



NeuroLifeNow

Brain & Spine
Foundation

 THE
NEUROLOGICAL
ALLIANCE



"My reduced mobility restricts access to money saving options for everyday needs, for example, food and clothing."

Foreword

The UK Government will set out its fiscal plan on 17 November. The new Government has an unprecedented opportunity to show it is listening to you, the neurological community, by ensuring targeted support is available this winter and beyond. It is clear from your responses to the latest NeuroLifeNow questionnaire, that this has never been more needed.

We asked you how you were managing increasing costs now and in the future. You are clearly making decisions no one should have to make - nearly half of you said you were reducing your heating, 3 out of 10 are skipping meals and nearly 6 out of 10 are reducing their travel either by car and/or by public transport. 7% of you said you had had to lower or stop your care package, and 7% also said you were skipping prescriptions. Those living with multiple conditions seem to be being hit harder too. Those living with more than one neurological condition or living with a condition other than a neurological condition were more likely to report having to change their spending and/or borrowing as a result of the crisis.

"I'm not sure how to run all of my medical equipment. I'm tube fed on a pump, have breathing machines, air mattress, hospital bed, ceiling joists, through floor lift - all need electricity."

"If benefit payments are not increased, we will really struggle."

At the same time, lots of you told us you weren't sure how you were going to cope financially. You told us that you were 'slipping through the net' of financial support, as this has not been targeted. Many of you also told us, however, the importance of financial support when you did get it, with support such as Personal Independence Payments (PIP) helping you to manage some of the extra costs you face.

15% of you said you were likely to miss the payment of bills, and 16% said you were likely to increase your debt. Nearly a quarter of you told us that you would reduce spend on healthcare.

We also asked you about your experiences of social care – many of you told us about the challenges you had faced in trying to access the care you need. 21% would like to access home care but haven't, and 14% need home adaptations but haven't accessed these. Many of you reported a system in crisis, with inadequate care provision in your area, inaccurate care assessments and long waits for support.

Respondents reported that the social care system is non-existent as services are lacking, hard to reach, or not available in their area.

"... social care for those of us with these conditions is really lacking. So far I have received help with benefits, but the help stops there. There is no real care for the effects of your symptoms on your day-to-day life."

The picture has never been starker, nor the case more urgent. The 17 November must provide targeted support for the one in six living with a neurological condition and those closest to them, starting with uprating benefits such as PIP in line with inflation.

Without action now, we fear that many will be faced with worsening symptoms and increased isolation – surely the choice for the UK Government is an obvious one.

If you need to talk, The Brain and Spine Foundation's free, UK-wide Helpline provides a trusted and safe space where you can seek professional insight, emotional support, and guidance from neuroscience-trained nurses. Call **0808 808 1000** (Mon-Thurs, 9am – 4pm) or email helpline@brainandspine.org.uk.

Thank you,

Marc Smith, CEO
Georgina Carr, CEO

Brain and Spine Foundation
Neurological Alliance (England)

NEUROLIFENOW ANALYSIS REPORT

September and October Questionnaire Responses

Published November 2022

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Background

There are more people in the UK living with a neurological condition than cancer, heart disease or diabetes. Change is needed urgently because the current system is under-funded, inadequately resourced, and fails individuals and families too often. [NeuroLifeNow](#) is a platform designed to support people with neurological conditions to share experiences of their care. Insights are shared with NHS Commissioners, UK Governments and clinicians to influence how neurological services are delivered and to drive positive change. The data in this report is derived from responses received between 1 September – 31 October 2022. The full questionnaire and data tables are available in the appendices.

Key findings

- 244 people shared their experiences in September and October, with 70% female respondents and 28% male. 1% said they preferred not to say and 1% preferred to self-describe.
- 74 different neurological conditions and symptoms were represented in the survey. A total of 128 respondents, equating to 52% of respondents, indicated they have multiple (i.e. more than one) neurological condition.
- 48% of you said you were reducing heating as a result of increases to the cost of living. 30% are skipping meals and 39% are reducing their travel by car. 20% reported reducing their travel by public transport. 40% of you living with more than one neurological condition reported skipping meals.
- To cope with changes to the cost of living in future, 15% told us you would miss a bill payment, 16% said you would increase your debt and 23% will reduce spend on healthcare.
- 7% of you would like access to respite care but haven't got it. 13% would like access to community transport but haven't got it, and 14% require adaptations for the home but haven't accessed these. In general, people of working age (18 – 55) tended to report greater need for social care. Overall, however, the minority of you either accessed care or reported a need for it. For those who had tried to access social care, many reported long delays or reductions in care packages.

Qualitative data - cost of living

We asked you about your experience of the cost of living rises in this survey. We have created a word cloud below to share with you the words most commonly used, demonstrating the shared experience of our community.

Word Cloud - cost of living



Fig 1: Word cloud of the words used by respondents to the questions relating to the cost-of-living crisis.

Thematic analysis - cost of living

A thematic analysis was conducted for responses to the question, and 4 main themes emerged:

- **Theme 1: financial impacts**
 - Struggling due to increased costs
 - Cutting down on spending
 - Seeking financial help from others
- **Theme 2: deteriorating mental health**
- **Theme 3: impacts related to medical conditions**
 - “The costs of being disabled”
 - Compromising medical needs
- **Theme 4: slipping through the net - more support needed**

Theme 1: Financial impacts

Struggling due to increased costs

You reported struggles due to increasing costs of living.

“Struggled paying the rent.”

“I am living off my savings until I get the state pension but will still struggle.”

“...not being able to afford to exist.”

Cutting down on spending

To cope with the increasing costs of living, some of you have resorted to cutting down spending:

“We’ve cut down on food, heat is on just a little, but it may have to go off and just put a fan heater on before personal care.”

“We had already made cuts in the first place, we are not using our aids that rely on electricity as much as we should do, we only cook in the microwave and small tabletop oven anyway for years. We are boiling the kettle and putting the boiled water in a flask, have bought door curtains, and cut food down as we didn’t have any luxuries to start with.”

“As my social housing accommodation is not insulated, I have always turned off five of the nine radiators to control heating costs. I have also got rid of my tumble dryer and decommission my freezer once it is empty in a week or so. I have installed LED light bulbs in the rooms I use.”

Seeking financial help from others

Some of you have also started or considered seeking financial help from others, such as their family members.

“It’s embarrassing being 63 years old and having to start borrowing from your elderly mother just to have bare basics, she can afford to do this or I wouldn’t take up her offer.”

“... we cannot pay our bills without borrowing from my elderly mother who is worried sick about us, she can afford to lend or I wouldn’t have let her.”

“I’ve thought about taking out a loan to help me pay for things like thicker curtains to keep the draughts out, but with no real prospect of being able to pay it back, it feels like it’d just make things worse.”

Theme 2: Deteriorating mental health

The cost-of-living crisis has also impacted respondents’ mental health, induced more anxiety and worried due to the uncertainties faced.

“I’m very worried about the increase of the cost of living.”

“The fear of rising costs is adding to my mental strain. This is almost as bad as when it actually happens”

“Really anxious about how I can afford to pay bills and afford to eat”

Theme 3: Impacts related to medical conditions

One important theme that emerged are the impacts related to your medical conditions. Respondents must bear extra costs of being disabled due to their conditions, and also have to compromise their medical needs (e.g., turn off heating, cancel appointments) as they cannot afford the costs anymore.

"The costs of being disabled"

"The increase in cost to charge electrical mobility aids I cannot live without is not a choice"

"I have later this year got an ataxia clinic appointment (expertise and funding agreed by Wales accepted with gratitude) but paying for transport and overnight hotel stay are costly. Fear cost of travel & hotel means with like past history cancelled appointments"

"Reduced mobility restricts access to money saving options for everyday needs - food, clothing, etc"

Compromising medical needs

"I have cancelled hospital appointments as cannot afford fuel and parking costs"

"Reduced heating affects condition with increased pain"

"In addition to foregoing health impairments, I am severely Speech Impaired (Dysarthria) and require Speech Therapy, Physical Therapy and Occupational Therapy I cannot pay for this care therefore I do not receive needed care. I need to be seen by a Neurologist and a Gastroenterologist and am unable to pay co-pays and therefore forego this needed care as well."

"I'm now unable to do much needed work and adaptations to my home as I'm unable to afford it."

Theme 4: Slipped through the net - More support needed

You expressed your feelings of having 'slipped through the net' for help and support and recognised that more support is needed.

"Single and disabled - no extra person for support or income makes it far harder to make ends meet. As I have some savings, I do not qualify for UC or the associated uplifts/handouts. My demographic slips through the net. Legacy benefits should receive same assistance as UC claimants."

"Can't get help required from CQC Disability Companies for help with household chores due to all of them being short staffed (C-19) & not taking any new customers. I am constantly covered in multiple minor injuries all over my body. That reduces my sleep levels which then causes additional seizures and injuries."

"Because I have to work, I'm not entitled to extra help with bills and cost of living. This means that, come the winter, when I am working from home, I will have increased costs and no help."

"The Government need to focus help on the disabled, lower income families who really are struggling."

"There is not enough financial help being given to people who are just over the benefits threshold."

"Putting all people on benefits in the same bracket is unfair because we don't have the option to work or earn money."

"Being in the middle bracket is hard we don't qualify for handouts but barely manage at times"

"I have strictly shielded way past the end of SEISS help, yet it stopped for all at the same time. Being self-employed and unable to work has been very difficult."

Quantitative data – Cost of living crisis leading to changes in behaviour

Did the respondents change their behaviour following the cost-of-living crisis?

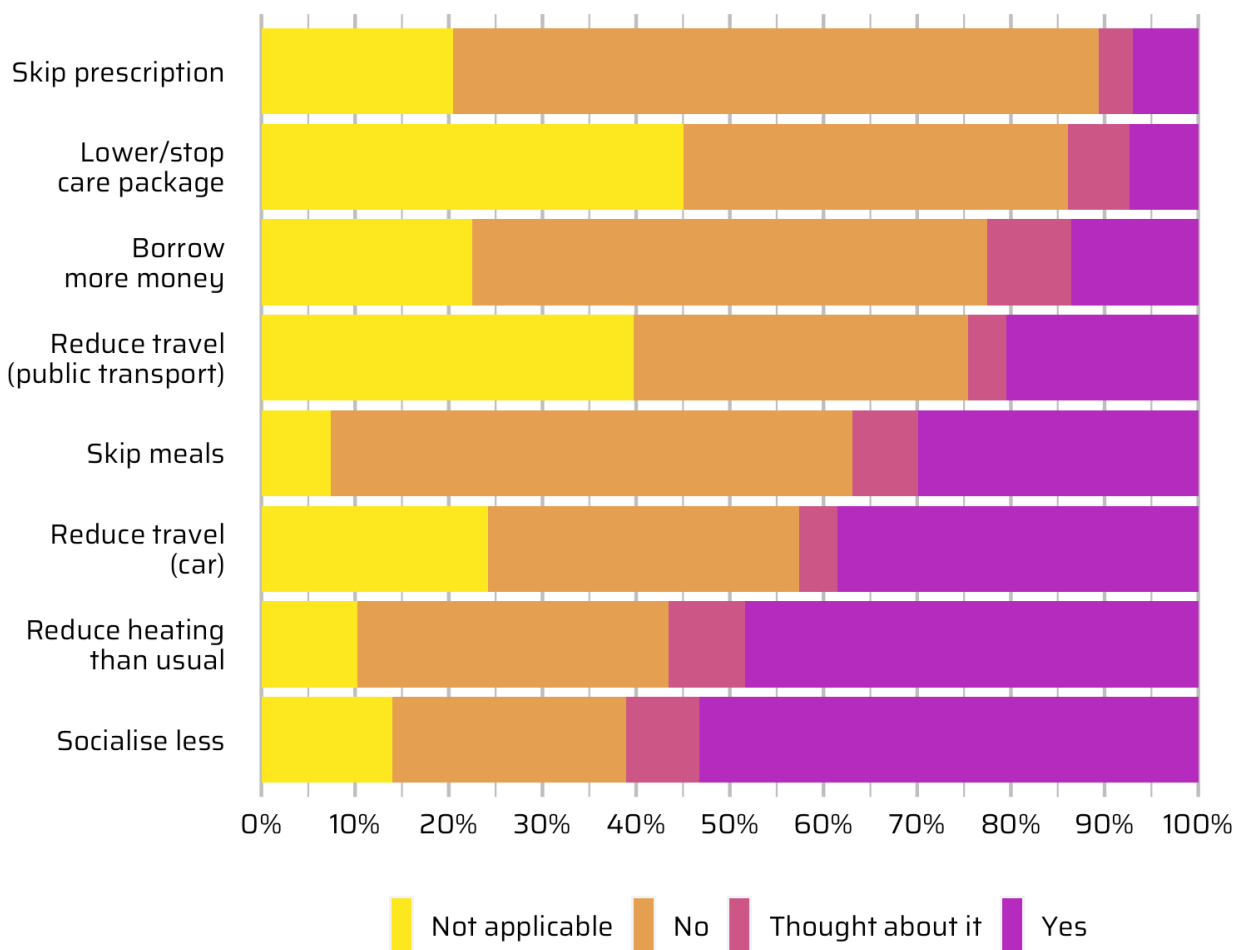


Fig 2: How respondents' behaviour has changed due to the cost-of-living crisis.

Table 1: How respondents' behaviour has changed due to the cost-of-living crisis.

Changes made	Option chosen	Respondents	Percentage
Skip meals	Yes	73	30
	Thought about it	17	7
	No	136	56
	Not applicable	18	7
Socialise less	Yes	130	53

Changes made	Option chosen	Respondents	Percentage
	Thought about it	19	8
	No	61	25
	Not applicable	34	14
Skip prescription	Yes	17	7
	Thought about it	9	4
	No	168	69
	Not applicable	50	20
Lower/stop care package	Yes	18	7
	Thought about it	16	7
	No	100	41
	Not applicable	110	45
Reduce travel (car)	Yes	94	39
	Thought about it	10	4
	No	81	33
	Not applicable	59	24
Reduce travel (public transport)	Yes	50	20
	Thought about it	10	4
	No	87	36
	Not applicable	97	40
Reduce heating than usual	Yes	118	48
	Thought about it	20	8
	No	81	33
	Not applicable	25	10
Borrow more money	Yes	33	14
	Thought about it	22	9
	No	134	55
	Not applicable	55	23

Change of behaviour due to cost of living crisis: Does it differ among people with/without multiple neurological conditions?

