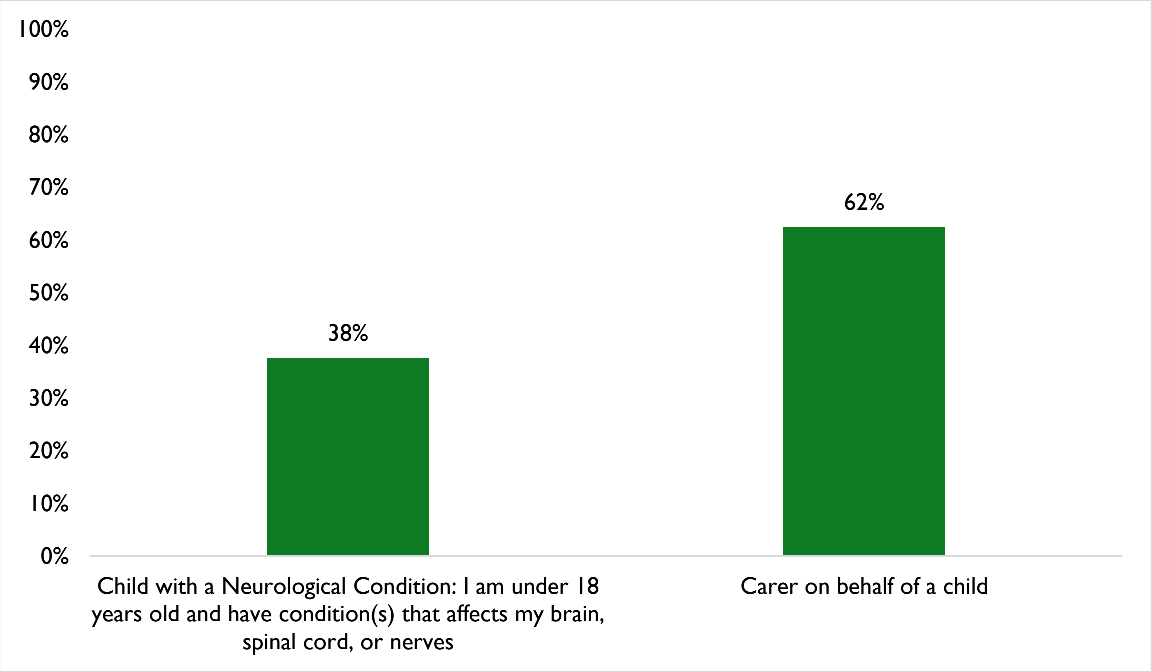

Figure 77. base n = 402

Q – What is your neurological condition?

The five most commonly reported conditions among children were:

1. Hydrocephalus – 23%
2. Autism – 20%
3. Other (please specify) – 16%
4. Neurodegenerative disorder – 14%
5. Neurofibromatosis – 14%

Condition	%
Acquired Brain Injury	3%
Autism	20%
Autoimmune Encephalitis	1%
Brain tumour	3%
Carpal tunnel syndrome	1%
Cavernoma	1%
Cerebral palsy	4%
Charcot-Marie-Tooth disease	1%
Chiari Malformation	3%
Chronic Headache	3%
Chronic inflammatory demyelinating polyneuropathy	1%
Cluster headache	1%
Dystonia	5%
Epilepsy	13%
Foetal Alcohol Spectrum Disorder	1%
Functional Neurological Disorder	10%
Head injury	1%
Hydrocephalus	23%
Idiopathic intracranial hypertension	1%
Migraine	3%

Condition	%
Myalgic encephalomyelitis (ME)	1%
Narcolepsy	1%
Neurodegenerative disorder – please tell us which one	1%
Neurofibromatosis	5%
Prematurity (e.g. neonatal brain injury)	1%
Spina bifida	14%
Stroke / TIA	1%
Tourette syndrome	20%
Tuberous sclerosis	1%
Prefer not to say	1%
I'm not sure	6%
Other	14%

Figure 78. base n = 146

Q – What is their neurological condition?

Carer reporting on behalf of a child or young person

The five most commonly reported conditions as reported by carers were:

- Autism – 27%
- Epilepsy – 27%
- Hydrocephalus – 16%
- Spina Bifida – 13%
- Cerebral Palsy – 15%

Condition	%
Awaiting diagnosis	8%
Acquired Brain Injury	4%
Ataxia	0%
Autism	27%
Autoimmune Encephalitis	1%
Brain Tumour	1%
Cavernoma	0%
Cerebral Palsy	15%
Charcot-Marie-Tooth Disease	0%
Chiari Malformation	6%
Chronic Headache	0%
Chronic Inflammatory Demyelinating Polyneuropathy	0%
Cluster Headache	0%
Congenital Hemiplegia	1%
Cerebrospinal Fluid (CSF) Leak	0%
Dravet Syndrome	2%
Dystonia	5%
Encephalitis/Autoimmune Encephalitis	2%
Epilepsy	27%
Essential Tremor	0%
Familial Dysautonomia	0%

Condition	**%**
Foetal Alcohol Spectrum Disorder	1%
Fibromyalgia	0%
Functional Neurological Disorder (FND)	10%
Hydrocephalus	16%
Lennox Gasteut Syndrome	2%
Long Covid Related Neurological Symptoms	0%
Meningitis	2%
Migraine	4%
Multiple Sclerosis (MS)	0%
Muscular Dystrophy	1%
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	2%
Neurofibromatosis	4%
Peripheral Neuropathy	0%
Periodic Limb Movement Disorder Of Sleep (Plmd)	0%
Restless Legs Syndrome (Rls)	1%
Rett’s Syndrome	0%
Spina Bifida	13%
Spinal Muscular Atrophy	1%
Stroke / Tia	1%
Vasculitis	0%
Prefer not to say	0%
Other (please specify)	19%

Figure 79. base n = 244

Q – How does your neurological condition(s) affect you?

The most commonly reported impact was on thinking and learning, selected by 74% of respondents. Many also reported difficulties related to sleep and energy (62%), mood (62%), and movement (61%). Just under half (46%) experienced challenges with how they see, hear, or feel (e.g. blurry vision, hearing issues, dizziness, or pain). A smaller group (23%) said they were still figuring out how their condition affects them.

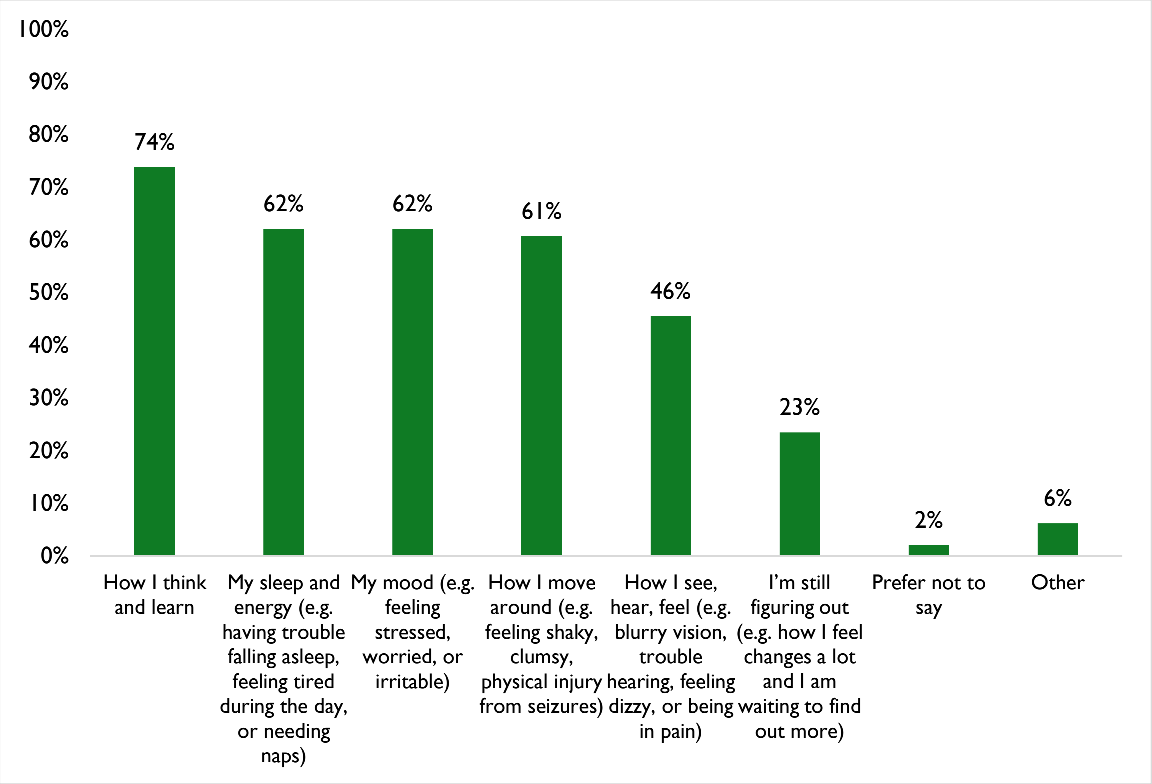

Figure 80. base n = 145

Q – Does the person you care for experience any of the following challenges? (Bladder and bowel symptoms)

Carer reporting on behalf of a child or young person

Carers most commonly reported that the child or young person they support experiences some level of difficulty with bladder and bowel symptoms, with 67% selecting at least 'A little'. Specifically, 28% were affected 'very much', 10% 'quite a lot', 11% 'somewhat', and 17% 'a little'. Just under a third (31%) of carers said the child or young person experienced no impact, while 2% were unsure or preferred not to say.

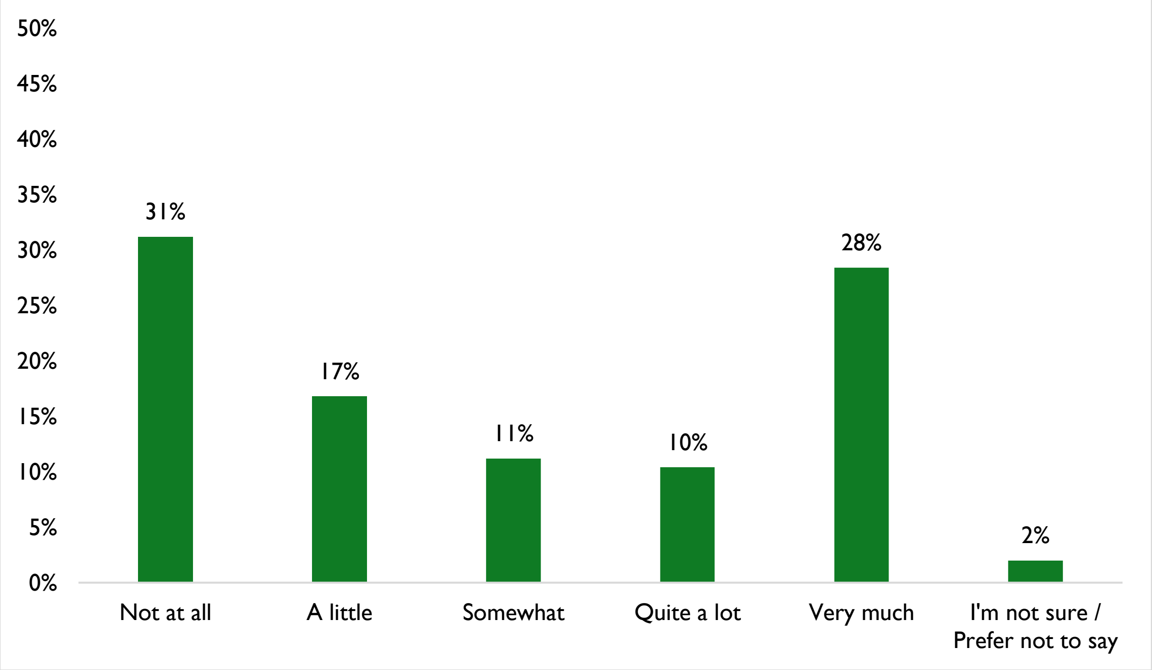

Figure 81. base n = 250

Q – Does the person you care for experience any of the following challenges? (Breathing difficulties)

Carer reporting on behalf of a child or young person

Most carers (68%) reported that the child or young person they support does not experience breathing difficulties. However, around one quarter (25%) reported some level of difficulty, including 15% 'a little', 8% 'somewhat', 2% 'quite a lot', and 6% 'very much'.

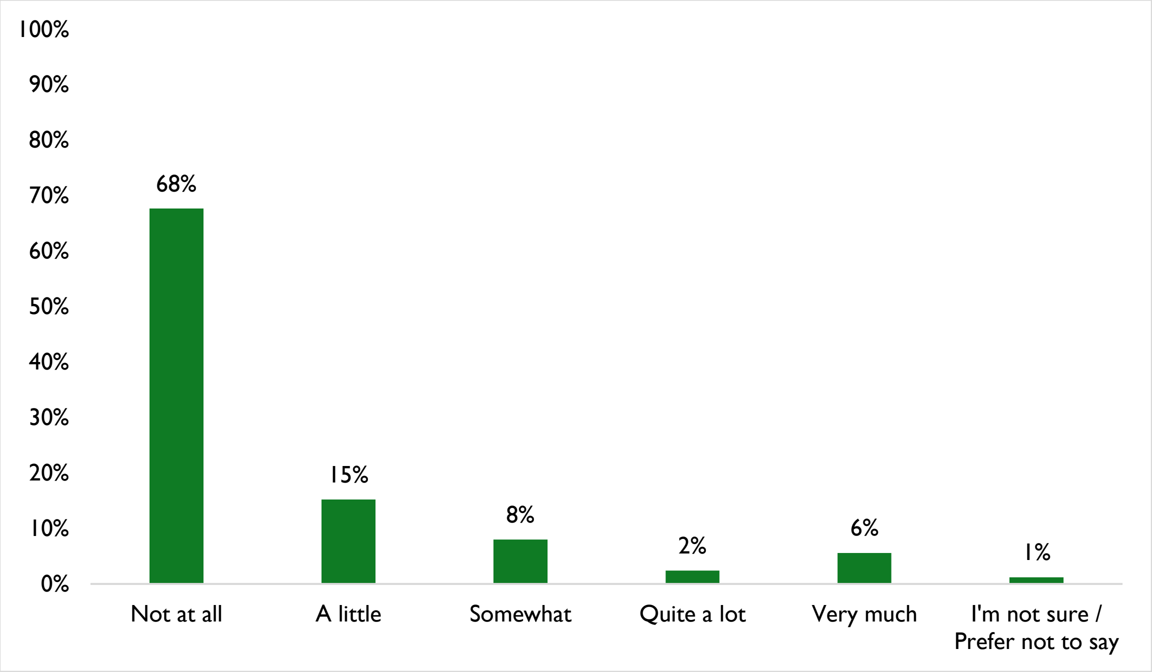

Figure 82. base n = 250

Q – Does the person you care for experience any of the following challenges? (Communication)

Carer reporting on behalf of a child or young person

Just under a third (31%) of carers said the child or young person they support was affected 'very much'. A further 8% were affected 'quite a lot', 8% 'somewhat', and 20% 'a little'. 32% of carers reported no impact on communication, and 1% were unsure or preferred not to say.

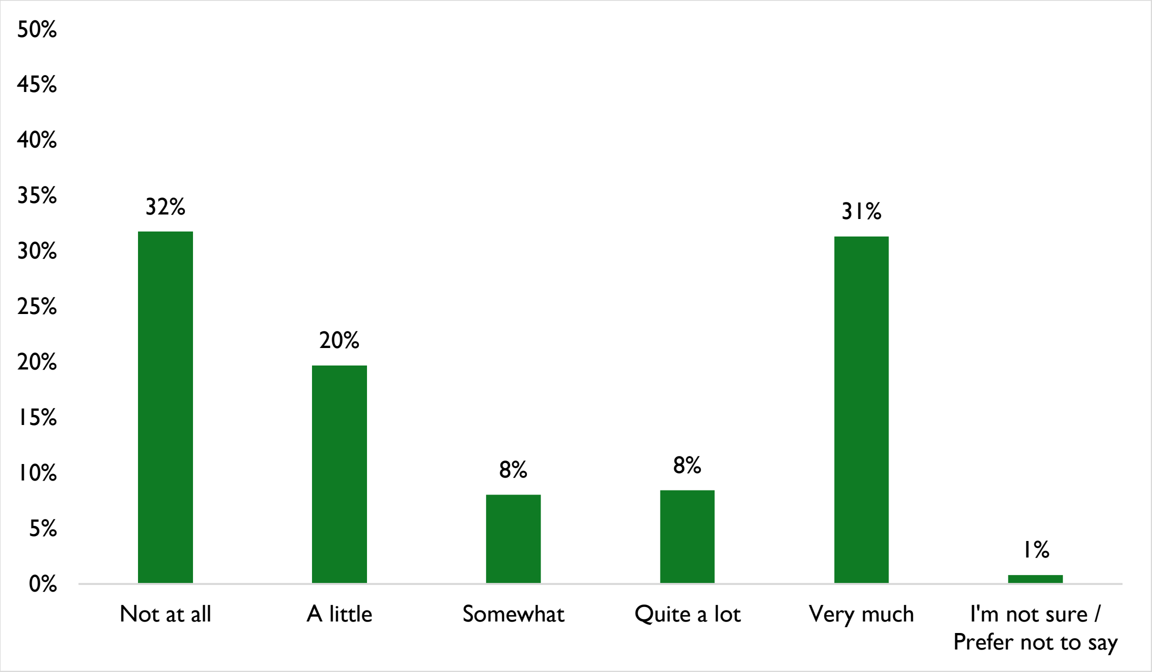

Figure 83. base n = 249

Q – Does the person you care for experience any of the following challenges? (Eating and drinking)

Carer reporting on behalf of a child or young person

35% of carers said the child or young person’s neurological condition did not affect their ability to eat and drink. 22% said it affected them ‘very much’, 10% ‘quite a lot’, 12% ‘somewhat’, and 22% ‘a little’.
0% selected ‘I’m not sure’ or ‘Prefer not to say’; this may reflect rounding rather than no selections.

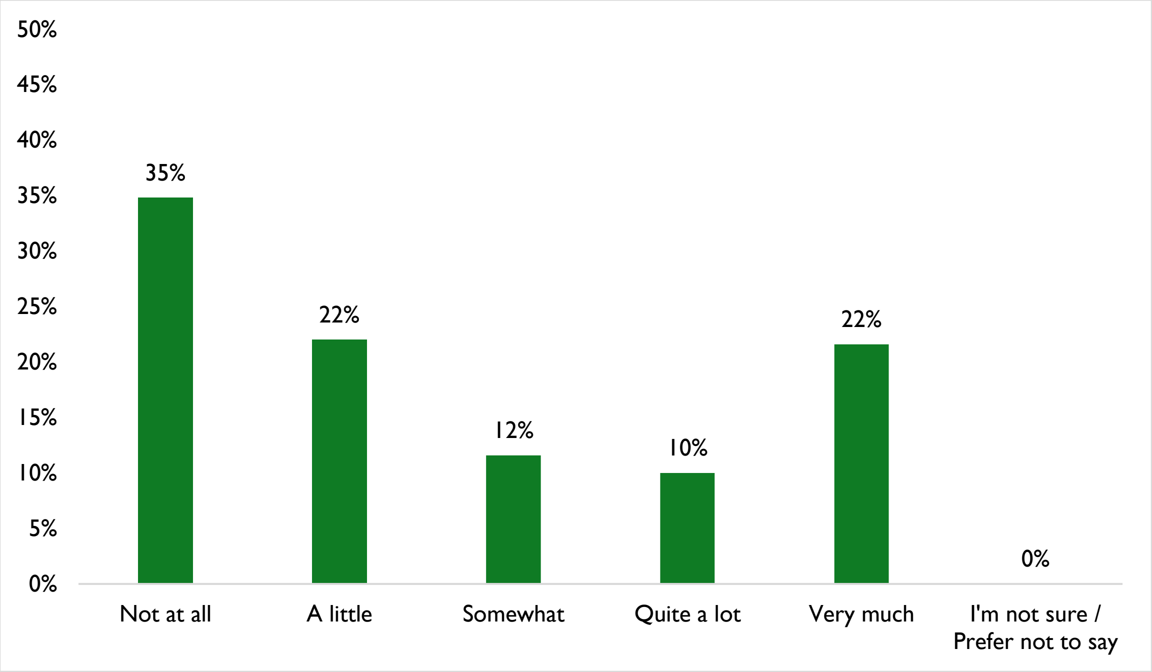

Figure 654. base n = 250

Q – Does the person you care for experience any of the following challenges? (Fatigue)

Carer reporting on behalf of a child or young person

The majority (87%) of carers reported that the child or young person they support experienced some level of fatigue. This included 21% affected 'a little', 20% 'somewhat', 16% 'quite a lot', and 29% 'very much'. A smaller proportion (13%) reported no impact from fatigue, while 2% were unsure or preferred not to say.

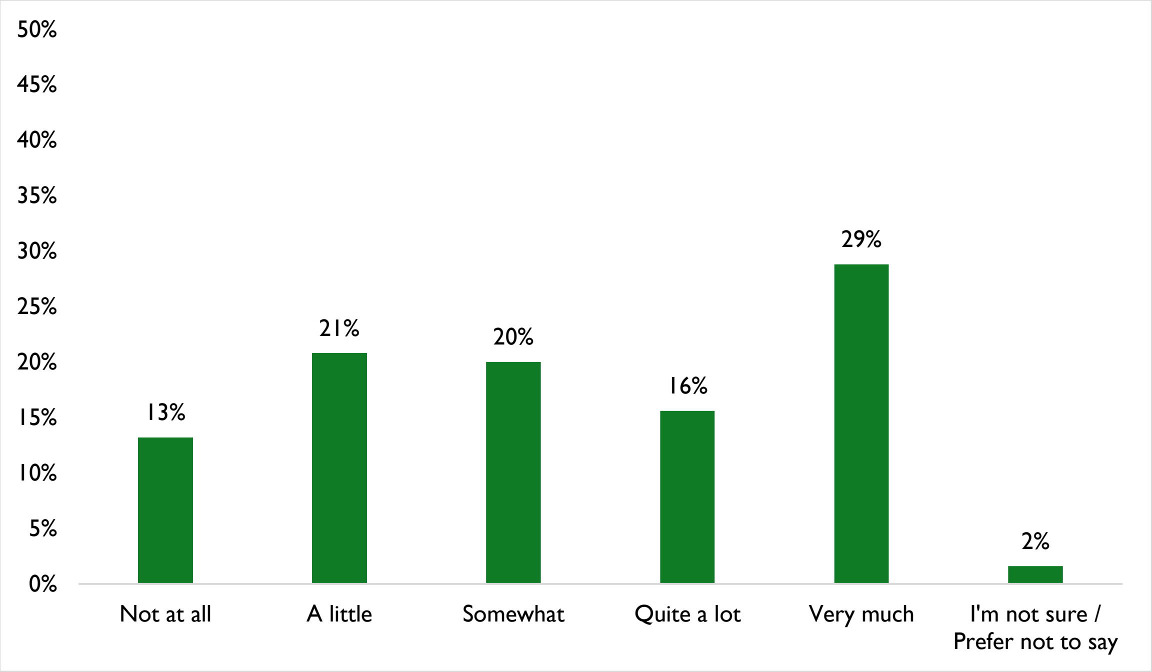

Figure 85. base n = 250

Q – Does the person you care for experience any of the following challenges? (Hearing)

Carer reporting on behalf of a child or young person

The majority (74%) of carers reported that the child or young person they support experienced no hearing difficulties. However, 12% were affected 'a little', 7% 'somewhat', and a smaller proportion (6%) reported more significant impacts ('quite a lot' or 'very much').
2% were unsure or preferred not to say.

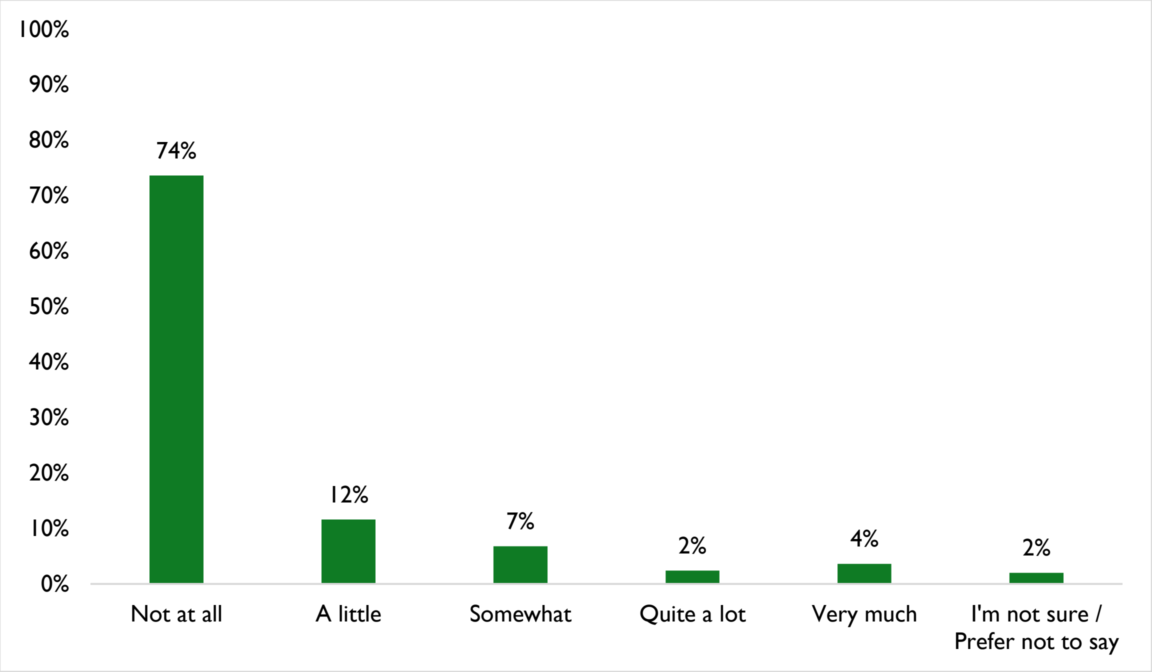

Figure 86. base n = 250

Q – Does the person you care for experience any of the following challenges? (Mood and mental health issues, e.g. anxiety, irritability, social withdrawal, psychosis, impulsive behaviour)

Carer reporting on behalf of a child or young person

Just over a third (37%) of carers reported that the child or young person they support was very much affected by mood and mental health issues. A further 16% were affected 'quite a lot', 12% 'somewhat', and 14% 'a little'. 16% reported no impact, and 4% were unsure or preferred not to say.

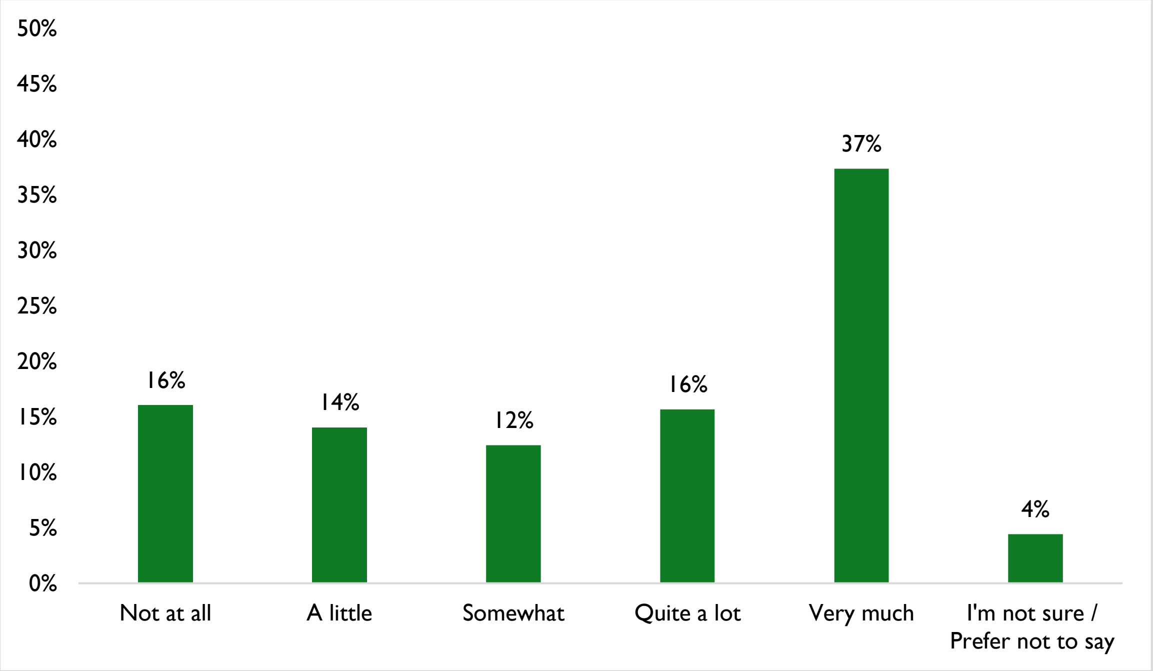

Figure 87. base n = 249

Q – Does the person you care for experience any of the following challenges? (Movement, e.g. tremor, stiffness, difficulty with balance, etc.)

Carer reporting on behalf of a child or young person

Over a third (37%) of carers said the child or young person they support was very much affected by movement-related difficulties. A further 21% were affected ‘quite a lot’, 13% ‘somewhat’, and 14% ‘a little’. 14% reported no impact, and 1% were unsure or preferred not to say.

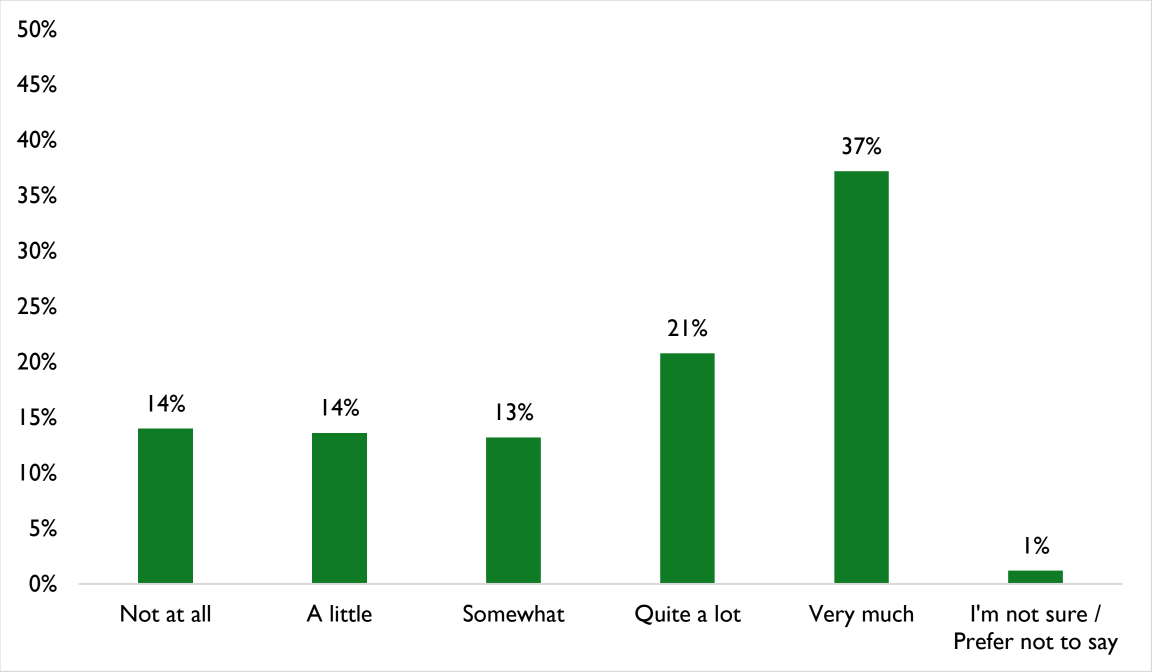

Figure 88. base n = 250

Q – Does the person you care for experience any of the following challenges? (Pain)

Carer reporting on behalf of a child or young person

Responses were varied. 18% of carers said the child or young person they support was very much affected by pain, 12% were affected 'quite a lot', 21% 'somewhat', and 19% 'a little'.
22% reported no impact, and 9% were unsure or preferred not to say.

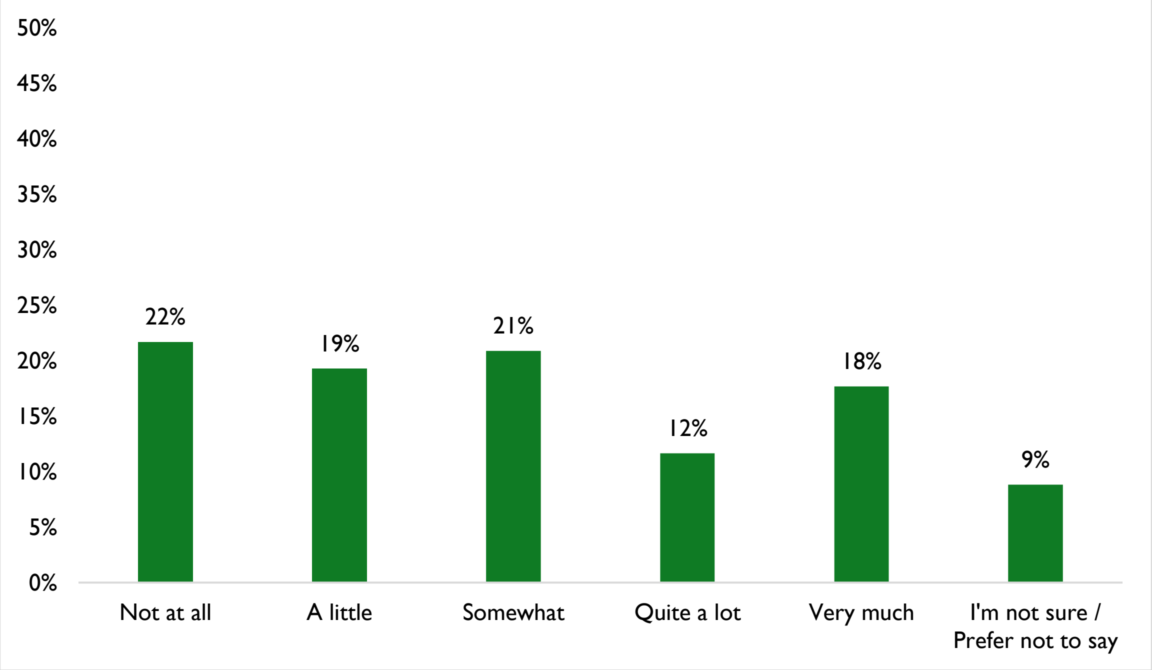

Figure 89. base n = 249

Q – Does the person you care for experience any of the following challenges? (Seizures)

Carer reporting on behalf of a child or young person

Just over half of carers (51%) said the child or young person they support did not experience seizures. However, more than a third (38%) reported some level of impact, including 16% 'very much', 10% 'quite a lot', 10% 'somewhat', and 8% 'a little'. 3% were unsure or preferred not to say.

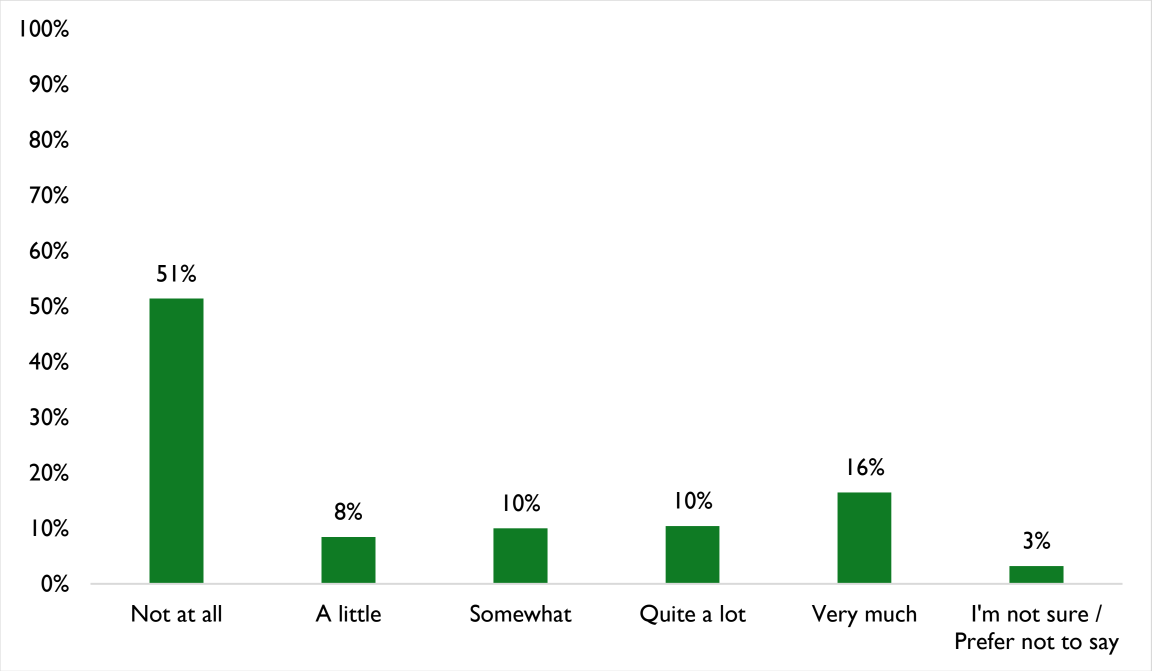

Figure 90. base n = 249

Q – Does the person you care for experience any of the following challenges? (Sensation, e.g. numbness, tingling, hypersensitivity, etc.)

Carer reporting on behalf of a child or young person

Just over a quarter (27%) of carers said the child or young person they support did not experience sensation-related difficulties. However, a similar proportion (28%) reported significant challenges, including 'very much' (16%) or 'quite a lot' (12%). Milder impacts were reported by a further third, with 19% selecting 'somewhat' and 13% 'a little'. 13% were unsure or preferred not to say.