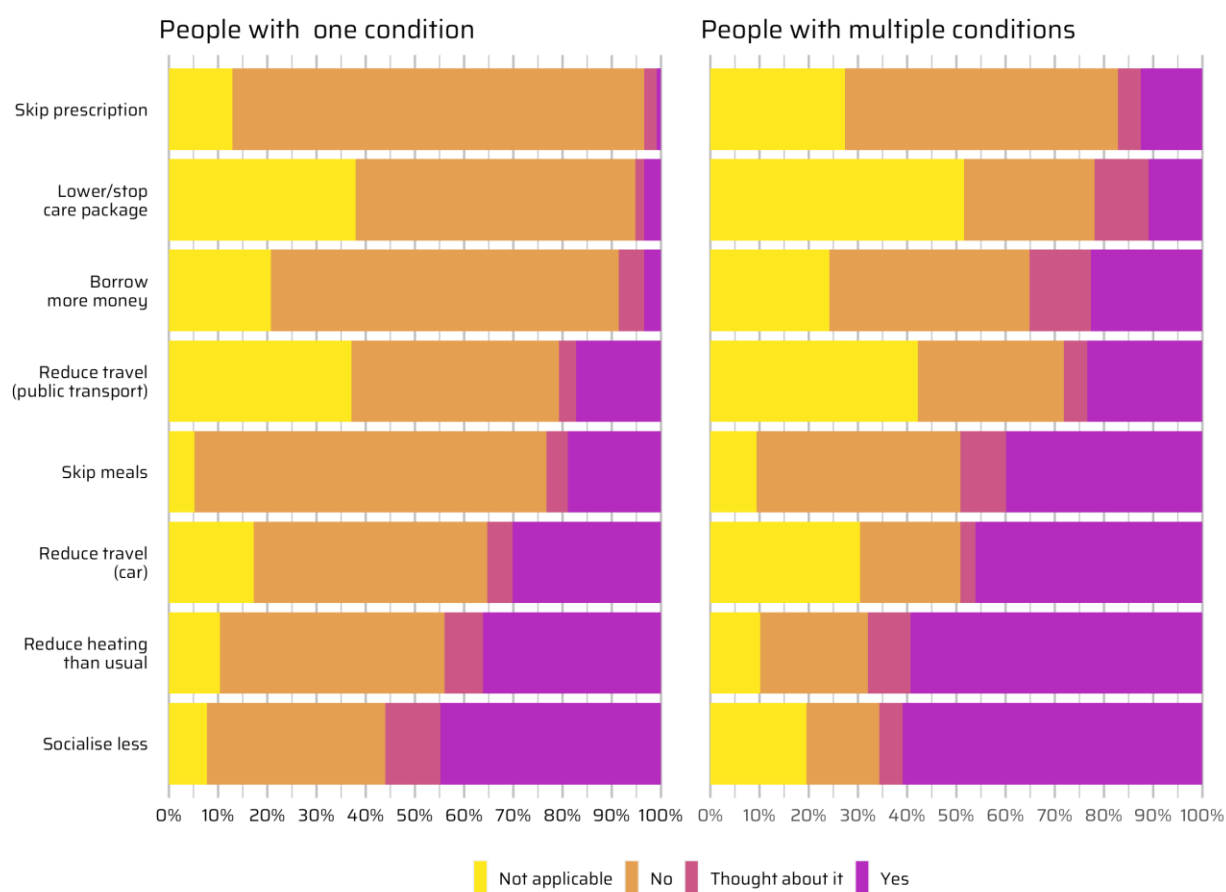


Fig 3: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they have one neurological condition or multiple neurological conditions.

Table 2: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they have one neurological condition or multiple neurological conditions.

Changes made	Option chosen	Respondents	Percentage	Group
Skip prescription	Yes	16	12	Multiple conditions
	Thought about it	6	5	
	No	71	55	
	Not applicable	35	27	
Lower/stop care package	Yes	14	11	
	Thought about it	14	11	

Changes made	Option chosen	Respondents	Percentage	Group
Borrow more money	No	34	27	
	Not applicable	66	52	
	Yes	29	23	
	Thought about it	16	12	
	No	52	41	
Reduce travel (public transport)	Not applicable	31	24	
	Yes	30	23	
	Thought about it	6	5	
	No	38	30	
	Not applicable	54	42	
Skip meals	Yes	51	40	
	Thought about it	12	9	
	No	53	41	
	Not applicable	12	9	
	Yes	59	46	
Reduce travel (car)	Thought about it	4	3	
	No	26	20	
	Not applicable	39	30	
	Yes	76	59	
	Thought about it	11	9	
Reduce heating than usual	No	28	22	
	Not applicable	13	10	
	Yes	78	61	
	Thought about it	6	5	
	No	19	15	
Socialise less	Not applicable	25	20	
	Yes	1	1	
	Thought about it	3	3	
	No	97	84	
	Not applicable	15	13	
Skip prescription	Yes	4	3	One condition
	Thought about it			
	No			
	Not applicable			
	Yes			
Lower/stop care package	Yes			
	Thought about it			
	No			
	Not applicable			
	Yes			

Changes made	Option chosen	Respondents	Percentage	Group
	Thought about it	2	2	
	No	66	57	
	Not applicable	44	38	
Borrow more money	Yes	4	3	
	Thought about it	6	5	
	No	82	71	
	Not applicable	24	21	
Reduce travel (public transport)	Yes	20	17	
	Thought about it	4	3	
	No	49	42	
	Not applicable	43	37	
Skip meals	Yes	22	19	
	Thought about it	5	4	
	No	83	72	
	Not applicable	6	5	
Reduce travel (car)	Yes	35	30	
	Thought about it	6	5	
	No	55	47	
	Not applicable	20	17	
Reduce heating than usual	Yes	42	36	
	Thought about it	9	8	
	No	53	46	
	Not applicable	12	10	
Socialise less	Yes	52	45	
	Thought about it	13	11	
	No	42	36	
	Not applicable	9	8	

Change of behaviour due to cost-of-living crisis: Does this differ by people with co-occurring non-neurological conditions?

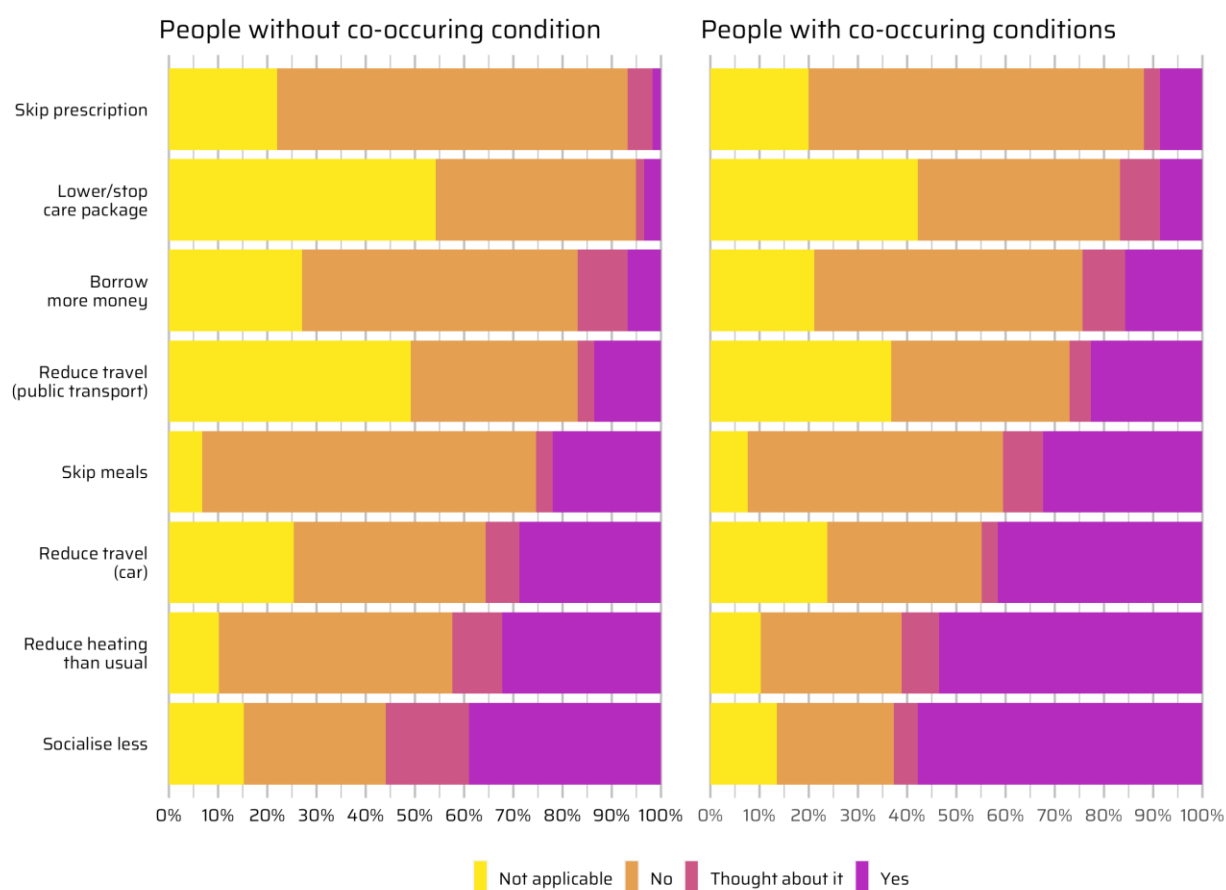


Fig 4: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they have co-occurring non-neurological conditions or not.

Table 3: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they have co-occurring non-neurological conditions or not.

Changes made	Option chosen	Respondents	Percentage	Group
Skip prescription	Yes	1	2	Individuals without co-occurring conditions
	Thought about it	3	5	
	No	42	71	
	Not applicable	13	22	
Lower/stop care package	Yes	2	3	Individuals with co-occurring conditions
	Thought about it	1	2	
	No	24	41	
	Not applicable	32	54	

Changes made	Option chosen	Respondents	Percentage	Group
Borrow more money	Yes	4	7	Individuals with co-occurring conditions
	Thought about it	6	10	
	No	33	56	
	Not applicable	16	27	
Reduce travel (public transport)	Yes	8	14	
	Thought about it	2	3	
	No	20	34	
	Not applicable	29	49	
Skip meals	Yes	13	22	
	Thought about it	2	3	
	No	40	68	
	Not applicable	4	7	
Reduce travel (car)	Yes	17	29	
	Thought about it	4	7	
	No	23	39	
	Not applicable	15	25	
Reduce heating than usual	Yes	19	32	
	Thought about it	6	10	
	No	28	47	
	Not applicable	6	10	
Socialise less	Yes	23	39	
	Thought about it	10	17	
	No	17	29	
	Not applicable	9	15	
Skip prescription	Yes	16	9	
	Thought about it	6	3	
	No	126	68	
	Not applicable	37	20	
Lower/stop care package	Yes	16	9	
	Thought about it	15	8	
	No	76	41	
	Not applicable	78	42	
Borrow more money	Yes	29	16	
	Thought about it	16	9	
	No	101	55	
	Not applicable	39	21	
Reduce travel (public transport)	Yes	42	23	
	Thought about it	8	4	
	No	67	36	

Changes made	Option chosen	Respondents	Percentage	Group
	Not applicable	68	37	
Skip meals	Yes	60	32	
	Thought about it	15	8	
	No	96	52	
	Not applicable	14	8	
Reduce travel (car)	Yes	77	42	
	Thought about it	6	3	
	No	58	31	
	Not applicable	44	24	
Reduce heating than usual	Yes	99	54	
	Thought about it	14	8	
	No	53	29	
	Not applicable	19	10	
Socialise less	Yes	107	58	
	Thought about it	9	5	
	No	44	24	
	Not applicable	25	14	

Change of behaviour due to cost-of-living crisis: Does this differ by age groups?

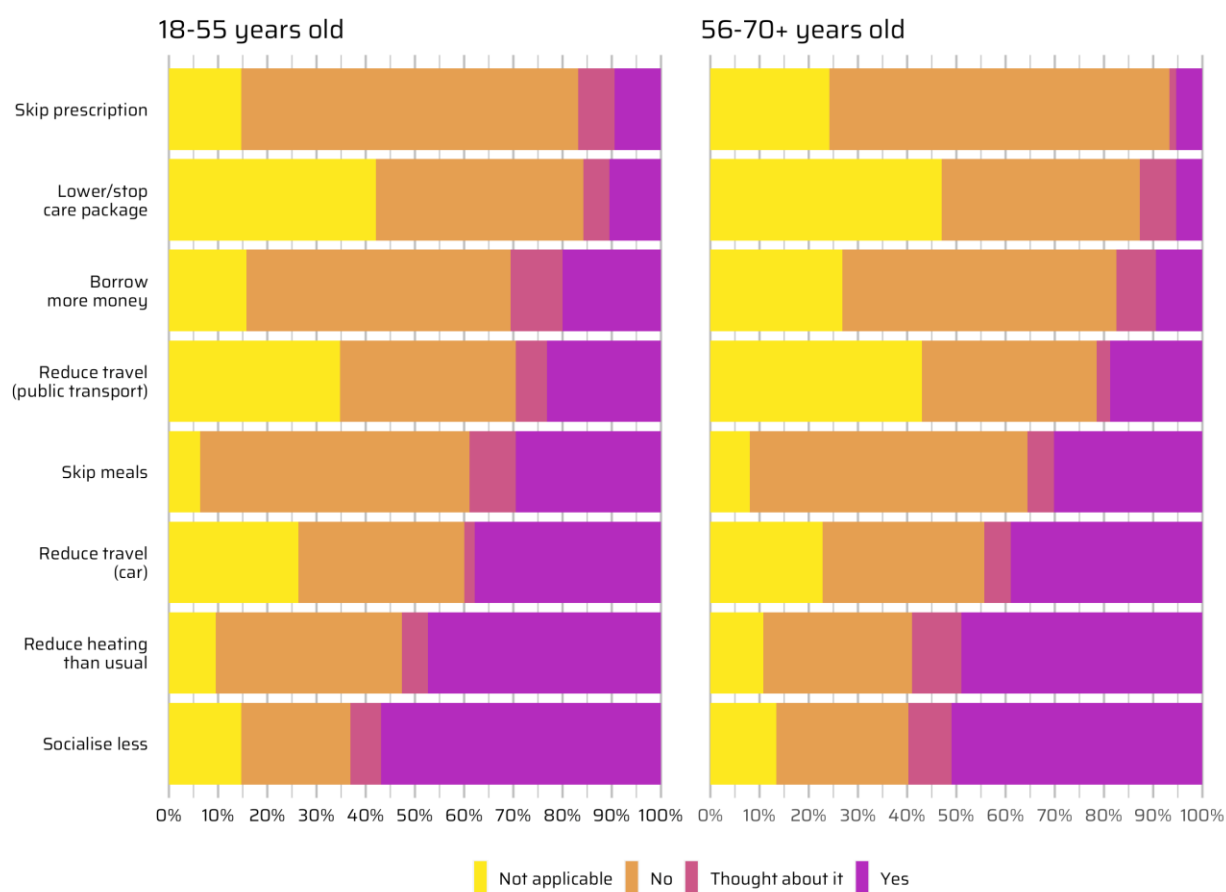


Fig 5: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on their age group.

Table 4: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on their age group.

Changes made	Option chosen	Respondents	Percentage	Age Group
Skip prescription	Yes	9	9	18-55 years old
	Thought about it	7	7	
	No	65	68	
	Not applicable	14	15	
Lower/stop care package	Yes	10	11	18-55 years old
	Thought about it	5	5	
	No			

Changes made	Option chosen	Respondents	Percentage	Age Group
	No	40	42	
	Not applicable	40	42	
	Yes	19	20	
	Thought about it	10	11	
Borrow more money	No	51	54	18-55 years old
	Not applicable	15	16	
	Yes	22	23	
	Thought about it	6	6	
Reduce travel (public transport)	No	34	36	
	Not applicable	33	35	
	Yes	28	29	
	Thought about it	9	9	
Skip meals	No	52	55	18-55 years old
	Not applicable	6	6	
	Yes	36	38	
	Thought about it	2	2	
Reduce travel (car)	No	32	34	18-55 years old
	Not applicable	25	26	
	Yes	45	47	
	Thought about it	5	5	
Reduce heating than usual	No	36	38	18-55 years old
	Not applicable	9	9	
	Yes	54	57	
	Thought about it	6	6	
Socialise less	No	21	22	18-55 years old
	Not applicable	14	15	
	Yes	8	5	
	Thought about it	2	1	
Skip prescription	No	103	69	56-70+ years old
	Not applicable	36	24	
	Yes	8	5	
	Thought about it			
Lower/stop care package	Yes	8	5	
	Thought about it			

Changes made	Option chosen	Respondents	Percentage	Age Group
	Thought about it	11	7	56-70+ years old
	No	60	40	
	Not applicable	70	47	
Borrow more money	Yes	14	9	56-70+ years old
	Thought about it	12	8	
	No	83	56	
	Not applicable	40	27	
Reduce travel (public transport)	Yes	28	19	56-70+ years old
	Thought about it	4	3	
	No	53	36	
	Not applicable	64	43	
Skip meals	Yes	45	30	56-70+ years old
	Thought about it	8	5	
	No	84	56	
	Not applicable	12	8	
Reduce travel (car)	Yes	58	39	56-70+ years old
	Thought about it	8	5	
	No	49	33	
	Not applicable	34	23	
Reduce heating than usual	Yes	73	49	56-70+ years old
	Thought about it	15	10	
	No	45	30	
	Not applicable	16	11	
Socialise less	Yes	76	51	56-70+ years old
	Thought about it	13	9	
	No	40	27	
	Not applicable	20	13	

Change of behaviour due to cost-of-living crisis: Does this differ by gender?

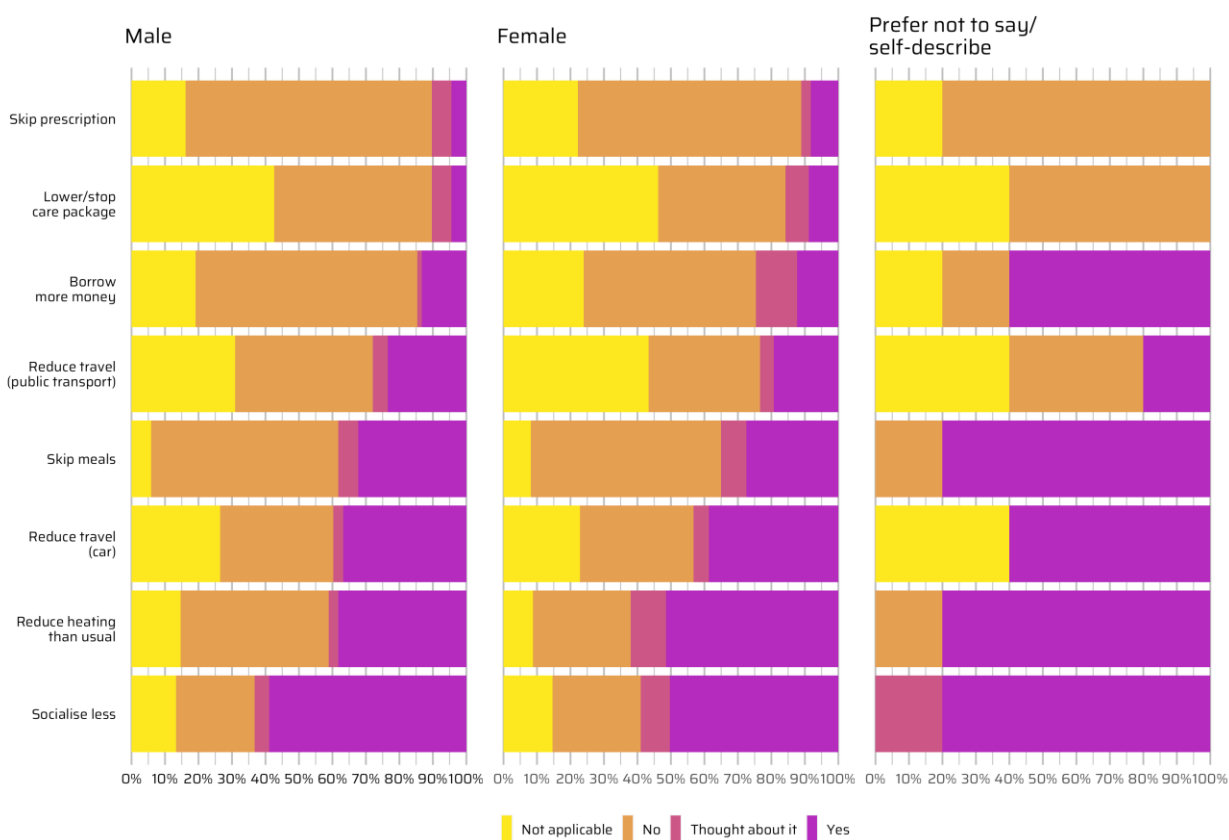


Fig 6: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on their gender.

Table 5: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on their gender.

Changes made	Option chosen	Respondents	Percentage	Gender
Skip prescription	Yes	3	4	Male
	Thought about it	4	6	
	No	50	74	
	Not applicable	11	16	
Lower/stop care package	Yes	3	4	Male
	Thought about it	4	6	
	No	32	47	
	Not applicable	29	43	
Borrow more money	Yes	9	13	Male
	Thought about it	1	1	

Changes made	Option chosen	Respondents	Percentage	Gender
	No	45	66	
	Not applicable	13	19	
Reduce travel (public transport)	Yes	16	24	Male
	Thought about it	3	4	
	No	28	41	
	Not applicable	21	31	
Skip meals	Yes	22	32	Male
	Thought about it	4	6	
	No	38	56	
	Not applicable	4	6	
Reduce travel (car)	Yes	25	37	Male
	Thought about it	2	3	
	No	23	34	
	Not applicable	18	26	
Reduce heating than usual	Yes	26	38	Male
	Thought about it	2	3	
	No	30	44	
	Not applicable	10	15	
Socialise less	Yes	40	59	Male
	Thought about it	3	4	
	No	16	24	
	Not applicable	9	13	
Skip prescription	Yes	14	8	Female
	Thought about it	5	3	
	No	114	67	
	Not applicable	38	22	
Lower/stop care package	Yes	15	9	Female
	Thought about it	12	7	
	No	65	38	
	Not applicable	79	46	
Borrow more money	Yes	21	12	Female
	Thought about it	21	12	
	No	88	51	
	Not applicable	41	24	
Reduce travel (public transport)	Yes	33	19	Female
	Thought about it	7	4	
	No	57	33	
	Not applicable	74	43	
Skip meals	Yes	47	27	Female

Changes made	Option chosen	Respondents	Percentage	Gender
	Thought about it	13	8	
	No	97	57	
	Not applicable	14	8	
Reduce travel (car)	Yes	66	39	Female
	Thought about it	8	5	
	No	58	34	
	Not applicable	39	23	
Reduce heating than usual	Yes	88	51	Female
	Thought about it	18	11	
	No	50	29	
	Not applicable	15	9	
Socialise less	Yes	86	50	Female
	Thought about it	15	9	
	No	45	26	
	Not applicable	25	15	
Skip prescription	Yes	0	0	Prefer not to say/self-describe
	Thought about it	0	0	
	No	4	80	
	Not applicable	1	20	
Lower/stop care package	Yes	0	0	Prefer not to say/self-describe
	Thought about it	0	0	
	No	3	60	
	Not applicable	2	40	
Borrow more money	Yes	3	60	Prefer not to say/self-describe
	Thought about it	0	0	
	No	1	20	
	Not applicable	1	20	
Reduce travel (public transport)	Yes	1	20	Prefer not to say/self-describe
	Thought about it	0	0	
	No	2	40	
	Not applicable	2	40	
Skip meals	Yes	4	80	Prefer not to say/self-describe
	Thought about it	0	0	
	No	1	20	
	Not applicable	0	0	
Reduce travel (car)	Yes	3	60	Prefer not to say/self-describe
	Thought about it	0	0	
	No	0	0	
	Not applicable	2	40	

Changes made	Option chosen	Respondents	Percentage	Gender
Reduce heating than usual	Yes	4	80	Prefer not to say/self-describe
	Thought about it	0	0	
	No	1	20	
	Not applicable	0	0	
Socialise less	Yes	4	80	Prefer not to say/self-describe
	Thought about it	1	20	
	No	0	0	
	Not applicable	0	0	

Change of behaviour due to cost-of-living crisis: Does this differ by employment status?

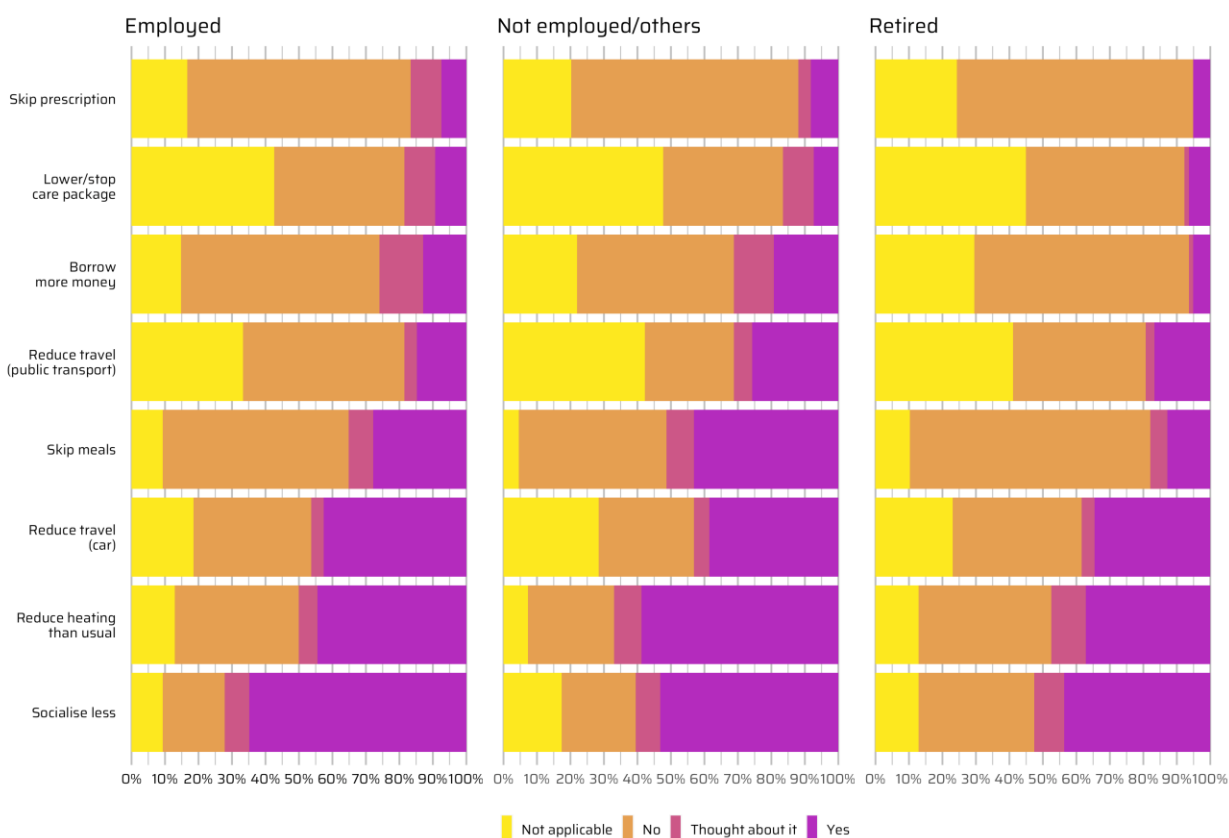


Fig 7: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on their employment status.