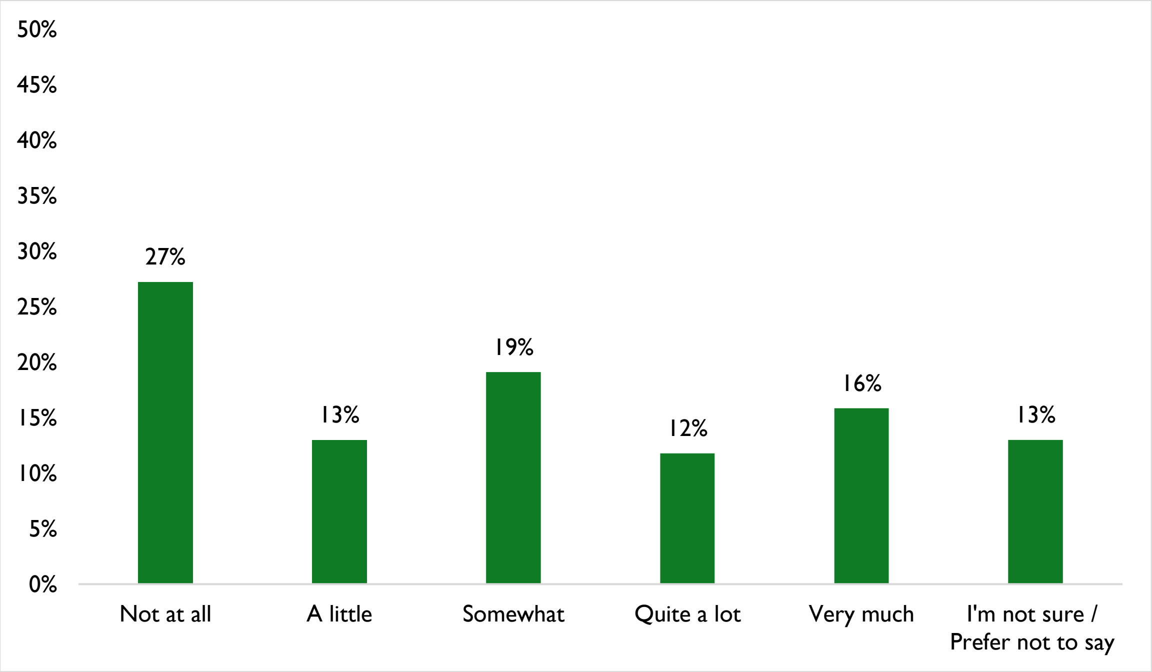

Figure 91. base n = 246

Q – Does the person you care for experience any of the following challenges? (Sleep, e.g. difficulty falling asleep, excessive daytime sleepiness)

Carer reporting on behalf of a child or young person

Over two-thirds of carers (66%) reported that the child or young person they support experienced some level of sleep-related difficulty. This included 34% ‘very much’, 16% ‘quite a lot’, 16% ‘somewhat’, and 16% ‘a little’. 17% said the neurological condition did not affect the child or young person’s sleep, and 2% were unsure or preferred not to say.

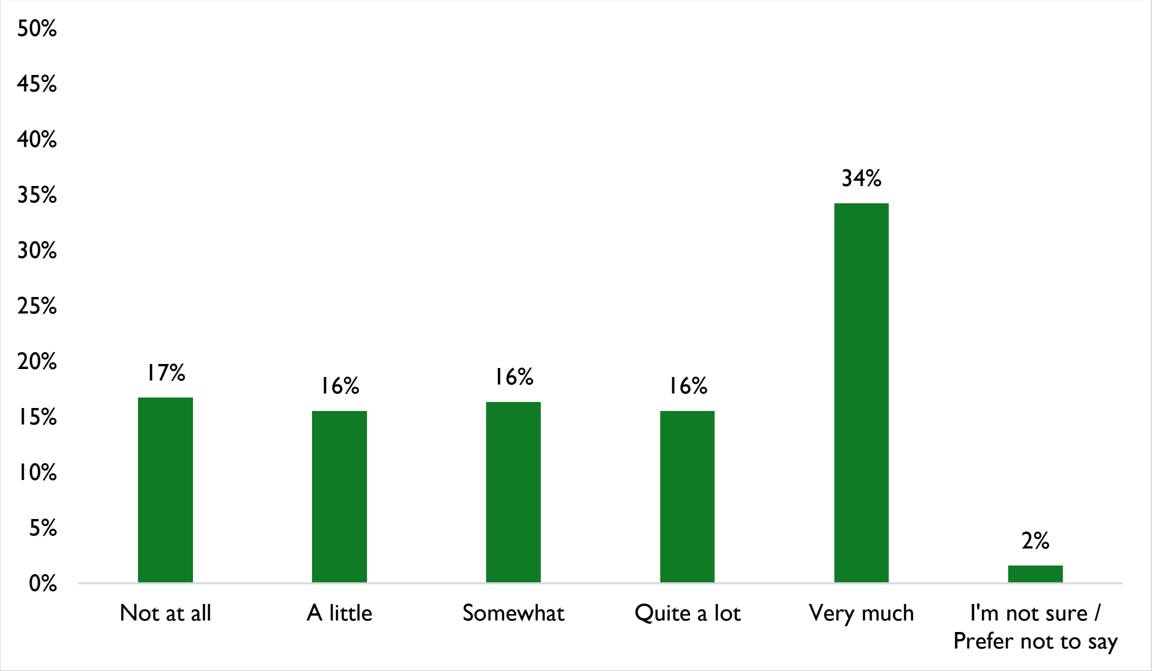

Figure 92. base n = 251

Q – Does the person you care for experience any of the following challenges? (Thinking and memory, e.g. difficulty concentrating, confusion, memory problems, difficulty planning) *Carer reporting on behalf of a child or young person*

Just over two-thirds (67%) of carers said the child or young person they support experienced some level of difficulty related to thinking and memory. This included 39% 'very much', 15% 'quite a lot', 13% 'somewhat', and 13% 'a little'. 10% reported no impact, and a further 10% were unsure or preferred not to say.

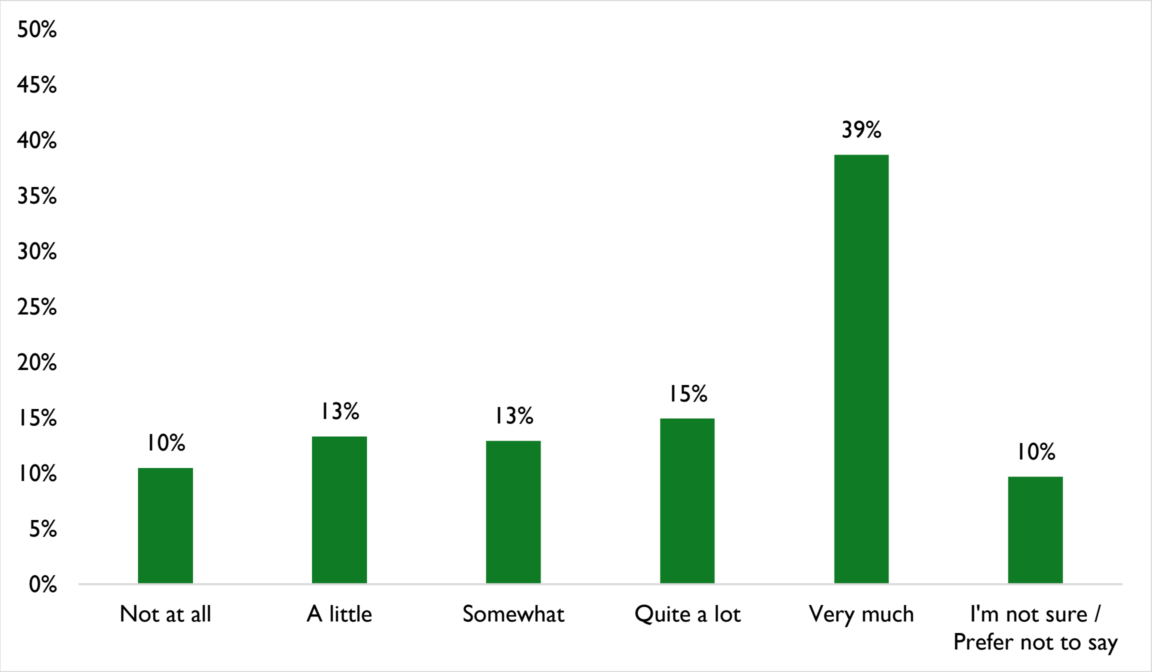

Figure 93. base n = 248

Q – Does the person you care for experience any of the following challenges? (Vision)

Carer reporting on behalf of a child or young person

Nearly half of carers (47%) reported that the child or young person they support did not experience any vision-related challenges. However, 20% were affected ‘a little’, 11% ‘somewhat’, 7% ‘quite a lot’, and 13% ‘very much’. 2% were unsure or preferred not to say.

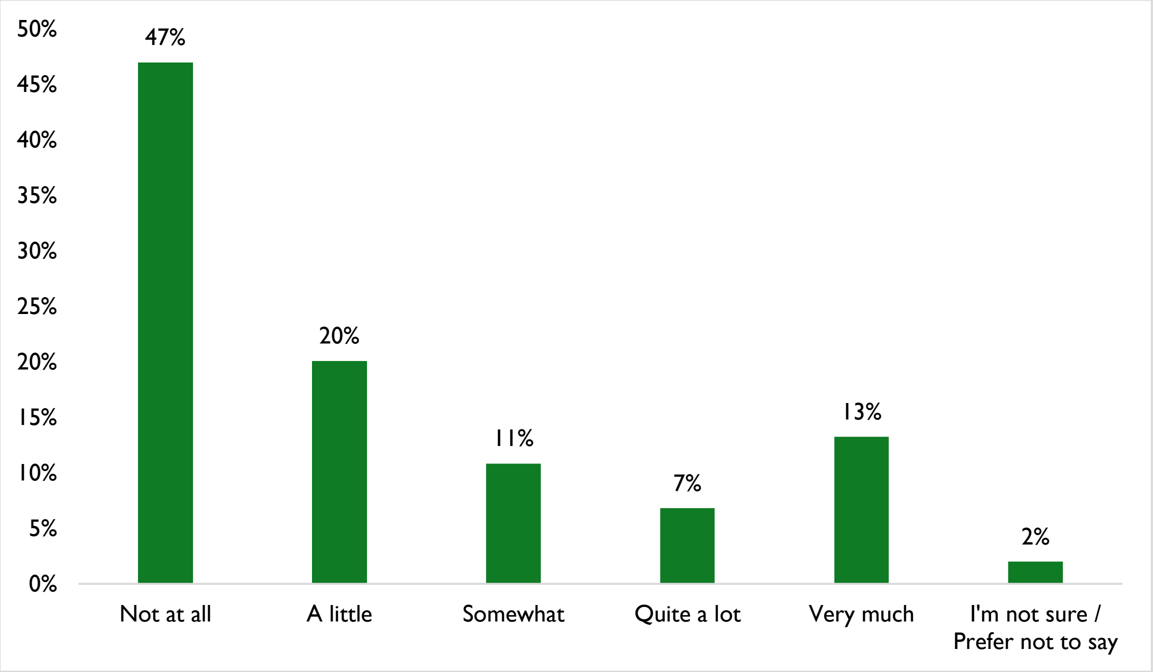

Figure 9466. base n = 249

Q – When were you first told that you had your condition(s)?

Most respondents had lived with their condition(s) for a significant period. 38% said they had known for a long time (more than a year, but not their whole life), and 35% reported always having had their condition(s). A smaller group (17%) had been diagnosed around a year ago, 6% within the past few months, and 2% just recently.

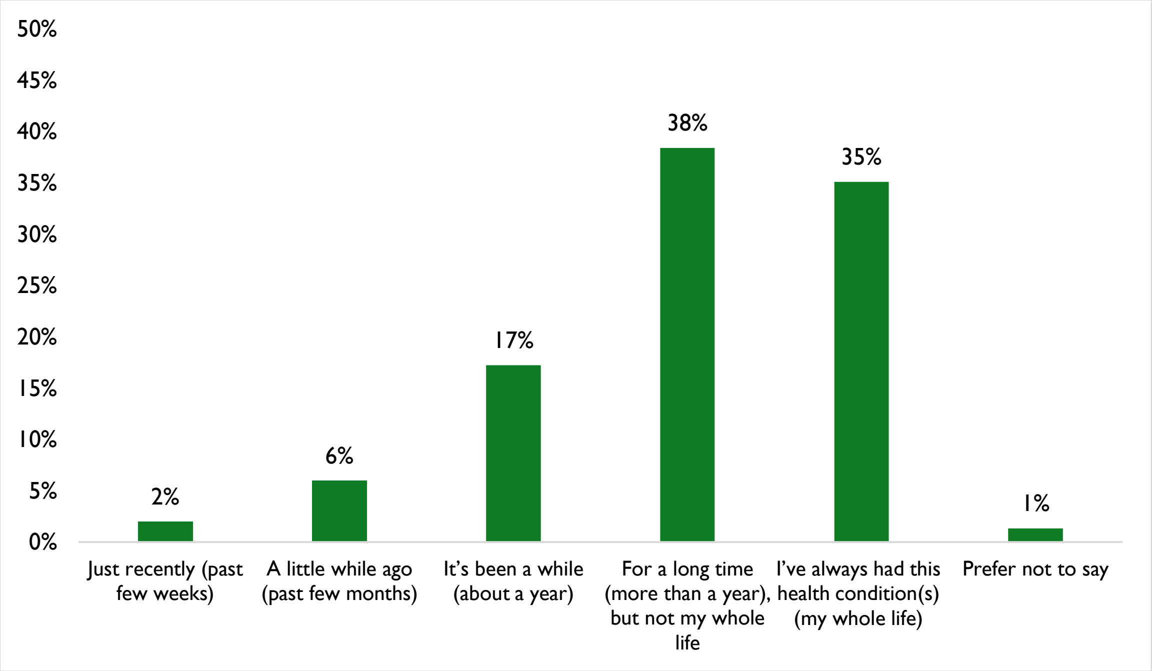

Figure 95. base n = 151

Q – What is your age?

Responses were mostly from older children / young people, with 44% of the sample aged 14-17, 22% were 7-10, and 18% were 11-13. 15% were younger than 7, and 1% preferred not to say.

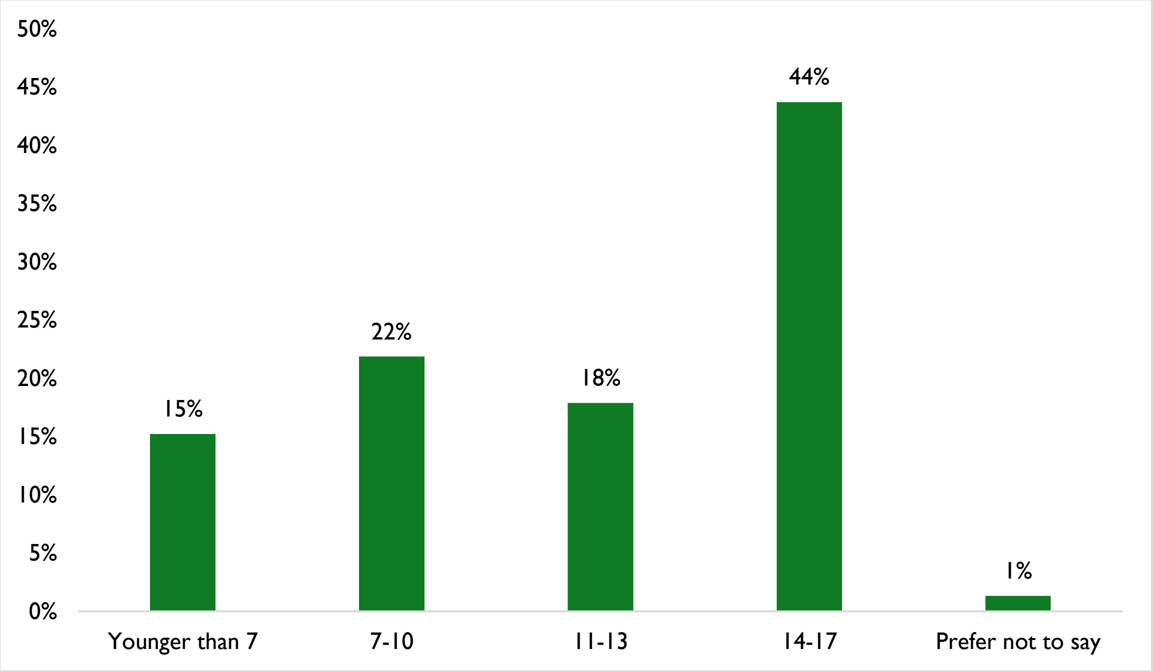

Figure 96. base n = 151

Q – How old is the person you care for?
Carer reporting on behalf of a child or young person

Most carers supported children or young people aged 6-12 (44%) or 13-17 (36%). 20% said the child or young person they cared for was aged 0-5.

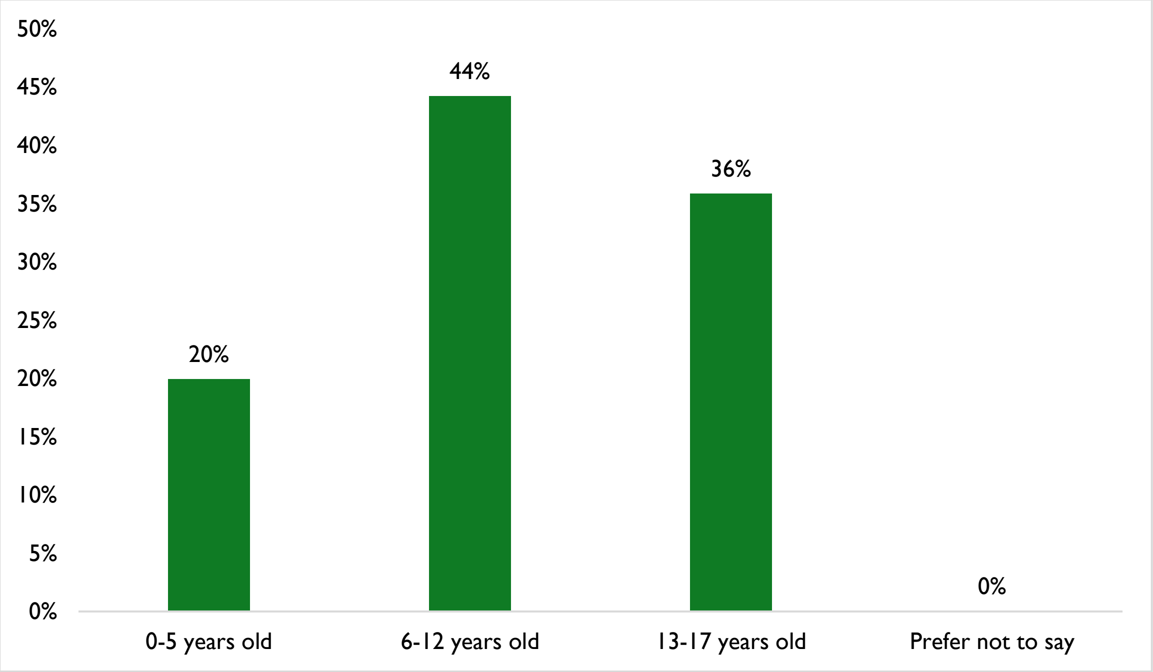

Figure 97. base n = 251

Q – Which of the following describes how you think of yourself?

Half (50%) of respondents identified as boys, and 46% as girls. 1% chose to write their own answer, and 3% preferred not to say.

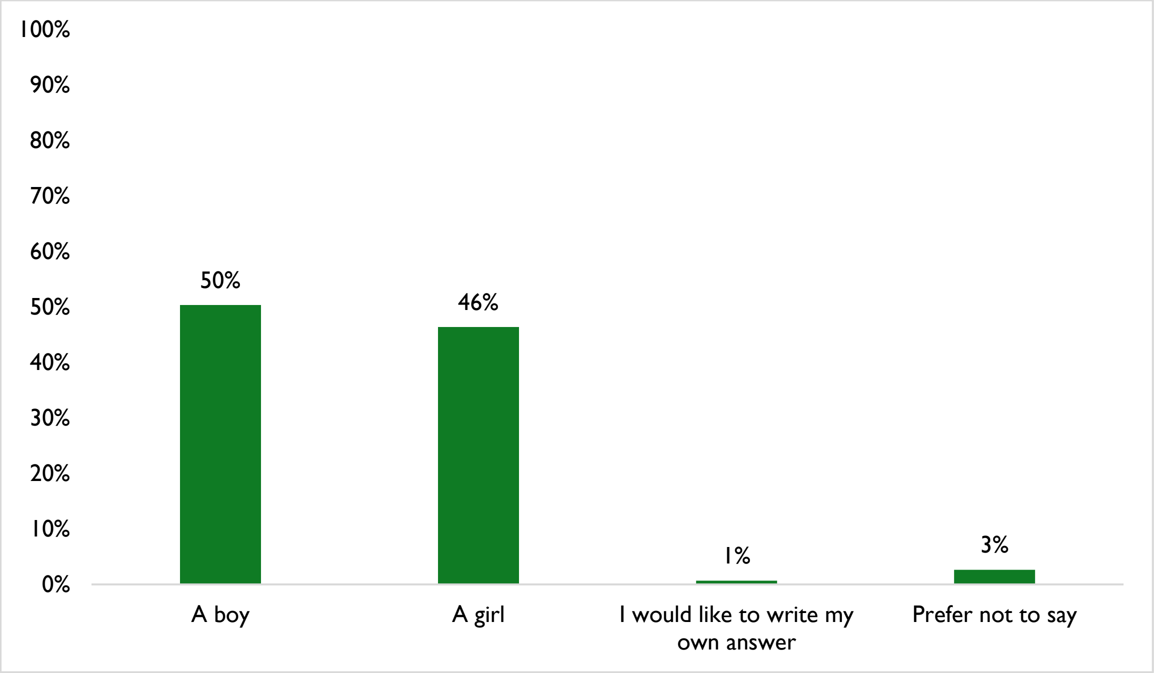

Figure 98. base n = 151

Q – Which of the following describes how the person you care for thinks of themselves? – (Carer reporting on behalf of a child or young person)

Carers reported that 50% of the children or young people they support identify as female and 48% as male. 2% were described as thinking of themselves in another way.

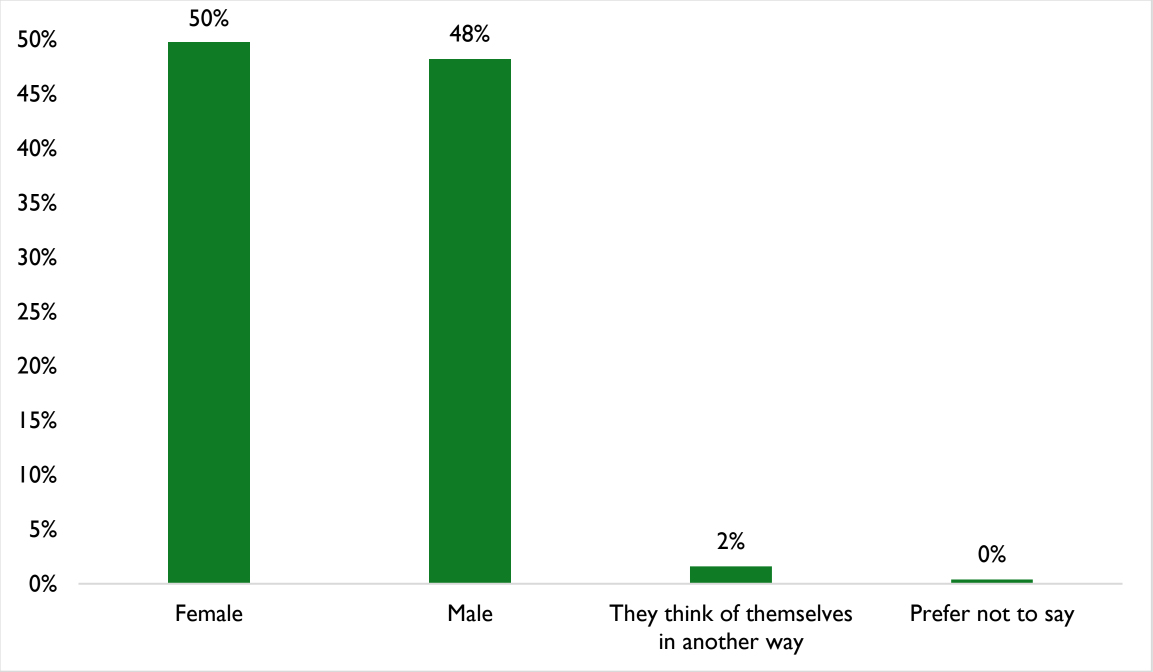

Figure 99. base n = 251

Q – What is your ethnic group?

Most respondents (91%) identified as White (including English, Welsh, Scottish, Northern Irish, British, Irish, Gypsy or Irish Traveller, Roma, or any other White background). 4% identified with mixed or multiple ethnic groups, and 3% as Black, Black British, Caribbean or African. 1% identified as Asian or Asian British, and 1% selected "Other ethnic group". A further 1% chose to write their own answer, and 1% preferred not to say.

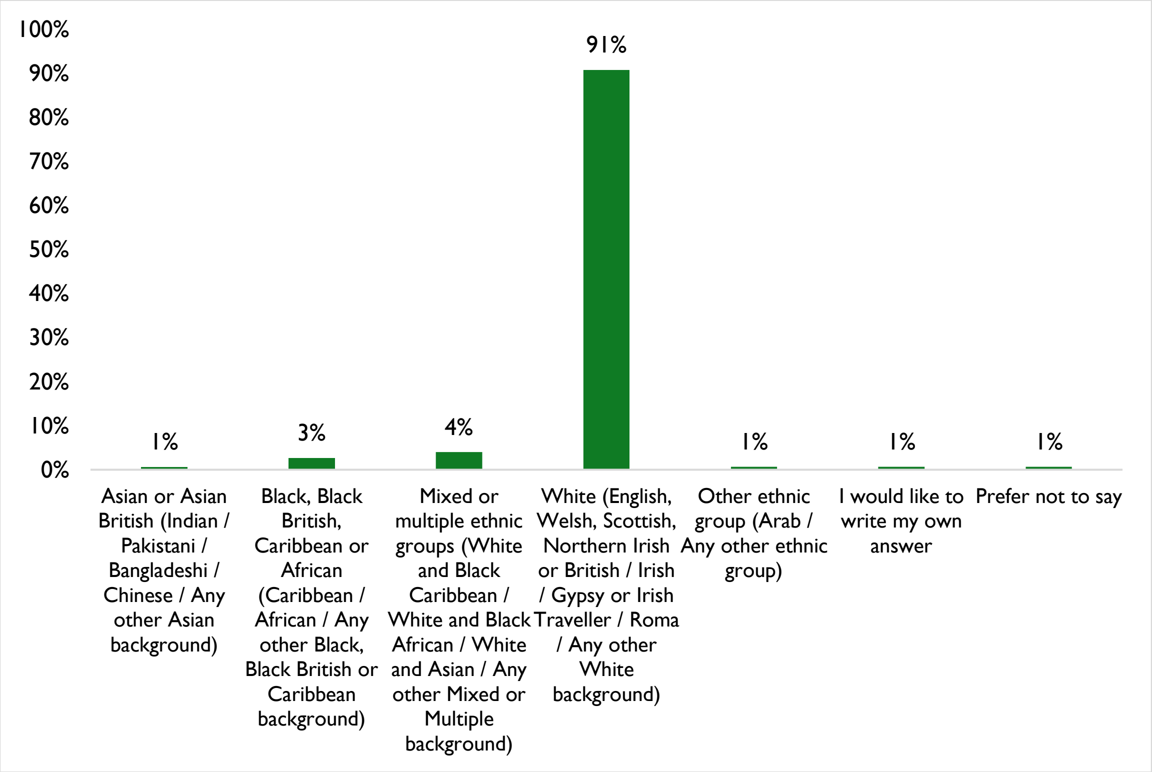

Figure 100. base n = 151

Q – What is their ethnic group?
Carer reporting on behalf of a child or young person

The majority of carers (91%) said the child or young person they care for is White (including English, Welsh, Scottish, Northern Irish, British, Irish, Gypsy or Irish Traveller, Roma, or any other White background). 4% identified them as being from mixed or multiple ethnic groups, and 2% as Black, Black British, Caribbean or African. 1% were described as Asian or Asian British, and 1% of carers preferred not to say.

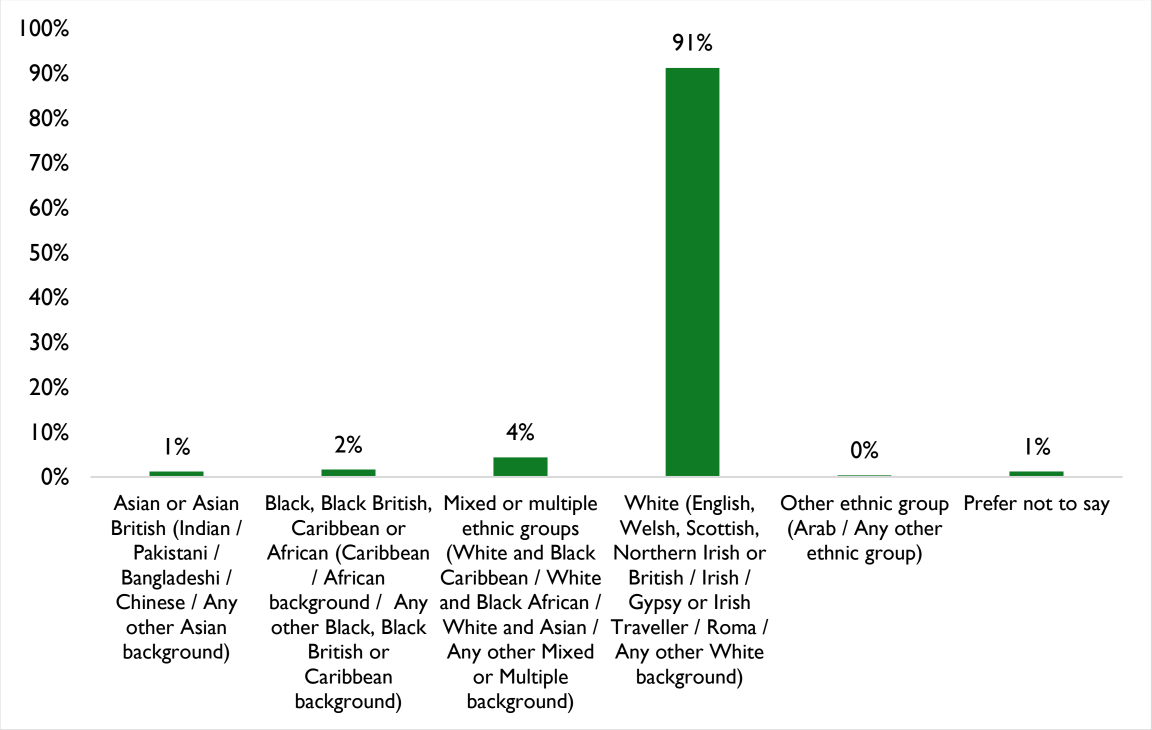

Figure 101. base n = 251

Q – Where do you live? [POSTCODE – CODED]

Respondents were spread across a wide range of local health commissioners, with the highest proportion citing NHS Cheshire and Merseyside Integrated Care Board (9%). Several other commissioners were each cited by 5% of respondents, including Cwm Taf Morgannwg University Health Board, NHS Kent and Medway Integrated Care Board, NHS North East and North Cumbria Integrated Care Board, and NHS South East London Integrated Care Board.

Local Health Commissioner	%
Ayrshire and Arran	1%
Betsi Cadwaladr University Health Board	2%
Cardiff and Vale University Health Board	2%
Cwm Taf Morgannwg University Health Board	5%
Fife	2%
Grampian	2%
Greater Glasgow and Clyde	1%
Highland	1%
Hywel Dda University Health Board	1%
Lanarkshire	2%
Lothian	1%
NHS BATH AND NORTH EAST SOMERSET, SWINDON AND WILTSHIRE INTEGRATED CARE BOARD	2%
NHS BEDFORDSHIRE, LUTON AND MILTON KEYNES INTEGRATED CARE BOARD	2%
NHS BIRMINGHAM AND SOLIHULL INTEGRATED CARE BOARD	3%
NHS BLACK COUNTRY INTEGRATED CARE BOARD	2%
NHS BRISTOL, NORTH SOMERSET AND SOUTH GLOUCESTERSHIRE INTEGRATED CARE BOARD	2%
NHS BUCKINGHAMSHIRE, OXFORDSHIRE AND BERKSHIRE WEST INTEGRATED CARE BOARD	1%

Local Health Commissioner	%
NHS CAMBRIDGESHIRE AND PETERBOROUGH INTEGRATED CARE BOARD	1%
NHS CHESHIRE AND MERSEYSIDE INTEGRATED CARE BOARD	9%
NHS COVENTRY AND WARWICKSHIRE INTEGRATED CARE BOARD	1%
NHS DERBY AND DERBYSHIRE INTEGRATED CARE BOARD	2%
NHS DORSET INTEGRATED CARE BOARD	2%
NHS GLOUCESTERSHIRE INTEGRATED CARE BOARD	2%
NHS GREATER MANCHESTER INTEGRATED CARE BOARD	3%
NHS HAMPSHIRE AND ISLE OF WIGHT INTEGRATED CARE BOARD	2%
NHS HEREFORDSHIRE AND WORCESTERSHIRE INTEGRATED CARE BOARD	1%
NHS HERTFORDSHIRE AND WEST ESSEX INTEGRATED CARE BOARD	2%
NHS HUMBER AND NORTH YORKSHIRE INTEGRATED CARE BOARD	3%
NHS KENT AND MEDWAY INTEGRATED CARE BOARD	5%
NHS LANCASHIRE AND SOUTH CUMBRIA INTEGRATED CARE BOARD	2%
NHS LEICESTER, LEICESTERSHIRE AND RUTLAND INTEGRATED CARE BOARD	1%
NHS LINCOLNSHIRE INTEGRATED CARE BOARD	2%
NHS NORFOLK AND WAVENEY INTEGRATED CARE BOARD	1%
NHS NORTH EAST AND NORTH CUMBRIA INTEGRATED CARE BOARD	5%
NHS NORTH EAST LONDON INTEGRATED CARE BOARD	1%
NHS NORTH WEST LONDON INTEGRATED CARE BOARD	2%
NHS NORTHAMPTONSHIRE INTEGRATED CARE BOARD	2%
NHS NOTTINGHAM AND NOTTINGHAMSHIRE INTEGRATED CARE BOARD	3%
NHS SHROPSHIRE, TELFORD AND WREKIN INTEGRATED CARE BOARD	1%

Local Health Commissioner	%
NHS SOMERSET INTEGRATED CARE BOARD	2%
NHS SOUTH EAST LONDON INTEGRATED CARE BOARD	5%
NHS SOUTH WEST LONDON INTEGRATED CARE BOARD	2%
NHS SUFFOLK AND NORTH EAST ESSEX INTEGRATED CARE BOARD	4%
NHS SUSSEX INTEGRATED CARE BOARD	2%
NHS WEST YORKSHIRE INTEGRATED CARE BOARD	1%
Northern Health Board	2%
Southern Health Board	2%
Swansea Bay University Health Board	2%

Figure 102. base n = 129

Q – What is their postcode? [CODED]

Carer reporting on behalf of a child or young person

Carers also reported a spread across different local health commissioners for the children or young people they support. NHS South East London Integrated Care Board and Tayside accounted for 5% of responses each – the highest proportion of responses for a single board. This was followed by Grampian, Greater Glasgow and Clyde, and NHS Hertfordshire and West Essex Integrated Care Board, each with 4%.

Local Health Commissioner	%
Aneurin Bevan University Health Board	2%
Ayrshire and Arran	1%
Betsi Cadwaladr University Health Board	3%
Borders	0%
Cardiff and Vale University Health Board	0%
Cwm Taf Morgannwg University Health Board	1%
Dumfries and Galloway	0%
Eastern Health Board	2%
Fife	3%
Forth Valley	2%
Grampian	4%
Greater Glasgow and Clyde	4%
Highland	1%
Hywel Dda University Health Board	1%
Lanarkshire	3%
Lothian	2%
NHS BATH AND NORTH EAST SOMERSET, SWINDON AND WILTSHIRE INTEGRATED CARE BOARD	0%

Local Health Commissioner	%
NHS BEDFORDSHIRE, LUTON AND MILTON KEYNES INTEGRATED CARE BOARD	2%
NHS BIRMINGHAM AND SOLIHULL INTEGRATED CARE BOARD	0%
NHS BLACK COUNTRY INTEGRATED CARE BOARD	1%
NHS BRISTOL, NORTH SOMERSET AND SOUTH GLOUCESTERSHIRE INTEGRATED CARE BOARD	0%
NHS BUCKINGHAMSHIRE, OXFORDSHIRE AND BERKSHIRE WEST INTEGRATED CARE BOARD	1%
NHS CAMBRIDGESHIRE AND PETERBOROUGH INTEGRATED CARE BOARD	0%
NHS CHESHIRE AND MERSEYSIDE INTEGRATED CARE BOARD	2%
NHS CORNWALL AND THE ISLES OF SCILLY INTEGRATED CARE BOARD	1%
NHS COVENTRY AND WARWICKSHIRE INTEGRATED CARE BOARD	0%
NHS DERBY AND DERBYSHIRE INTEGRATED CARE BOARD	1%
NHS DEVON INTEGRATED CARE BOARD	2%
NHS DORSET INTEGRATED CARE BOARD	2%
NHS FRIMLEY INTEGRATED CARE BOARD	1%
NHS GLOUCESTERSHIRE INTEGRATED CARE BOARD	2%
NHS GREATER MANCHESTER INTEGRATED CARE BOARD	2%
NHS HAMPSHIRE AND ISLE OF WIGHT INTEGRATED CARE BOARD	1%
NHS HEREFORDSHIRE AND WORCESTERSHIRE INTEGRATED CARE BOARD	0%
NHS HERTFORDSHIRE AND WEST ESSEX INTEGRATED CARE BOARD	4%
NHS HUMBER AND NORTH YORKSHIRE INTEGRATED CARE BOARD	1%
NHS KENT AND MEDWAY INTEGRATED CARE BOARD	1%
NHS LANCASHIRE AND SOUTH CUMBRIA INTEGRATED CARE BOARD	0%

Local Health Commissioner	%
NHS LEICESTER, LEICESTERSHIRE AND RUTLAND INTEGRATED CARE BOARD	2%
NHS LINCOLNSHIRE INTEGRATED CARE BOARD	1%
NHS MID AND SOUTH ESSEX INTEGRATED CARE BOARD	1%
NHS NORFOLK AND WAVENEY INTEGRATED CARE BOARD	3%
NHS NORTH CENTRAL LONDON INTEGRATED CARE BOARD	1%
NHS NORTH EAST AND NORTH CUMBRIA INTEGRATED CARE BOARD	2%
NHS NORTH EAST LONDON INTEGRATED CARE BOARD	1%
NHS NORTH WEST LONDON INTEGRATED CARE BOARD	0%
NHS NORTHAMPTONSHIRE INTEGRATED CARE BOARD	1%
NHS NOTTINGHAM AND NOTTINGHAMSHIRE INTEGRATED CARE BOARD	2%
NHS SHROPSHIRE, TELFORD AND WREKIN INTEGRATED CARE BOARD	0%
NHS SOMERSET INTEGRATED CARE BOARD	0%
NHS SOUTH EAST LONDON INTEGRATED CARE BOARD	5%
NHS SOUTH WEST LONDON INTEGRATED CARE BOARD	2%
NHS SOUTH YORKSHIRE INTEGRATED CARE BOARD	3%
NHS STAFFORDSHIRE AND STOKE-ON-TRENT INTEGRATED CARE BOARD	2%
NHS SUFFOLK AND NORTH EAST ESSEX INTEGRATED CARE BOARD	1%
NHS SURREY HEARTLANDS INTEGRATED CARE BOARD	1%
NHS SUSSEX INTEGRATED CARE BOARD	2%
NHS WEST YORKSHIRE INTEGRATED CARE BOARD	1%
Northern Health Board	1%
Orkney	0%

Local Health Commissioner	%
Powys Teaching Health Board	0%
Shetland	0%
Southern Health Board	1%
Swansea Bay University Health Board	0%
Tayside	5%
Western Health Board	1%
Western Isles	1%

Figure 103. base n = 217

Q – Where do you live? [POSTCODE – CODED]

Over three-quarters (78%) of children and young people reported being based in England. Smaller proportions were from Wales (10%), Scotland (9%), and Northern Ireland (4%).