Table 6: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on their employment status.

Changes made	Option chosen	Respondents	Percentage	Employment Status
Skip prescription	Yes	4	7	Employed
	Thought about it	5	9	
	No	36	67	
	Not applicable	9	17	
Lower/stop care package	Yes	5	9	Employed
	Thought about it	5	9	
	No	21	39	
	Not applicable	23	43	
Borrow more money	Yes	7	13	Employed
	Thought about it	7	13	
	No	32	59	
	Not applicable	8	15	
Reduce travel (public transport)	Yes	8	15	Employed
	Thought about it	2	4	
	No	26	48	
	Not applicable	18	33	
Skip meals	Yes	15	28	Employed
	Thought about it	4	7	
	No	30	56	
	Not applicable	5	9	
Reduce travel (car)	Yes	23	43	Employed
	Thought about it	2	4	
	No	19	35	
	Not applicable	10	19	
Reduce heating than usual	Yes	24	44	Employed
	Thought about it	3	6	
	No	20	37	
	Not applicable	7	13	
Socialise less	Yes	35	65	Employed
	Thought about it	4	7	
	No	10	19	
	Not applicable	5	9	
Skip prescription	Yes	9	8	Not employed/others
	Thought about it	4	4	
	No	74	68	
	Not applicable	22	20	
Lower/stop care package	Yes	8	7	Not employed/others
	Thought about it	10	9	

Changes made	Option chosen	Respondents	Percentage	Employment Status
	No	39	36	
	Not applicable	52	48	
Borrow more money	Yes	21	19	Not employed/others
	Thought about it	13	12	
	No	51	47	
	Not applicable	24	22	
Reduce travel (public transport)	Yes	28	26	Not employed/others
	Thought about it	6	6	
	No	29	27	
	Not applicable	46	42	
Skip meals	Yes	47	43	Not employed/others
	Thought about it	9	8	
	No	48	44	
	Not applicable	5	5	
Reduce travel (car)	Yes	42	39	Not employed/others
	Thought about it	5	5	
	No	31	28	
	Not applicable	31	28	
Reduce heating than usual	Yes	64	59	Not employed/others
	Thought about it	9	8	
	No	28	26	
	Not applicable	8	7	
Socialise less	Yes	58	53	Not employed/others
	Thought about it	8	7	
	No	24	22	
	Not applicable	19	17	
Skip prescription	Yes	4	5	Retired
	Thought about it	0	0	
	No	55	71	
	Not applicable	19	24	
Lower/stop care package	Yes	5	6	Retired
	Thought about it	1	1	
	No	37	47	
	Not applicable	35	45	
Borrow more money	Yes	4	5	Retired
	Thought about it	1	1	
	No	50	64	
	Not applicable	23	29	

Changes made	Option chosen	Respondents	Percentage	Employment Status
Reduce travel (public transport)	Yes	13	17	Retired
	Thought about it	2	3	
	No	31	40	
	Not applicable	32	41	
Skip meals	Yes	10	13	Retired
	Thought about it	4	5	
	No	56	72	
	Not applicable	8	10	
Reduce travel (car)	Yes	27	35	Retired
	Thought about it	3	4	
	No	30	38	
	Not applicable	18	23	
Reduce heating than usual	Yes	29	37	Retired
	Thought about it	8	10	
	No	31	40	
	Not applicable	10	13	
Socialise less	Yes	34	44	Retired
	Thought about it	7	9	
	No	27	35	
	Not applicable	10	13	

Change of behaviour due to cost-of-living crisis: Does this differ by number of dependents?

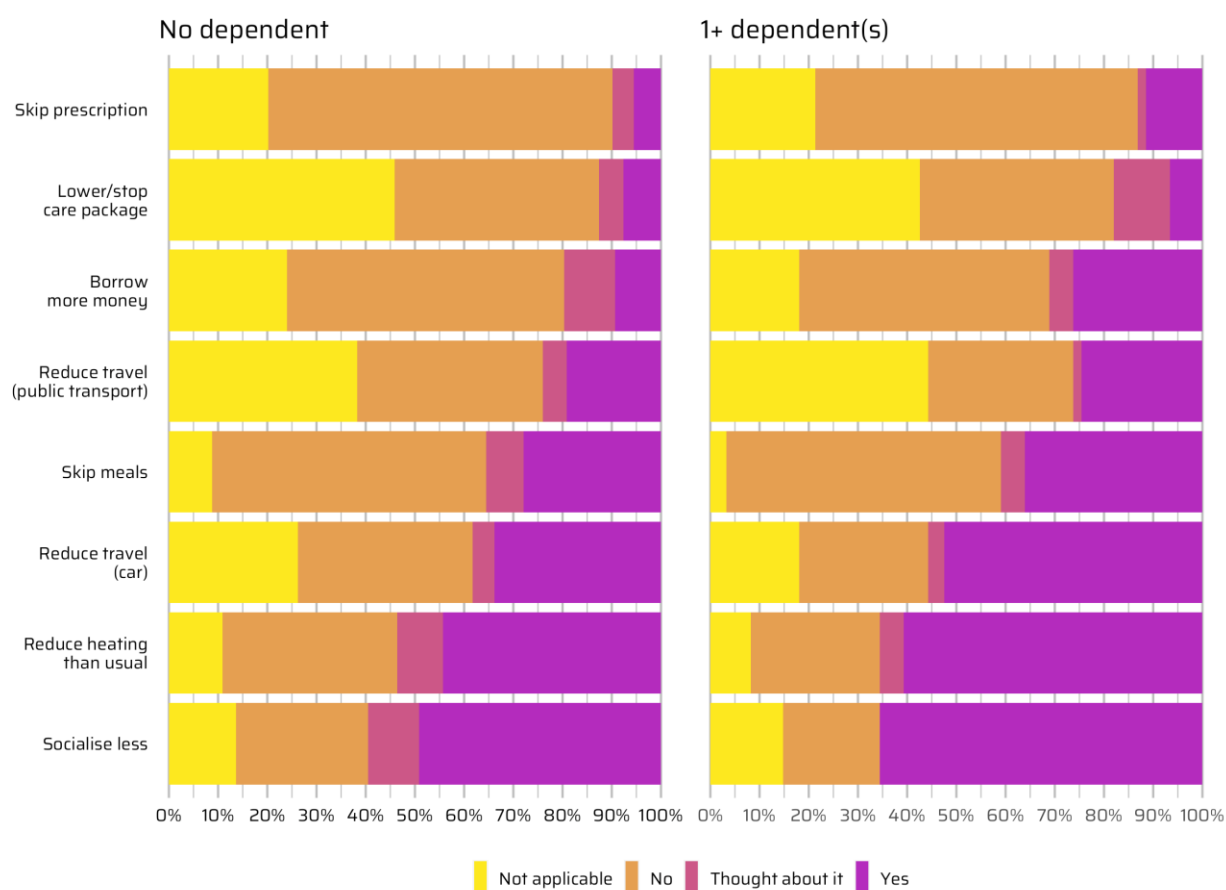


Fig 8: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they have dependents or not.

Table 7: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they have dependents or not.

Changes made	Option chosen	Respondents	Percentage	Number of Dependents
Skip prescription	Yes	10	5	No dependent
	Thought about it	8	4	
	No	128	70	
	Not applicable	37	20	
Lower/stop care package	Yes	14	8	No dependent
	Thought about it	9	5	
	No	76	42	
	Not applicable	84	46	

Changes made	Option chosen	Respondents	Percentage	Number of Dependents
Borrow more money	Yes	17	9	No dependent
	Thought about it	19	10	
	No	103	56	
	Not applicable	44	24	
Reduce travel (public transport)	Yes	35	19	No dependent
	Thought about it	9	5	
	No	69	38	
	Not applicable	70	38	
Skip meals	Yes	51	28	No dependent
	Thought about it	14	8	
	No	102	56	
	Not applicable	16	9	
Reduce travel (car)	Yes	62	34	No dependent
	Thought about it	8	4	
	No	65	36	
	Not applicable	48	26	
Reduce heating than usual	Yes	81	44	No dependent
	Thought about it	17	9	
	No	65	36	
	Not applicable	20	11	
Socialise less	Yes	90	49	No dependent
	Thought about it	19	10	
	No	49	27	
	Not applicable	25	14	
Skip prescription	Yes	7	11	1+ dependent(s)
	Thought about it	1	2	
	No	40	66	
	Not applicable	13	21	
Lower/stop care package	Yes	4	7	1+ dependent(s)
	Thought about it	7	11	
	No	24	39	
	Not applicable	26	43	
Borrow more money	Yes	16	26	1+ dependent(s)
	Thought about it	3	5	
	No	31	51	
	Not applicable	11	18	
Reduce travel (public transport)	Yes	15	25	1+ dependent(s)
	Thought about it	1	2	
	No	18	30	

Changes made	Option chosen	Respondents	Percentage	Number of Dependents
	Not applicable	27	44	
Skip meals	Yes	22	36	1+ dependent(s)
	Thought about it	3	5	
	No	34	56	
	Not applicable	2	3	
Reduce travel (car)	Yes	32	52	1+ dependent(s)
	Thought about it	2	3	
	No	16	26	
	Not applicable	11	18	
Reduce heating than usual	Yes	37	61	1+ dependent(s)
	Thought about it	3	5	
	No	16	26	
	Not applicable	5	8	
Socialise less	Yes	40	66	1+ dependent(s)
	Thought about it	0	0	
	No	12	20	
	Not applicable	9	15	

Change of behaviour due to cost-of-living crisis: Does this differ by extent of mental health needs met?

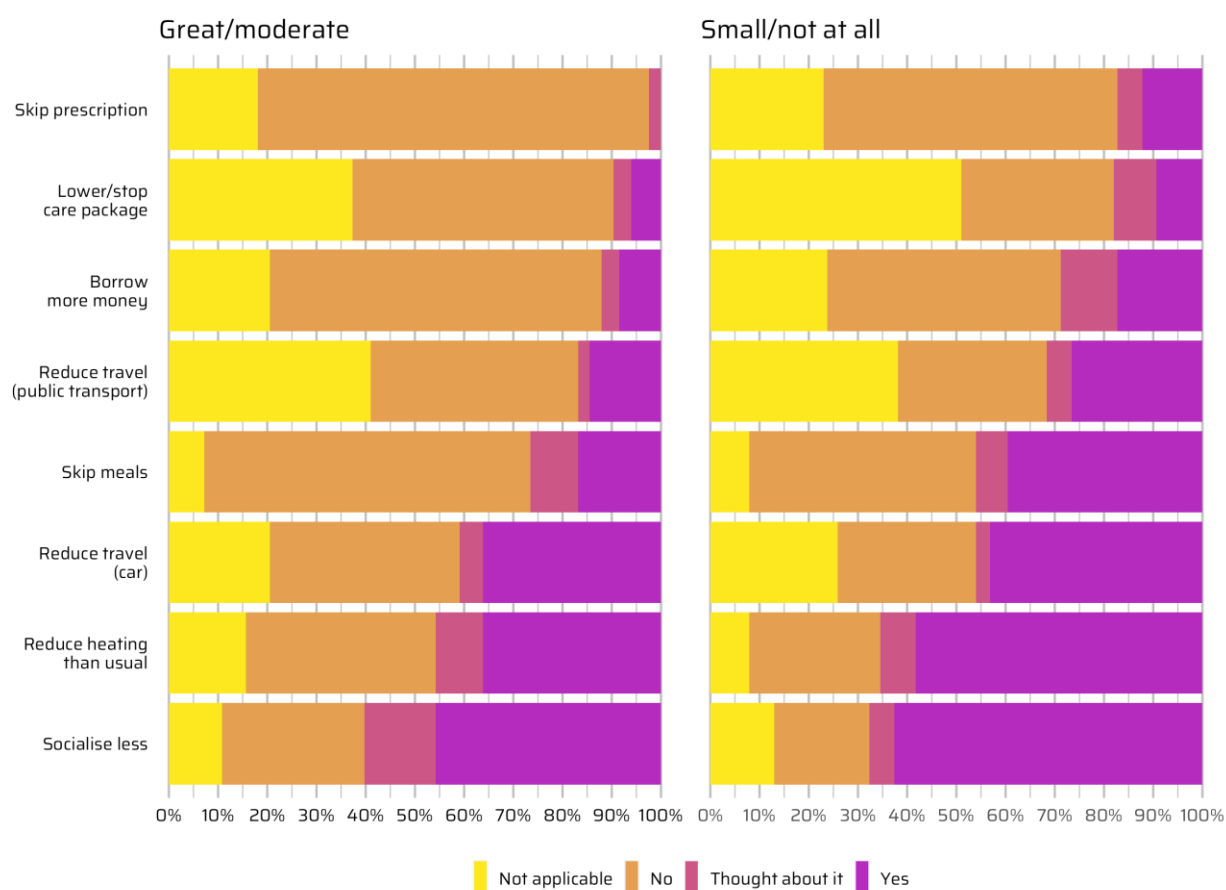


Fig 9: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on mental health need.

Table 8: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on mental health need.