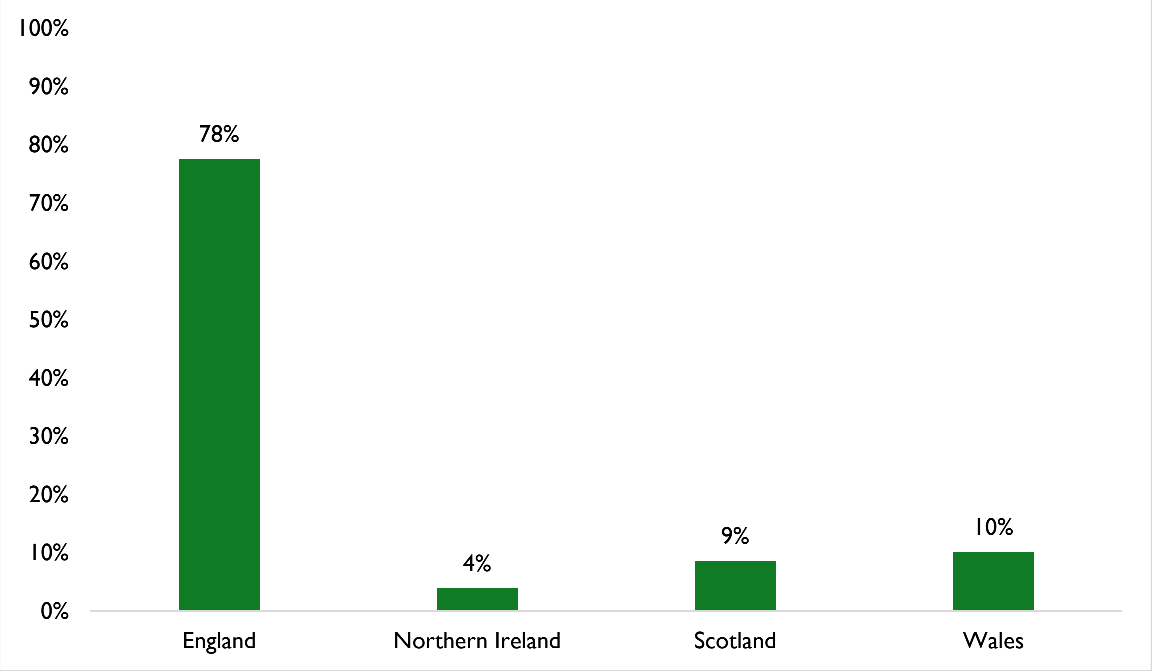

Figure 104. base n = 129

Q – What is their postcode? [CODED]

Carer reporting on behalf of a child or young person

Carers most commonly reported that the child or young person they support lived in England (61%). Over a quarter (26%) were based in Scotland, while smaller proportions were reported in Wales (8%) and Northern Ireland (5%).

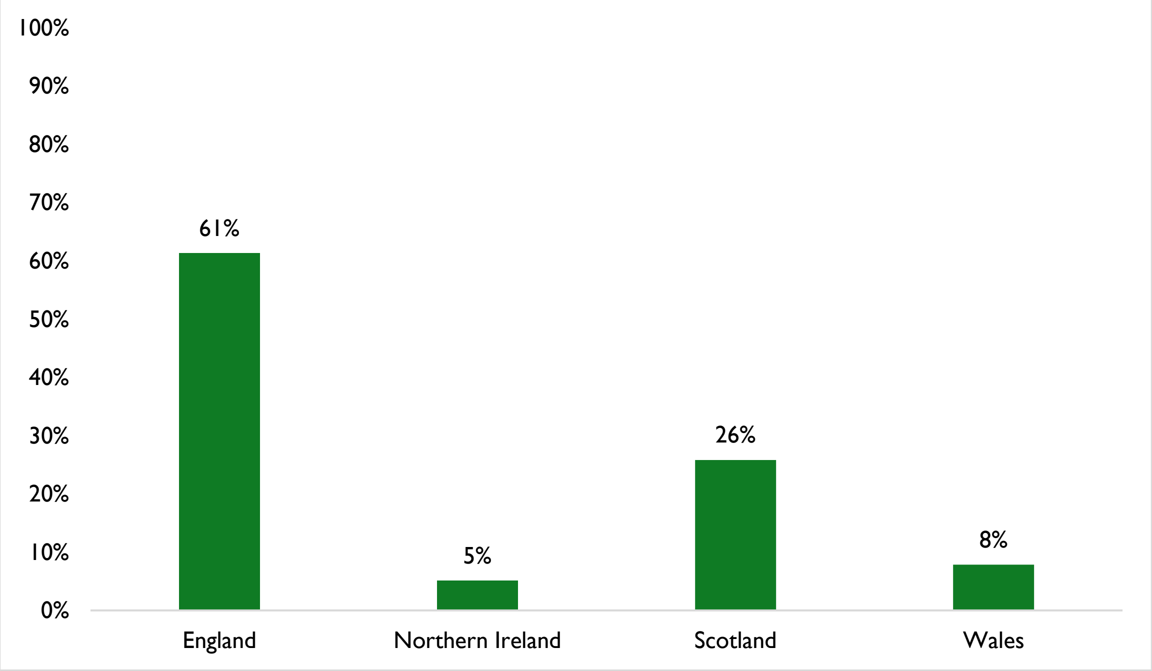

Figure 105. base n = 217

Q – Do you receive free school meals?

Just under one in five (19%) respondents said they received free school meals. The majority (76%) reported that they did not. A small proportion were unsure (4%) or preferred not to say (1%).

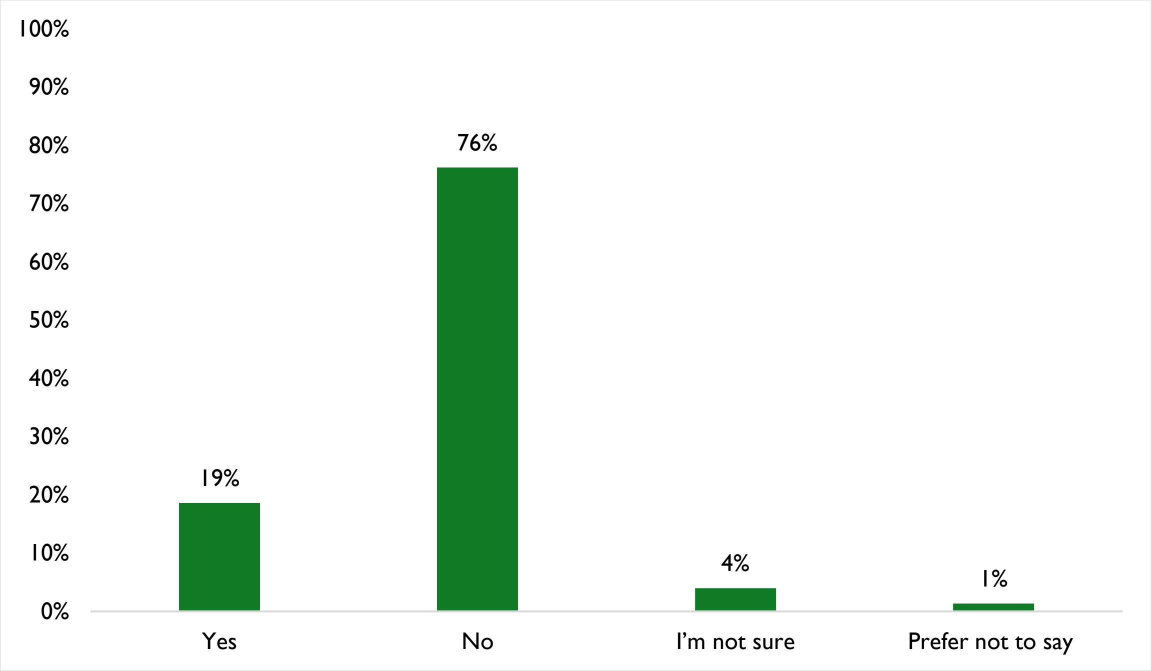

Figure 106. base n = 151

Q – Do your family / parents / guardians have enough money to be able to buy everything they need in a normal month?

Over half (58%) said their family always had enough money to meet their needs in a typical month, while 25% said this was true "sometimes". Smaller proportions said this was the case "occasionally" (9%), "rarely" (3%) or "never" (1%). A few were unsure (3%) or preferred not to say (1%).

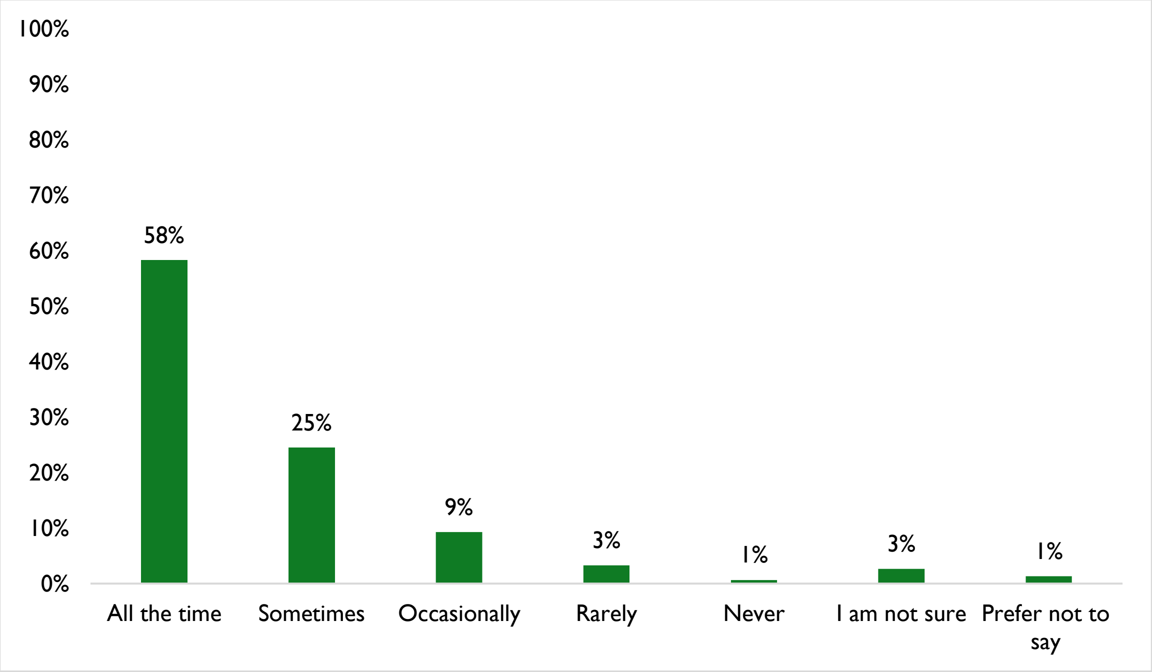

Figure 107. base n = 151

Q – What type of school/college do you go to?

Two-thirds (67%) of respondents reported attending a regular school (primary, secondary or college). A further 9% went to a special needs school, while 5% were homeschooled. An additional 9% said they didn't go to school, and 8% selected "other". A small number (3%) preferred not to answer.

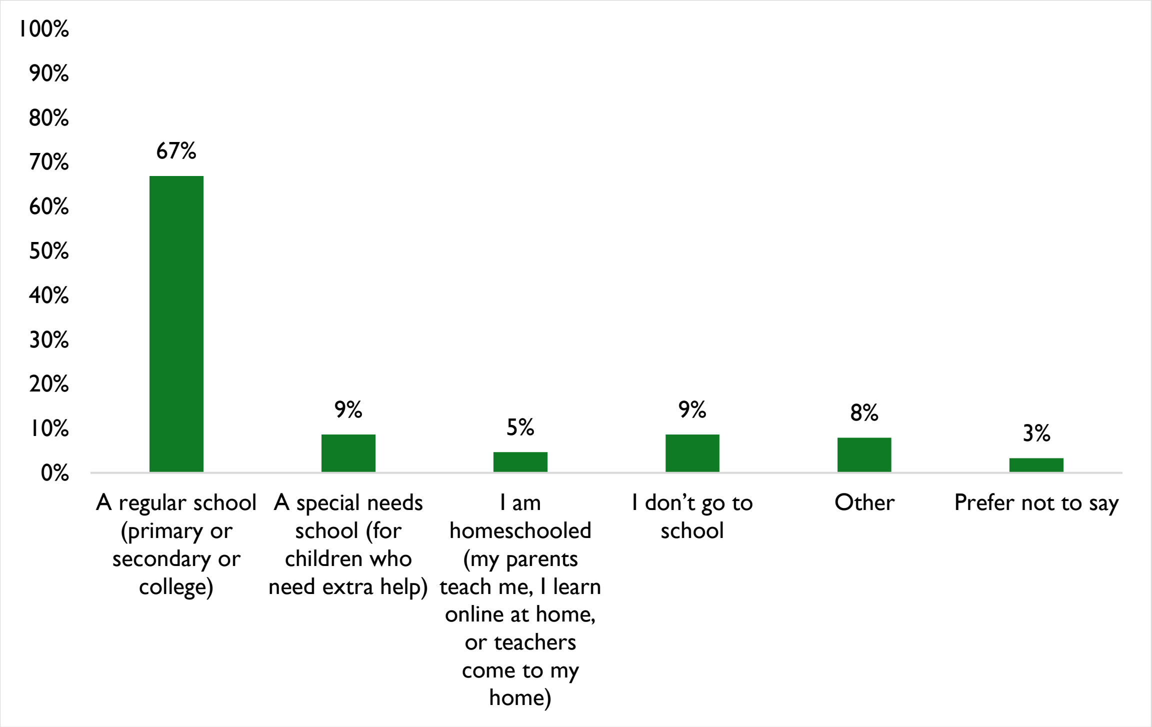

Figure 108. base n = 151

Q – My health makes me feel…

The most common feelings associated with health were frustration and anger (56%) and feeling worried or stressed (51%). Nearly half (48%) said they felt left out or like they were missing out, and 39% reported feeling scared about the future. Smaller proportions said they felt like they couldn't keep up (38%) or were proud of how they handled things (32%). Fewer reported feeling mostly okay (20%), hopeful about the future (7%) or happy that they are unique (10%). A small number (6%) preferred not to answer.

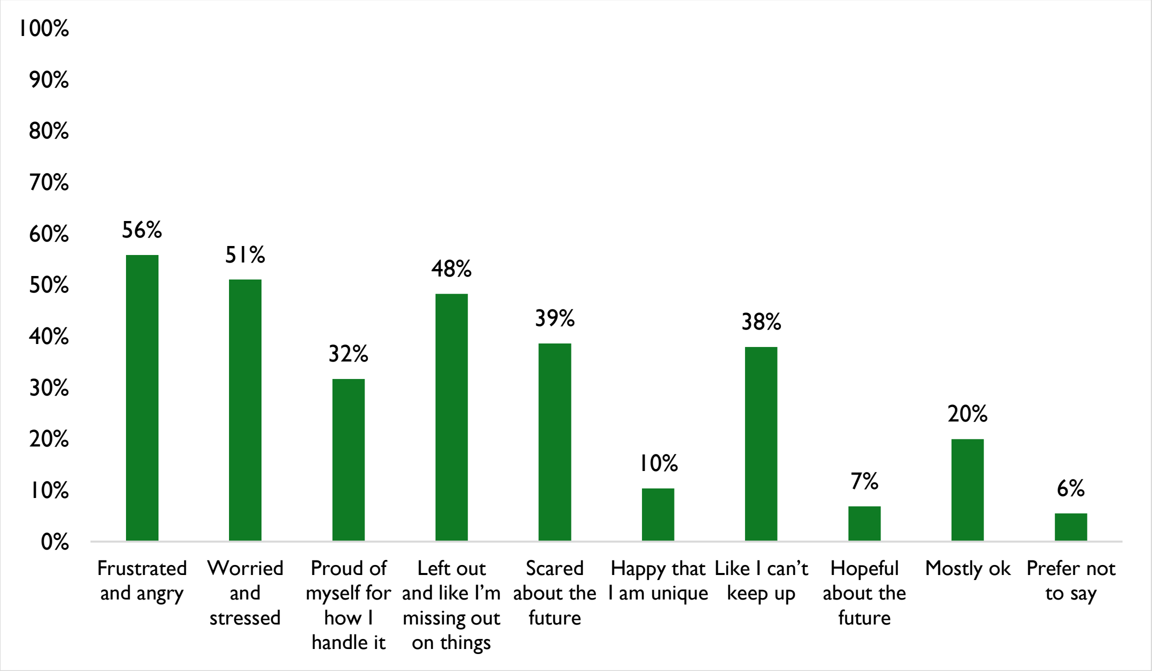

Figure 109. base n = 145

Q – Do you get support from outside your home?

Respondents indicated a variety of sources from which they receive support. The most commonly reported source was school support for schoolwork, cited by 38% of respondents. This was closely followed by support from a specialist doctor, nurse, or allied health professional, at 35%. Other sources included:

- Support from school for happiness and well-being – 24%
- Support from a charity – 18%
- Support from school for attendance – 16%
- Support from CAMHS (HSE/NHS mental health services) – 15%

Around a quarter (24%) reported not receiving any support. A smaller proportion reported receiving support from other sources (7%) or chose not to say (1%).

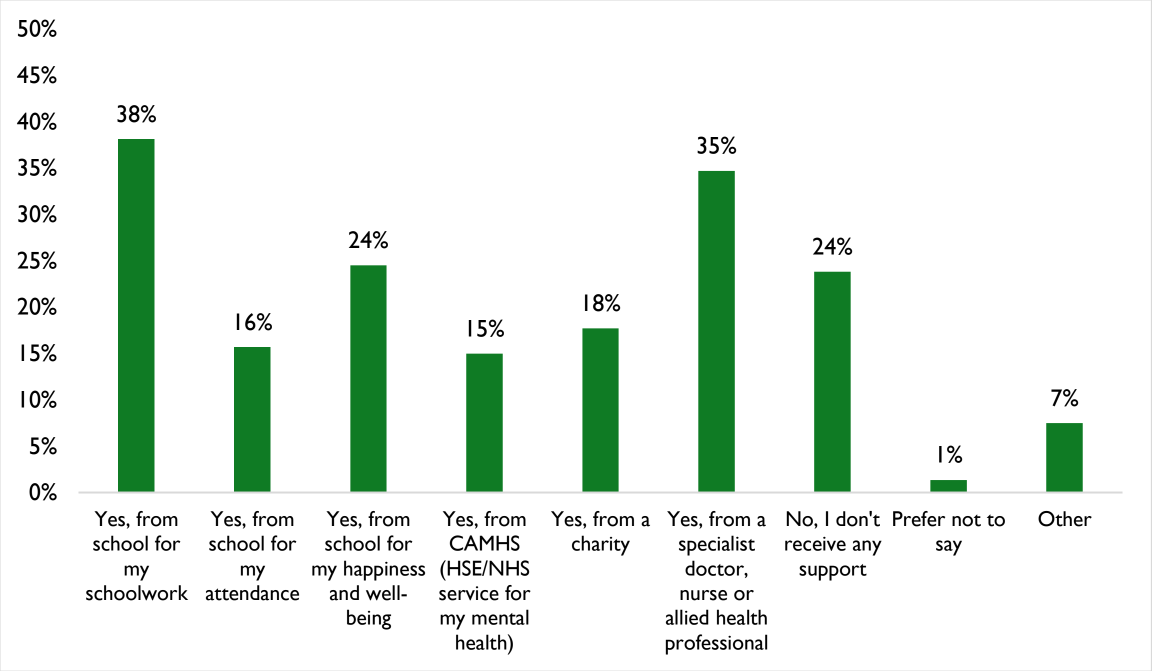

Figure 110. base n = 147

Q – Would you be interested in taking part in research studies about your neurological condition(s) to help others learn more about how to help kids like you?

Just over half (51%) said they would be interested in taking part in research. Around a quarter (27%) were not sure, while 19% said they would not be interested. A small proportion (2%) preferred not to answer.

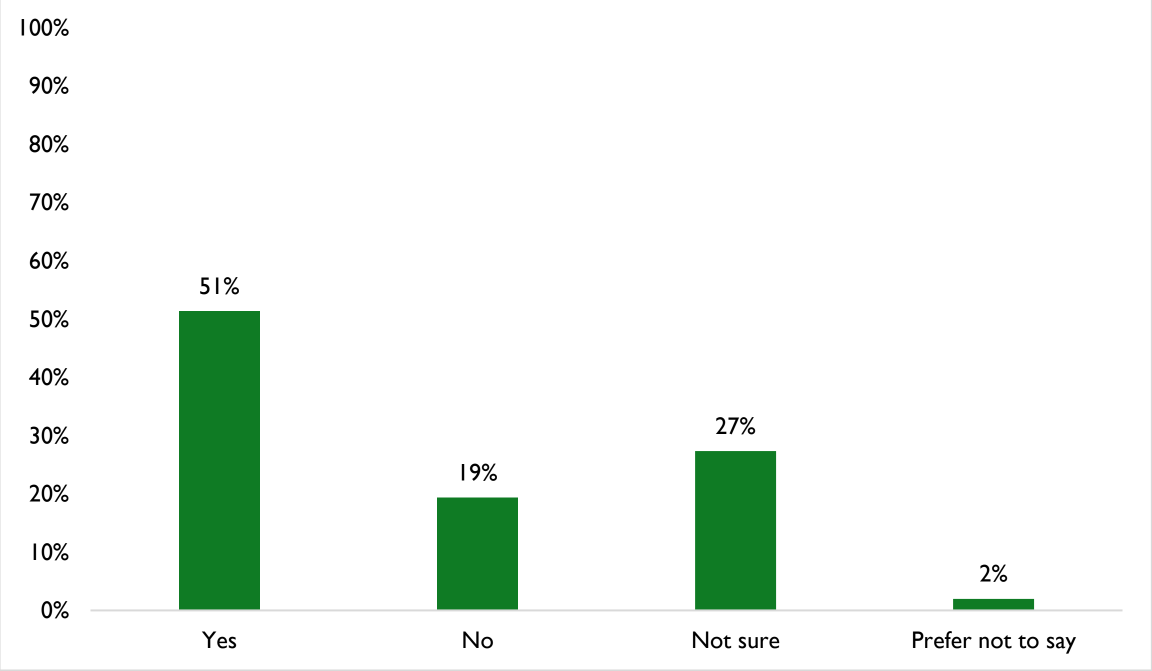

Figure 111. base n = 150

Q – Have you already taken part in research about your neurological condition?

A large majority (81%) had not previously taken part in research about their neurological condition. A small proportion (13%) said they had, while 5% were unsure and 1% preferred not to say.

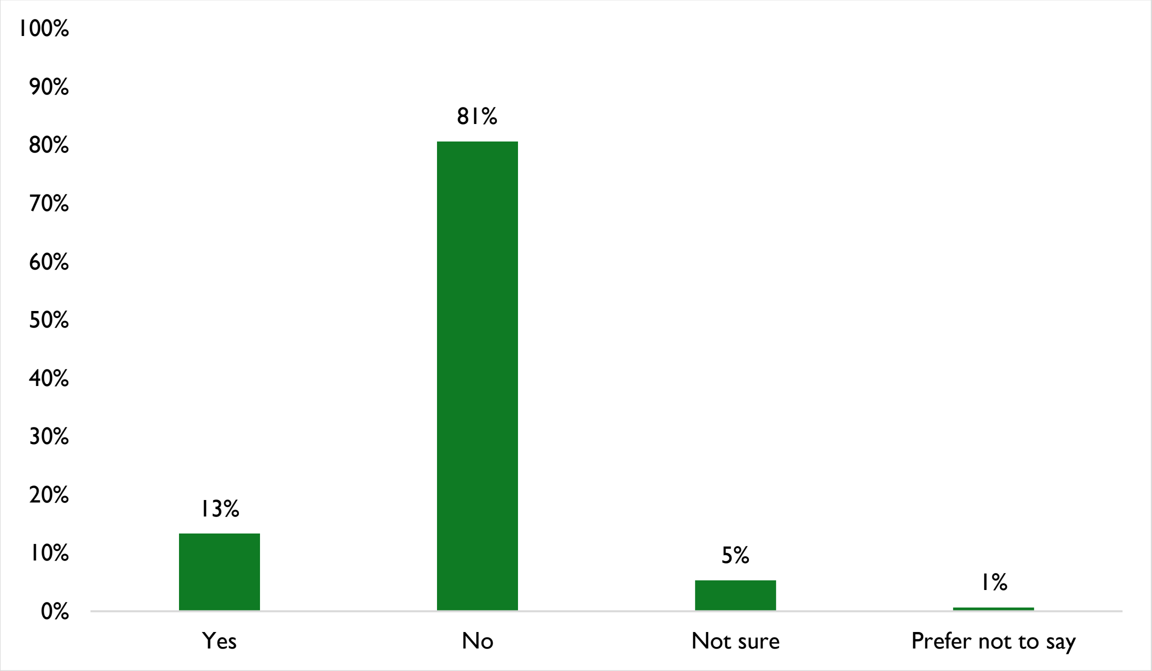

Figure 112. base n = 150

Q – How many times have you seen a health care professional (e.g. a doctor, nurse, physiotherapist) in the past year about your neurological condition(s)?

Most respondents had seen a healthcare professional multiple times over the past year, with 31% having done so 1-2 times and 30% more than 10 times. Others reported 3-5 times (20%) or 6-9 times (13%). A small number had not seen any professionals (5%), and 1% didn't know or couldn't recall.

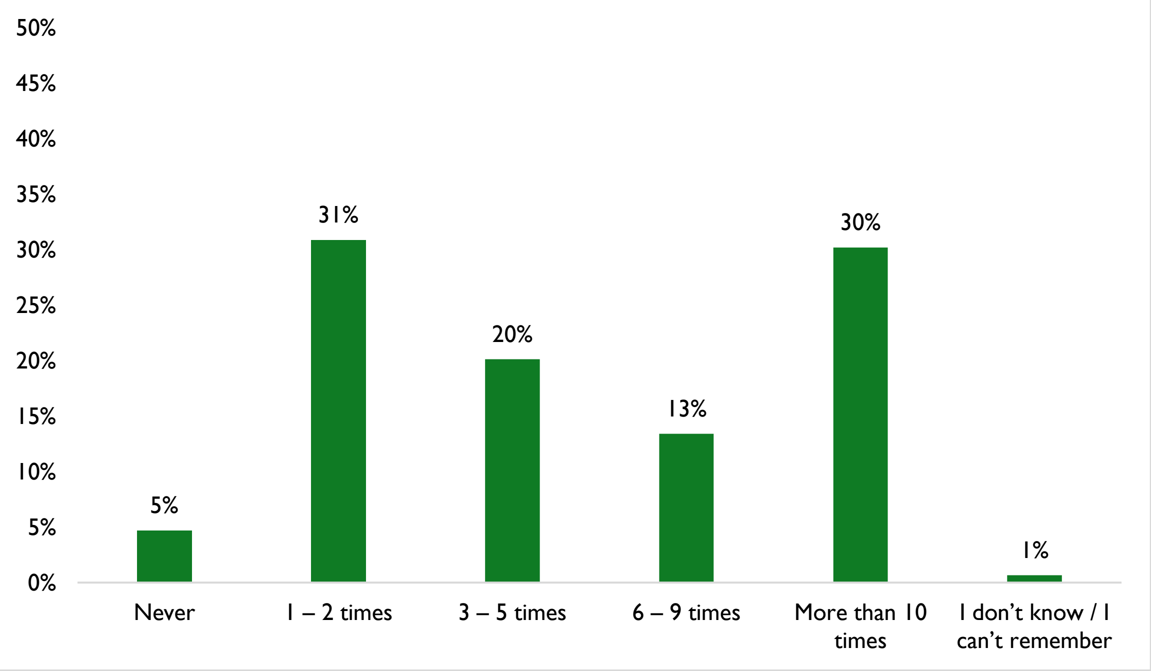

Figure 113. base n = 149

Q – I understand what is happening with my health

Half of respondents agreed or strongly agreed that they understood what was happening with their health. However, around a third expressed uncertainty or disagreement – 15% neither agreed nor disagreed, 15% disagreed, and 12% strongly disagreed. A further 7% said they didn't know, and 1% preferred not to say.

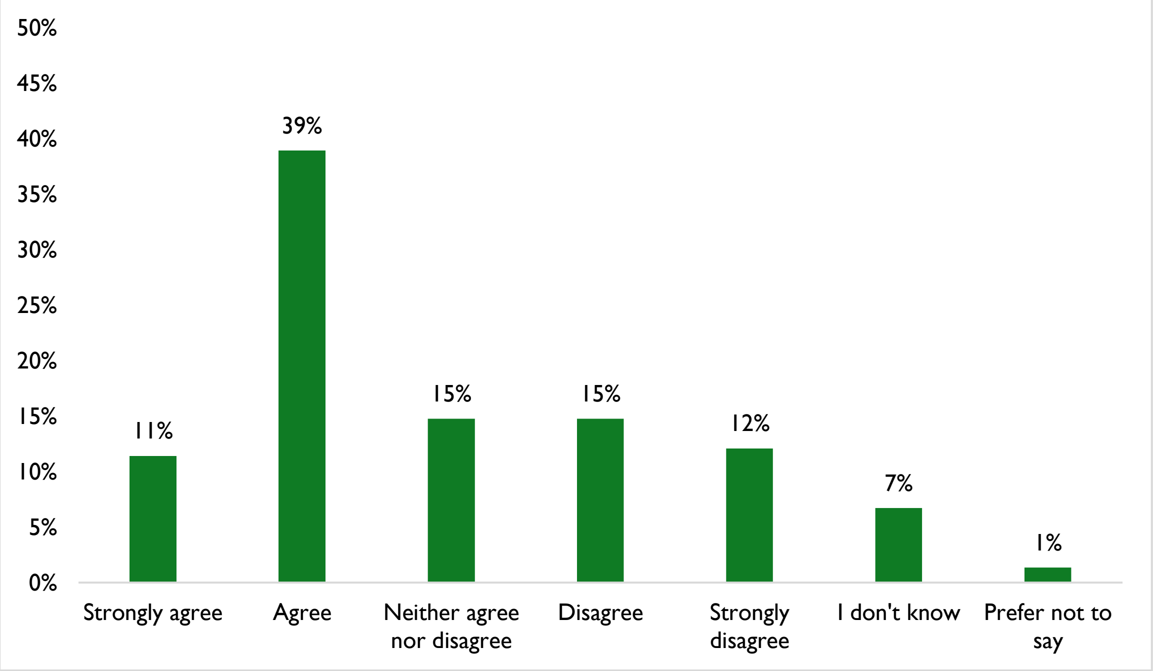

Figure 114. base n = 149

Q – I feel mostly scared or nervous before an appointment

Over half of respondents said they felt scared or nervous before an appointment, with 36% agreeing and 21% strongly agreeing. A further 13% neither agreed nor disagreed, while 14% disagreed and 11% strongly disagreed. A small number were unsure (4%) or preferred not to say (1%).

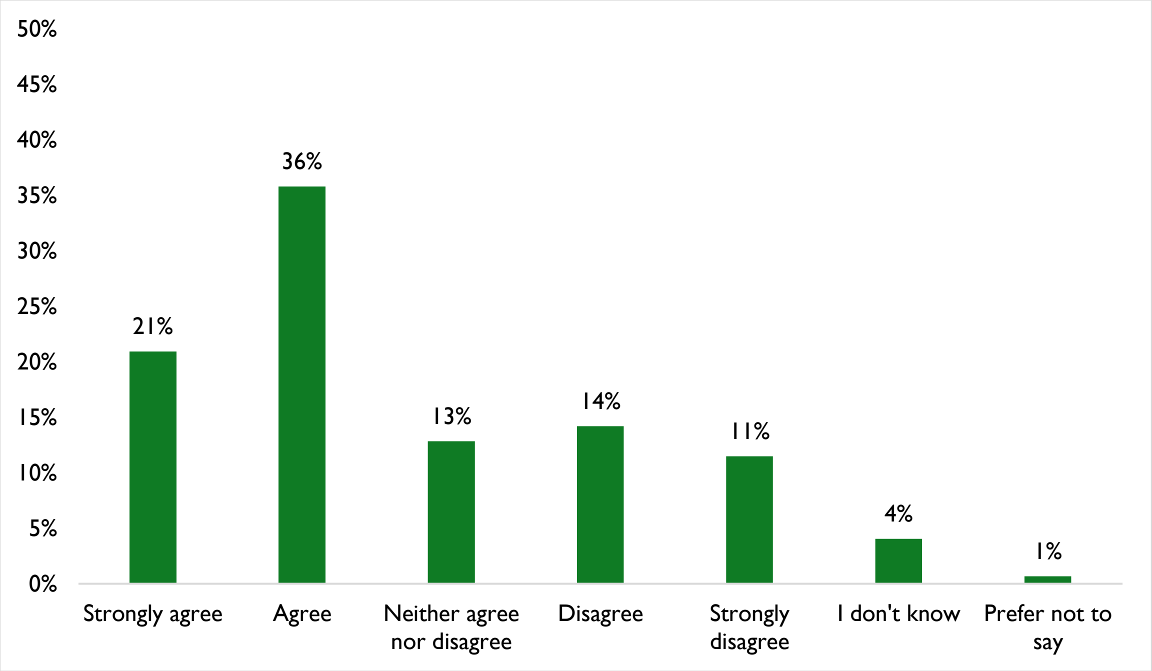

Figure 115. base n = 148

Q – I miss out on things because of appointments to do with my health

Almost half agreed they missed out on things due to appointments, including 35% who agreed and 13% who strongly agreed. However, a substantial group did not share this view – 23% disagreed and 10% strongly disagreed. 15% were neutral, while a small minority (2%) said they didn't know and 1% preferred not to say.

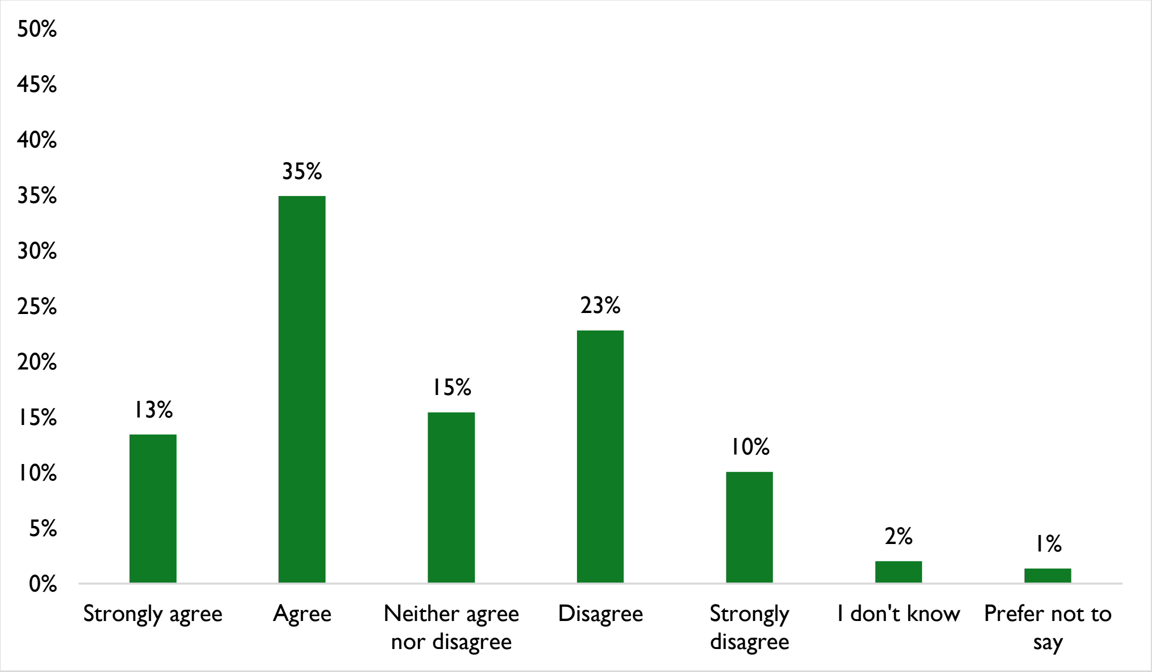

Figure 116. base n = 149

Q – Healthcare professionals use words I understand

Over half felt healthcare professionals used language they could understand, with 34% agreeing and 17% strongly agreeing. However, around a quarter disagreed to some extent (16% disagreed, 7% strongly disagreed), while 18% were neutral. A small number said they didn't know (5%) or preferred not to say (1%).

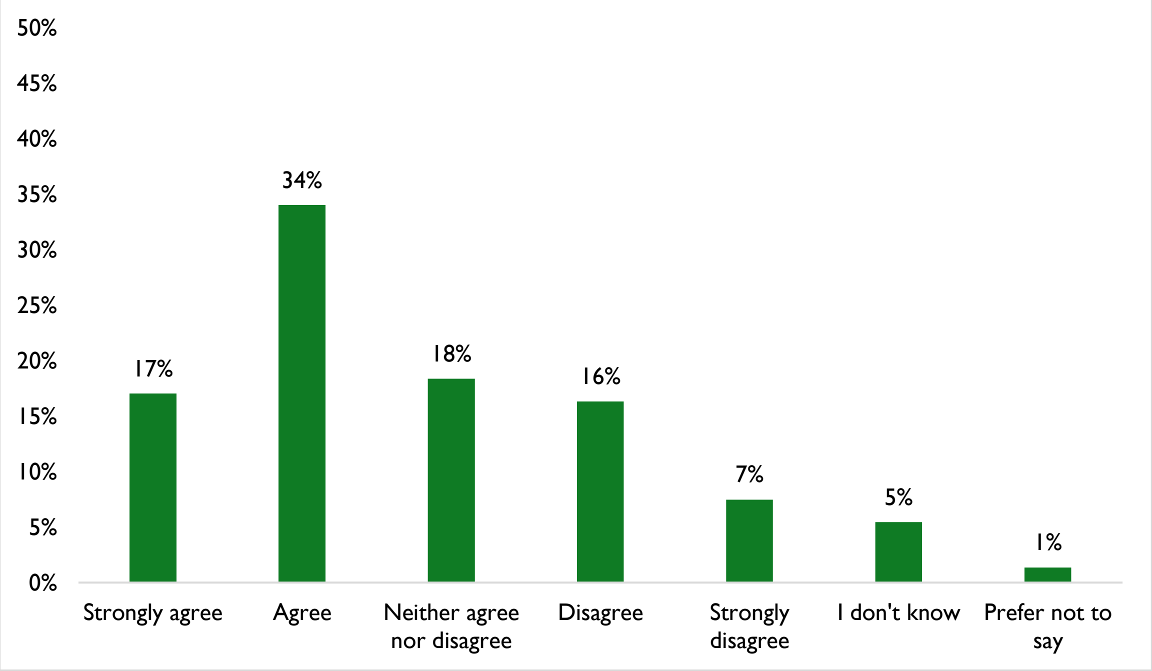

Figure 117. base n = 147

Q – I don’t always feel involved in decisions about my health

Just over a third of young people said they didn’t always feel involved in decisions about their health, including 27% who agreed and 8% who strongly agreed. A further third (34%) felt more positively, saying they disagreed (25%) or strongly disagreed (9%). Around a quarter (23%) were neutral, and a small number were unsure (5%) or preferred not to say (3%).