Changes made	Option chosen	Respondents	Percentage	Mental Health Need
Skip prescription	Yes	0	0	Moderate/great
	Thought about it	2	2	
	No	66	80	
	Not applicable	15	18	
Lower/stop care package	Yes	5	6	Moderate/great
	Thought about it	3	4	
	No	44	53	
	Not applicable	31	37	

Changes made	Option chosen	Respondents	Percentage	Mental Health Need
Borrow more money	Yes	7	8	Moderate/great
	Thought about it	3	4	
	No	56	67	
	Not applicable	17	20	
Reduce travel (public transport)	Yes	12	14	Moderate/great
	Thought about it	2	2	
	No	35	42	
	Not applicable	34	41	
Skip meals	Yes	14	17	Moderate/great
	Thought about it	8	10	
	No	55	66	
	Not applicable	6	7	
Reduce travel (car)	Yes	30	36	Moderate/great
	Thought about it	4	5	
	No	32	39	
	Not applicable	17	20	
Reduce heating than usual	Yes	30	36	Moderate/great
	Thought about it	8	10	
	No	32	39	
	Not applicable	13	16	
Socialise less	Yes	38	46	Moderate/great
	Thought about it	12	14	
	No	24	29	
	Not applicable	9	11	
Skip prescription	Yes	17	12	Not at all/small
	Thought about it	7	5	
	No	83	60	
	Not applicable	32	23	
Lower/stop care package	Yes	13	9	Not at all/small
	Thought about it	12	9	
	No	43	31	
	Not applicable	71	51	
Borrow more money	Yes	24	17	Not at all/small
	Thought about it	16	12	
	No	66	47	
	Not applicable	33	24	
Reduce travel (public transport)	Yes	37	27	Not at all/small
	Thought about it	7	5	
	No	42	30	

Changes made	Option chosen	Respondents	Percentage	Mental Health Need
	Not applicable	53	38	
Skip meals	Yes	55	40	Not at all/small
	Thought about it	9	6	
	No	64	46	
	Not applicable	11	8	
Reduce travel (car)	Yes	60	43	Not at all/small
	Thought about it	4	3	
	No	39	28	
	Not applicable	36	26	
Reduce heating than usual	Yes	81	58	Not at all/small
	Thought about it	10	7	
	No	37	27	
	Not applicable	11	8	
Socialise less	Yes	87	63	Not at all/small
	Thought about it	7	5	
	No	27	19	
	Not applicable	18	13	

Change of behaviour due to cost-of-living crisis: Does this differ by feeling of anxiety?

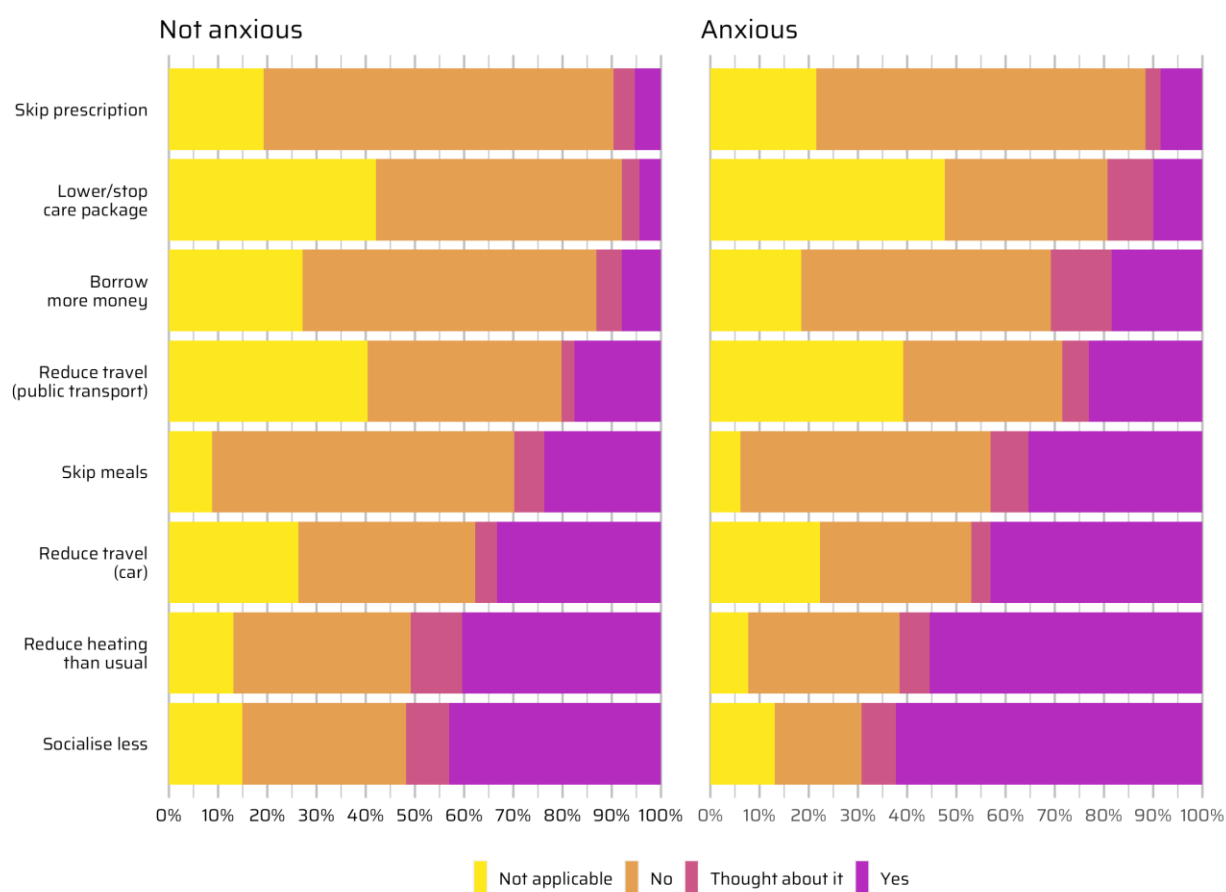


Fig 10: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they are reporting feelings of anxiety.

Table 9: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they are reporting feelings of anxiety.

Changes made	Option chosen	Respondents	Percentage	Anxiety
Skip prescription	Yes	6	5	Not anxious
	Thought about it	5	4	
	No	81	71	
	Not applicable	22	19	
Lower/stop care package	Yes	5	4	Not anxious
	Thought about it	4	4	
	No	57	50	
	Not applicable	48	42	

Changes made	Option chosen	Respondents	Percentage	Anxiety
Borrow more money	Yes	9	8	Not anxious
	Thought about it	6	5	
	No	68	60	
	Not applicable	31	27	
Reduce travel (public transport)	Yes	20	18	Not anxious
	Thought about it	3	3	
	No	45	39	
	Not applicable	46	40	
Skip meals	Yes	27	24	Not anxious
	Thought about it	7	6	
	No	70	61	
	Not applicable	10	9	
Reduce travel (car)	Yes	38	33	Not anxious
	Thought about it	5	4	
	No	41	36	
	Not applicable	30	26	
Reduce heating than usual	Yes	46	40	Not anxious
	Thought about it	12	11	
	No	41	36	
	Not applicable	15	13	
Socialise less	Yes	49	43	Not anxious
	Thought about it	10	9	
	No	38	33	
	Not applicable	17	15	
Skip prescription	Yes	11	8	Anxious
	Thought about it	4	3	
	No	87	67	
	Not applicable	28	22	
Lower/stop care package	Yes	13	10	Anxious
	Thought about it	12	9	
	No	43	33	
	Not applicable	62	48	
Borrow more money	Yes	24	18	Anxious
	Thought about it	16	12	
	No	66	51	
	Not applicable	24	18	
Reduce travel (public transport)	Yes	30	23	Anxious
	Thought about it	7	5	
	No	42	32	

Changes made	Option chosen	Respondents	Percentage	Anxiety
	Not applicable	51	39	
Skip meals	Yes	46	35	Anxious
	Thought about it	10	8	
	No	66	51	
	Not applicable	8	6	
Reduce travel (car)	Yes	56	43	Anxious
	Thought about it	5	4	
	No	40	31	
	Not applicable	29	22	
Reduce heating than usual	Yes	72	55	Anxious
	Thought about it	8	6	
	No	40	31	
	Not applicable	10	8	
Socialise less	Yes	81	62	Anxious
	Thought about it	9	7	
	No	23	18	
	Not applicable	17	13	

Change of behaviour due to cost-of-living crisis: Does this differ by feeling of hopelessness?

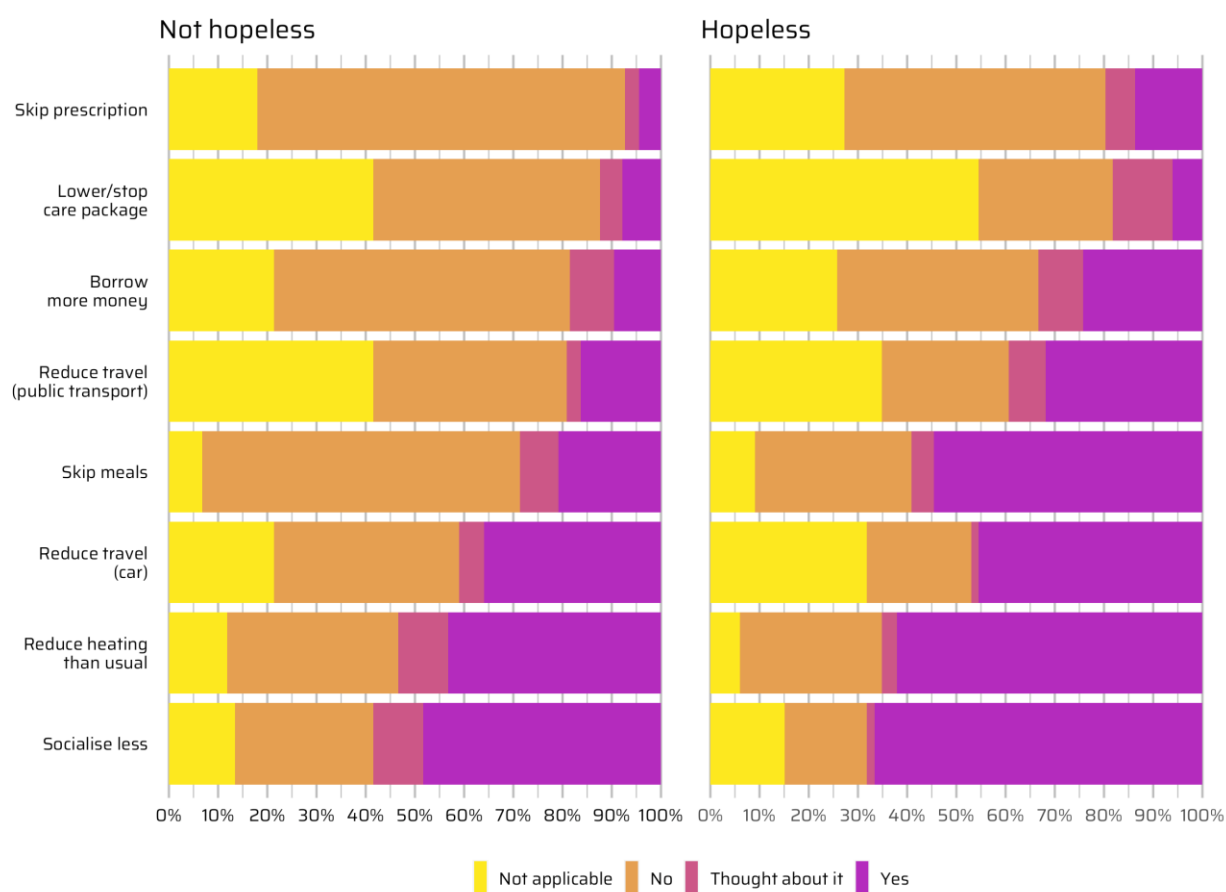


Fig 11: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they are reporting feelings of hopelessness.

Table 10: How respondents' behaviour has changed due to the cost-of-living crisis vary dependent on if they are reporting feelings of hopelessness.

Changes made	Option chosen	Respondents	Percentage	Hopelessness
Skip prescription	Yes	8	4	Not hopeless
	Thought about it	5	3	
	No	133	75	
	Not applicable	32	18	
Lower/stop care package	Yes	14	8	Not hopeless
	Thought about it	8	4	
	No	82	46	
	Not applicable	74	42	

Changes made	Option chosen	Respondents	Percentage	Hopelessness
Borrow more money	Yes	17	10	Not hopeless
	Thought about it	16	9	
	No	107	60	
	Not applicable	38	21	
Reduce travel (public transport)	Yes	29	16	Not hopeless
	Thought about it	5	3	
	No	70	39	
	Not applicable	74	42	
Skip meals	Yes	37	21	Not hopeless
	Thought about it	14	8	
	No	115	65	
	Not applicable	12	7	
Reduce travel (car)	Yes	64	36	Not hopeless
	Thought about it	9	5	
	No	67	38	
	Not applicable	38	21	
Reduce heating than usual	Yes	77	43	Not hopeless
	Thought about it	18	10	
	No	62	35	
	Not applicable	21	12	
Socialise less	Yes	86	48	Not hopeless
	Thought about it	18	10	
	No	50	28	
	Not applicable	24	13	
Skip prescription	Yes	9	14	Hopeless
	Thought about it	4	6	
	No	35	53	
	Not applicable	18	27	
Lower/stop care package	Yes	4	6	Hopeless
	Thought about it	8	12	
	No	18	27	
	Not applicable	36	55	
Borrow more money	Yes	16	24	Hopeless
	Thought about it	6	9	
	No	27	41	
	Not applicable	17	26	
Reduce travel (public transport)	Yes	21	32	Hopeless
	Thought about it	5	8	
	No	17	26	

Changes made	Option chosen	Respondents	Percentage	Hopelessness
	Not applicable	23	35	
Skip meals	Yes	36	55	Hopeless
	Thought about it	3	5	
	No	21	32	
	Not applicable	6	9	
Reduce travel (car)	Yes	30	45	Hopeless
	Thought about it	1	2	
	No	14	21	
	Not applicable	21	32	
Reduce heating than usual	Yes	41	62	Hopeless
	Thought about it	2	3	
	No	19	29	
	Not applicable	4	6	
Socialise less	Yes	44	67	Hopeless
	Thought about it	1	2	
	No	11	17	
	Not applicable	10	15	