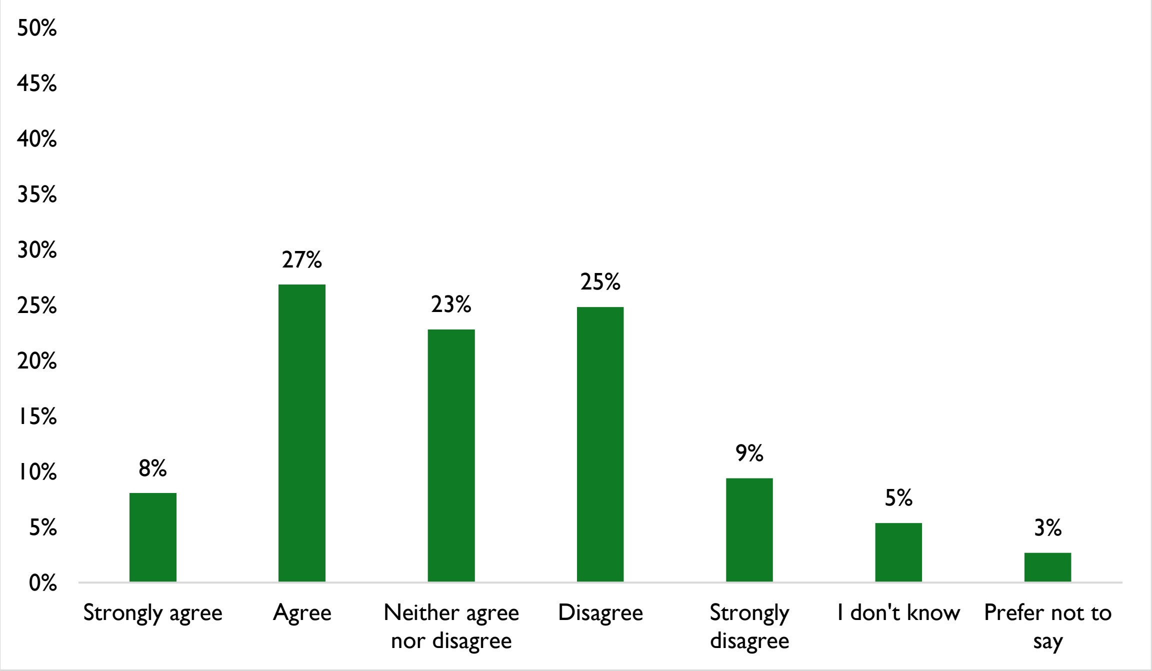

Figure 118. base n = 149

Q – I feel supported and listened to by healthcare professionals

Just under half agreed that they felt supported and listened to by healthcare professionals (35% agree, 9% strongly agree). However, a notable proportion disagreed (19%) or strongly disagreed (11%), while 21% neither agreed nor disagreed. A small number were unsure (4%) or preferred not to say (1%).

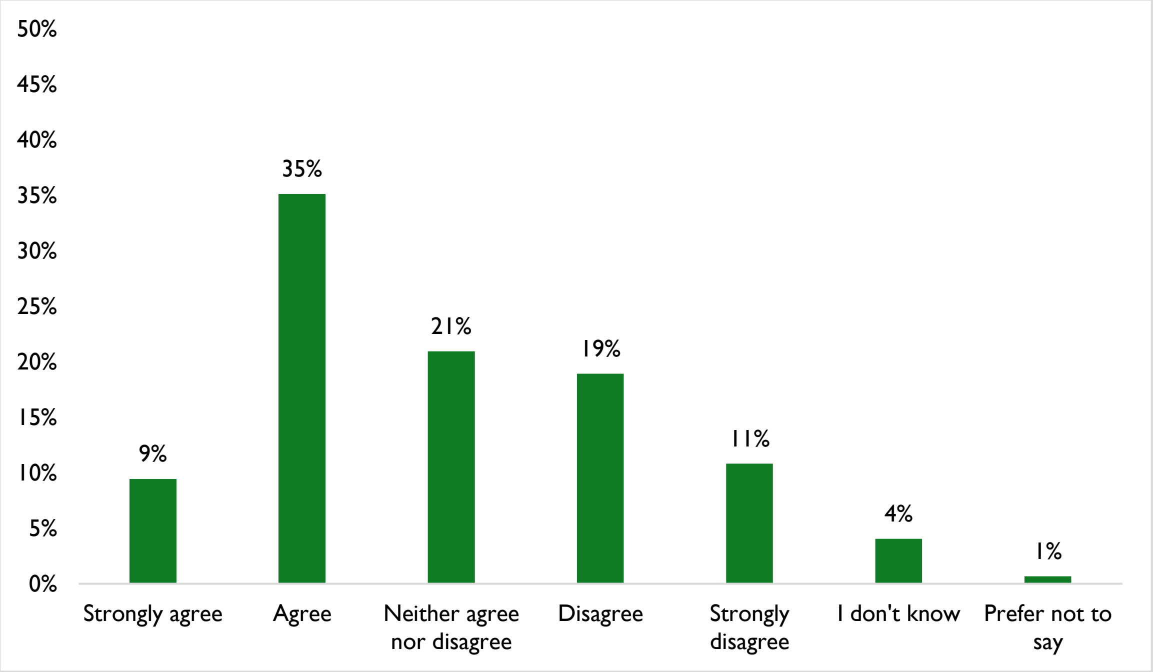

Figure 119. base n = 148

Q – I feel comfortable asking my doctor and other healthcare professionals questions

Just over half felt comfortable asking questions, with 37% agreeing and 14% strongly agreeing. However, around a quarter disagreed (16%) or strongly disagreed (11%), while 15% neither agreed nor disagreed. A small number were unsure (5%) or preferred not to say (1%).

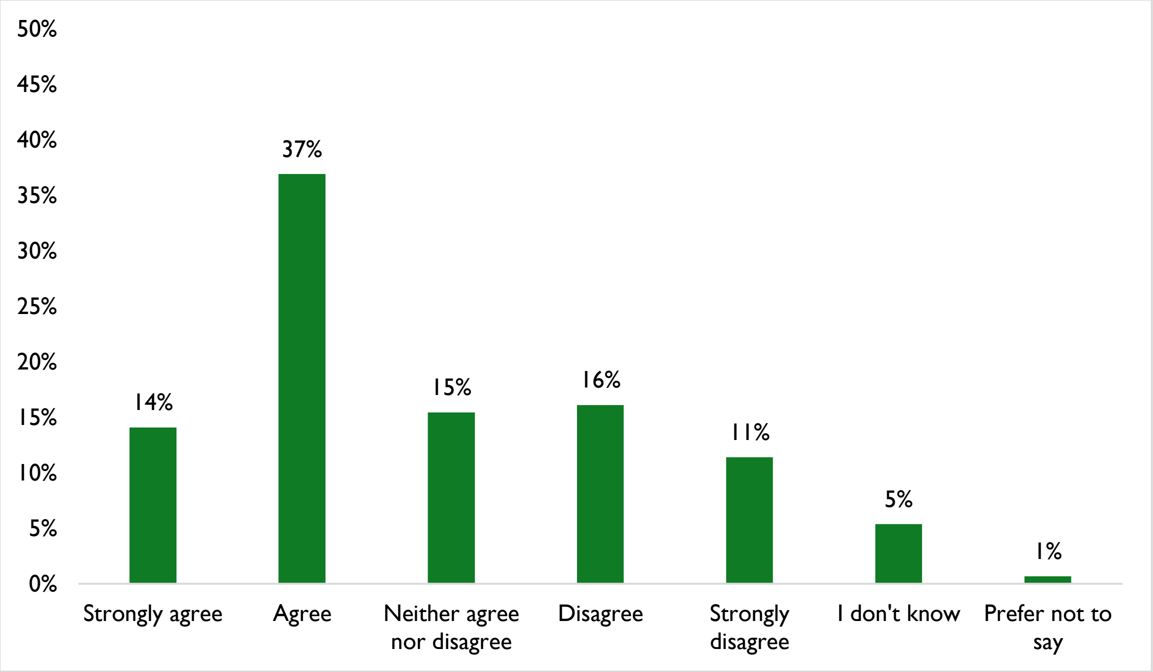

Figure 120. base n = 149

Q – I need more support or information from healthcare professionals

Around half of young people said they needed more support or information, with 26% strongly agreeing and 25% agreeing. A further 23% were neutral, while one in five disagreed (17%) or strongly disagreed (3%). 6% were unsure and 1% preferred not to say.

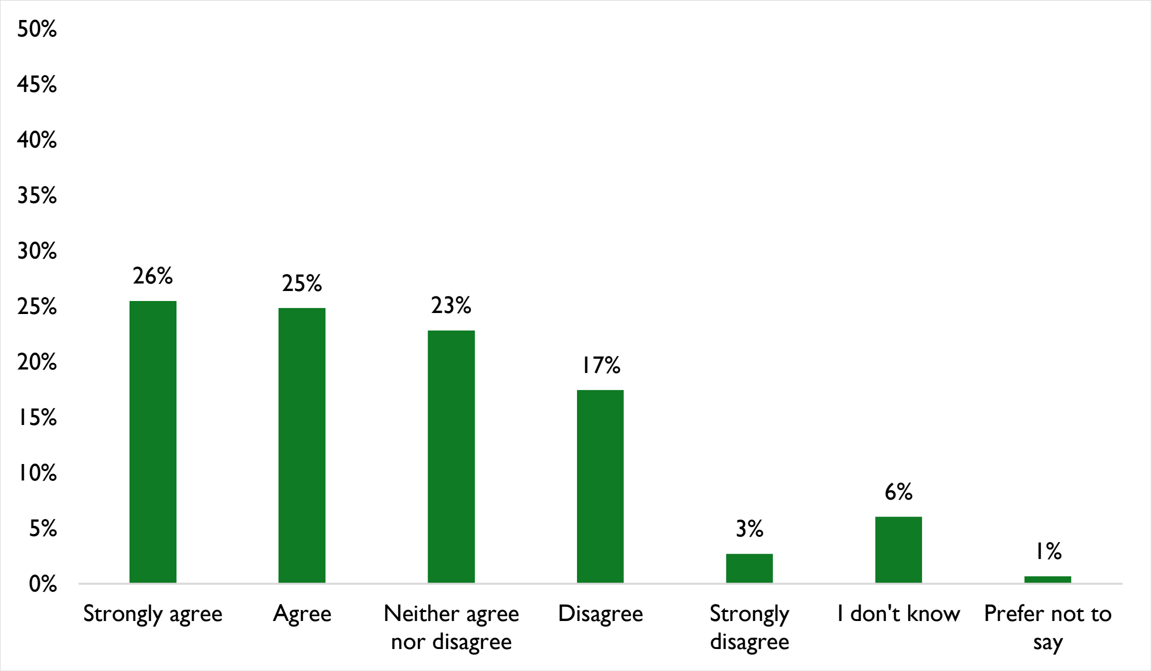

Figure 121. base n = 149

Q – Have you received any information about moving from children's care to adult care?

Over half (52%) of the sample said they had not received any information about the transition to adult care. A further 23% said they didn't know where to get the information, while 13% wanted to know more. Only 3% said they had received detailed information, and 7% had received some but needed more. A small number didn't know or preferred not to say.

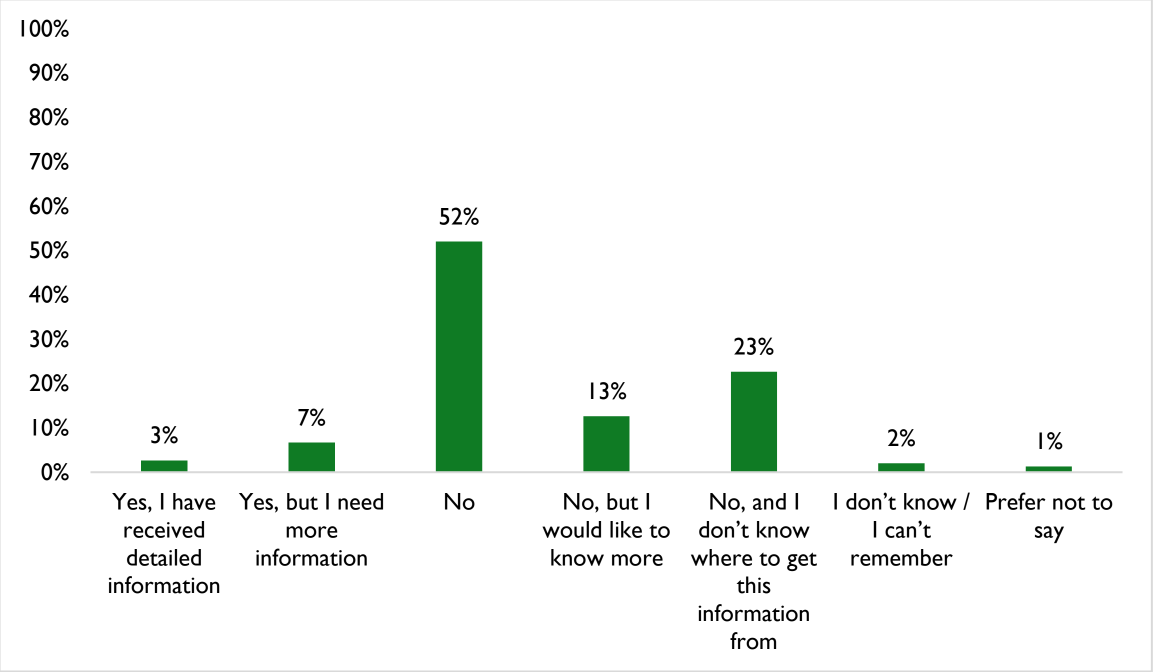

Figure 122. base n = 150

Q – If you are moving between children's and adult's services, do you have a named worker?

Most young people (77%) did not have a named worker to support their transition between services. Just 4% said they did, while 16% were unsure and 3% preferred not to say.

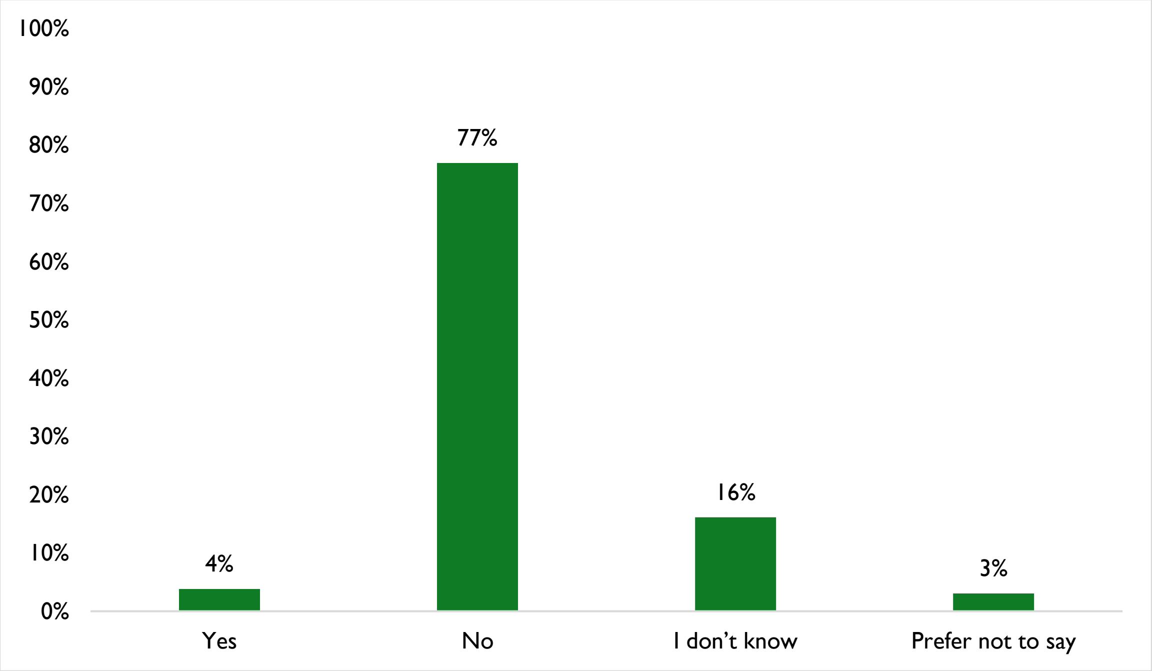

Figure 123. base n = 130

4.3 Results from the carer’s survey

Q – Do you support more than one person?

The vast majority of carers (84%) said they support only one person. Around 15% reported supporting more than one person, while 1% preferred not to say.

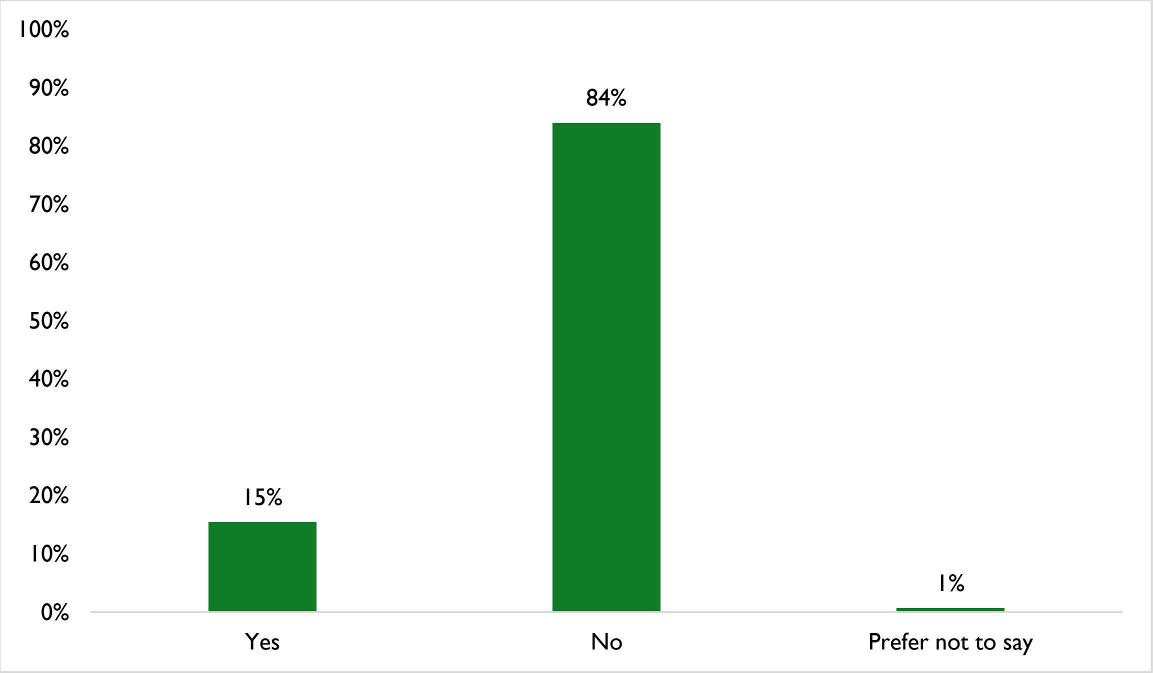

Figure 6724. base n = 1245

Q – What is your relationship to the person you care for?

Carers most commonly identified as a parent or guardian (47%) or a spouse/partner (37%). Other relationships included child (9%), other family member (3%), and friend/neighbour (1%). A small number were paid caregivers (1%), selected “Other” (1%), or preferred not to say (1%).

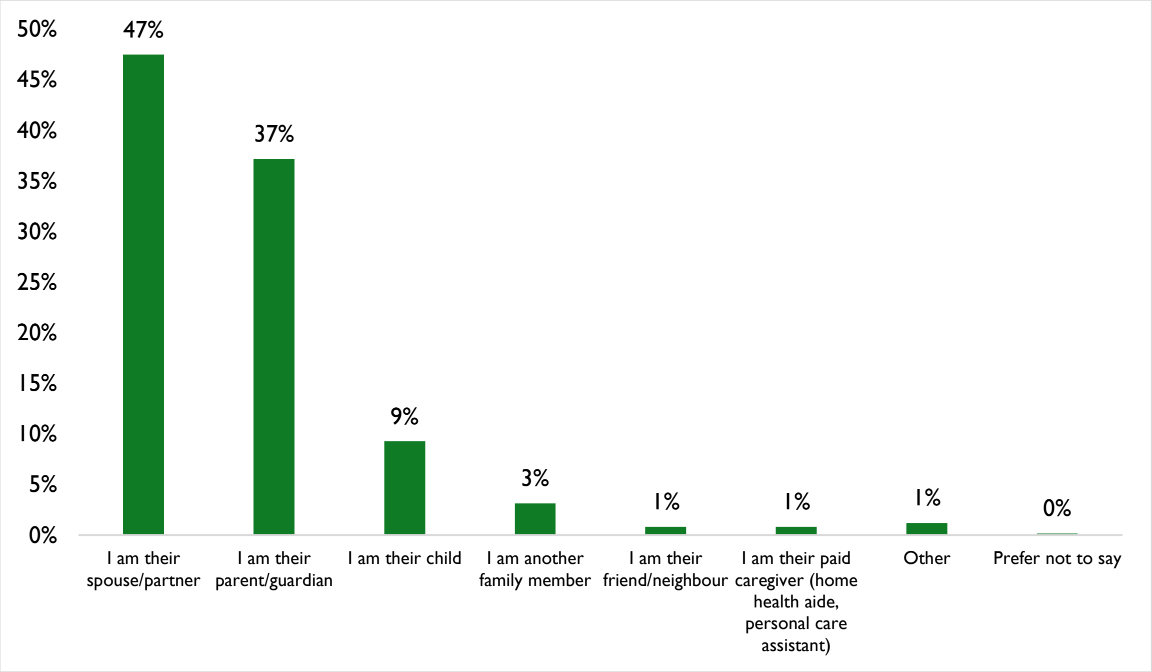

Figure 1685. base n = 1243

Q – How long have you been caring for them?

Just under half of carers (46%) reported providing care for between 1-5 years. Around 29% have cared for over 10 years, 20% for between 6-10 years, and 6% for less than a year.

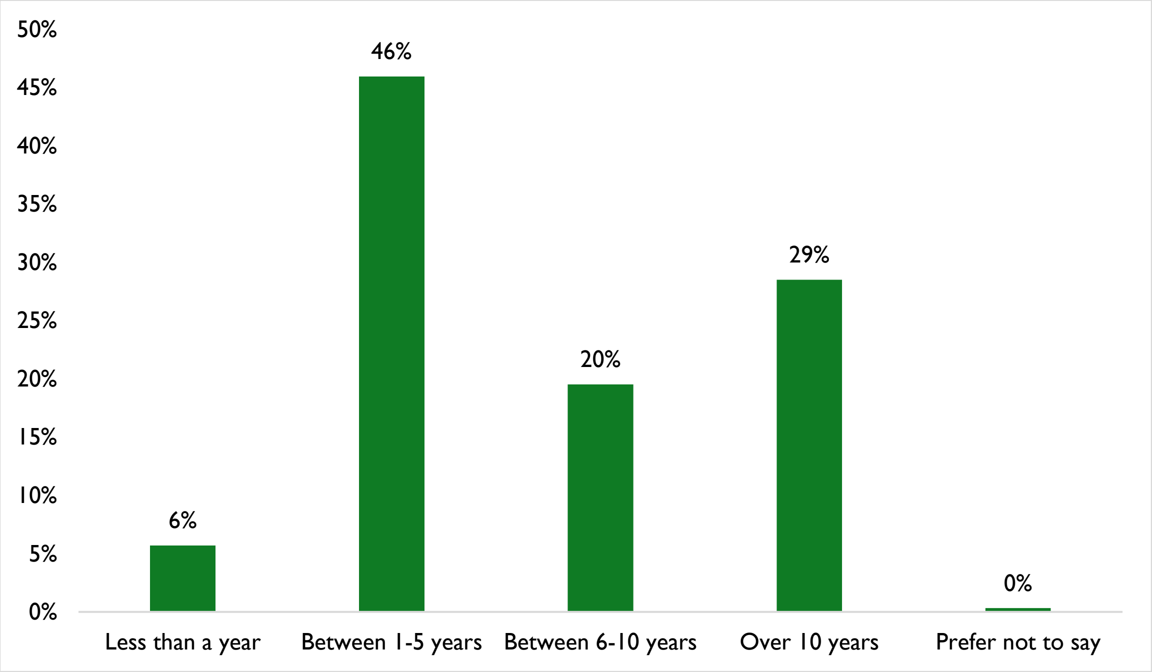

Figure 126. base n = 1245

Q – How much time do you spend caring for this person?

Over half (52%) of carers reported spending 50 or more hours per week providing care. Smaller groups reported providing 35-49 hours (13%), 20-34 hours (13%), 10-19 hours (10%), or 0-9 hours (9%) of care per week. A small proportion (3%) selected “Prefer not to say”.

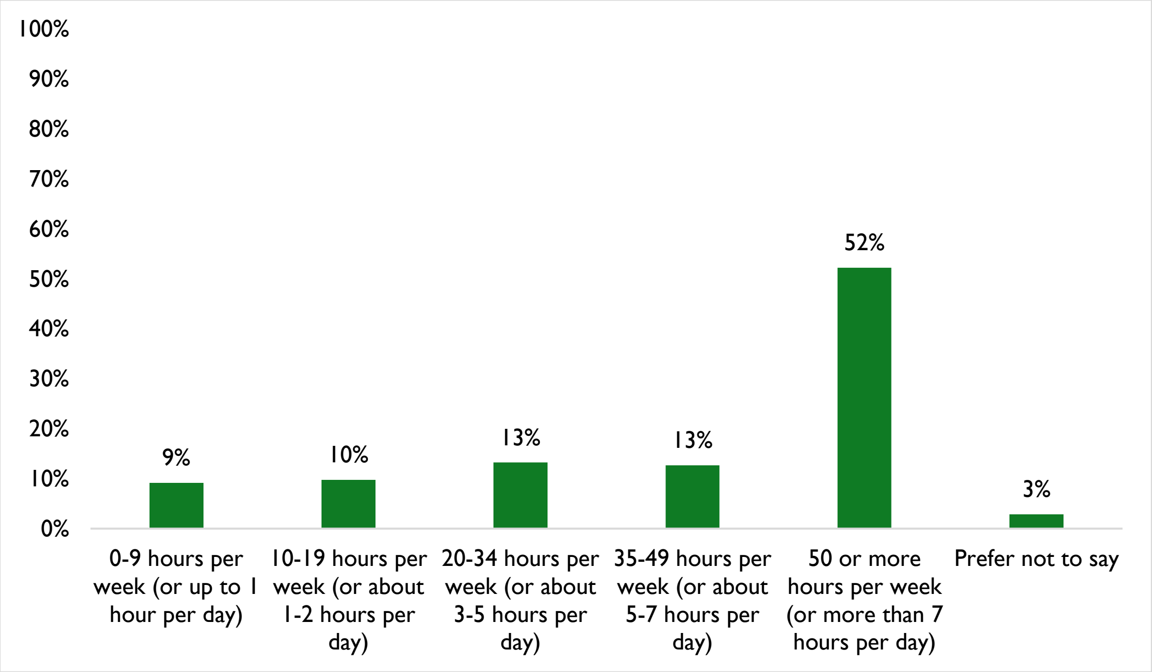

Figure 127. base n = 1246

Q – What are your caring responsibilities for this person?

Nearly three-quarters (73%) of respondents said they are the main carer for the person they support. Around 19% said they share the main caring role with someone else, while 8% help but someone else is the main carer. A very small proportion (1%) selected “Prefer not to say”.

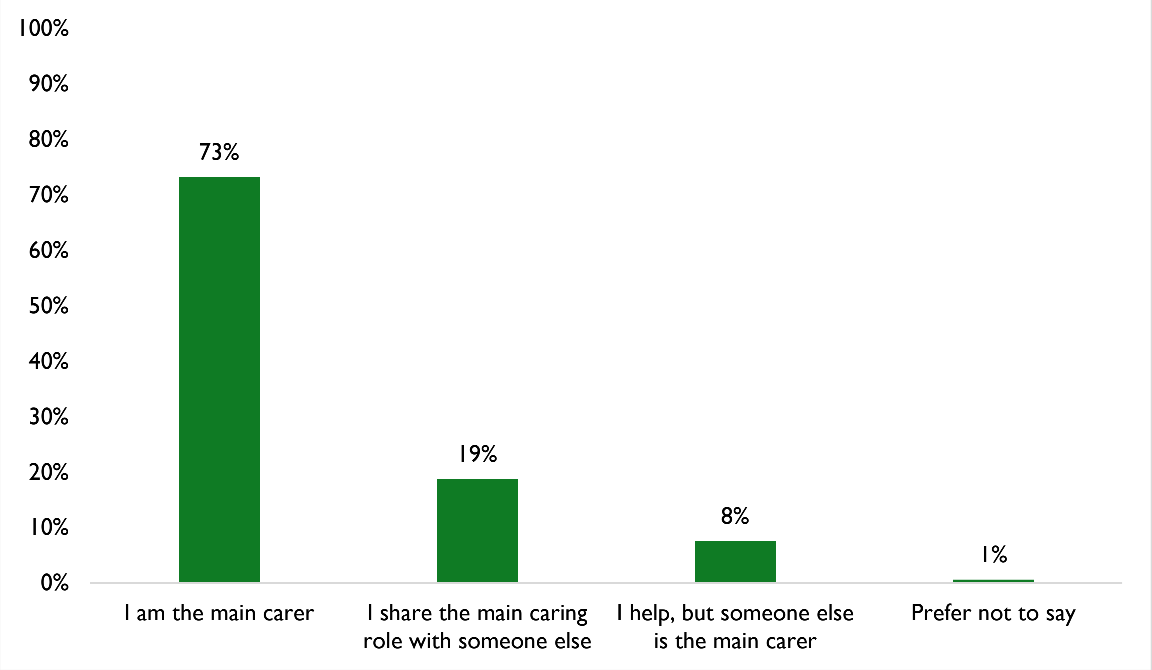

Figure 128. base n = 1244

Q – What type(s) of care do you provide for this person?

Almost all carers reported providing emotional care (94%), such as companionship and reassurance. A large majority also provide physical care (79%) and financial care (73%). Just 1% selected "I'm not sure / Prefer not to say".

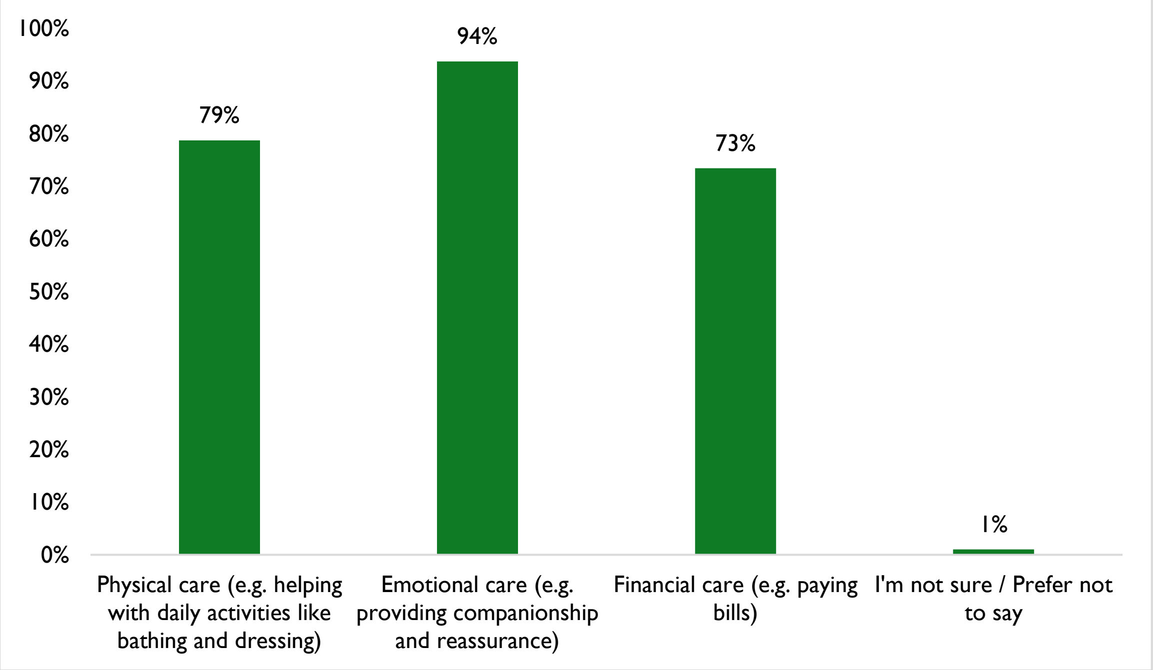

Figure 129. base n = 1185

Q – How independent would you say the person you care for is in their daily activities without your assistance?

Just under half (48%) of carers said the person they care for is not independent and requires assistance with most or all daily activities. A third (32%) reported the person is somewhat independent, needing help with some tasks but managing others alone. A smaller group said the person is mostly independent (16%) or completely independent (4%).

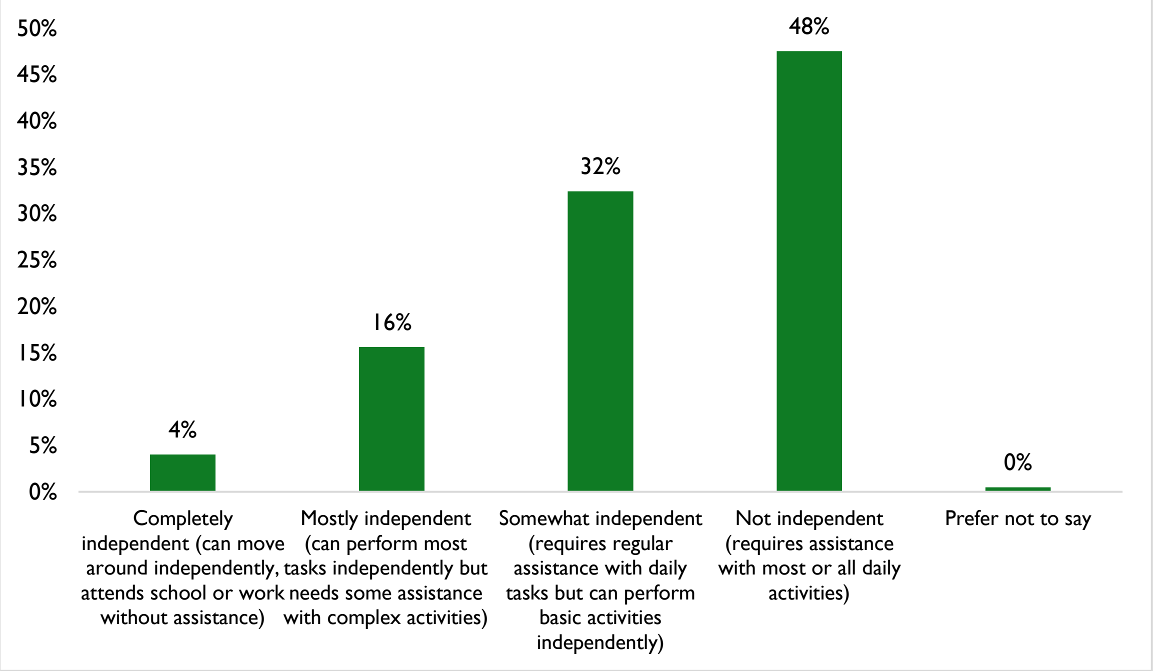

Figure 130. base n = 1244

Q – How involved are you in making decisions for the person you care for?

The majority of carers (59%) reported they are fully involved in all decision-making. Over a quarter (28%) said they are involved in most decisions, although the person they care for makes the final choice. Around 10% are involved in some decisions, and 3% said they are not involved in any decisions.

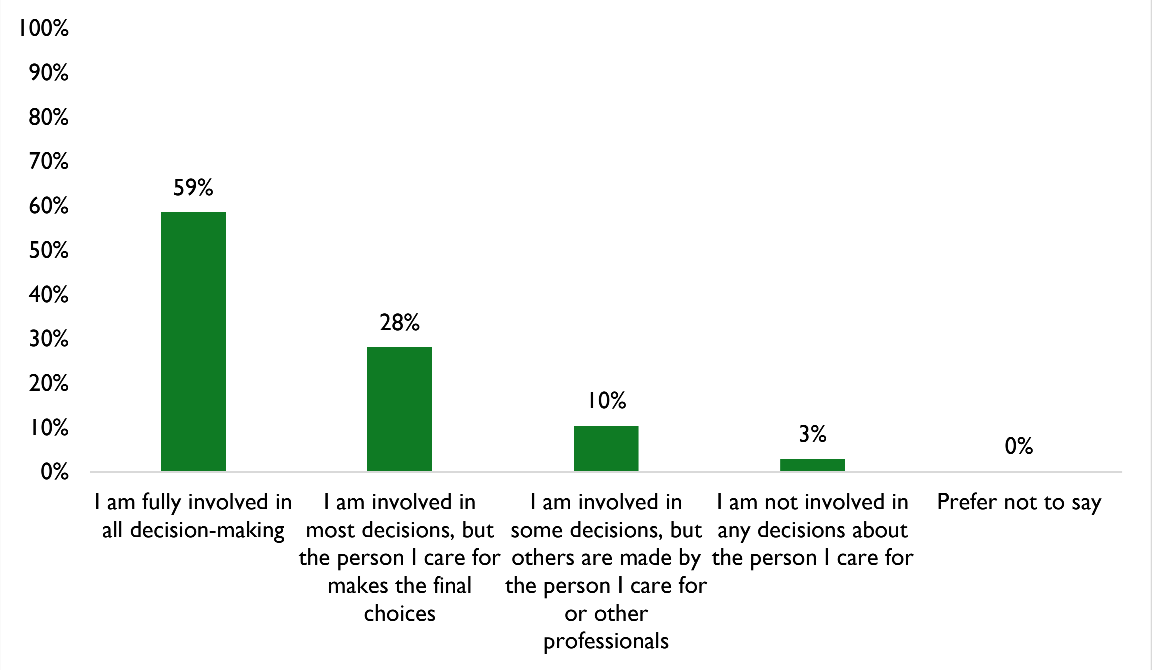

Figure 131. base n = 1241

Q – How do you feel most of the time about your own life?

Most carers find day-to-day life challenging to some degree. The largest group (42%) said they sometimes find day-to-day life challenging, while 26% said they regularly find it challenging. A smaller portion (16%) said they feel confident and capable, and another 16% said they find every day challenging.

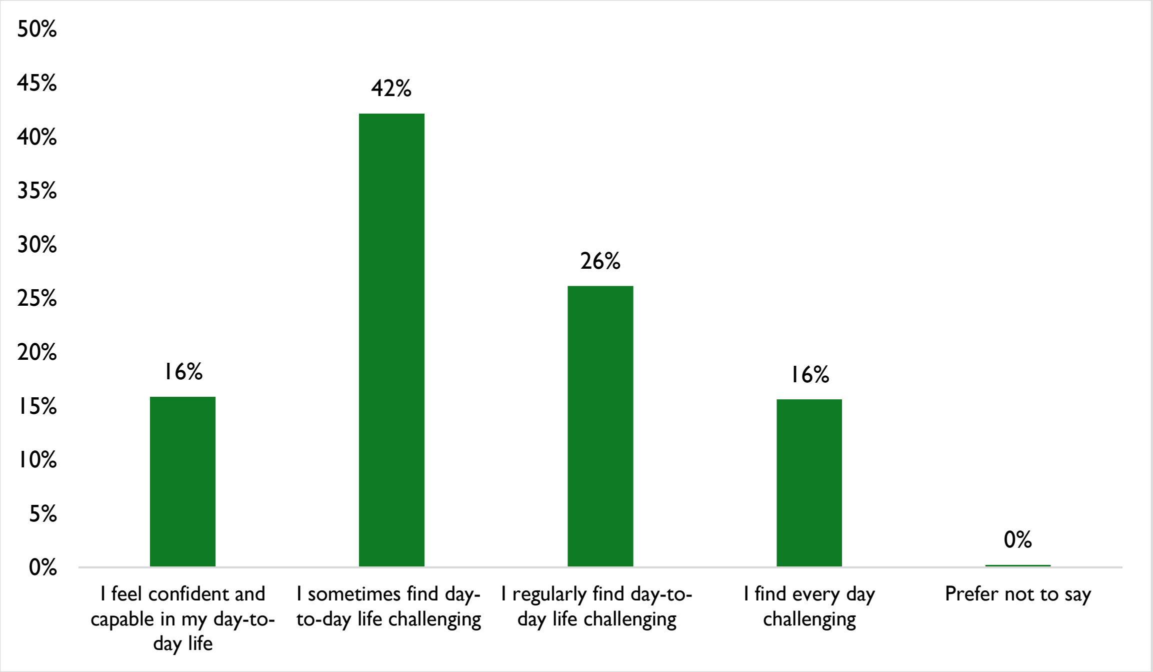

Figure 132. base n = 1243

Q – To what extent do you feel that you are able to meet the day-to-day needs of the person you provide care for?

Three-quarters of carers felt confident in their ability to meet the needs of the person they care for, with 51% agreeing and 26% strongly agreeing. Around one in ten neither agreed nor disagreed (10%), while smaller proportions disagreed (9%) or strongly disagreed (3%).

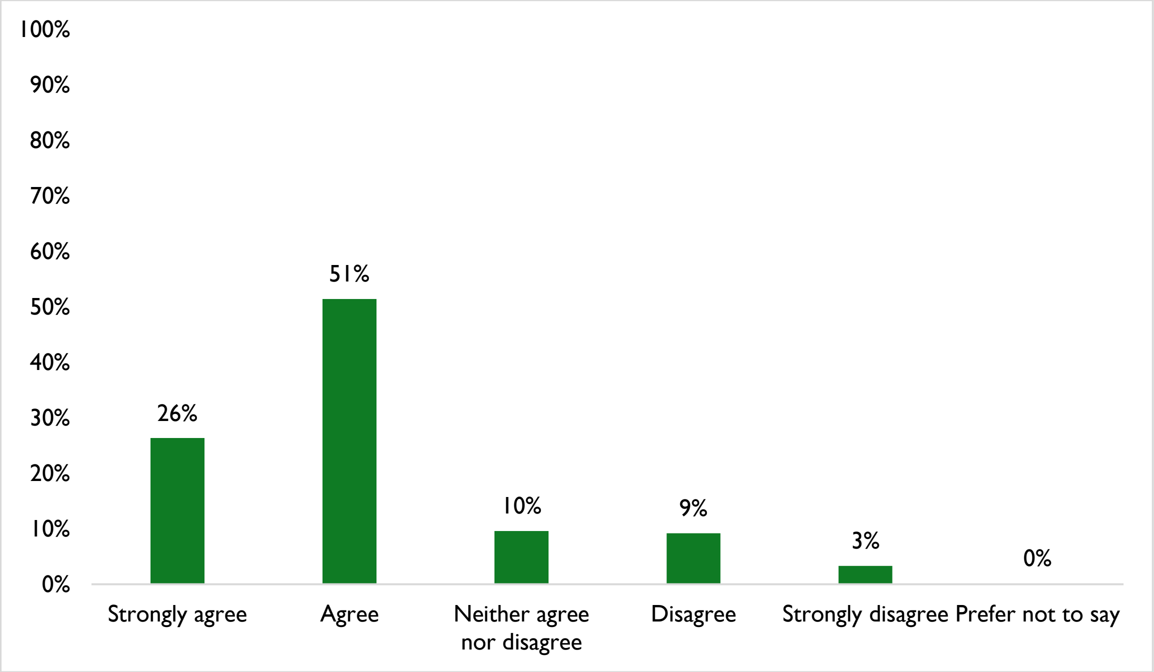

Figure 133. base n = 1241

Q – To what extent do you feel that you are able to meet the health and wellbeing needs of the person you provide care for?

Most carers felt confident in meeting the health and wellbeing needs of the person they care for. Nearly half (48%) agreed, while 22% strongly agreed. Around one in eight (12%) neither agreed nor disagreed, and a similar proportion (15%) disagreed. A small number (3%) strongly disagreed.

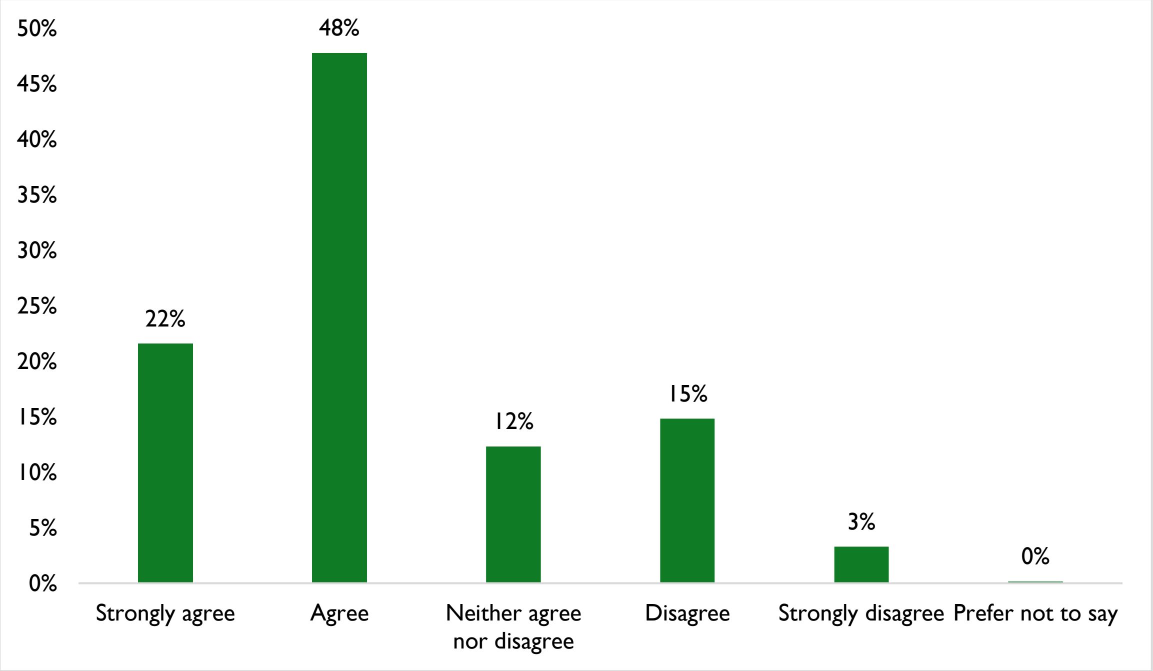

Figure 134. base n = 1241

Q – To what extent do you feel that you are able to manage your own day-to-day needs?

The majority of carers felt they were able to manage their own daily needs, with 40% agreeing and 17% strongly agreeing. However, nearly one in five (19%) disagreed, and 5% strongly disagreed. A further 18% neither agreed nor disagreed.

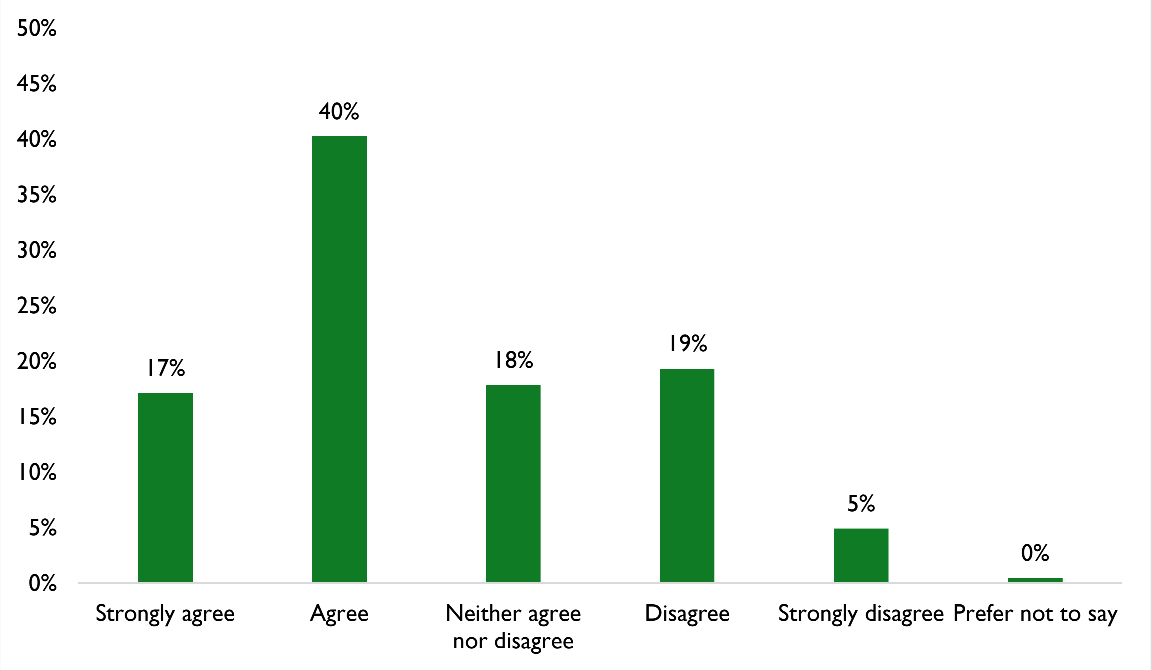

Figure 135. base n = 1242

Q – To what extent do you feel that you are able to manage your own health and wellbeing?

Half of carers agreed (36%) or strongly agreed (14%) that they were able to manage their own health and wellbeing. However, over a quarter disagreed (22%) or strongly disagreed (7%), and a further 20% neither agreed nor disagreed.

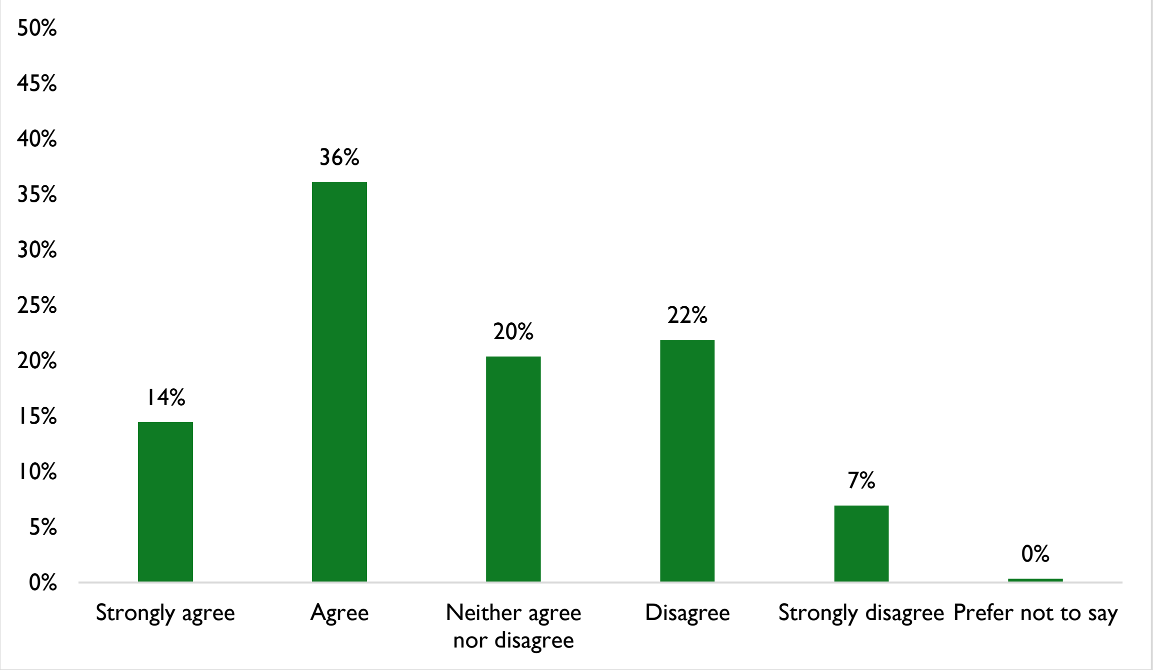

Figure 136. base n = 1241

Q – To what extent do you feel that you feel supported in your caring role?

Only around a quarter of carers agreed (18%) or strongly agreed (6%) that they felt supported in their caring role. However, over half either disagreed (31%) or strongly disagreed (19%), and over a quarter neither agreed nor disagreed (26%). Just 1% selected "Prefer not to say".

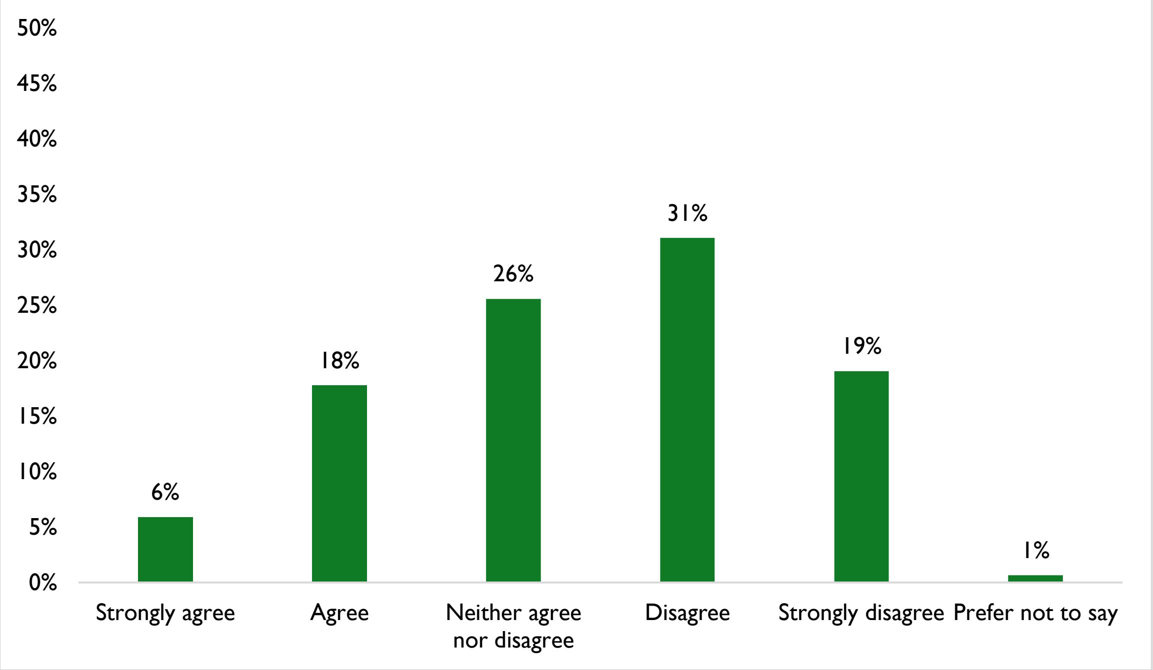

Figure 137. base n = 1239

Q – How much do other caring responsibilities (e.g. children, parents) affect your experience providing care?

A third of carers (33%) said these responsibilities do not affect their experience at all, while 19% said they affect it a little and 16% said somewhat. A further 17% said they affect their experience quite a lot and 12% said very much. Just 1% were not sure and 2% preferred not to say.

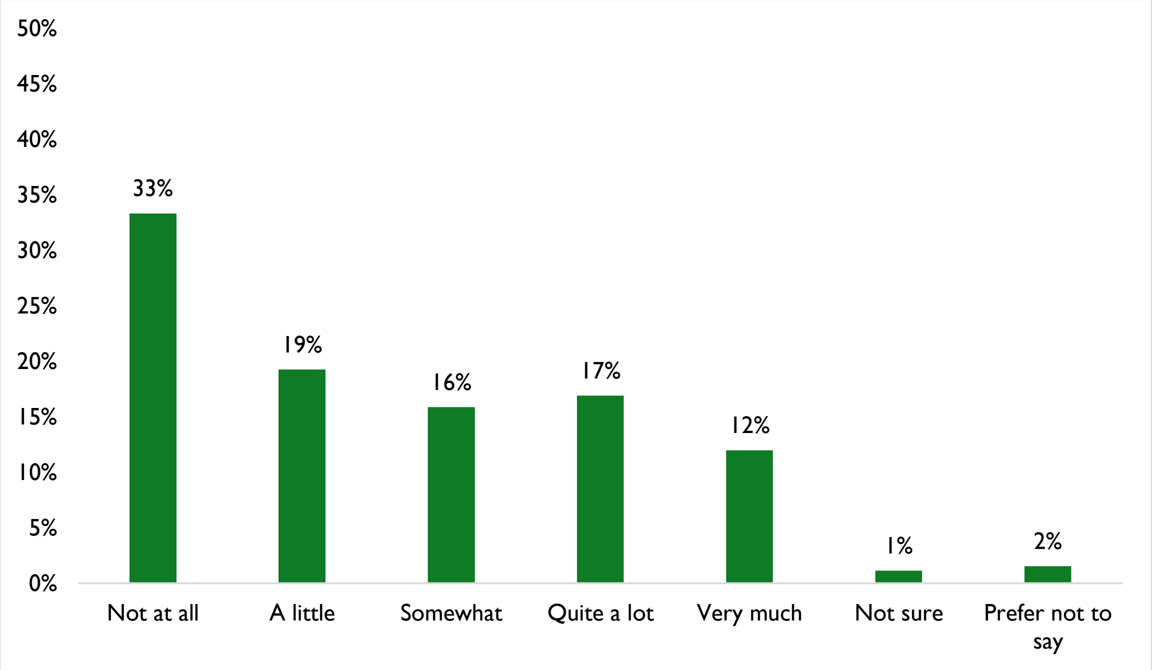

Figure 138. base n = 1236

Q – How much does working full or part-time affect your experience providing care?

Just over half (51%) said that working did not affect their caring experience at all. However, 22% said it affected them very much, with smaller proportions saying it affected them quite a lot (9%), somewhat (8%) or a little (6%). Only 1% were not sure and 2% preferred not to say.

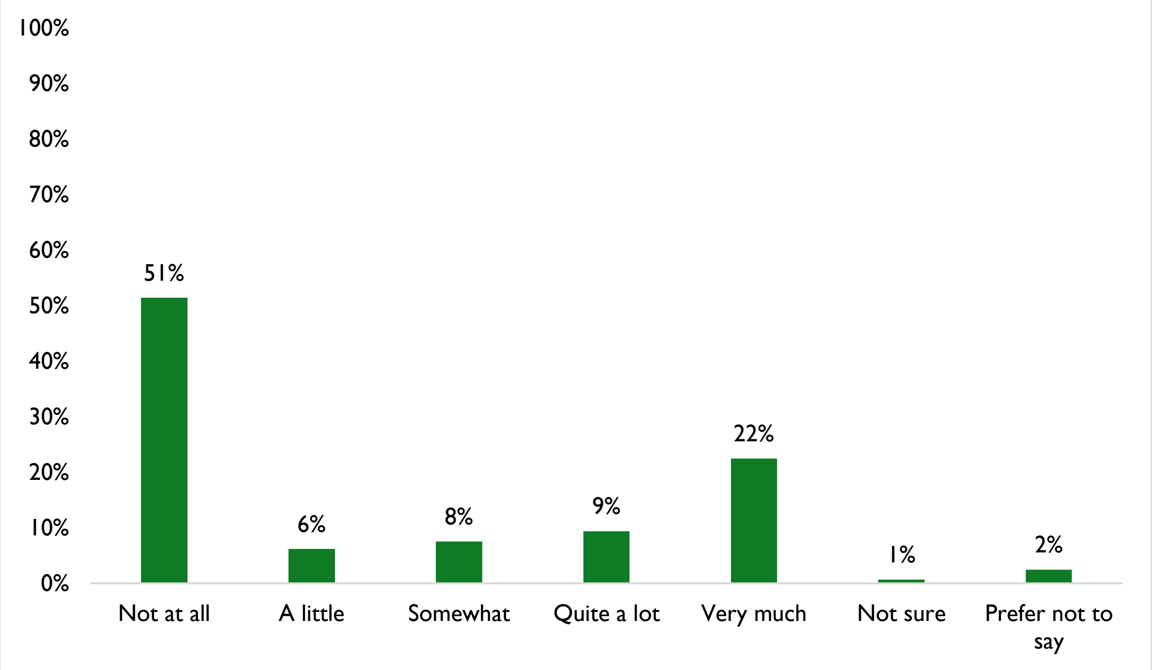

Figure 139. base n = 1234

Q – How much do educational commitments affect your experience providing care?

Three-quarters (75%) said that educational commitments did not affect their caring experience at all. A small proportion said it affected them a little (7%), somewhat (6%), quite a lot (4%) or very much (4%). A further 2% were not sure and 2% preferred not to say.

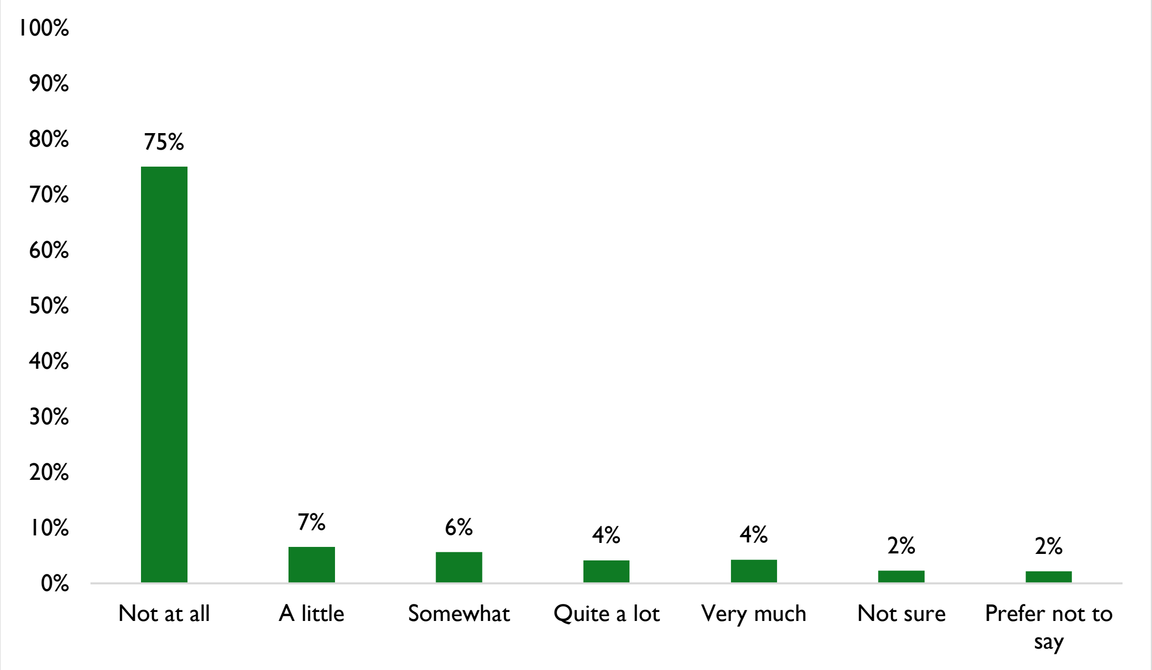

Figure 140. base n = 1228

Q – How much do your own health condition(s) affect your experience providing care?

Over half of respondents reported that their own health condition(s) impacted their caring role, including 27% who said it affected them a little, 25% somewhat, 14% quite a lot and 11% very much. In contrast, 21% said their health condition(s) did not affect their experience of providing care. A small proportion were not sure (1%) or preferred not to say (1%).

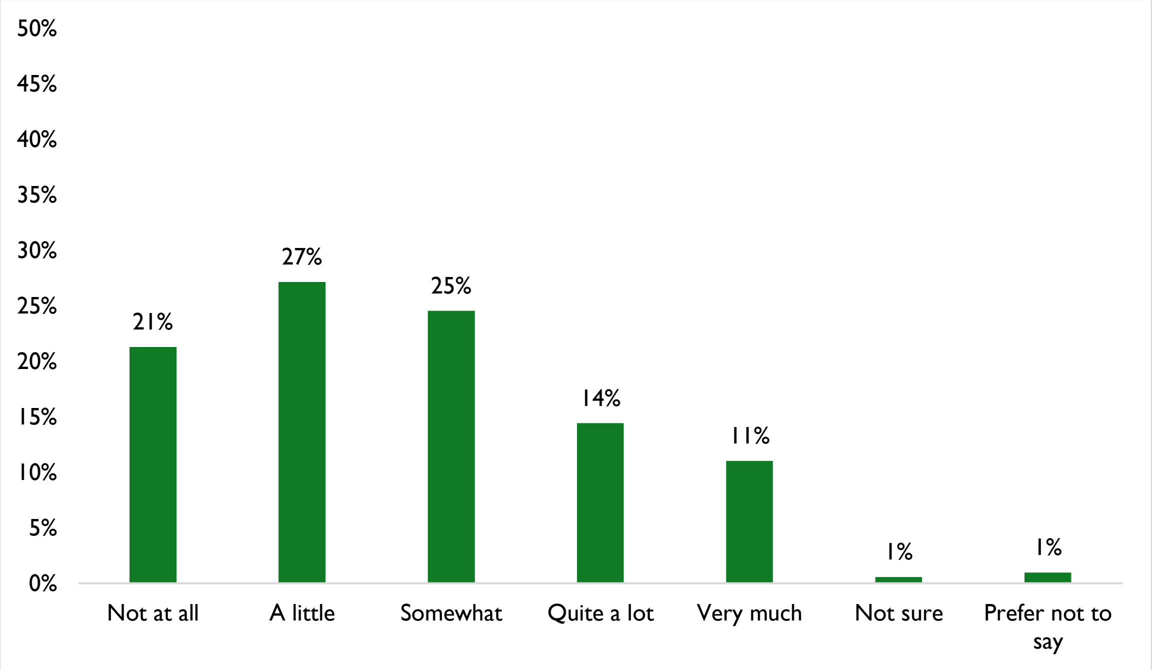

Figure 141. base n = 1234

Q – How much does a lack of knowledge or training in caring for this specific condition(s) affect your experience providing care?

Just under half of respondents felt that a lack of training or knowledge had at least some impact on their caring role, with 24% saying it affected them a little, 23% somewhat, 15% quite a lot, and 11% very much. However, 23% said it did not affect their experience of caring at all. A small number were not sure (3%) or preferred not to say (1%).

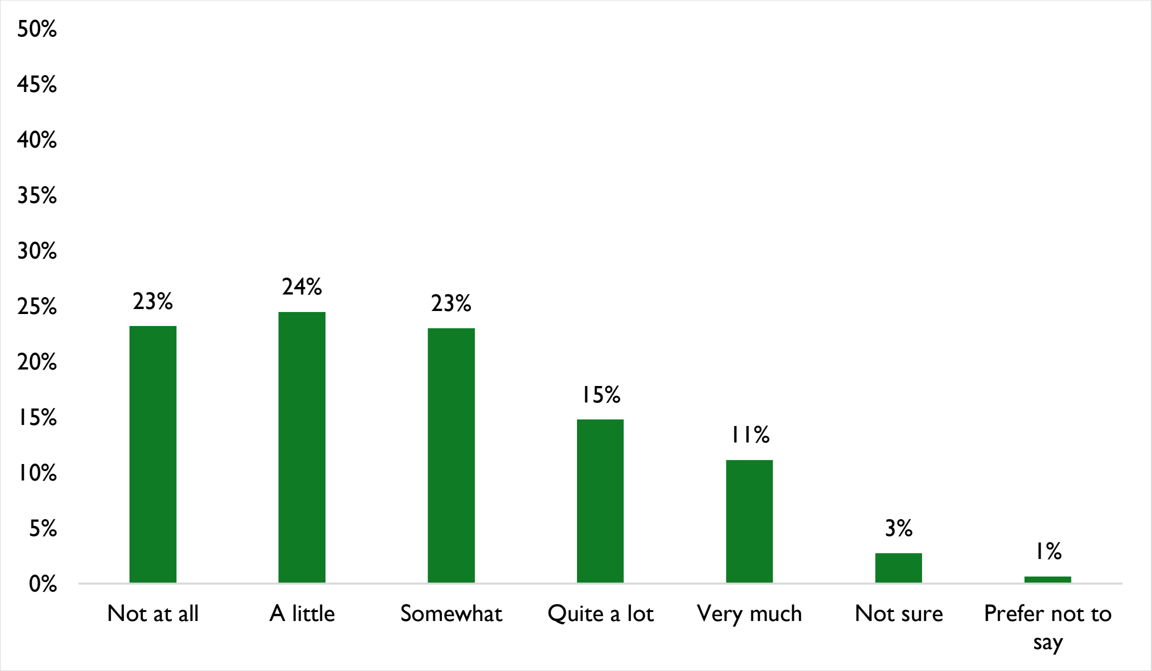

Figure 142. base n = 1238

Q – How much does a lack of access to reliable transportation affect your experience providing care?

More than half of respondents (57%) said lack of reliable transportation did not affect their caring experience at all. However, 39% reported at least some impact: 14% said it affected them a little, 9% somewhat, 7% quite a lot, and 9% very much. A small proportion were not sure (2%) or preferred not to say (1%).

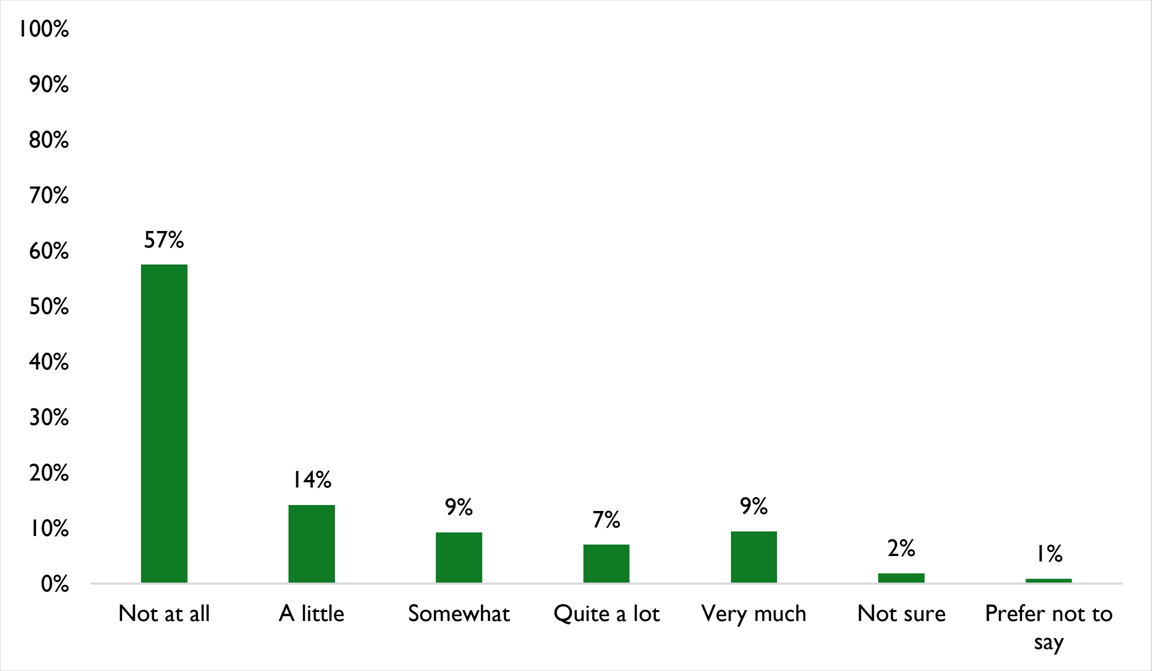

Figure 143. base n = 1236

Q – How much does a lack of access to healthcare professionals for the person you care for affect your experience providing care?

42% of respondents said that a lack of access to healthcare professionals affected their caring experience to a large extent – 25% said "very much" and 16% "quite a lot". A further 21% said it affected them "somewhat" and 22% "a little". Only 16% said it did not affect them at all. Very few were not sure (1%) or preferred not to say (0%).

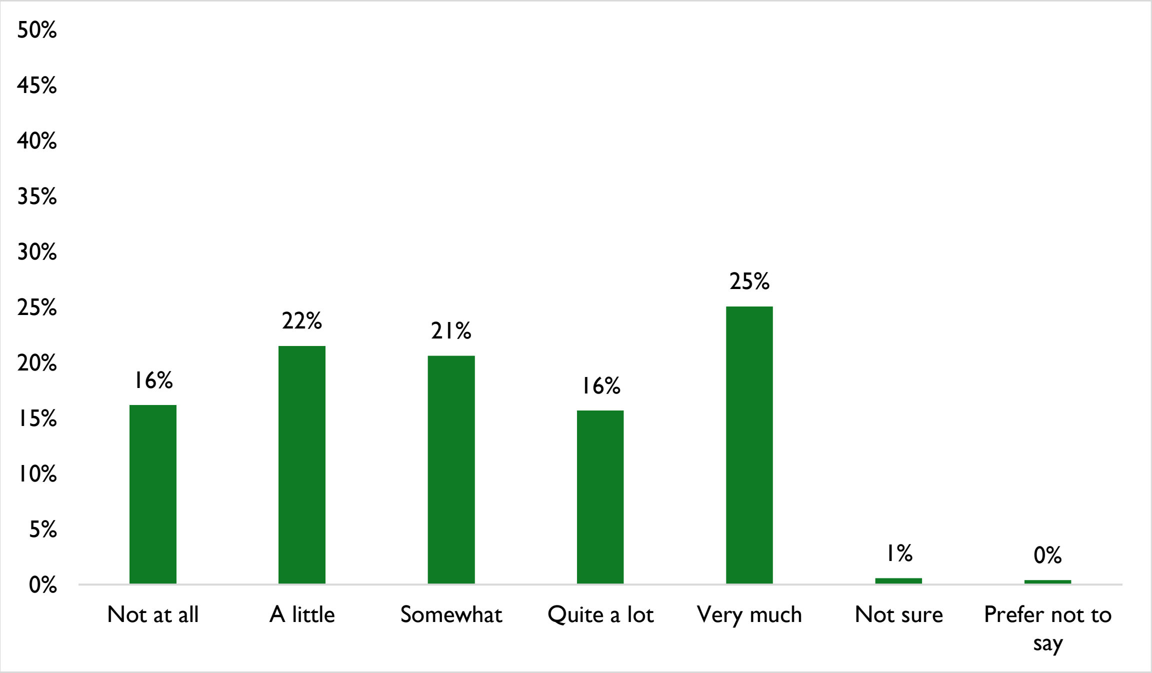

Figure 144. base n = 1237

Q – How much does limited mobility or physical abilities affect your experience providing care?

Just under a quarter of respondents said that limited mobility or physical abilities affected their experience to a large extent – 13% said "very much" and 9% "quite a lot". Another 14% said "somewhat" and 19% "a little". Notably, 42% reported that limited mobility or physical abilities did not affect their experience at all. A small proportion were unsure (2%) or preferred not to say (1%).

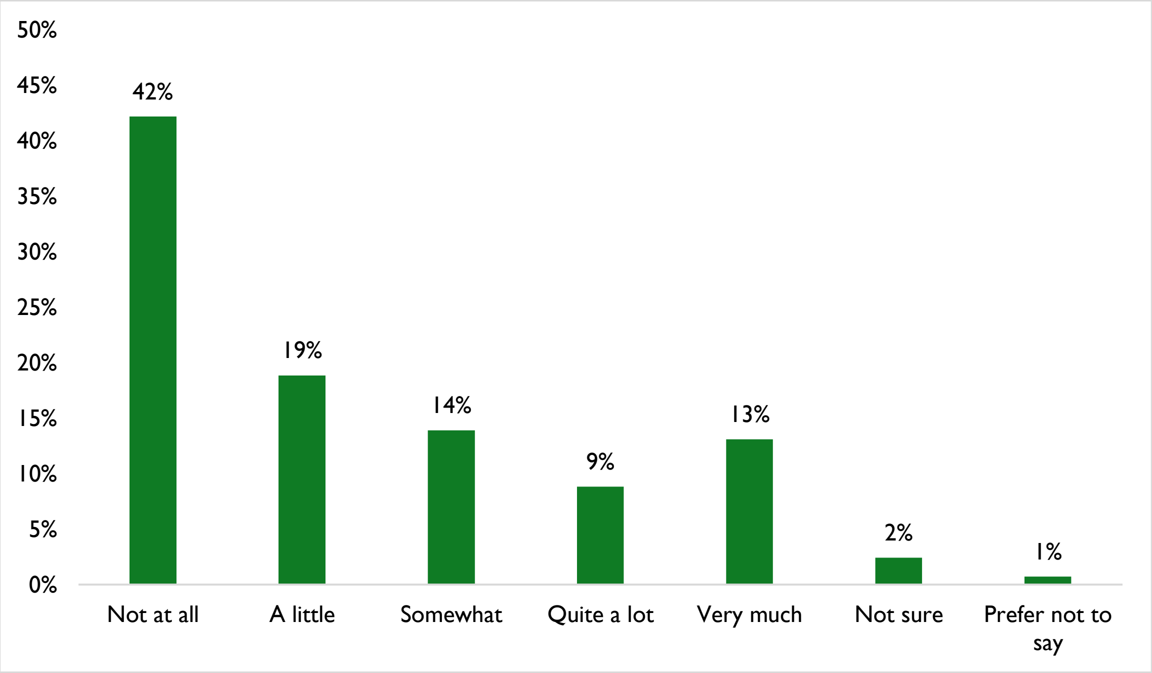

Figure 145. base n = 1236

Q – How much do the following affect your experience providing care? – Financial constraint

Around a quarter of respondents said that financial constraints affected their experience of providing care either “quite a lot” (13%) or “very much” (14%). An additional 39% said it affected them “somewhat” (18%) or “a little” (21%). Just under a third (31%) said financial constraints did not affect them at all. A small proportion were either not sure (1%) or preferred not to say (2%).