Coping with cost-of-living crisis

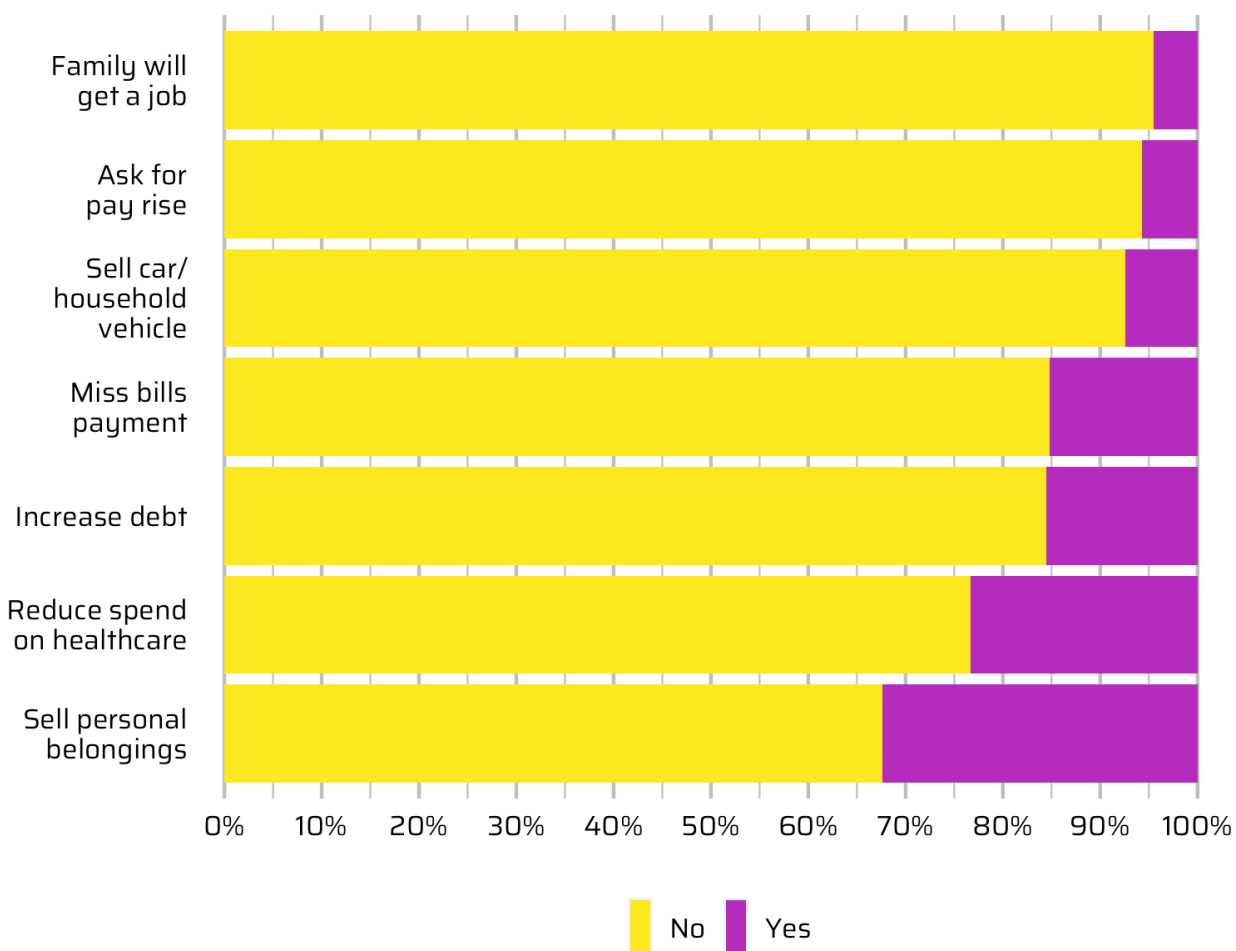


Fig 12: How respondents are coping with the cost-of-living crisis.

Table 11: How respondents are coping with the cost-of-living crisis.

Ways of coping	Yes/No	Respondents	Percentage
Family will get a job	Yes	11	5
	No	233	95
Ask for pay rise	Yes	14	6
	No	230	94
Sell car/ household vehicle	Yes	18	7
	No	226	93
Miss bills payment	Yes	37	15
	No	207	85
Increase debt	Yes	38	16
	No	206	84

Ways of coping	Yes/No	Respondents	Percentage
Reduce spend on healthcare	Yes	57	23
	No	187	77
Sell personal belongings	Yes	79	32
	No	165	68

Coping with cost-of-living crisis: Does it differ among people with/without multiple neurological conditions?

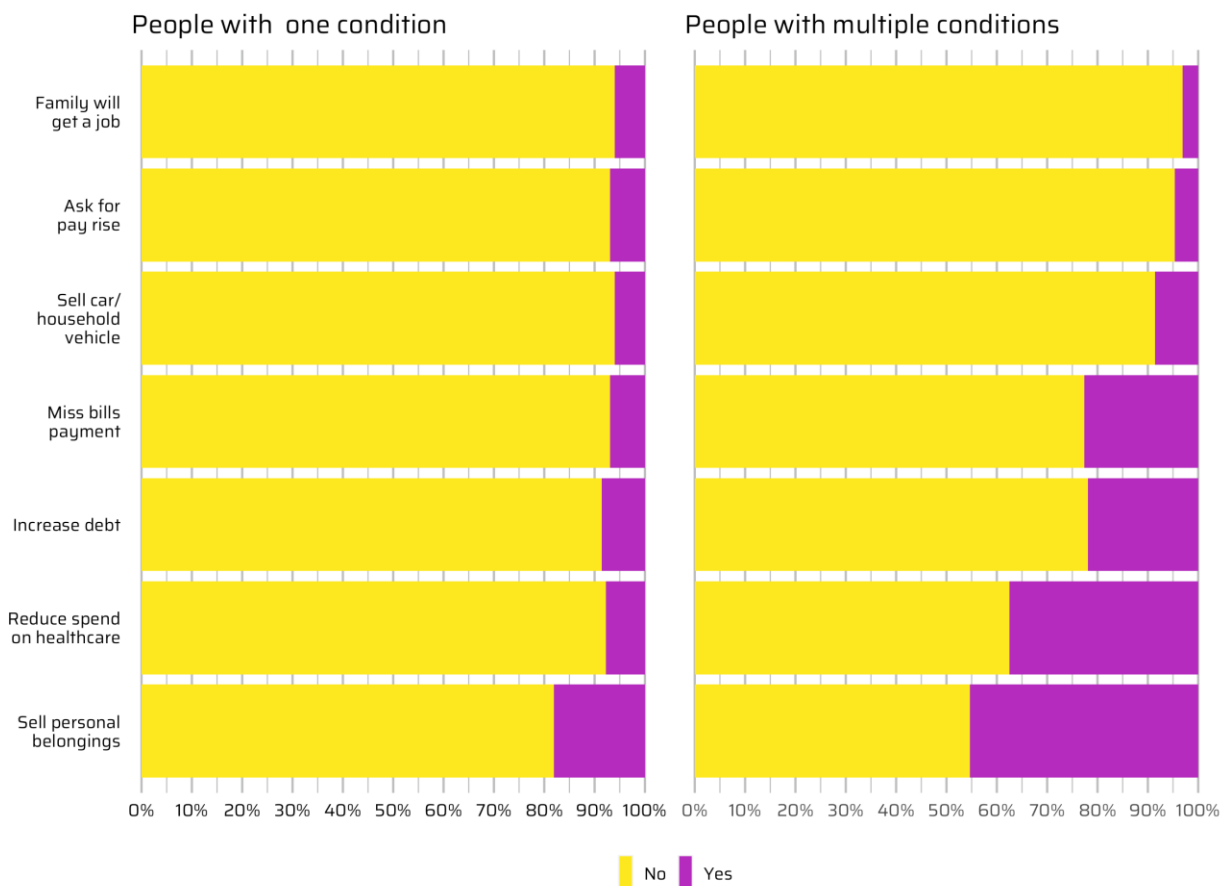


Fig 13: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they have one or multiple neurological conditions.

Table 12: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they have one or multiple neurological conditions.

Ways of coping	Yes/No	Respondents	Percentage	Number of Conditions
Family will get a job	Yes	4	3	Multiple conditions
	No	124	97	

Ways of coping	Yes/No	Respondents	Percentage	Number of Conditions
Ask for pay rise	Yes	6	5	One Condition
	No	122	95	
Sell car/ household vehicle	Yes	11	9	
	No	117	91	
Miss bills payment	Yes	29	23	
	No	99	77	
Increase debt	Yes	28	22	
	No	100	78	
Reduce spend on healthcare	Yes	48	38	
	No	80	62	
Sell personal belongings	Yes	58	45	
	No	70	55	
Family will get a job	Yes	7	6	
	No	109	94	
Ask for pay rise	Yes	8	7	
	No	108	93	
Sell car/ household vehicle	Yes	7	6	
	No	109	94	
Miss bills payment	Yes	8	7	
	No	108	93	
Increase debt	Yes	10	9	
	No	106	91	
Reduce spend on healthcare	Yes	9	8	
	No	107	92	
Sell personal belongings	Yes	21	18	
	No	95	82	

Coping with cost-of-living crisis: Does this differ by people with co-occurring non-neurological conditions?

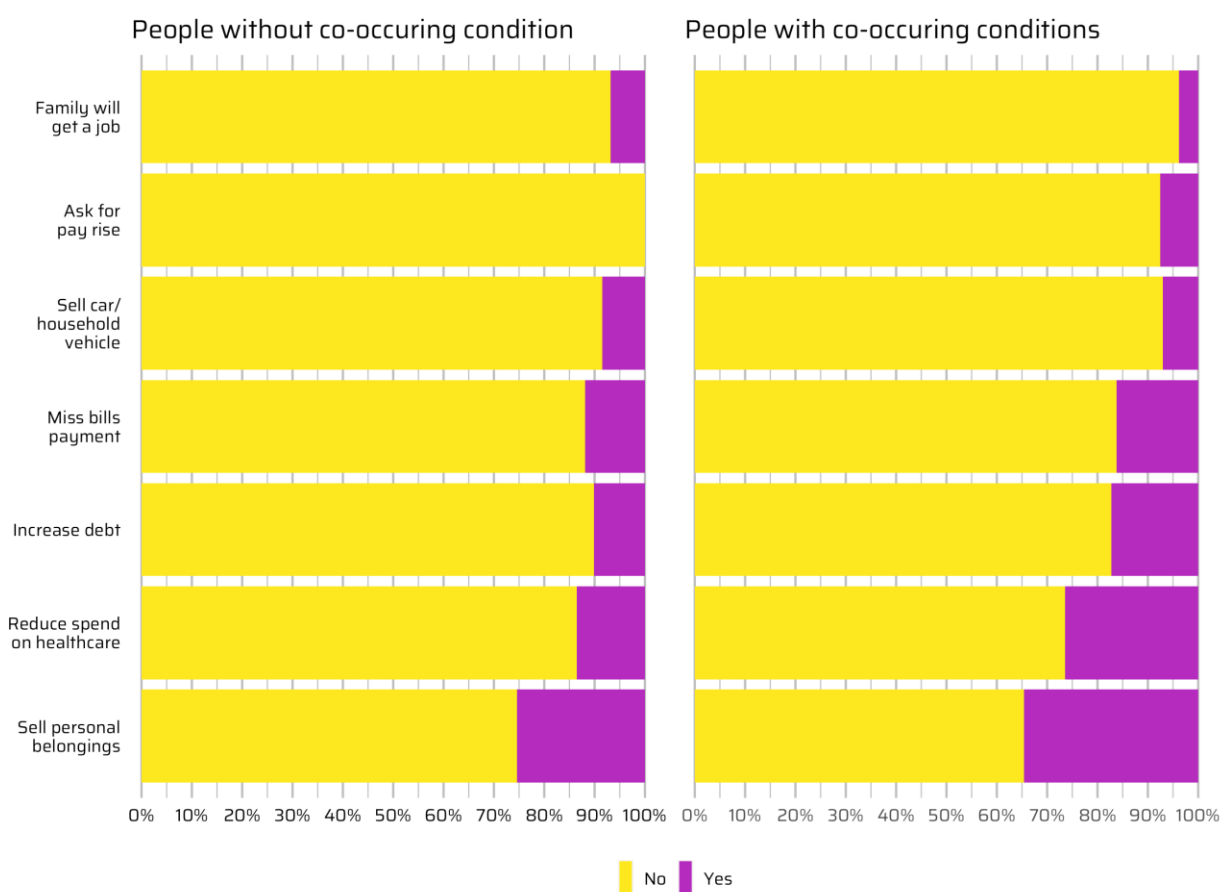


Figure 14: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they have a co-occurring non-neurological condition or not.

Table 13: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they have a co-occurring non-neurological condition or not.

Ways of coping	Yes/No	Respondents	Percentage	Co-occurring Conditions
Family will get a job	Yes	4	7	Individuals without co-occurring conditions
	No	55	93	
Ask for pay rise	Yes	0	0	
	No	59	100	
Sell car/ household vehicle	Yes	5	8	
	No	54	92	
Miss bills payment	Yes	7	12	
	No	52	88	

Ways of coping	Yes/No	Respondents	Percentage	Co-occurring Conditions
Increase debt	Yes	6	10	Individuals with co-occurring conditions
	No	53	90	
Reduce spend on healthcare	Yes	8	14	
	No	51	86	
Sell personal belongings	Yes	15	25	
	No	44	75	
Family will get a job	Yes	7	4	
	No	178	96	
Ask for pay rise	Yes	14	8	
	No	171	92	
Sell car/ household vehicle	Yes	13	7	
	No	172	93	
Miss bills payment	Yes	30	16	
	No	155	84	
Increase debt	Yes	32	17	
	No	153	83	
Reduce spend on healthcare	Yes	49	26	
	No	136	74	
Sell personal belongings	Yes	64	35	
	No	121	65	

Coping with cost-of-living crisis: Does this differ by age groups?