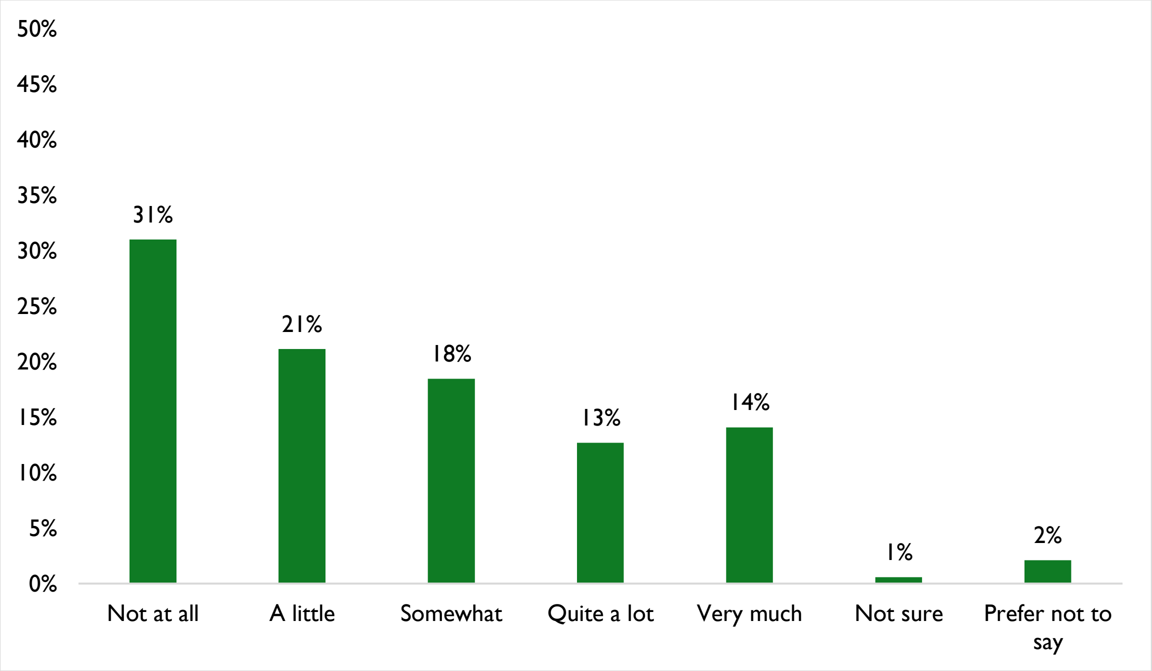

Figure 146. base n = 1236

Q In the past 12 months, have you used any of the following types of support for your caring responsibilities? – Financial support (e.g. Carer's Allowance, Personal Independence Payment, Scottish Carers Assistance)

One in five respondents (20%) said they had received financial support and that it met their needs. A similar proportion (18%) had received support but felt it did not meet their needs. Around a quarter (23%) said they had not been able to access this type of support. Over a third (35%) said financial support was not relevant to them, while 5% preferred not to say.

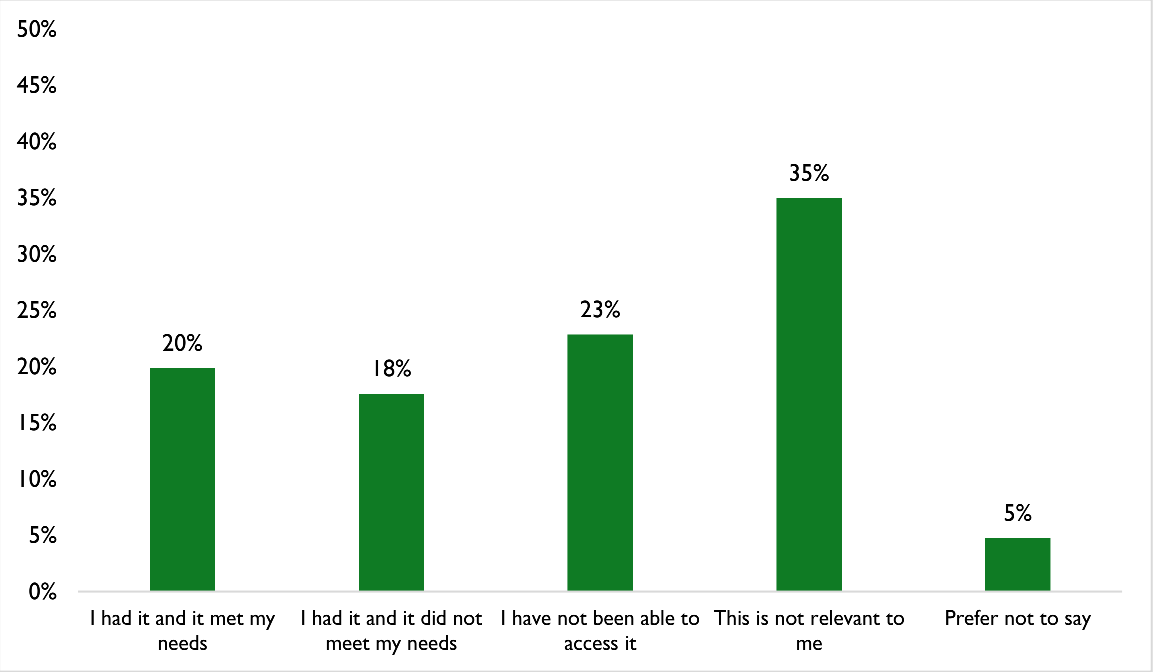

Figure 147. base n = 1239

Q – In the past 12 months, have you used any of the following types of support for your caring responsibilities? – Respite care (e.g. temporary care provided by someone else to give you a break)

A small proportion of respondents (10%) said they had accessed respite care in the past 12 months and that it met their needs, while a further 5% said it did not meet their needs. Over a third (37%) said they had not been able to access this type of support, while the largest share (44%) said it was not relevant to them. A small proportion (3%) preferred not to say.

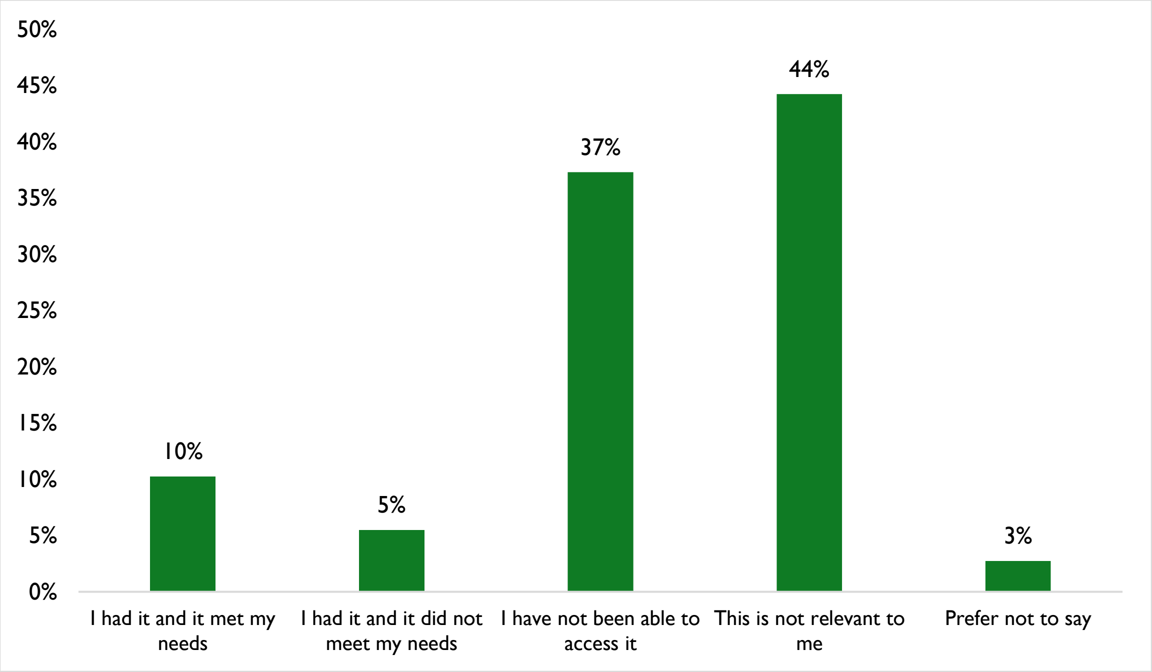

Figure 148. base n = 1239

Q – In the past 12 months, have you used any of the following types of support for your caring responsibilities? – Information and advice on benefits

Around a quarter of respondents (23%) said they had accessed information and advice on benefits in the past year and that it met their needs. A further 14% said they had used this support but that it did not meet their needs. Just over a quarter (27%) said they had not been able to access it, and nearly a third (32%) said it was not relevant to them. A small proportion (4%) preferred not to say.

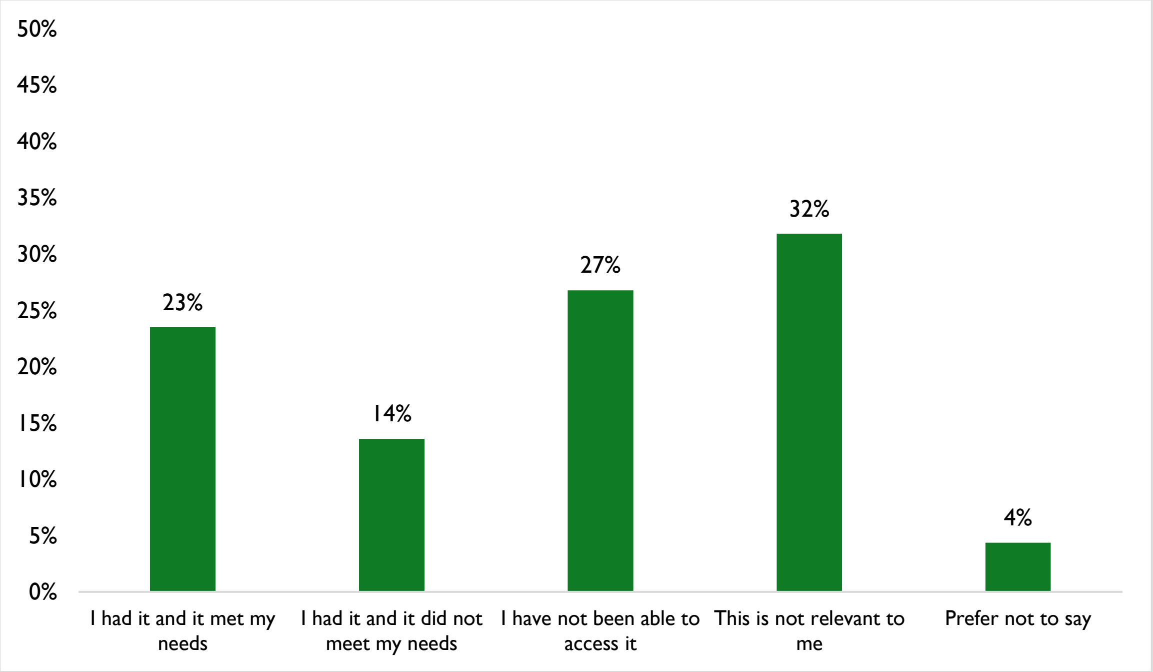

Figure 149. base n = 1236

Q – In the past 12 months, have you used any of the following types of support for your caring responsibilities? – Information and advice on accessing support

Just over a fifth of respondents (22%) said they had received information and advice on accessing support that met their needs, while a similar proportion (21%) said they had received it but that it did not meet their needs. More than a third (38%) said they had not been able to access this type of support. Around one in six (16%) said it was not relevant to them, and a small proportion (3%) preferred not to say.

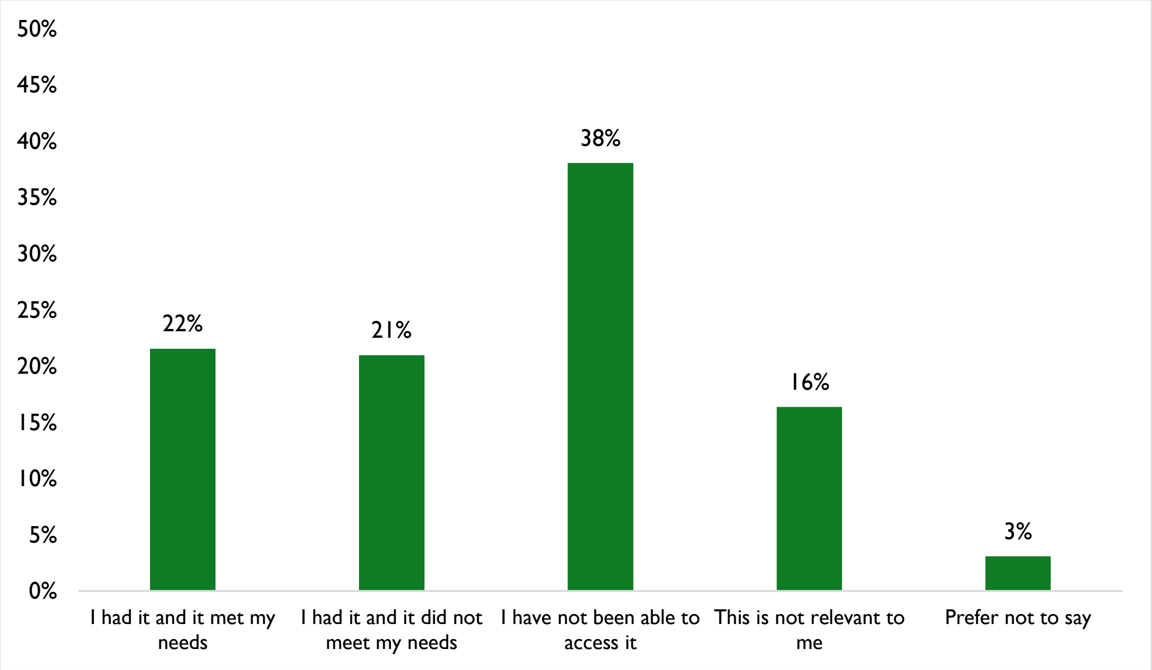

Figure 150. base n = 1235

Q – In the past 12 months, have you used any of the following types of support for your caring responsibilities? – Equipment and adaptations to the home of the person you provide care for

Around a third of respondents (35%) said they had used equipment or home adaptations that met their needs. A smaller 11% said they had accessed this support, but it did not meet their needs, while 22% said they had not been able to access it. Just under a third (29%) said this support was not relevant to them, and a small proportion (2%) preferred not to say.

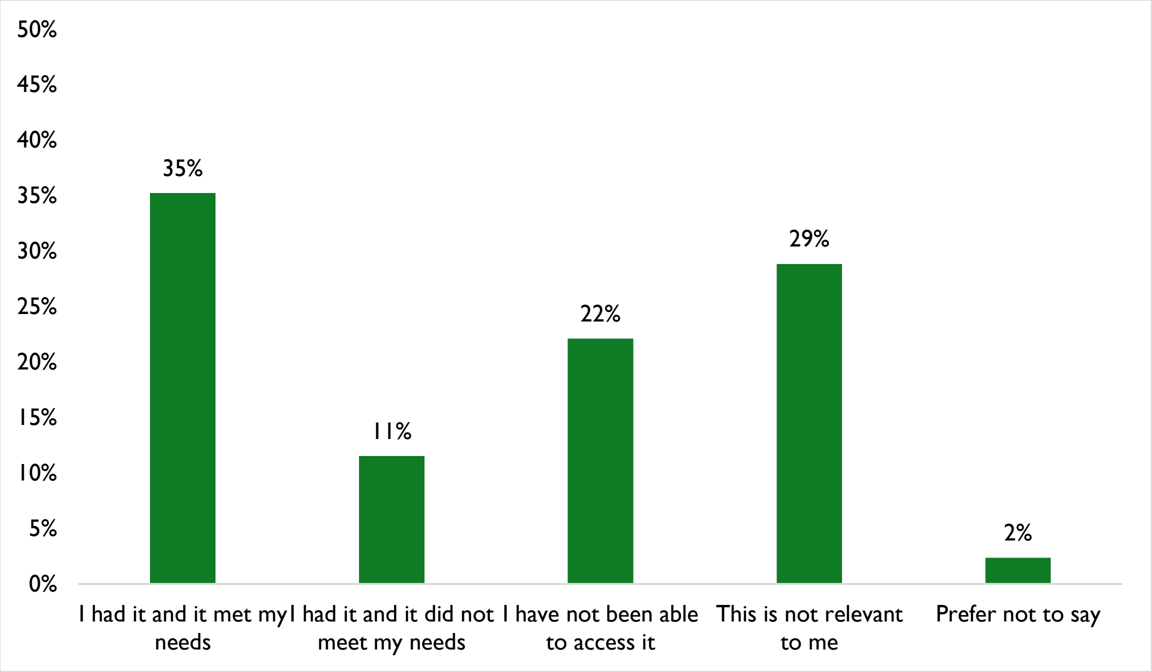

Figure 151. base n = 1235

Q – In the past 12 months, have you used any of the following types of support for your caring responsibilities? – Transport services to help you and the person you care for get to appointments and other activities

Just over one in ten respondents (11%) said they had used transport services that met their needs, while a smaller proportion (6%) said the services did not meet their needs. Around a quarter (25%) said they had not been able to access this support. Over half (56%) indicated that this type of support was not relevant to them, and a small proportion (2%) preferred not to say.

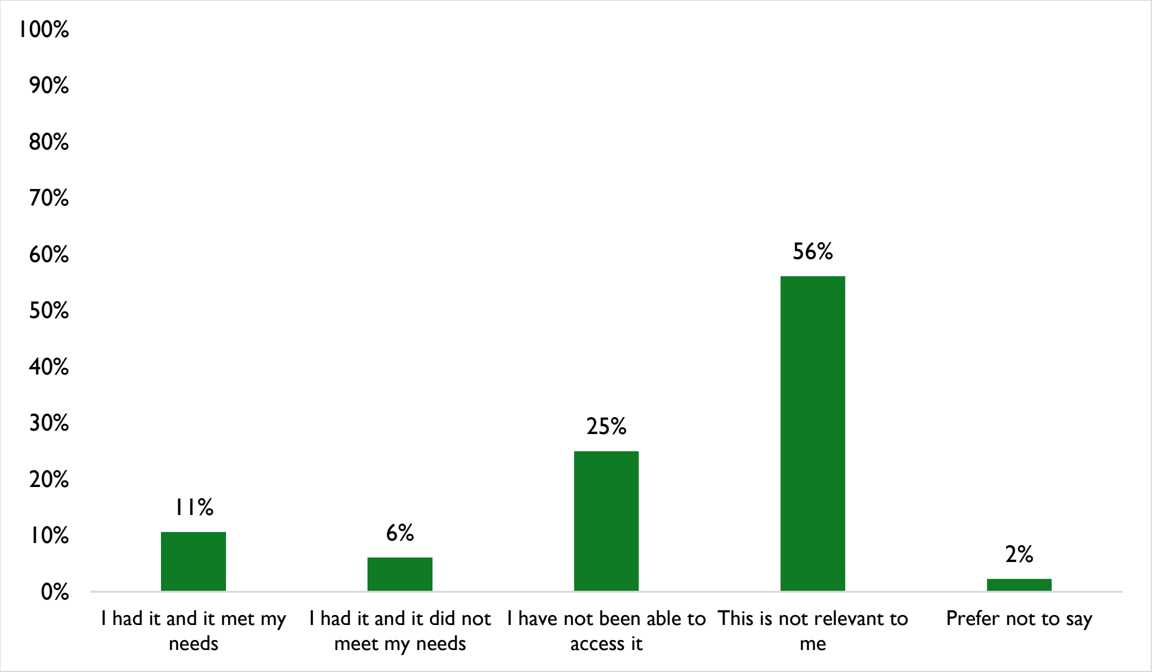

Figure 152. base n = 1236

Q – In the past 12 months, have you used any of the following types of support for your caring responsibilities? – Mental health and wellbeing support (e.g. carer recreational activities, counselling and therapy)

Around one in ten respondents (11%) said they had accessed mental health and wellbeing support that met their needs, while a smaller proportion (8%) said it did not meet their needs. Half of respondents (50%) said they had not been able to access this type of support. Just over a quarter (26%) said this support was not relevant to them, and 5% preferred not to say.

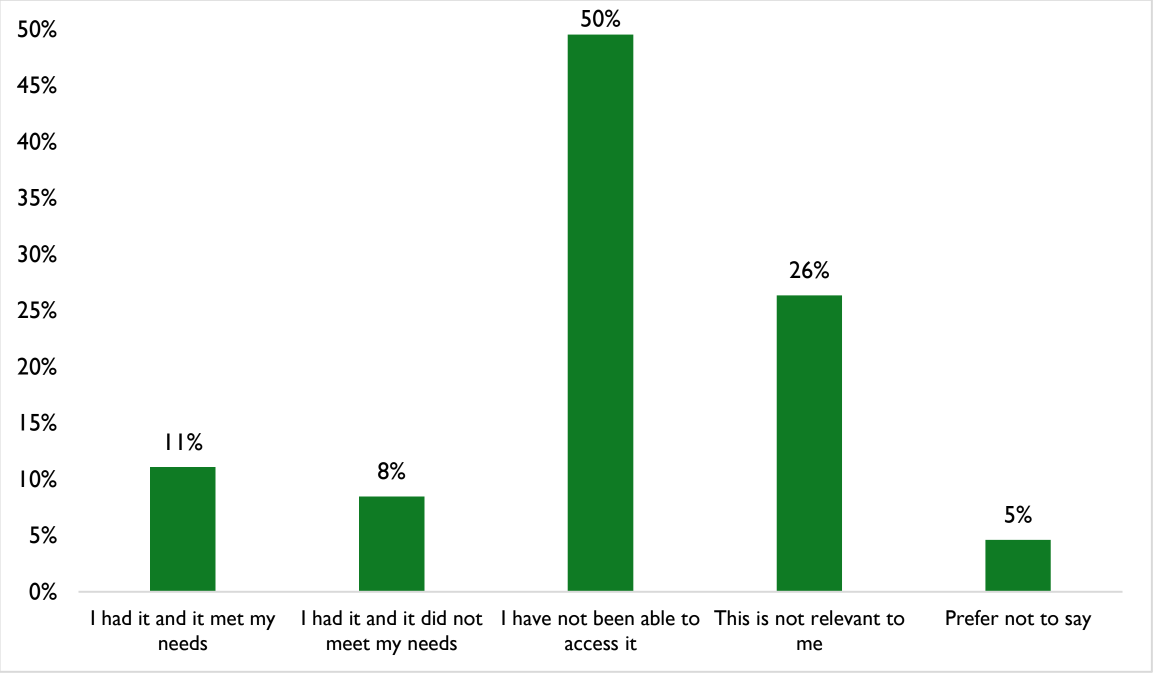

Figure 153. base n = 1238

Q – What is your age?

Respondents represented a wide range of ages. The most common age groups were 55-64 years (25%) and 65-74 years (22%), followed by 45-54 years (21%). Fourteen percent were aged 35-44, and 12% were 75 or older. Smaller proportions were aged 25-34 (5%) and 18-24 (1%).

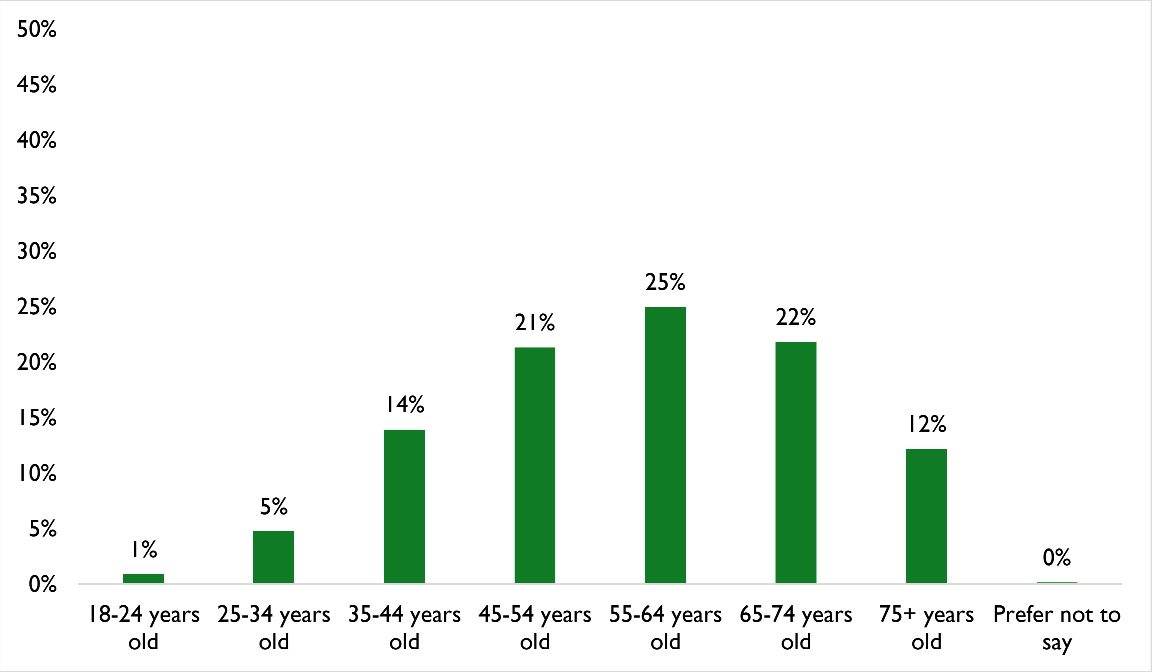

Figure 154. base n = 1242

Q – Which of the following describes how you think of yourself?

The majority of respondents identified as female (78%), while just over a fifth (21%) identified as male. Very few respondents (0%) selected “I think of myself in another way”.

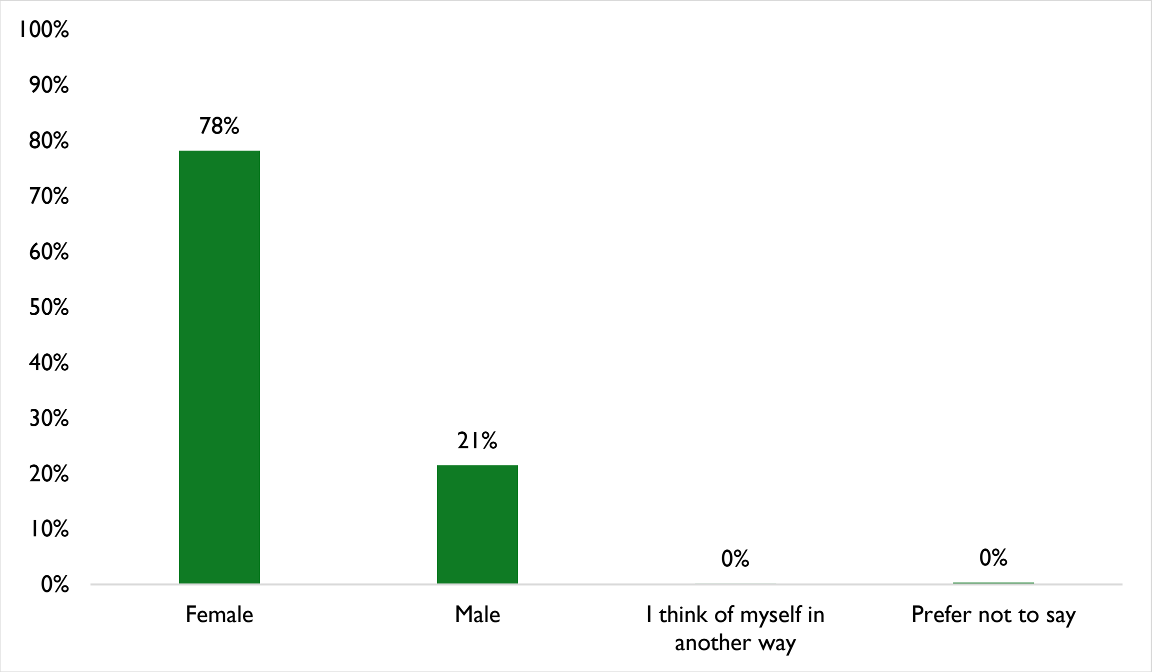

Figure 155. base n = 1241

Q – Which of the following best describes your ethnicity?

Almost all respondents (95%) described their ethnicity as White (including English, Welsh, Scottish, Northern Irish or British, Irish, Gypsy or Irish Traveller, or any other White background). A small proportion identified as Asian or Asian British (2%), Black, Black British, Caribbean or African (1%), or Mixed or multiple ethnic groups (1%). A further 1% preferred not to say. Very few respondents selected “Other ethnic group,” “I prefer to self-describe,” or “I don’t know.”

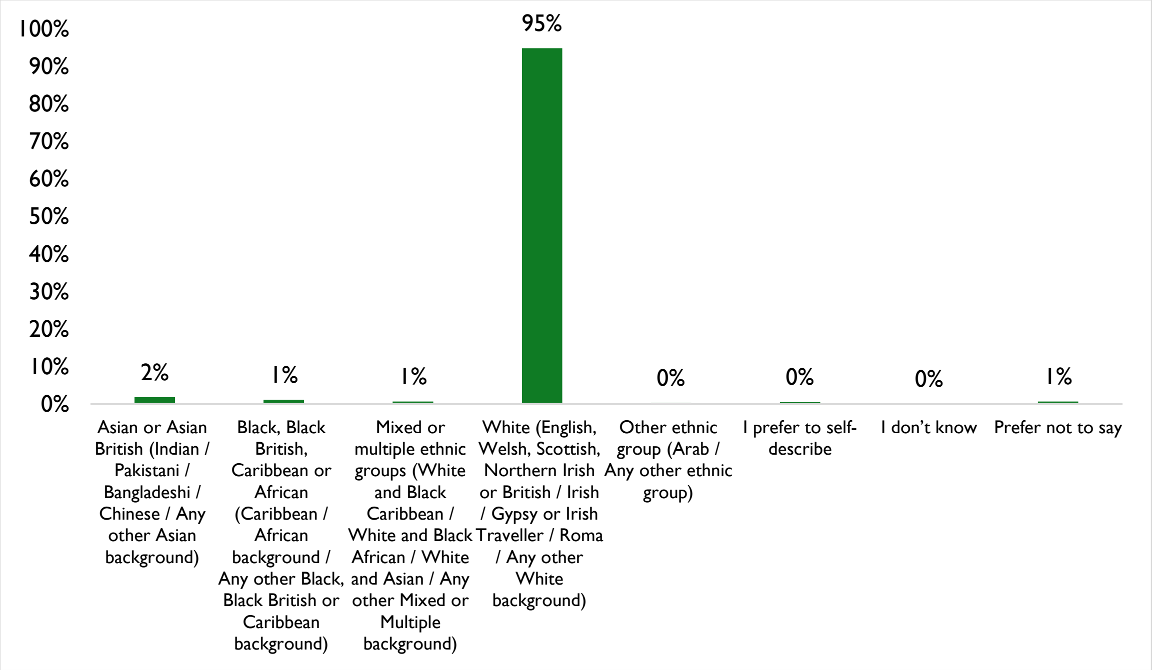

Figure 156. base n = 1241

Q – Do you have any long-term condition(s)?

Just over half of respondents (54%) reported having a long-term condition. 41% said they did not have any, while small proportions said they were not sure (3%) or preferred not to say (2%).

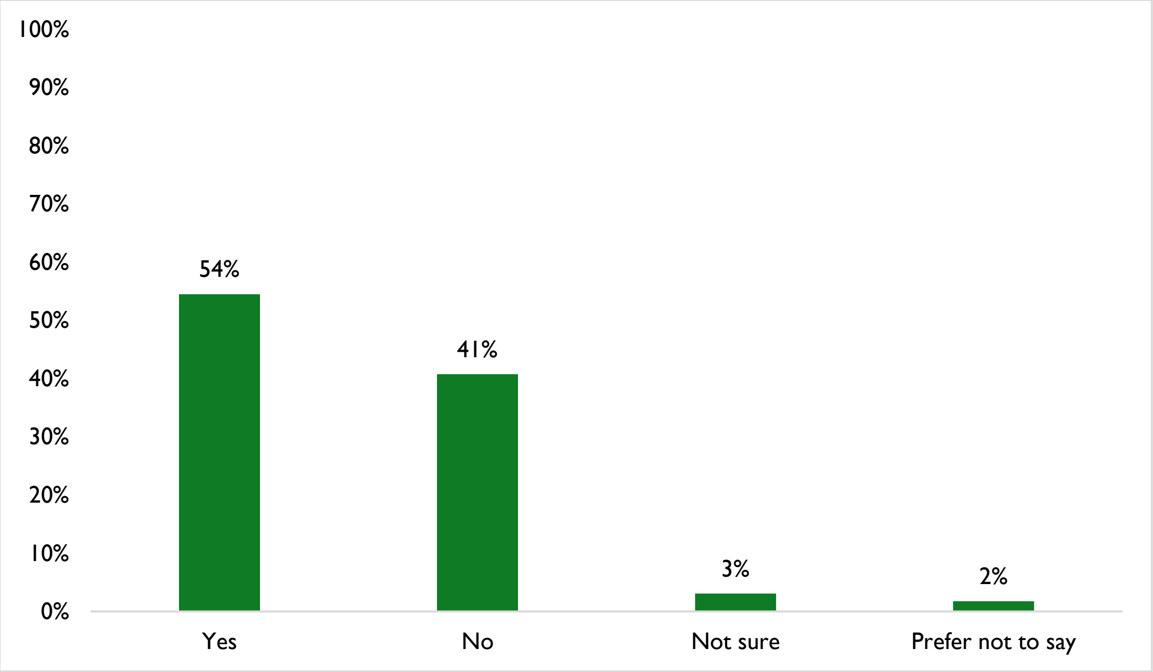

Figure 157. base n = 1241

Q – If you have any long-term condition(s), please tick all that apply to you.

Among those who reported having a long-term condition, the most commonly selected type was physical (e.g. arthritis, high blood pressure), mentioned by 43%. Just over one in five (22%) cited a mental health condition, while smaller proportions selected neurological (9%), sensory (7%), cognitive (3%), or other types of condition (7%). Around a third (34%) said they had no other conditions beyond those already selected. A small proportion said they were not sure (2%) or preferred not to say (3%).

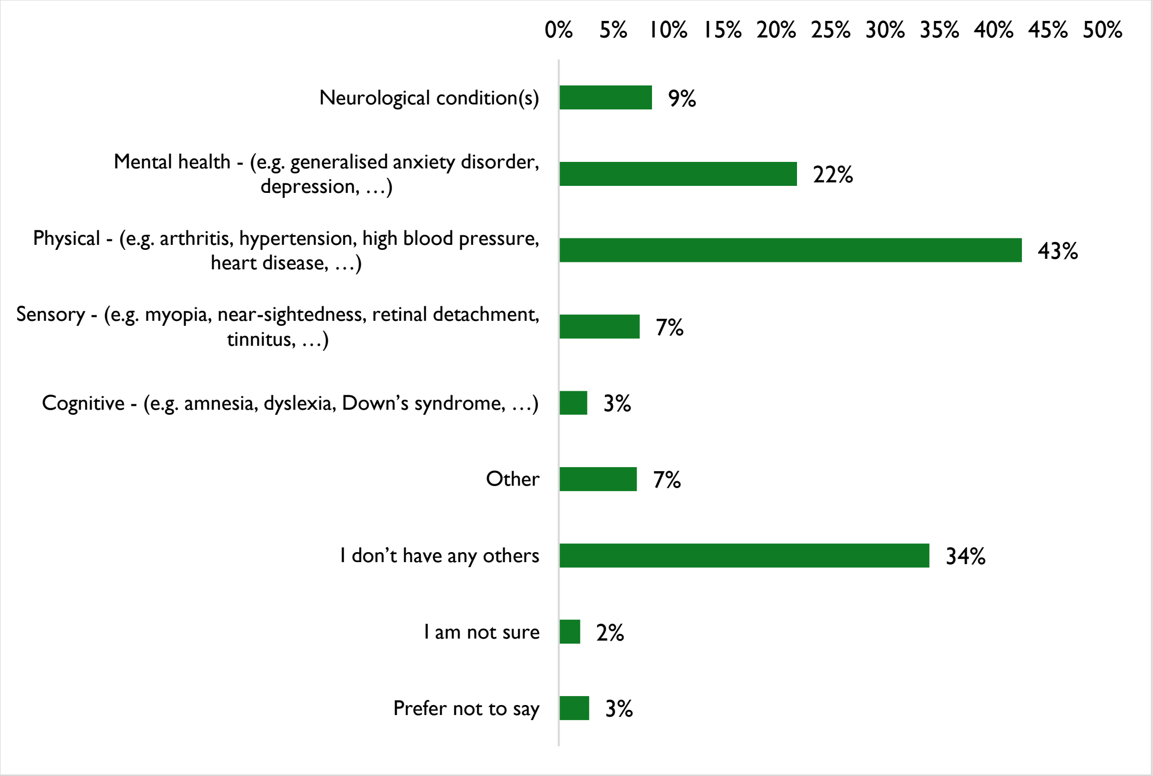

Figure 158. base n = 1223

Q – What is your postcode? [CODED]

Respondents were spread across a wide range of local health commissioners. No single commissioner represented a large share of respondents; the most commonly mentioned were NHS North East and North Cumbria (4%), NHS Gloucestershire (4%), and NHS Hampshire and Isle of Wight (4%). Most other local commissioners were selected by 3% or fewer of respondents, and many by just 1%. This indicates a broadly distributed sample across the UK's health commissioning bodies.

Local Health Commissioner	%
Aneurin Bevan University Health Board	1%
Ayrshire and Arran	1%
Betsi Cadwaladr University Health Board	3%
Borders	0%
Cardiff and Vale University Health Board	1%
Cwm Taf Morgannwg University Health Board	1%
Dumfries and Galloway	1%
Eastern Health Board	2%
Fife	1%
Forth Valley	1%
Grampian	2%
Greater Glasgow and Clyde	3%
Highland	1%
Hywel Dda University Health Board	1%
Lanarkshire	2%
Lothian	2%
NHS BATH AND NORTH EAST SOMERSET, SWINDON AND WILTSHIRE INTEGRATED CARE BOARD	1%
NHS BEDFORDSHIRE, LUTON AND MILTON KEYNES INTEGRATED CARE BOARD	2%
NHS BIRMINGHAM AND SOLIHULL INTEGRATED CARE BOARD	1%
NHS BLACK COUNTRY INTEGRATED CARE BOARD	1%

Local Health Commissioner	**%**
NHS BRISTOL, NORTH SOMERSET AND SOUTH GLOUCESTERSHIRE INTEGRATED CARE BOARD	1%
NHS BUCKINGHAMSHIRE, OXFORDSHIRE AND BERKSHIRE WEST INTEGRATED CARE BOARD	3%
NHS CAMBRIDGESHIRE AND PETERBOROUGH INTEGRATED CARE BOARD	1%
NHS CHESHIRE AND MERSEYSIDE INTEGRATED CARE BOARD	3%
NHS CORNWALL AND THE ISLES OF SCILLY INTEGRATED CARE BOARD	1%
NHS COVENTRY AND WARWICKSHIRE INTEGRATED CARE BOARD	1%
NHS DERBY AND DERBYSHIRE INTEGRATED CARE BOARD	2%
NHS DEVON INTEGRATED CARE BOARD	2%
NHS DORSET INTEGRATED CARE BOARD	2%
NHS FRIMLEY INTEGRATED CARE BOARD	1%
NHS GLOUCESTERSHIRE INTEGRATED CARE BOARD	4%
NHS GREATER MANCHESTER INTEGRATED CARE BOARD	2%
NHS HAMPSHIRE AND ISLE OF WIGHT INTEGRATED CARE BOARD	4%
NHS HEREFORDSHIRE AND WORCESTERSHIRE INTEGRATED CARE BOARD	2%
NHS HERTFORDSHIRE AND WEST ESSEX INTEGRATED CARE BOARD	2%
NHS HUMBER AND NORTH YORKSHIRE INTEGRATED CARE BOARD	2%
NHS KENT AND MEDWAY INTEGRATED CARE BOARD	2%
NHS LANCASHIRE AND SOUTH CUMBRIA INTEGRATED CARE BOARD	2%
NHS LEICESTER, LEICESTERSHIRE AND RUTLAND INTEGRATED CARE BOARD	1%
NHS LINCOLNSHIRE INTEGRATED CARE BOARD	1%
NHS MID AND SOUTH ESSEX INTEGRATED CARE BOARD	2%
NHS NORFOLK AND WAVENEY INTEGRATED CARE BOARD	2%
NHS NORTH CENTRAL LONDON INTEGRATED CARE BOARD	1%

Local Health Commissioner	%
NHS NORTH EAST AND NORTH CUMBRIA INTEGRATED CARE BOARD	4%
NHS NORTH EAST LONDON INTEGRATED CARE BOARD	1%
NHS NORTH WEST LONDON INTEGRATED CARE BOARD	1%
NHS NORTHAMPTONSHIRE INTEGRATED CARE BOARD	1%
NHS NOTTINGHAM AND NOTTINGHAMSHIRE INTEGRATED CARE BOARD	2%
NHS SHROPSHIRE, TELFORD AND WREKIN INTEGRATED CARE BOARD	1%
NHS SOMERSET INTEGRATED CARE BOARD	2%
NHS SOUTH EAST LONDON INTEGRATED CARE BOARD	2%
NHS SOUTH WEST LONDON INTEGRATED CARE BOARD	1%
NHS SOUTH YORKSHIRE INTEGRATED CARE BOARD	2%
NHS STAFFORDSHIRE AND STOKE-ON-TRENT INTEGRATED CARE BOARD	1%
NHS SUFFOLK AND NORTH EAST ESSEX INTEGRATED CARE BOARD	2%
NHS SURREY HEARTLANDS INTEGRATED CARE BOARD	2%
NHS SUSSEX INTEGRATED CARE BOARD	3%
NHS WEST YORKSHIRE INTEGRATED CARE BOARD	2%
Northern Health Board	1%
Orkney	0%
Powys Teaching Health Board	0%
Southern Health Board	0%
Swansea Bay University Health Board	1%
Tayside	2%
Western Health Board	0%
Western Isles	1%

Figure 159. base n = 1120

Q – What is your postcode? [CODED]

Nearly three-quarters of respondents (73%) were based in England. Smaller proportions were from Scotland (15%), Wales (8%), and Northern Ireland (4%). This reflects a predominantly England-based sample, with representation across the other UK nations.

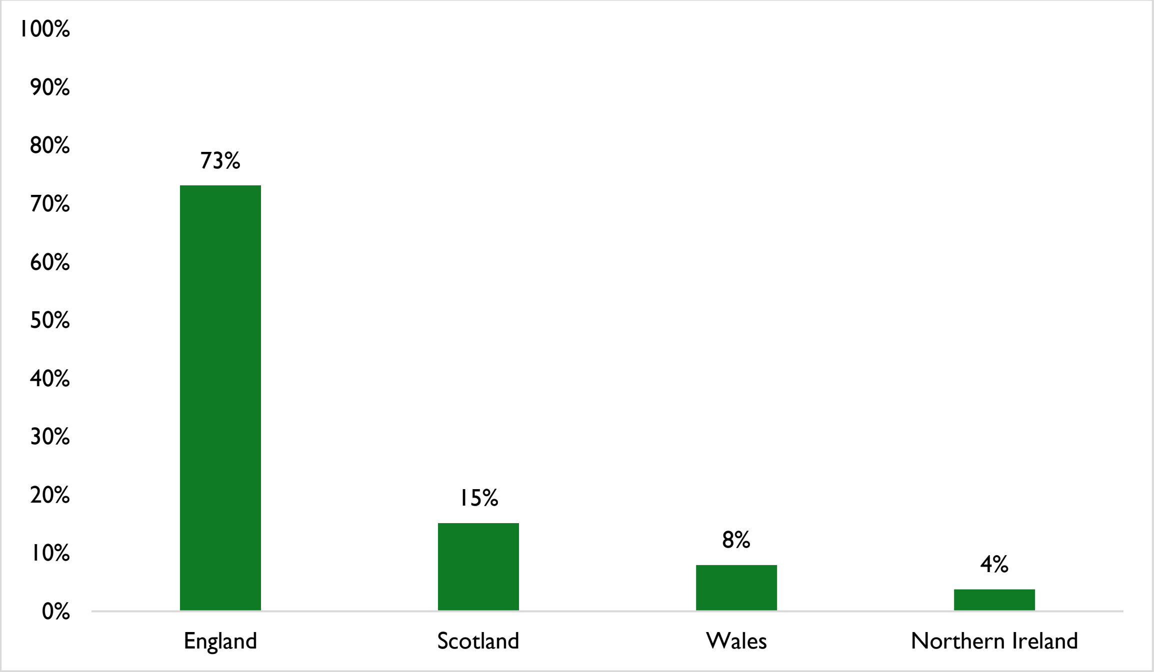

Figure 160. base n = 1120

Q – What is your highest level of education?

Respondents reported a wide range of educational backgrounds. The most commonly selected response was “University degree (e.g. Bachelor’s degree),” chosen by 29% of participants. Around one in five (18%) reported holding a “Postgraduate qualification (e.g. Master’s, PhD),” while 15% had “National/Scottish Vocational Qualifications or Higher National Certificate (NVQ/HNC)”.

Other qualifications were less common, with small proportions reporting “A levels or equivalent” (9%), “GCSEs or equivalent” (6%), “Apprenticeship” (2%), or “Entry level qualifications” (1%). A small proportion selected “Other” (3%), “None” (3%), or “Prefer not to say” (3%).

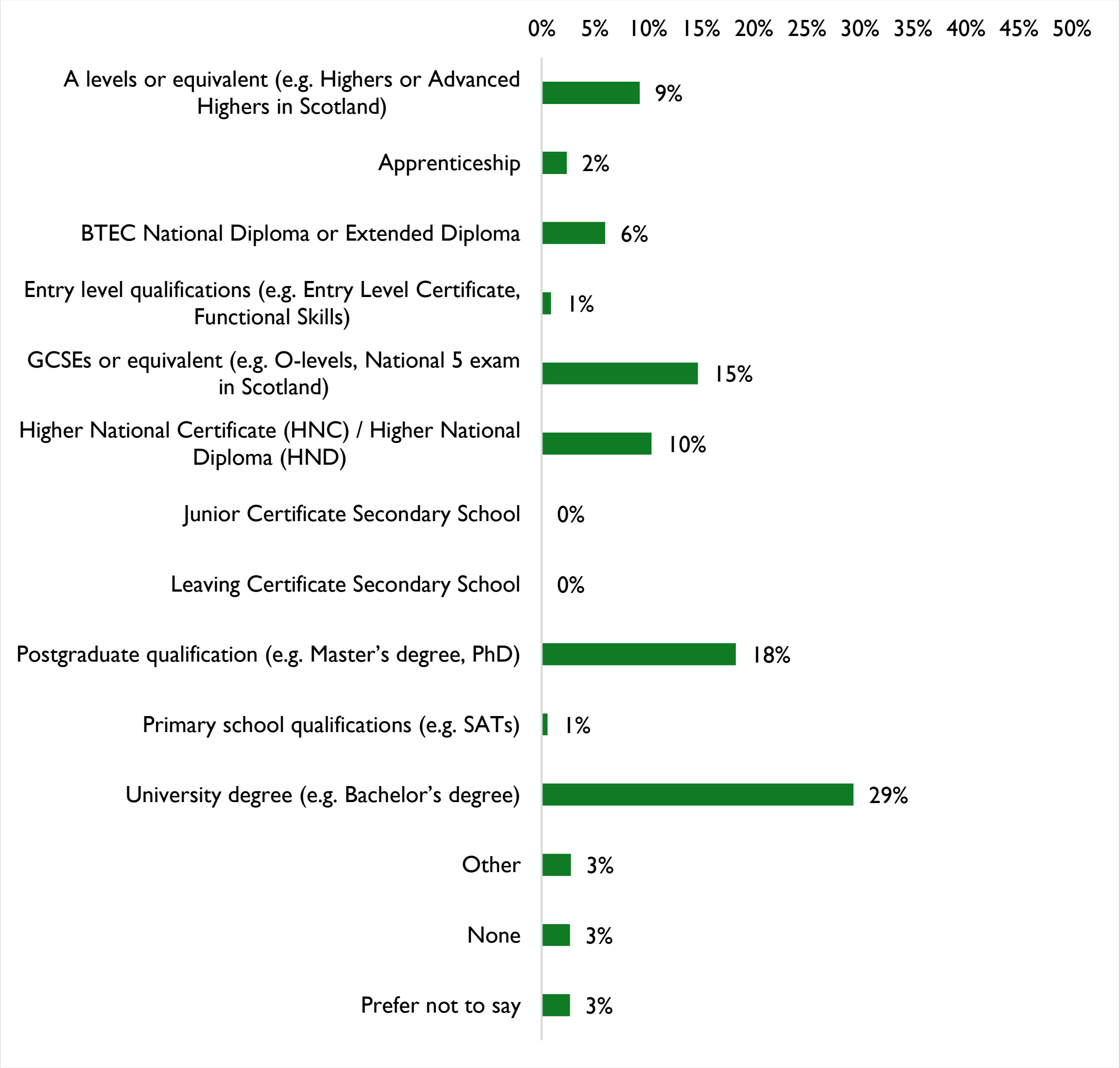

Figure 161. base n = 1234

Q – What is your current annual household income?

Respondents reported a broad range of annual household incomes. Around one quarter (24%) reported earning between £20,000 and £34,999, while nearly one in five (18%) said their household income was less than £20,000. A similar proportion (17%) reported earning £35,000-£49,999.

Smaller proportions reported higher income bands: 13% earned £50,000-£74,999, 5% earned £75,000-£99,999, and 4% reported earning £100,000 or more. Around one in five (19%) preferred not to disclose their income.

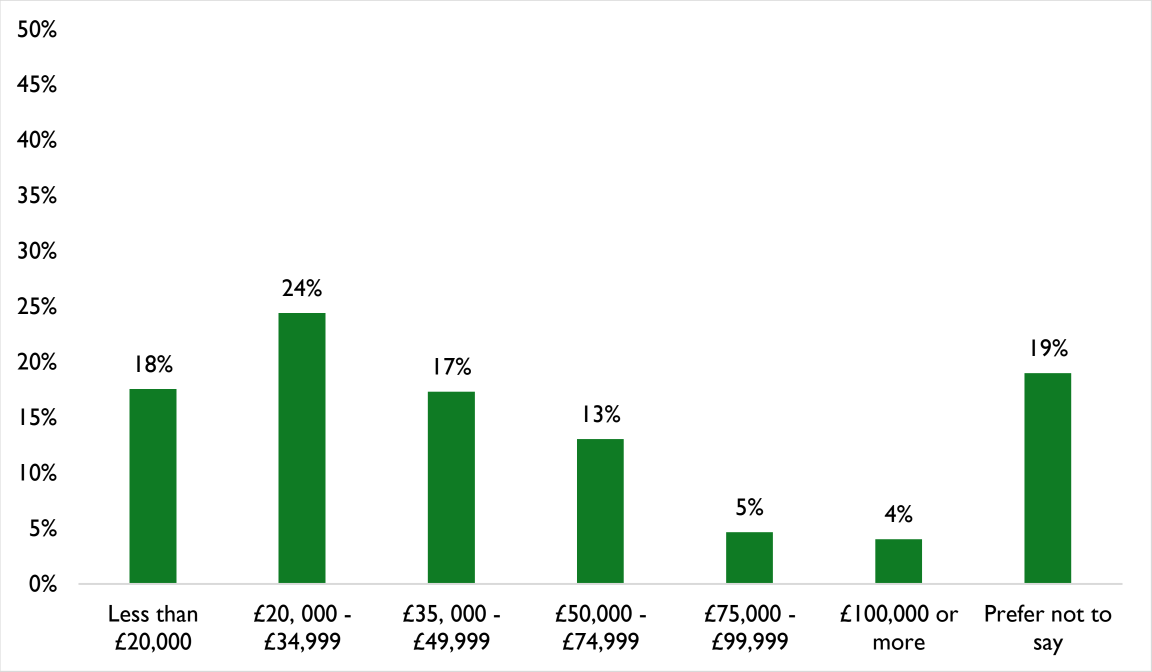

Figure 162. base n = 1242

Q – I understand the financial support that I am entitled to

Less than half of respondents agreed that they understood the financial support they were entitled to, and a further 10% strongly agreed. One in five (20%) neither agreed nor disagreed, while a similar proportion expressed uncertainty or disagreement – 19% disagreed and 8% strongly disagreed. A small proportion preferred not to say (2%).

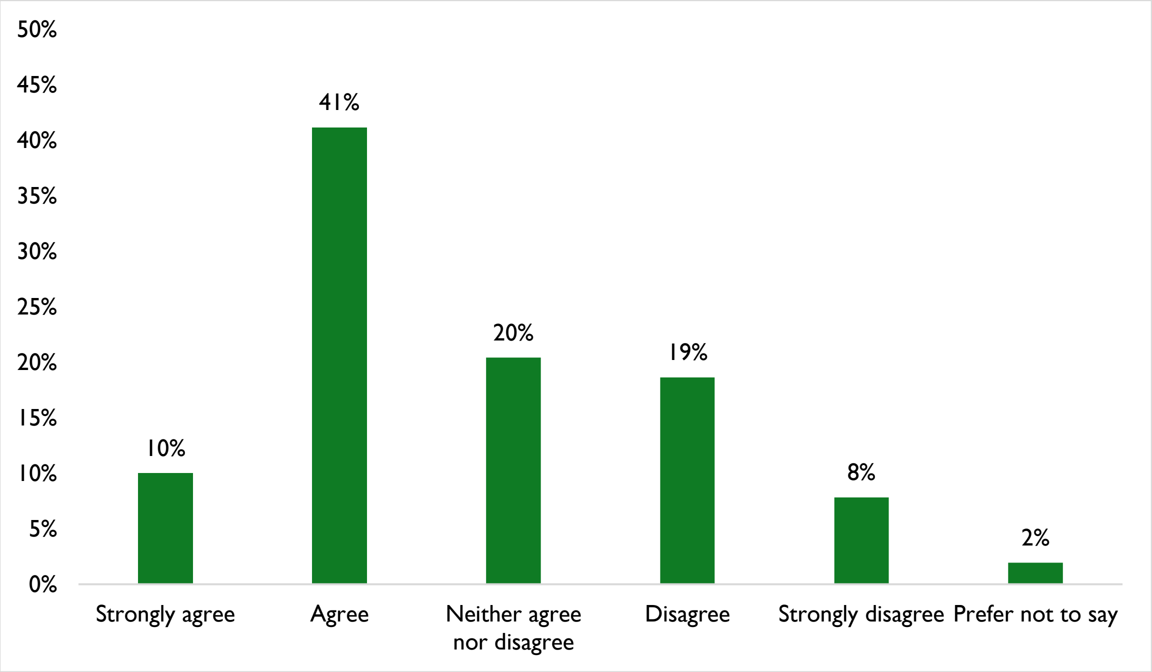

Figure 163. base n = 1239

Q – I receive sufficient financial support

Over two-fifths of respondents disagreed (29%) or strongly disagreed (16%) that they receive sufficient financial support. Just over one-fifth agreed (19%) or strongly agreed (3%). More than a quarter (28%) neither agreed nor disagreed. A small proportion preferred not to say (4%).

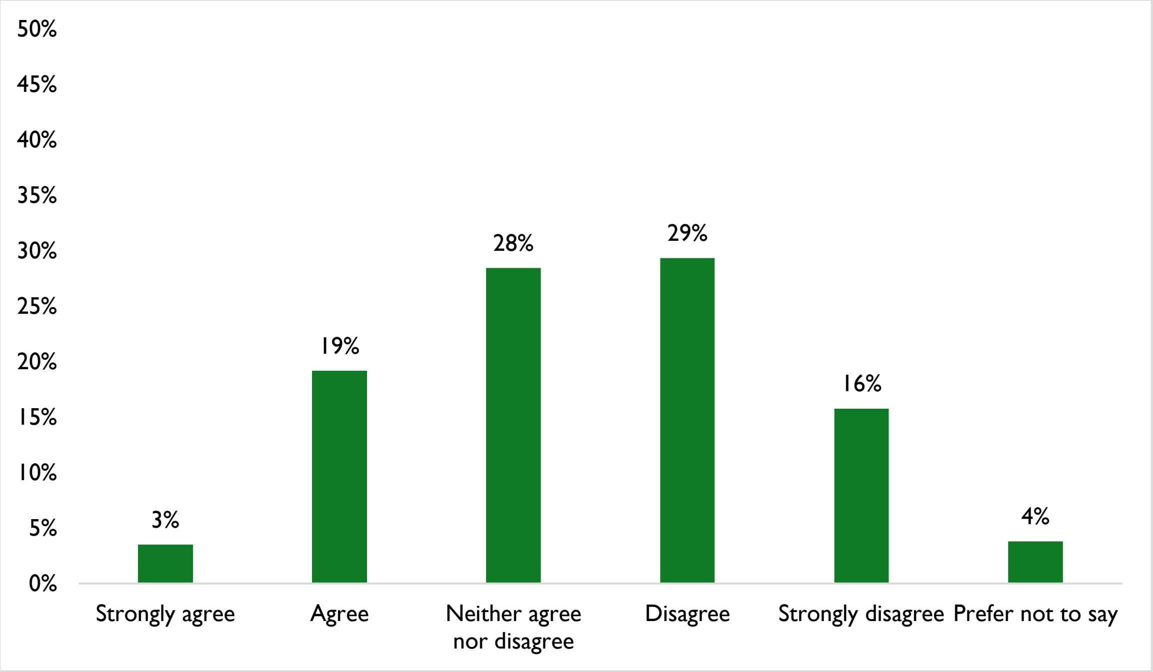

Figure 164. base n = 1237

Q – I have had to cut back on other expenses due to the costs of caring

Almost half of respondents agreed (30%) or strongly agreed (18%) that they had to cut back on other expenses due to the costs of caring. Around one-fifth disagreed (19%) or strongly disagreed (7%), while 22% neither agreed nor disagreed. A small proportion (3%) preferred not to say.

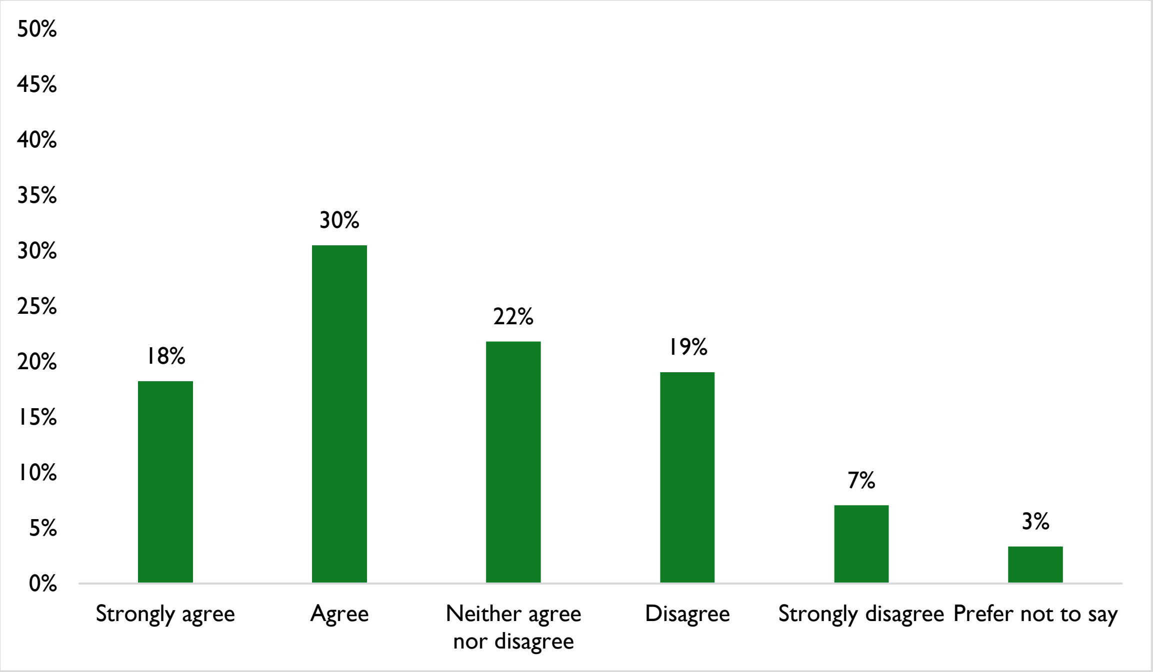

Figure 165. base n = 1233

Q – I have had to reduce my work hours or leave my job entirely due to caring responsibilities

Nearly half of respondents agreed (18%) or strongly agreed (30%) that they had reduced their work hours or left their job entirely due to caring responsibilities. Just over a quarter either disagreed (14%) or strongly disagreed (14%). A further 15% neither agreed nor disagreed, and 8% preferred not to say.

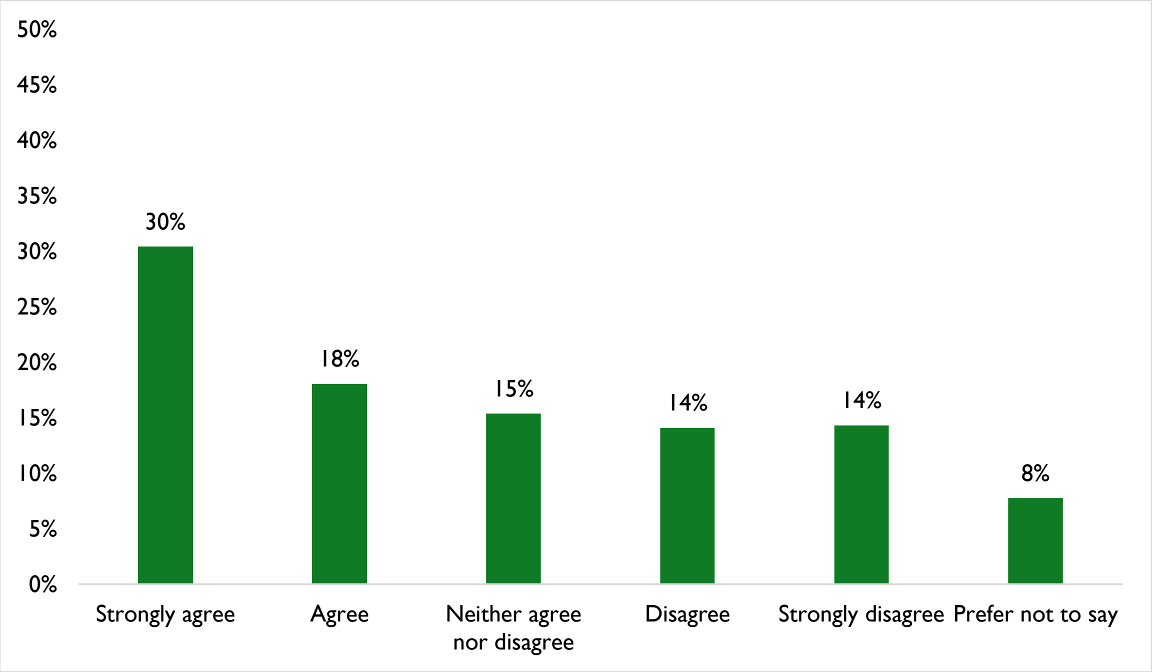

Figure 166. base n = 1236

Q – I am able to advance in my career

A small proportion of respondents agreed (5%) or strongly agreed (1%) that they were able to advance in their career. By contrast, over half disagreed (24%) or strongly disagreed (35%). Over a quarter (26%) neither agreed nor disagreed, and 9% preferred not to say.

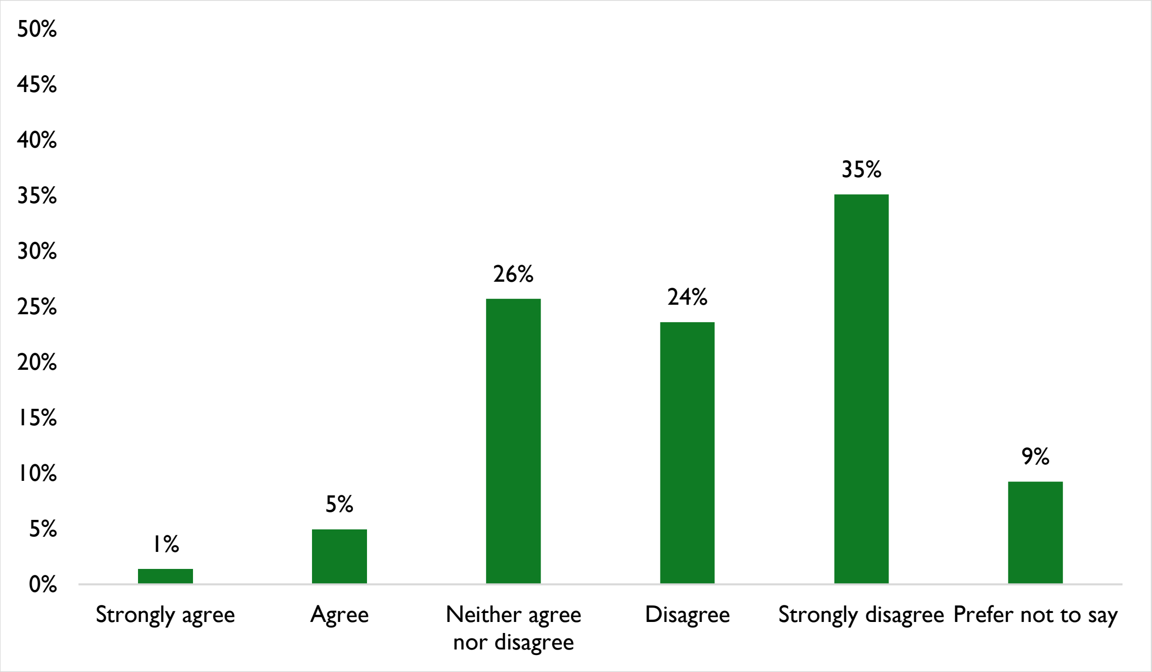

Figure 167. base n = 1233

Q – I am able to find time to pursue educational opportunities (e.g. courses, training) that I want to alongside my caring responsibilities

Just one in 10 respondents (2% strongly agreed and 8% agreed) said they were able to find time to pursue educational opportunities alongside their caring responsibilities. By contrast, a majority disagreed (28%) or strongly disagreed (34%). Around a fifth (22%) neither agreed nor disagreed, and 6% preferred not to say.

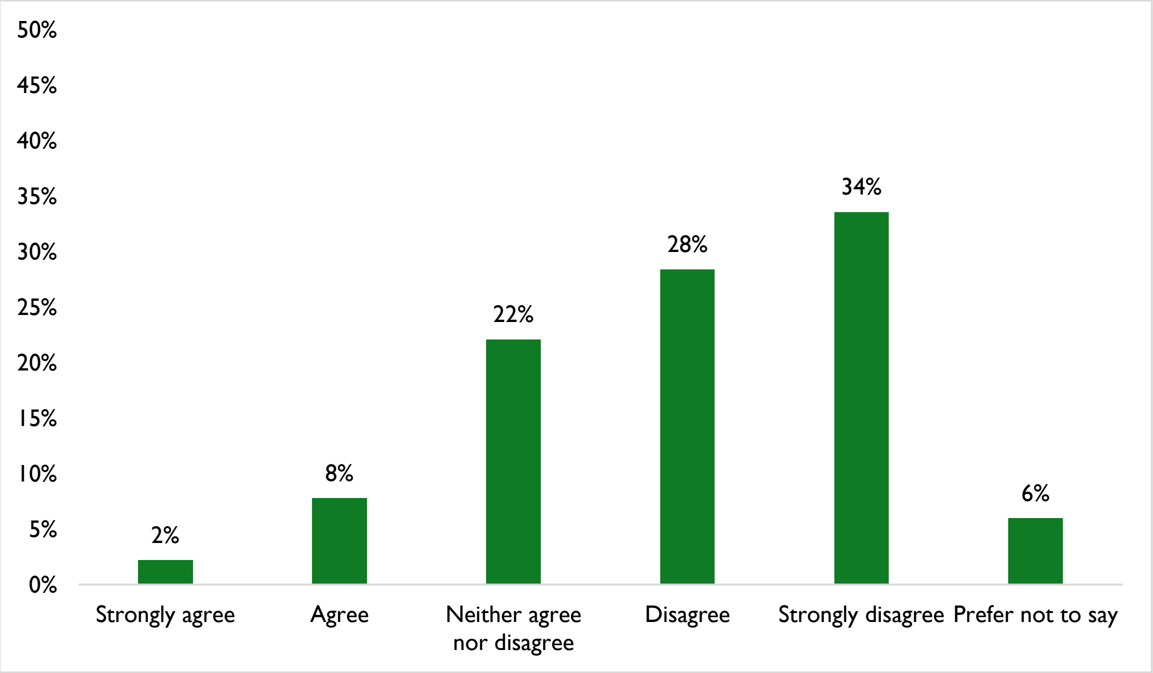

Figure 168. base n = 1236

Q – Please tell us which neurological condition(s) the person you support has

The most frequently reported neurological conditions were Progressive Supranuclear Palsy (15%), Epilepsy (15%), Parkinson's Disease (12%), and Autism (11%). A wide range of other conditions were mentioned in smaller proportions, each accounting for fewer than 10% of responses. Additionally, 8% selected "Other" and 3% said the person they supported was awaiting a diagnosis.

Condition	%
Awaiting diagnosis	3%
Acoustic Neuroma	0%
Acquired Brain Injury	5%
Alzheimer's Disease	3%
Ataxia	1%
Autism	11%
Autoimmune Encephalitis	0%
Batten Disease	0%
Behçet's	0%
Brain Tumour	2%
Brain Aneurysm	1%
Carpal Tunnel Syndrome	0%
Cavernoma	0%
Cerebral Palsy	5%
Charcot-Marie-Tooth Disease	0%
Chiari Malformation	2%
Chronic Headache	1%
Chronic Inflammatory Demyelinating Polyneuropathy	0%
Cluster Headache	1%
Corticobasal Degeneration (CBD)	5%
Congenital Hemiplegia	0%

Condition	%
Cerebrospinal Fluid (CSF) Leak	0%
Dementia	6%
Dravet Syndrome	1%
Down's Syndrome	0%
Dystonia	3%
Encephalitis/Autoimmune Encephalitis	1%
Epilepsy	15%
Essential Tremor	1%
Familial Dysautonomia	0%
Foetal Alcohol Spectrum Disorder	0%
Fibromyalgia	3%
Functional Neurological Disorder (FND)	8%
Guillain-Barre Syndrome	1%
Hemifacial Spasm	0%
Hereditary Spastic Paraplegia	0%
Huntington's Disease	3%
Hydrocephalus	6%
Idiopathic Intracranial Hypertension	0%
Lennox Gasteut Syndrome	1%
Long Covid Related Neurological Symptoms	1%
Meningitis	1%
Migraine	4%
Motor Neurone Disease (MND)	2%
Multifocal Motor Neuropathy	0%
Multiple Sclerosis (MS)	3%

Condition	**%**
Multiple System Atrophy (MSA)	5%
Muscular Dystrophy	0%
Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS)	6%
Myasthenia	0%
Narcolepsy	0%
Neurofibromatosis	1%
Neuromyelitis Optica	0%
Parkinson's Disease	12%
Peripheral Neuropathy	1%
Periodic Limb Movement Disorder Of Sleep (Plmd)	0%
Pernicious Anemia	1%
Poliomyelitis/Post-Polio Syndrome	0%
POEMS (Polyneuropathy, Organomegaly, Endocrinopathy, M-Protein, and Skin Changes)	0%
Progressive Supranuclear Palsy (PSP)	15%
Restless Legs Syndrome (Rls)	2%
Rett’s Syndrome	0%
Ring 20	0%
Spina Bifida	3%
Spinal Muscular Atrophy	0%
Spinal Tumour	0%
Spondylosis	1%
Stroke / Tia	3%
Vasculitis	0%
Prefer not to say	0%

Condition	**%**
Other	8%

Figure 169. base n = 1205

Q – Does the person you care for experience any of the following challenges? – Bladder and bowel symptoms

Over a quarter of respondents (29%) said the person they care for experienced bladder and bowel symptoms “very much”. Smaller proportions said they experienced these symptoms “quite a lot” (15%), “somewhat” (13%) or “a little” (20%). One in five (21%) said the person they care for did not experience these challenges at all. A very small number were either not sure (1%) or preferred not to say (less than 1%).

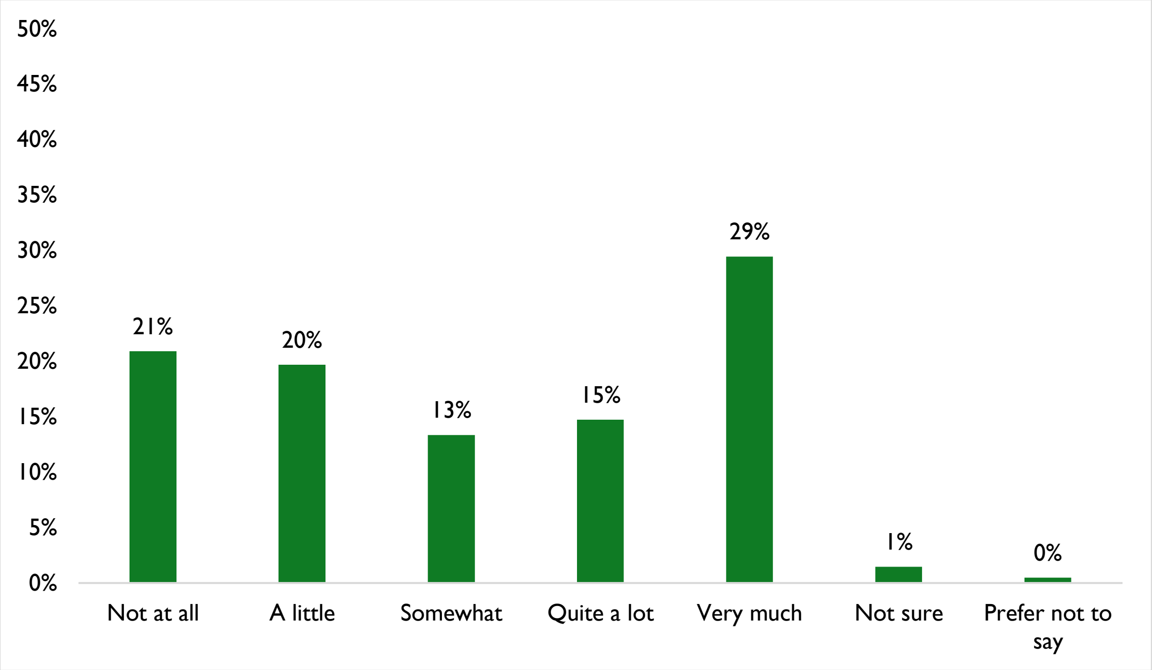

Figure 170. base n = 1230

Q – Does the person you care for experience any of the following challenges? – Breathing difficulties (e.g. shortness of breath, trouble breathing)

Nearly half of respondents (48%) said the person they care for did not experience breathing difficulties at all. Around one in five (22%) said they experienced these challenges “a little”, while others said “somewhat” (13%), “quite a lot” (7%) or “very much” (8%). A very small number were either not sure (1%) or preferred not to say (less than 1%).

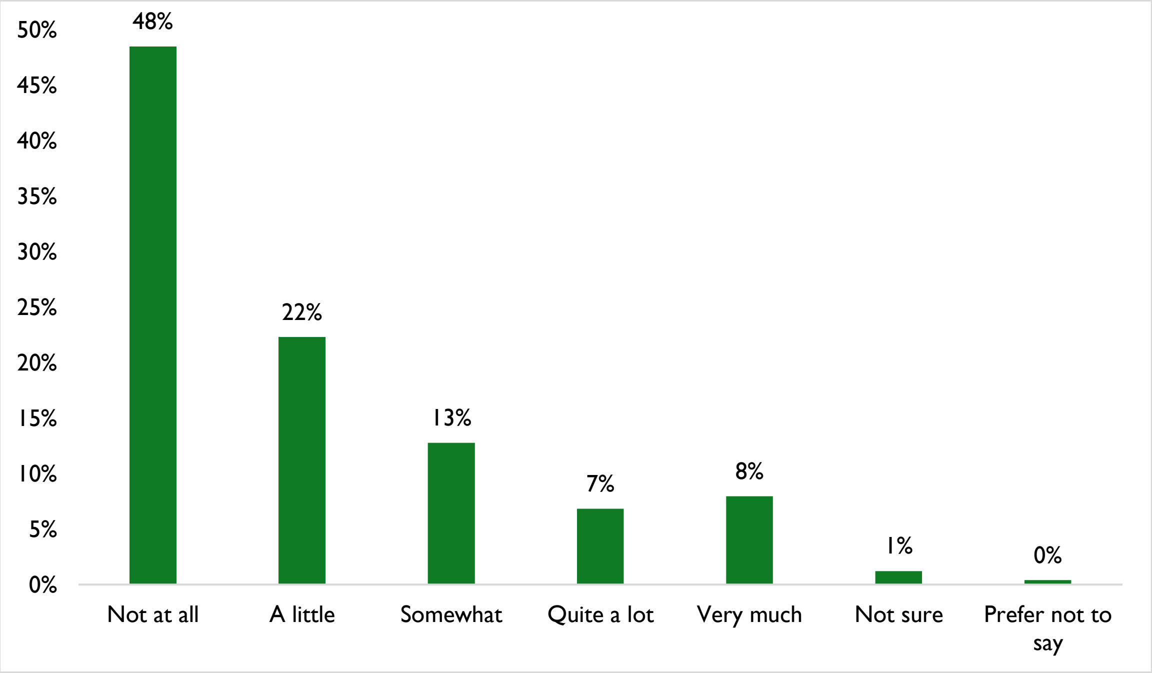

Figure 171. base n = 1229

Q – Does the person you care for experience any of the following challenges? – Communication (e.g. difficulty speaking clearly, slurred speech)

Over a third of respondents (34%) said the person they care for experienced communication challenges “very much”. Others said “quite a lot” (14%), “somewhat” (11%) or “a little” (20%). One in five (20%) said the person they care for did not experience these difficulties at all. A very small number were not sure (1%) or preferred not to say (less than 1%).