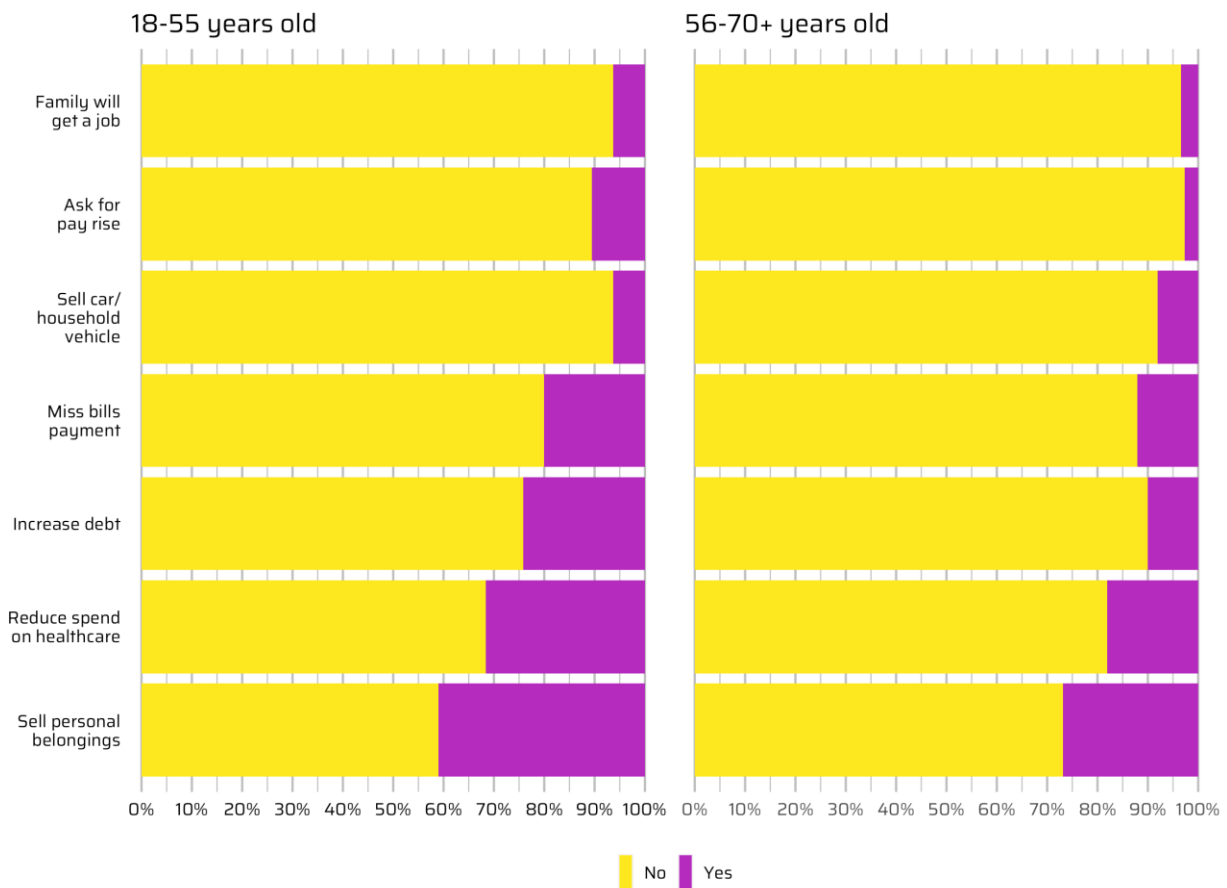


Figure 15: How respondents are coping with the cost-of-living crisis and how they vary dependent on age group.

Table 14: How respondents are coping with the cost-of-living crisis and how they vary dependent on age group.

Ways of coping	Yes/No	Respondents	Percentage	Age Group
Family will get a job	Yes	6	6	18-55 years old
	No	89	94	
Ask for pay rise	Yes	10	11	
	No	85	89	
Sell car/ household vehicle	Yes	6	6	
	No	89	94	
Miss bills payment	Yes	19	20	
	No	76	80	
Increase debt	Yes	23	24	

Ways of coping	Yes/No	Respondents	Percentage	Age Group
	No	72	76	56-70+ years old
Reduce spend on healthcare	Yes	30	32	
	No	65	68	
Sell personal belongings	Yes	39	41	
	No	56	59	
Family will get a job	Yes	5	3	
	No	144	97	
Ask for pay rise	Yes	4	3	
	No	145	97	
Sell car/ household vehicle	Yes	12	8	
	No	137	92	
Miss bills payment	Yes	18	12	
	No	131	88	
Increase debt	Yes	15	10	
	No	134	90	
Reduce spend on healthcare	Yes	27	18	
	No	122	82	
Sell personal belongings	Yes	40	27	
	No	109	73	

Coping with cost-of-living crisis: Does this differ by gender?

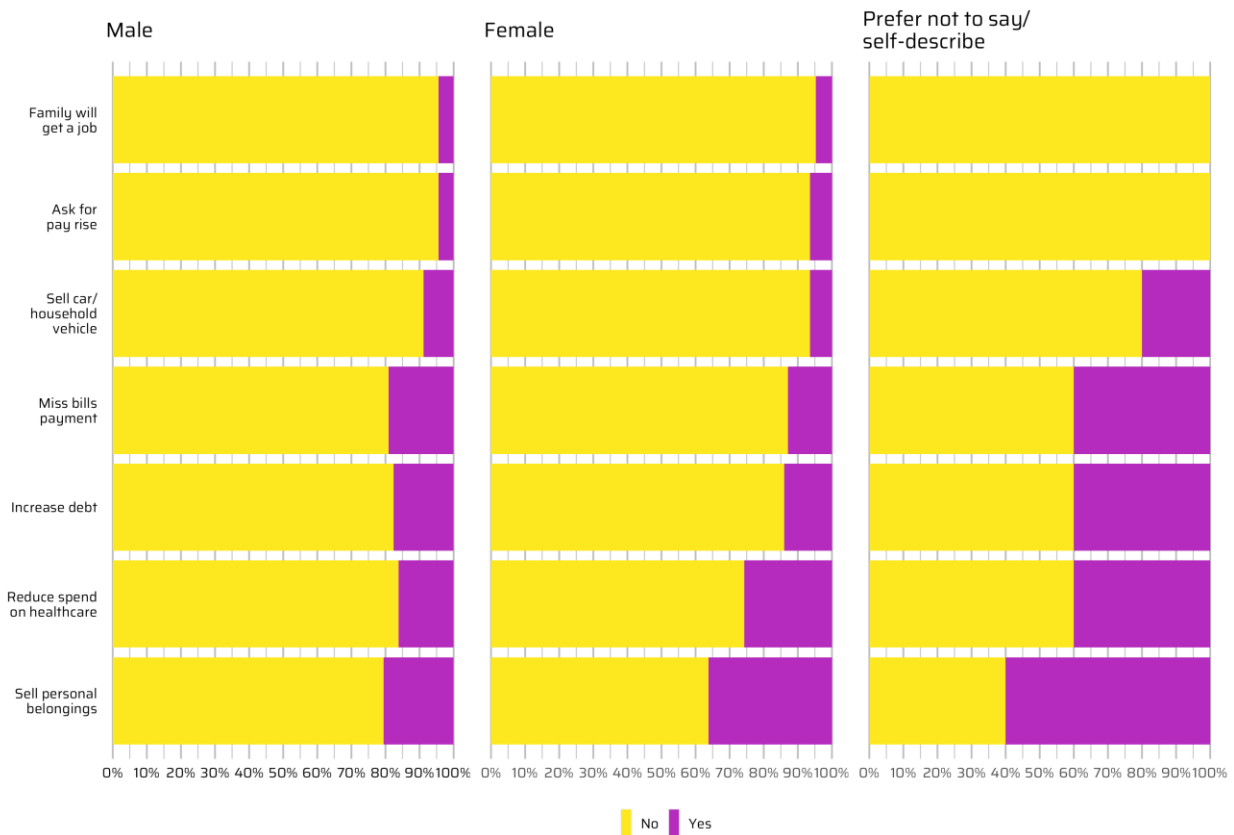


Figure 16: How respondents are coping with the cost-of-living crisis and how they vary dependent on gender.

Table 15: How respondents are coping with the cost-of-living crisis and how they vary dependent on gender.

Ways of coping	Yes/No	Respondents	Percentage	Gender
Family will get a job	Yes	3	4	Male
	No	65	96	
Ask for pay rise	Yes	3	4	
	No	65	96	
Sell car/ household vehicle	Yes	6	9	
	No	62	91	
Miss bills payment	Yes	13	19	
	No	55	81	
Increase debt	Yes	12	18	
	No	56	82	
	Yes	11	16	

Ways of coping	Yes/No	Respondents	Percentage	Gender
Reduce spend on healthcare	No	57	84	
Sell personal belongings	Yes	14	21	
	No	54	79	
Family will get a job	Yes	8	5	
	No	163	95	Female
Ask for pay rise	Yes	11	6	
	No	160	94	
Sell car/ household vehicle	Yes	11	6	
	No	160	94	
Miss bills payment	Yes	22	13	
	No	149	87	
Increase debt	Yes	24	14	
	No	147	86	
Reduce spend on healthcare	Yes	44	26	
	No	127	74	
Sell personal belongings	Yes	62	36	
	No	109	64	
Family will get a job	Yes	0	0	
	No	5	100	Prefer not to say/self-describe
Ask for pay rise	Yes	0	0	
	No	5	100	
Sell car/ household vehicle	Yes	1	20	
	No	4	80	
Miss bills payment	Yes	2	40	
	No	3	60	
Increase debt	Yes	2	40	
	No	3	60	
Reduce spend on healthcare	Yes	2	40	
	No	3	60	
Sell personal belongings	Yes	3	60	
	No	2	40	

Coping with cost-of-living crisis: Does this differ by employment status?

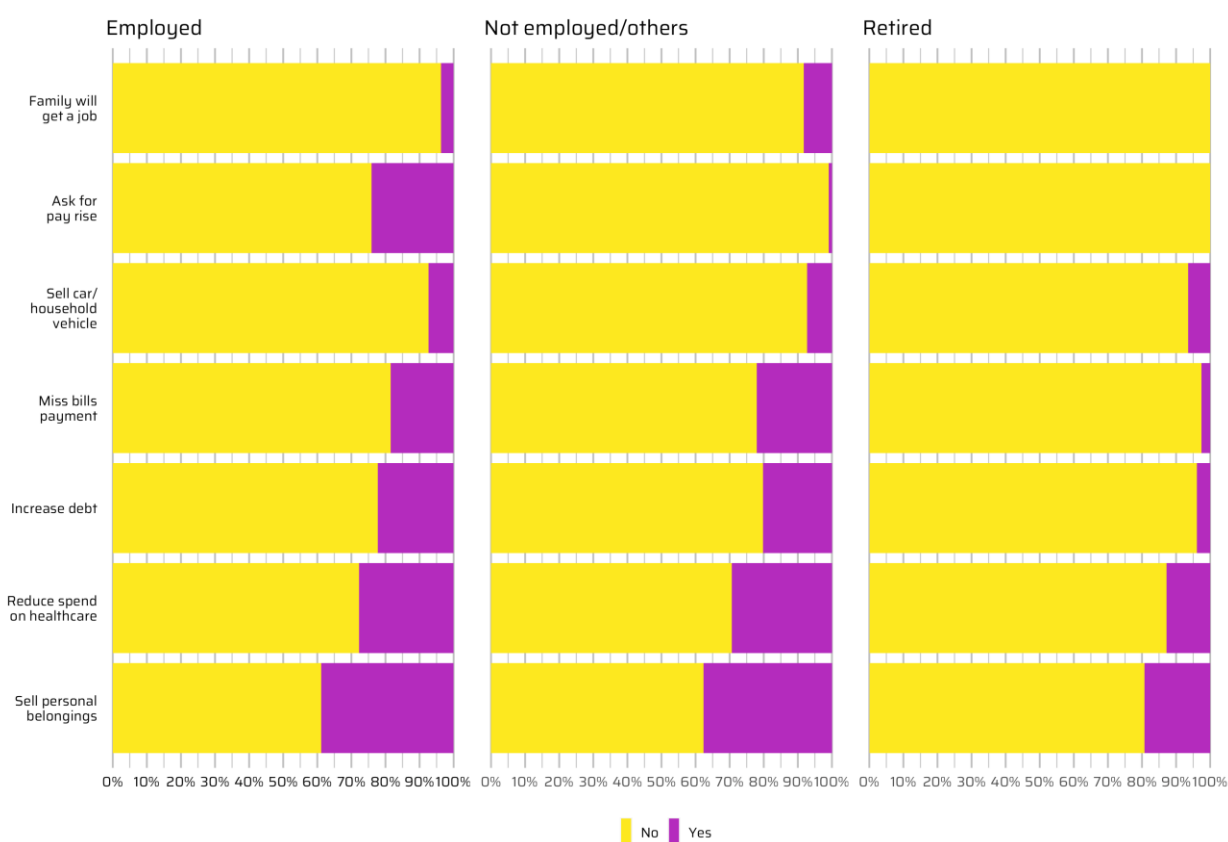


Figure 17: How respondents are coping with the cost-of-living crisis and how they vary dependent on employment status.

Table 16: How respondents are coping with the cost-of-living crisis and how they vary dependent on employment status.

Ways of coping	Yes/No	Respondents	Percentage	Group
Family will get a job	Yes	2	4	Employed
	No	52	96	
Ask for pay rise	Yes	13	24	
	No	41	76	
Sell car/ household vehicle	Yes	4	7	
	No	50	93	
Miss bills payment	Yes	10	19	
	No	44	81	
Increase debt	Yes	12	22	
	No	42	78	

Ways of coping	Yes/No	Respondents	Percentage	Group
Reduce spend on healthcare	Yes	15	28	Not employed/others
	No	39	72	
Sell personal belongings	Yes	21	39	
	No	33	61	
Family will get a job	Yes	9	8	
	No	100	92	
Ask for pay rise	Yes	1	1	
	No	108	99	
Sell car/ household vehicle	Yes	8	7	
	No	101	93	
Miss bills payment	Yes	24	22	
	No	85	78	
Increase debt	Yes	22	20	
	No	87	80	
Reduce spend on healthcare	Yes	32	29	
	No	77	71	
Sell personal belongings	Yes	41	38	
	No	68	62	
Family will get a job	Yes	0	0	Retired
	No	78	100	
Ask for pay rise	Yes	0	0	
	No	78	100	
Sell car/ household vehicle	Yes	5	6	
	No	73	94	
Miss bills payment	Yes	2	3	
	No	76	97	
Increase debt	Yes	3	4	
	No	75	96	
Reduce spend on healthcare	Yes	10	13	
	No	68	87	
Sell personal belongings	Yes	15	19	
	No	63	81	

Coping with cost-of-living crisis: Does this differ by number of dependents?