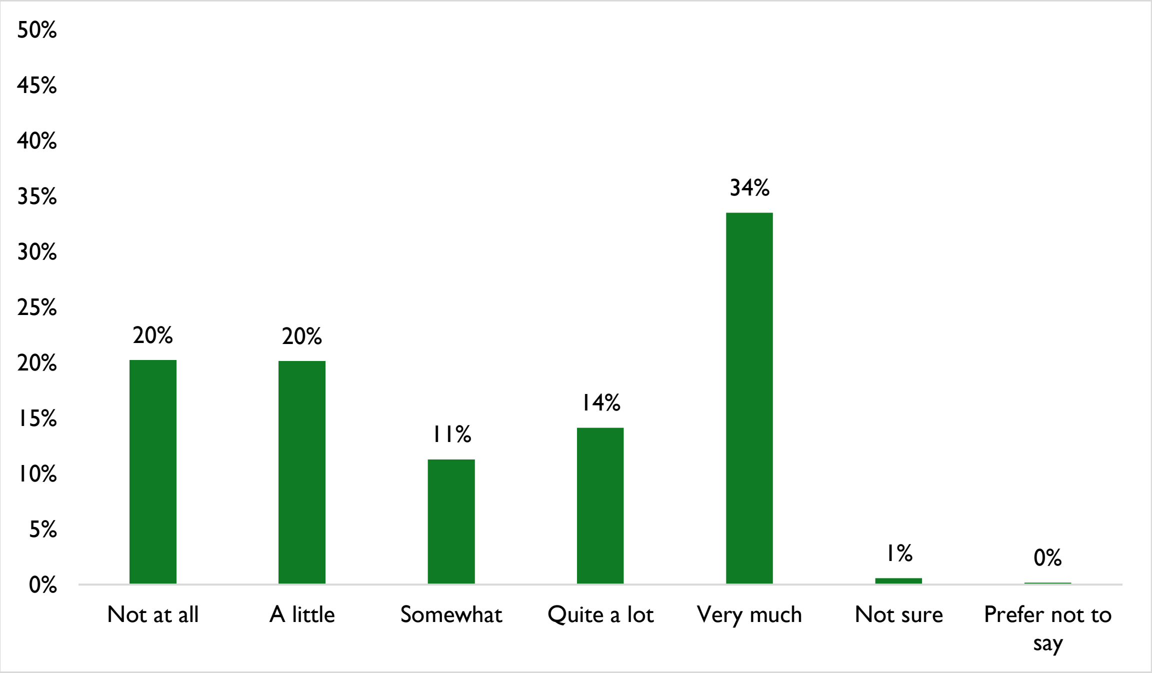

Figure 172. base n = 1232

Q – Does the person you care for experience any of the following challenges? – Eating and drinking

Just under a quarter (22%) of respondents said the person they care for experienced challenges with eating and drinking “very much”. Others reported this to be the case “quite a lot” (14%), “somewhat” (17%) or “a little” (22%). A slightly higher proportion (24%) said the person they care for did not experience this type of challenge at all.

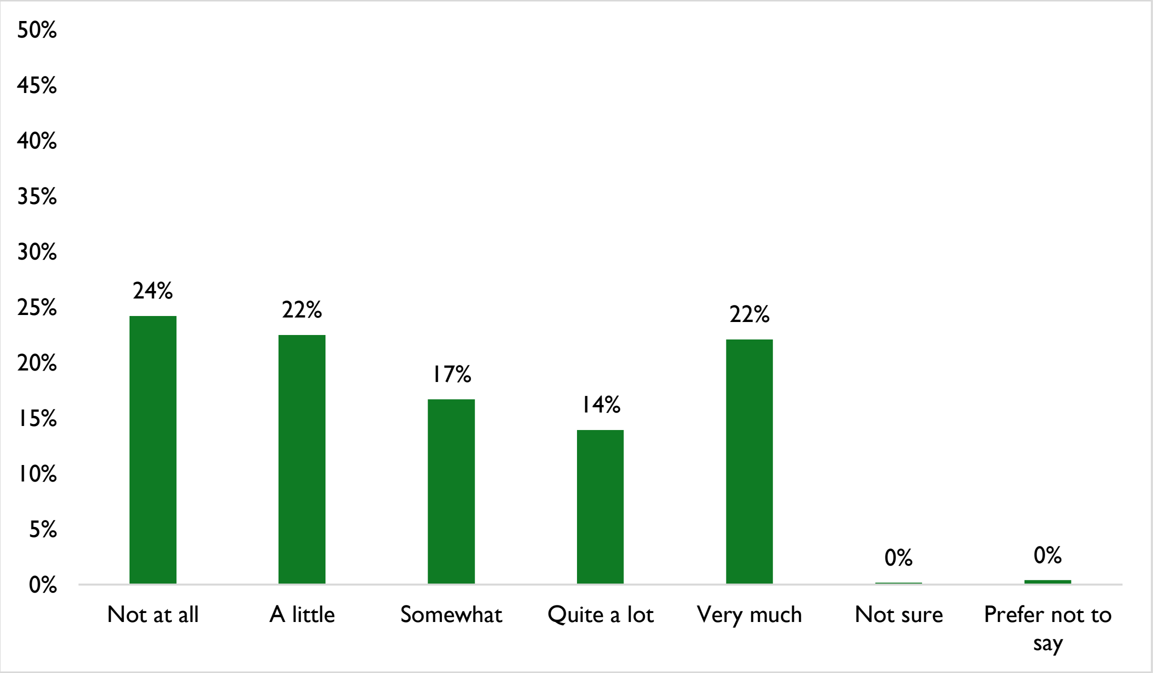

Figure 173. base n = 1227

Q – Does the person you care for experience any of the following challenges? – Fatigue

Just under half (44%) of respondents said the person they care for experienced fatigue "very much". Others reported this to be the case "quite a lot" (20%), "somewhat" (16%) or "a little" (12%). A small proportion (6%) said the person they care for did not experience fatigue at all, while 1% said they were not sure.

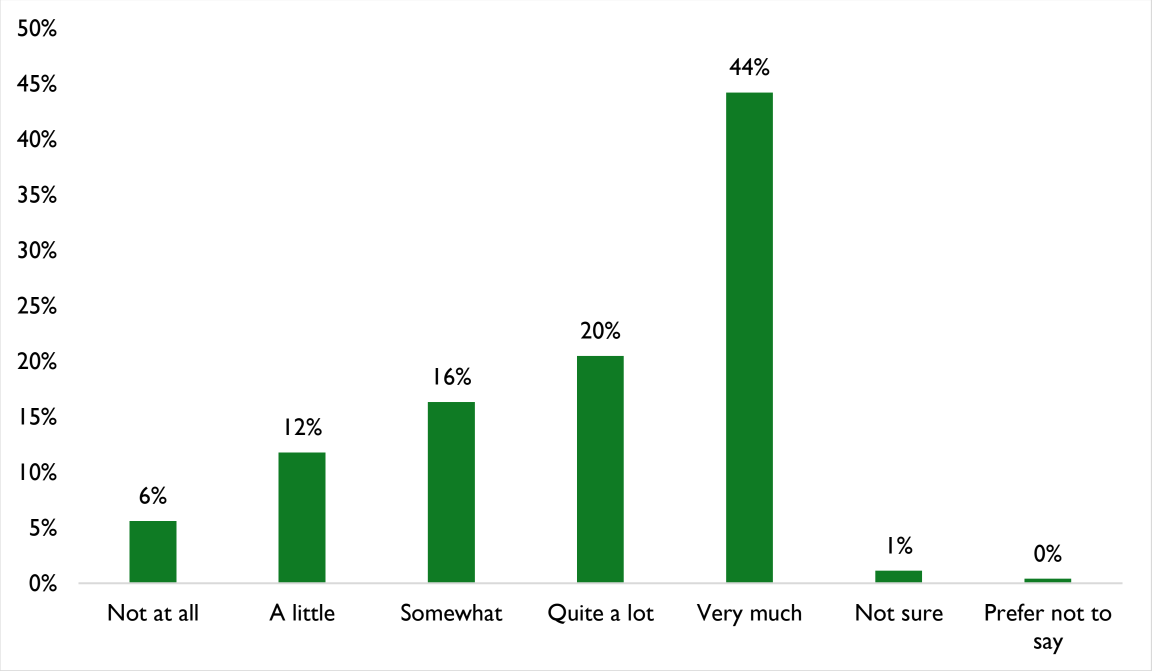

Figure 174. base n = 1230

Q – Does the person you care for experience any of the following challenges? – Hearing

Over half (55%) of respondents said the person they care for did not experience hearing difficulties at all. Just under a third reported the person experienced hearing difficulties “a little” (17%) or “somewhat” (13%), while smaller proportions said “quite a lot” (6%) or “very much” (7%). A small number (2%) said they were not sure.

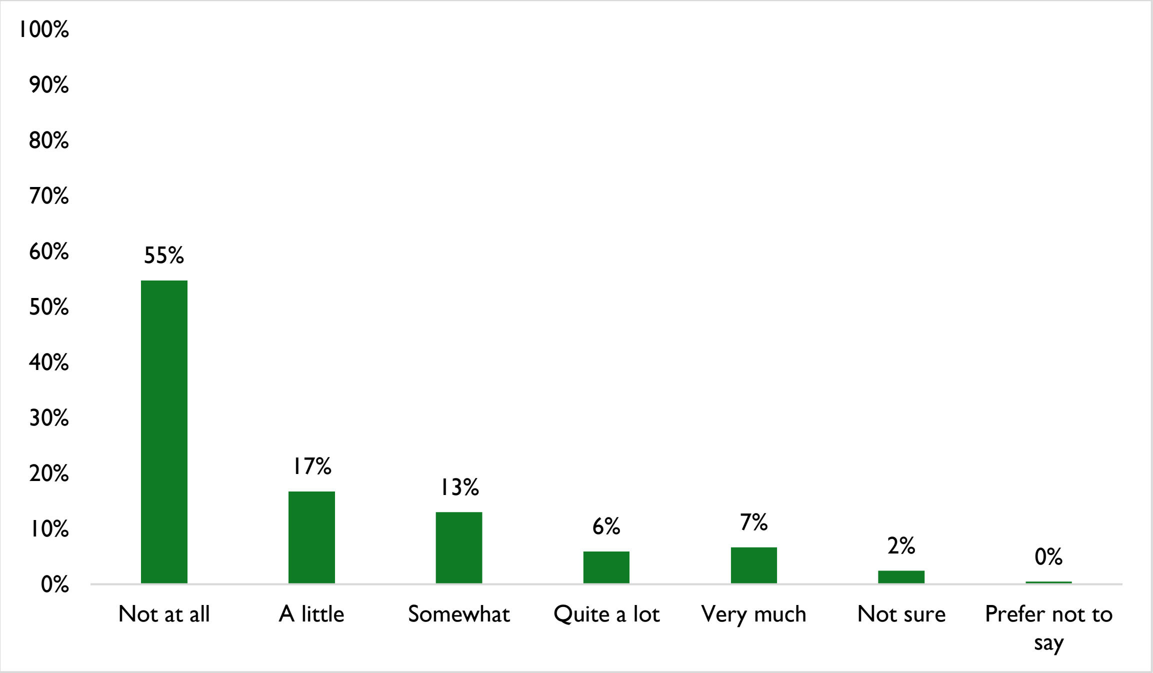

Figure 175. base n = 1232

Q – Does the person you care for experience any of the following challenges? – Mood and mental health issues (e.g. anxiety, irritability, social withdrawal, psychosis, impulsive behaviour)

Nearly a third (32%) of respondents said the person they care for experienced mood and mental health issues “very much”. Smaller proportions selected “a little” (19%), “somewhat” (18%), or “quite a lot” (18%). Only one in ten (10%) said “not at all”, and 2% were not sure.

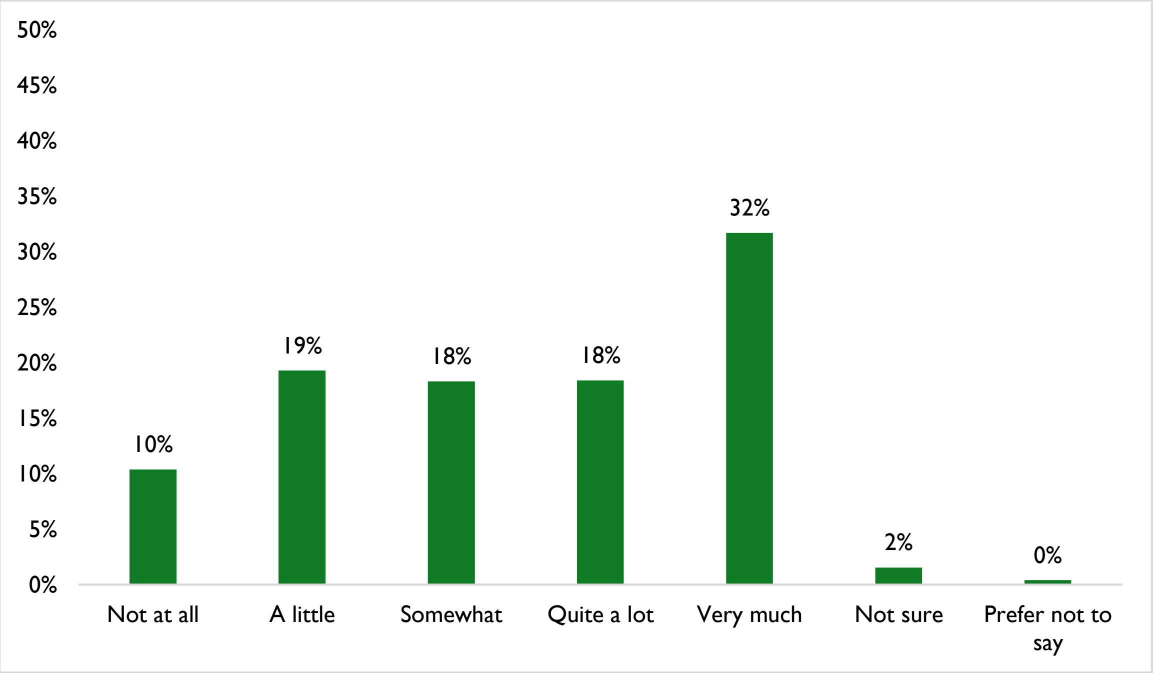

Figure 176. base n = 1234

Q – Does the person you care for experience any of the following challenges? – Movement (e.g. tremor, stiffness, difficulty with balance, etc.)

Over half (52%) of respondents said the person they care for experienced movement-related challenges “very much”. One in five (20%) said “quite a lot”, while 12% selected “somewhat” and 9% said “a little”. A small proportion (7%) said “not at all”, and 1% were not sure.

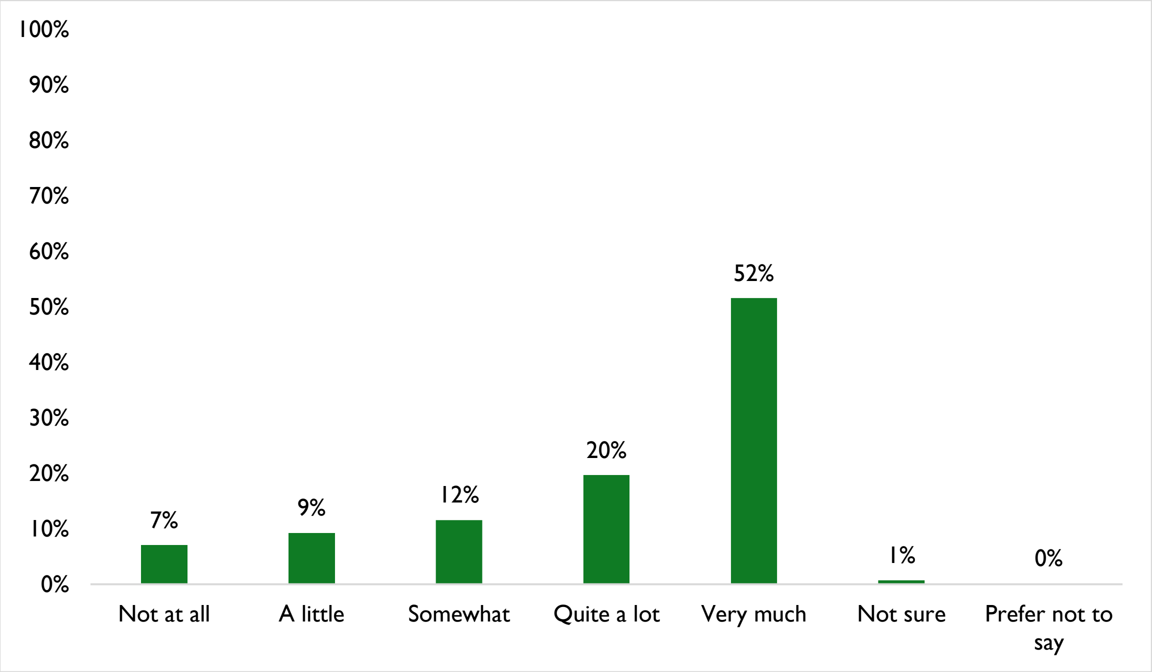

Figure 177. base n = 1235

Q – Does the person you care for experience any of the following challenges? – Pain

Responses were fairly evenly distributed across the scale. One in five (20%) said the person they care for experienced pain "very much", with an equal 20% saying "somewhat". A further 22% selected "a little", and 16% said "quite a lot". Another 16% said "not at all". A small number said they were "not sure" (5%) or "prefer not to say" (1%).

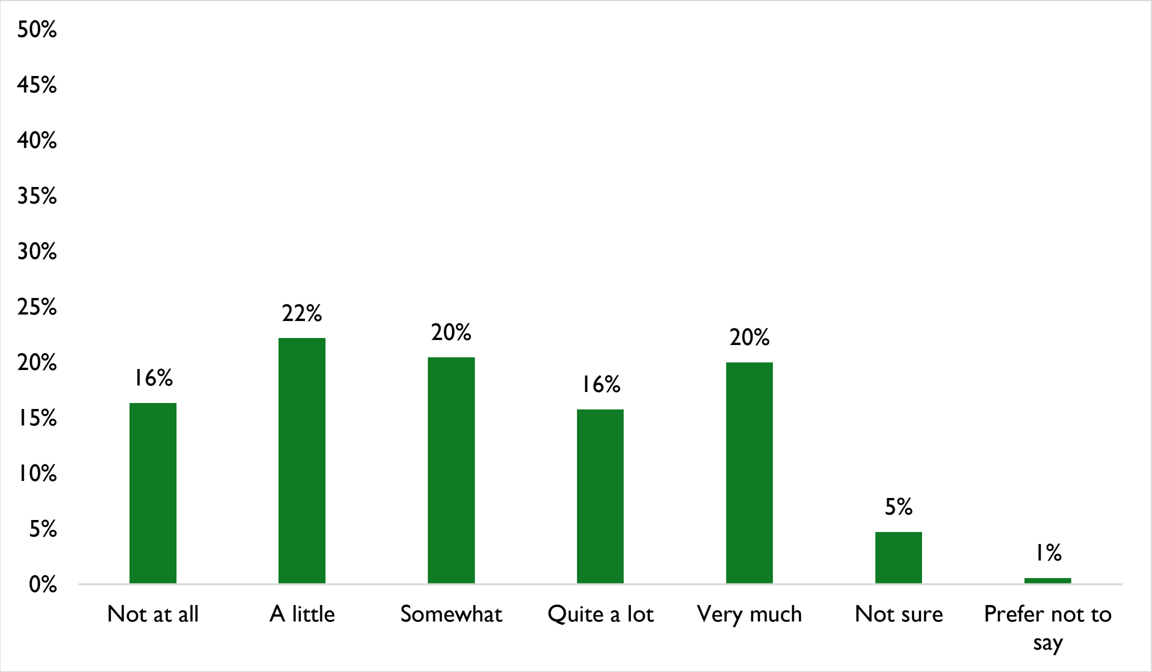

Figure 178. base n = 1231

Q – Does the person you care for experience any of the following challenges? – Seizures

Two-thirds (66%) said the person they care for does not experience seizures at all. Around 1 in 10 (10%) said they experience seizures “very much”, while 7% said “quite a lot”, 6% “somewhat”, and 7% “a little”. A small minority were “not sure” (3%).

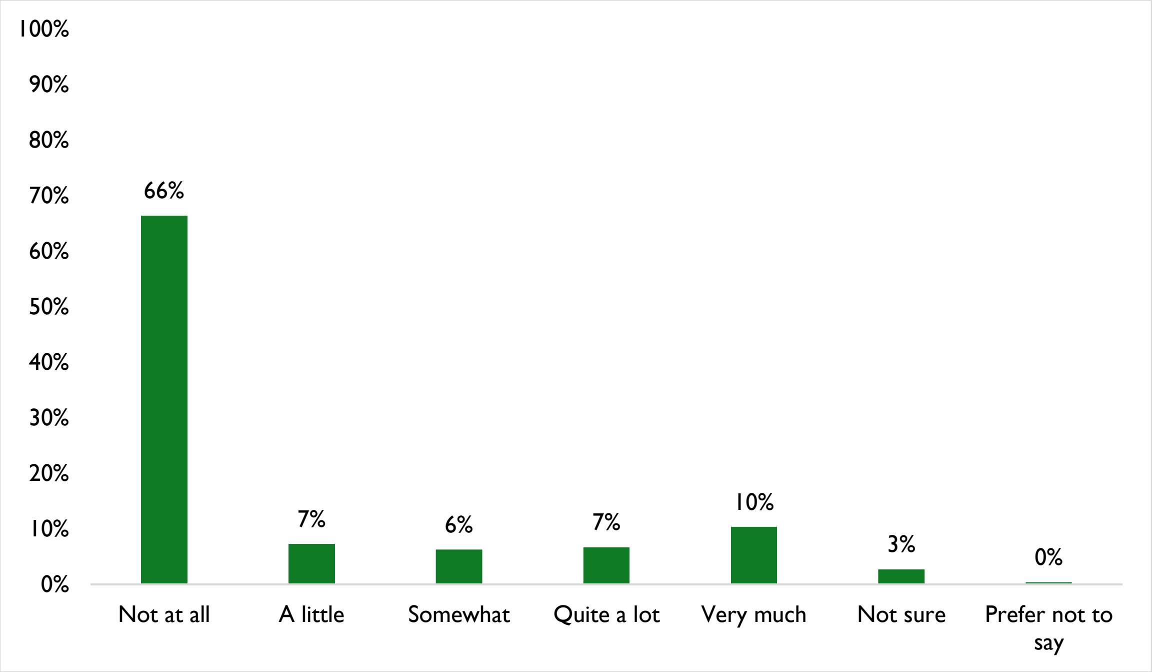

Figure 179. base n = 1229

Q – Does the person you care for experience any of the following challenges? – Sensation (e.g. numbness, tingling, pain, hypersensitivity, etc.)

Around 3 in 10 (30%) said the person they care for does not experience sensation-related challenges at all. Meanwhile, a higher proportion reported some level of difficulty, with 17% saying “a little”, 16% “somewhat”, 12% “quite a lot”, and 15% “very much”. One in ten (10%) were “not sure”.

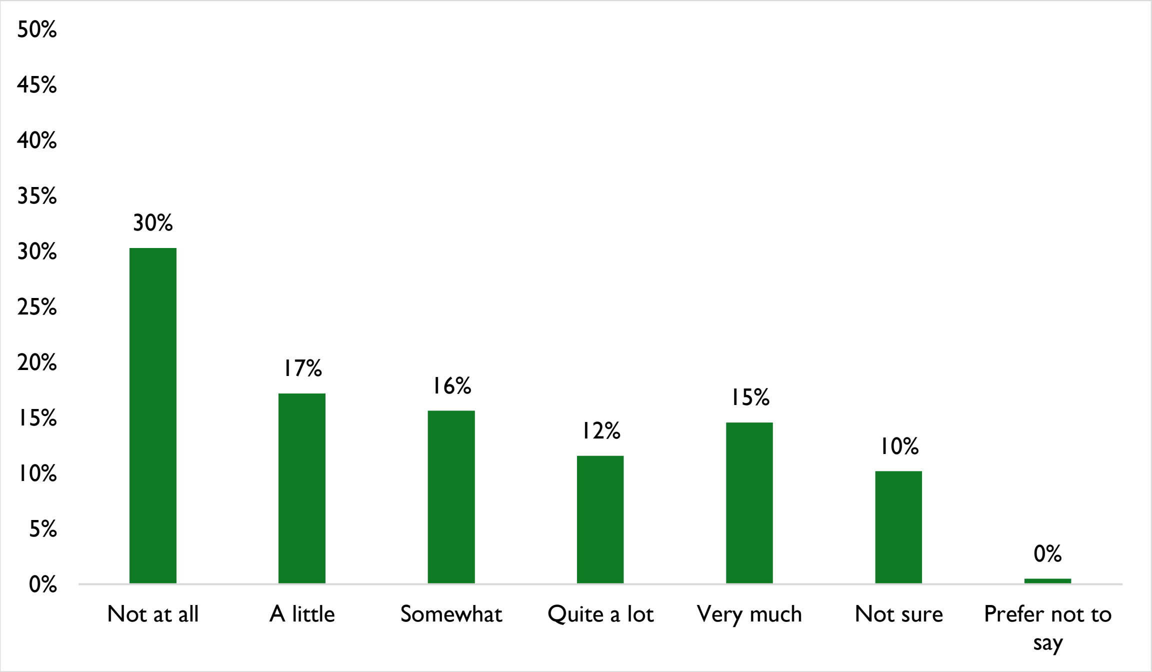

Figure 180. base n = 1227

Q – Does the person you care for experience any of the following challenges? – Sexual function

A third (33%) of respondents said the person they care for does not experience any challenges related to sexual function. A smaller proportion reported some difficulty, with 4% each selecting “a little”, “somewhat”, or “quite a lot”, and 17% saying “very much”. Notably, 21% said they were “not sure” and 17% selected “prefer not to say”.

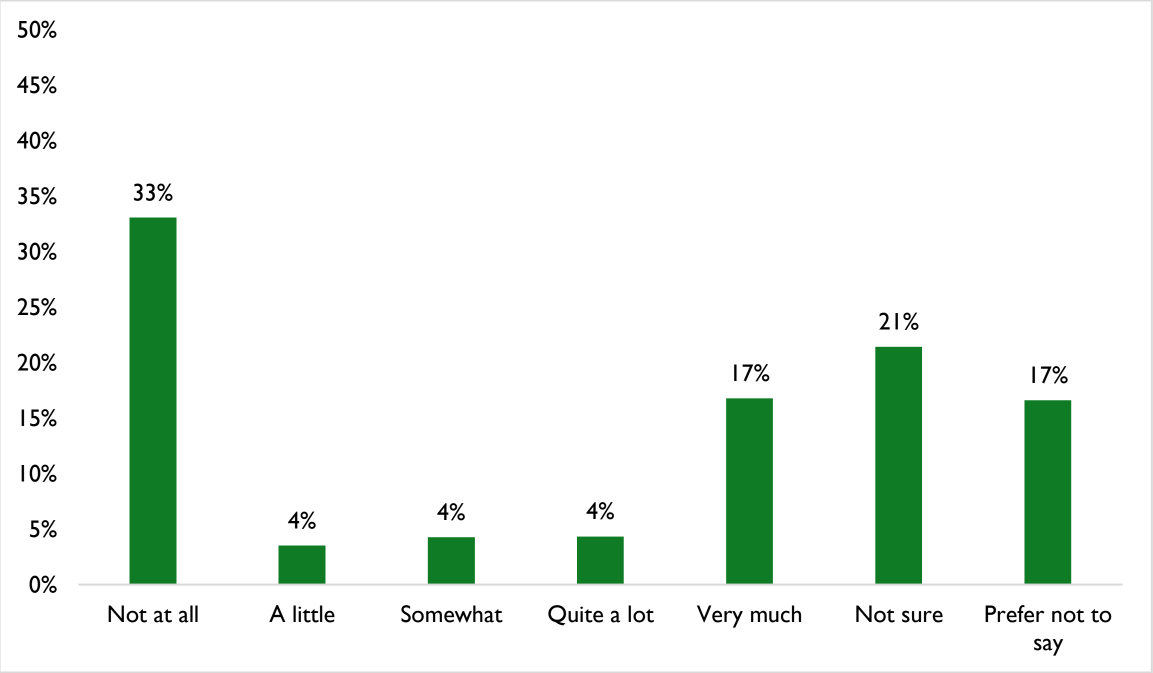

Figure 181. base n = 1222

Q – Does the person you care for experience any of the following challenges? – Sleep (e.g. difficulty falling asleep, excessive daytime sleepiness)

More than one in three respondents (37%) said the person they care for experiences sleep-related challenges "very much", with a further 20% selecting "quite a lot". Smaller proportions reported these difficulties to a lesser extent, including 17% "somewhat", 13% "a little" and 11% "not at all". Only 1% were "not sure".

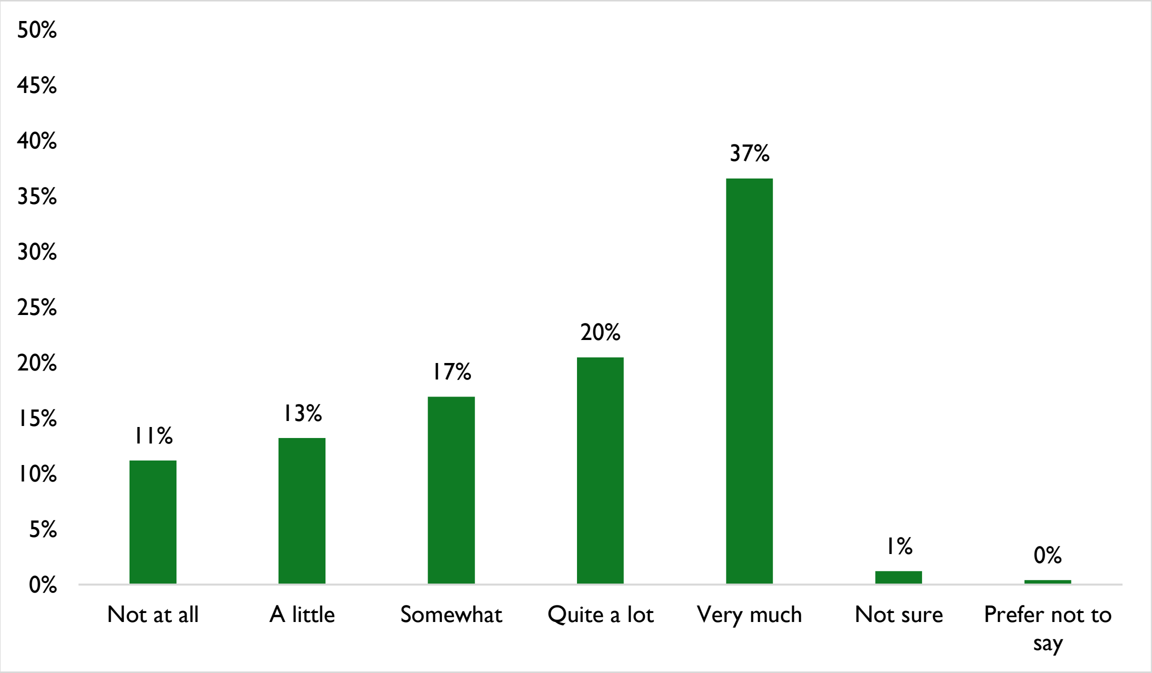

Figure 182. base n = 1235

Q – Does the person you care for experience any of the following challenges? – Thinking and memory (e.g. difficulty concentrating, confusion, memory problems, difficulty planning)

Over a third of respondents (39%) said the person they care for experiences difficulties with thinking and memory "very much". An additional 21% selected "quite a lot", while 16% said "somewhat" and 12% "a little". Just 9% said "not at all", 3% were "not sure".

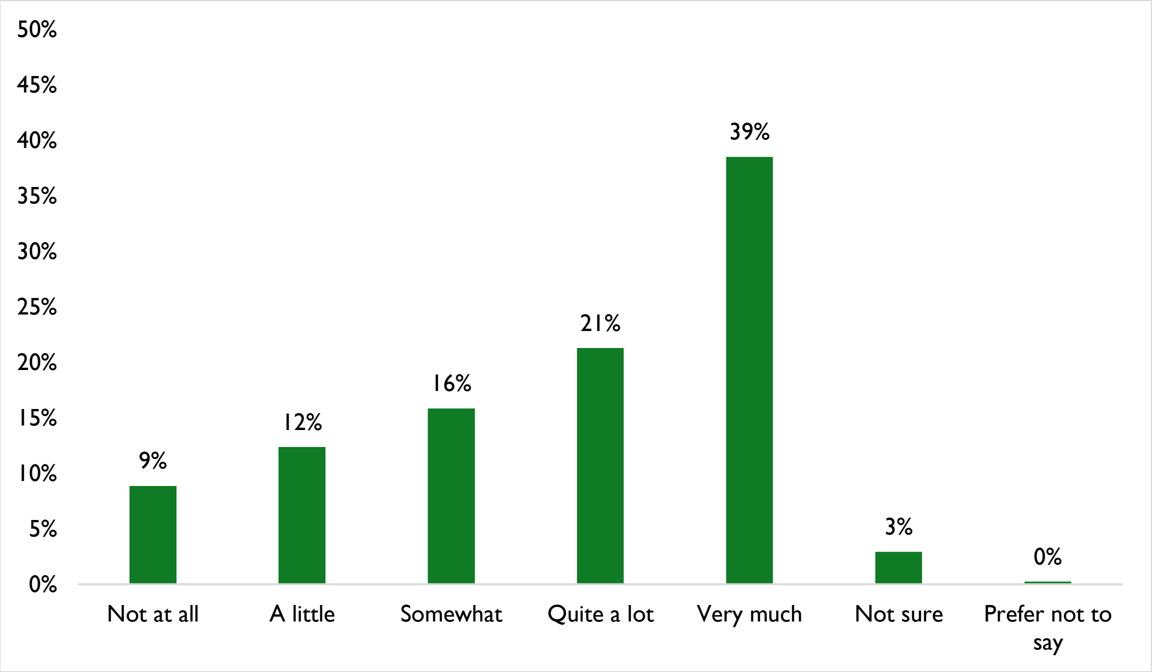

Figure 183. base n = 1231

Q – Does the person you care for experience any of the following challenges? – Vision

Around one in six (17%) said the person they care for experiences vision challenges "very much", with a further 11% choosing "quite a lot" and 15% "somewhat". Larger proportions selected "a little" (23%) or "not at all" (31%). Just 3% were "not sure".

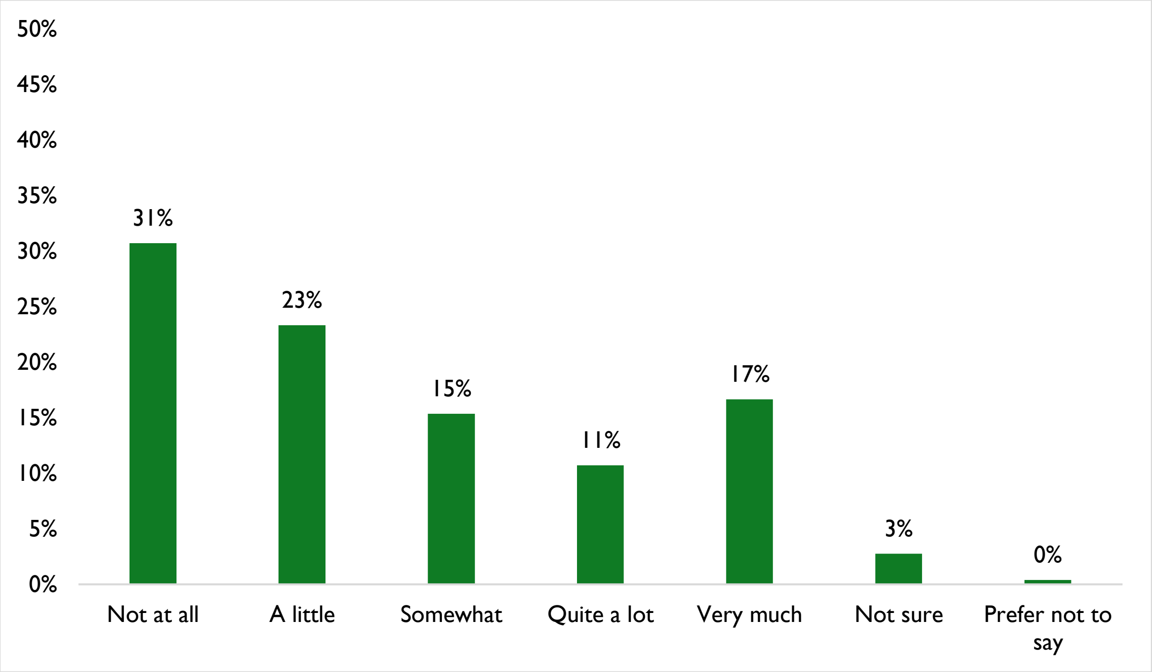

Figure 184. base n = 1230

Q – Has the person you care for completed their own survey?

Nearly nine in ten (89%) respondents said the person they care for had not completed their own My Neuro survey, while just over one in ten (11%) indicated that the person had completed it.

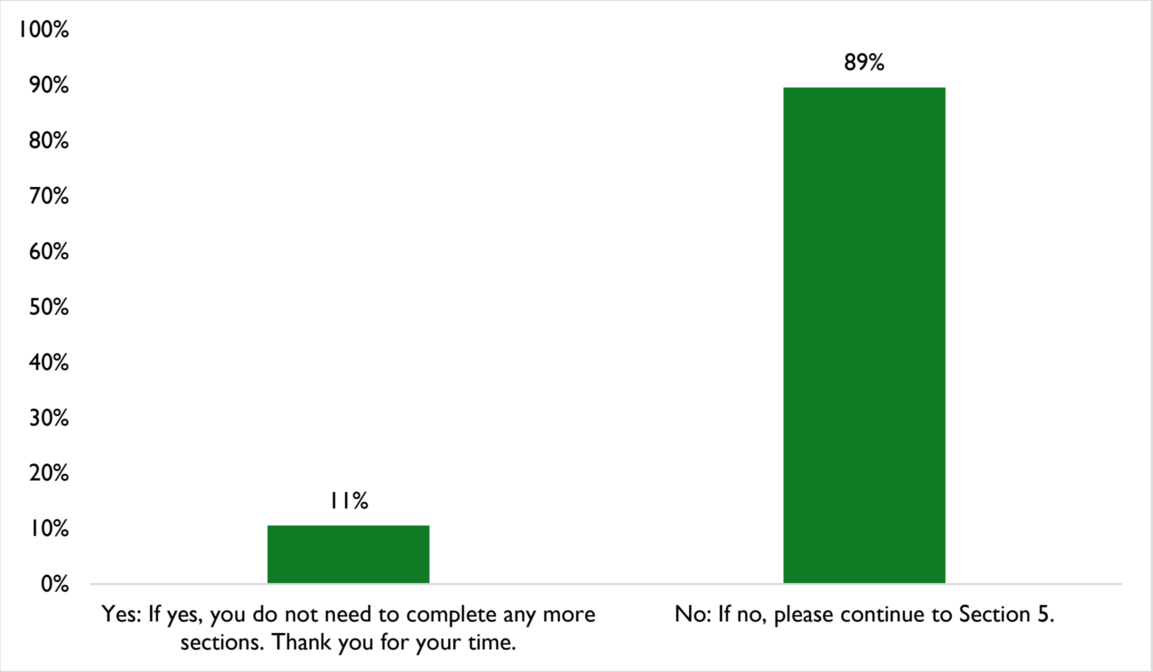

Figure 185. base n = 1238