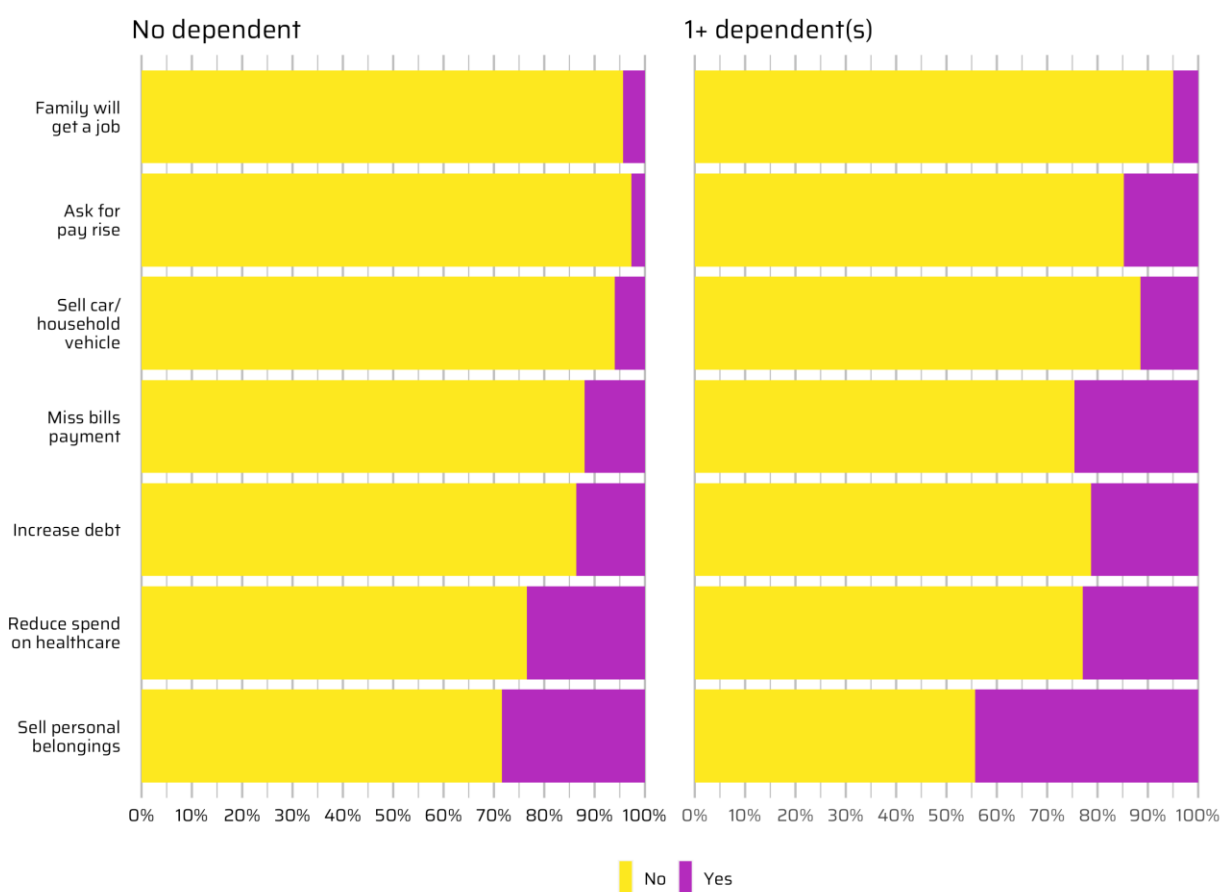


Figure 18: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they have dependents or not.

Table 17: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they have dependents or not.

Ways of coping	Yes/No	Respondents	Percentage	Dependents
Family will get a job	Yes	8	4	No dependents
	No	175	96	
Ask for pay rise	Yes	5	3	
	No	178	97	
Sell car/ household vehicle	Yes	11	6	
	No	172	94	
Miss bills payment	Yes	22	12	
	No	161	88	

Ways of coping	Yes/No	Respondents	Percentage	Dependents
Increase debt	Yes	25	14	
	No	158	86	
Reduce spend on healthcare	Yes	43	23	
	No	140	77	
Sell personal belongings	Yes	52	28	
	No	131	72	
Family will get a job	Yes	3	5	1+ dependent(s)
	No	58	95	
Ask for pay rise	Yes	9	15	
	No	52	85	
Sell car/ household vehicle	Yes	7	11	
	No	54	89	
Miss bills payment	Yes	15	25	
	No	46	75	
Increase debt	Yes	13	21	
	No	48	79	
Reduce spend on healthcare	Yes	14	23	
	No	47	77	
Sell personal belongings	Yes	27	44	
	No	34	56	

Coping with cost-of-living crisis: Does this differ by extent of mental health needs met?

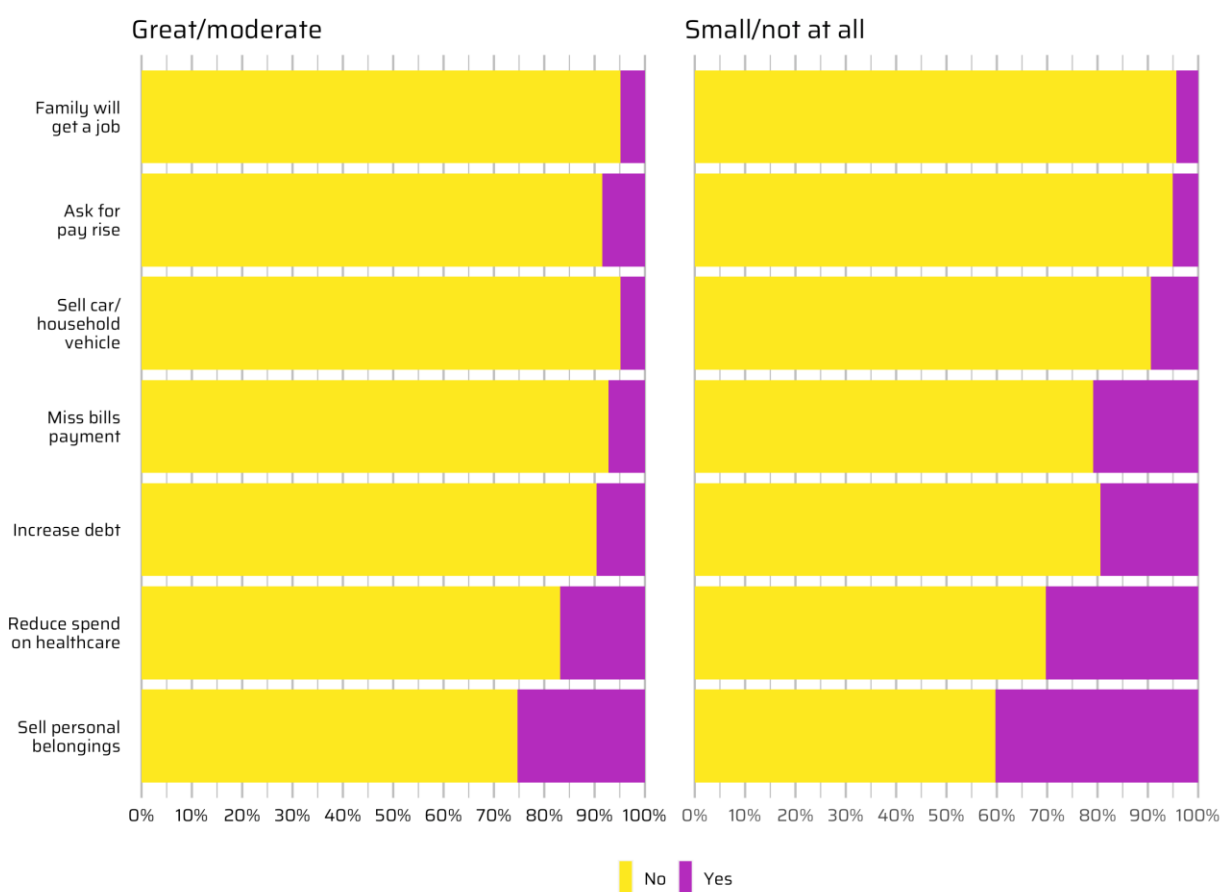


Figure 19: How respondents are coping with the cost-of-living crisis and how they vary dependent on the extent their mental health needs are being met.

Table 18: How respondents are coping with the cost-of-living crisis and how they vary dependent on the extent their mental health needs are being met.

Ways of coping	Yes/No	Respondents	Percentage	Group
Family will get a job	Yes	4	5	Moderate/great
	No	79	95	
Ask for pay rise	Yes	7	8	
	No	76	92	
Sell car/ household vehicle	Yes	4	5	
	No	79	95	
Miss bills payment	Yes	6	7	
	No	77	93	

Ways of coping	Yes/No	Respondents	Percentage	Group
Increase debt	Yes	8	10	
	No	75	90	
Reduce spend on healthcare	Yes	14	17	
	No	69	83	
Sell personal belongings	Yes	21	25	
	No	62	75	
Family will get a job	Yes	6	4	Not at all/small
	No	133	96	
Ask for pay rise	Yes	7	5	
	No	132	95	
Sell car/ household vehicle	Yes	13	9	
	No	126	91	
Miss bills payment	Yes	29	21	
	No	110	79	
Increase debt	Yes	27	19	
	No	112	81	
Reduce spend on healthcare	Yes	42	30	
	No	97	70	
Sell personal belongings	Yes	56	40	
	No	83	60	

Coping with cost-of-living crisis: Does this differ by feelings of anxiety?

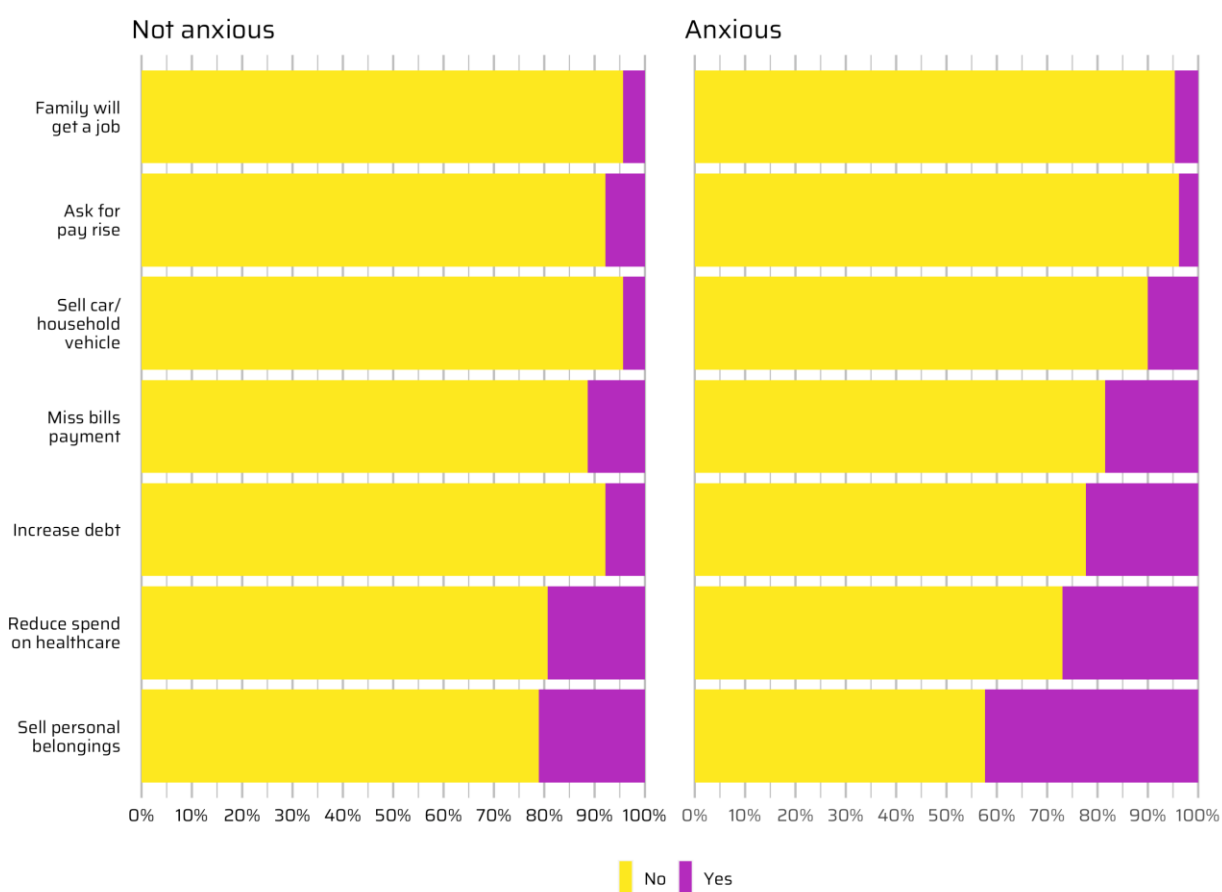


Figure 20: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they reported feelings of anxiety.

Table 19: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they reported feelings of anxiety.

Ways of coping	Yes/No	Respondents	Percentage	Anxious
Family will get a job	Yes	5	4	Not anxious
	No	109	96	
Ask for pay rise	Yes	9	8	
	No	105	92	
Sell car/ household vehicle	Yes	5	4	
	No	109	96	
Miss bills payment	Yes	13	11	
	No	101	89	

Ways of coping	Yes/No	Respondents	Percentage	Anxious
Increase debt	Yes	9	8	Anxious
	No	105	92	
Reduce spend on healthcare	Yes	22	19	
	No	92	81	
Sell personal belongings	Yes	24	21	
	No	90	79	
Family will get a job	Yes	6	5	
	No	124	95	
Ask for pay rise	Yes	5	4	
	No	125	96	
Sell car/ household vehicle	Yes	13	10	
	No	117	90	
Miss bills payment	Yes	24	18	
	No	106	82	
Increase debt	Yes	29	22	
	No	101	78	
Reduce spend on healthcare	Yes	35	27	
	No	95	73	
Sell personal belongings	Yes	55	42	
	No	75	58	

Coping with cost-of-living crisis: Does this differ by feeling of hopelessness?

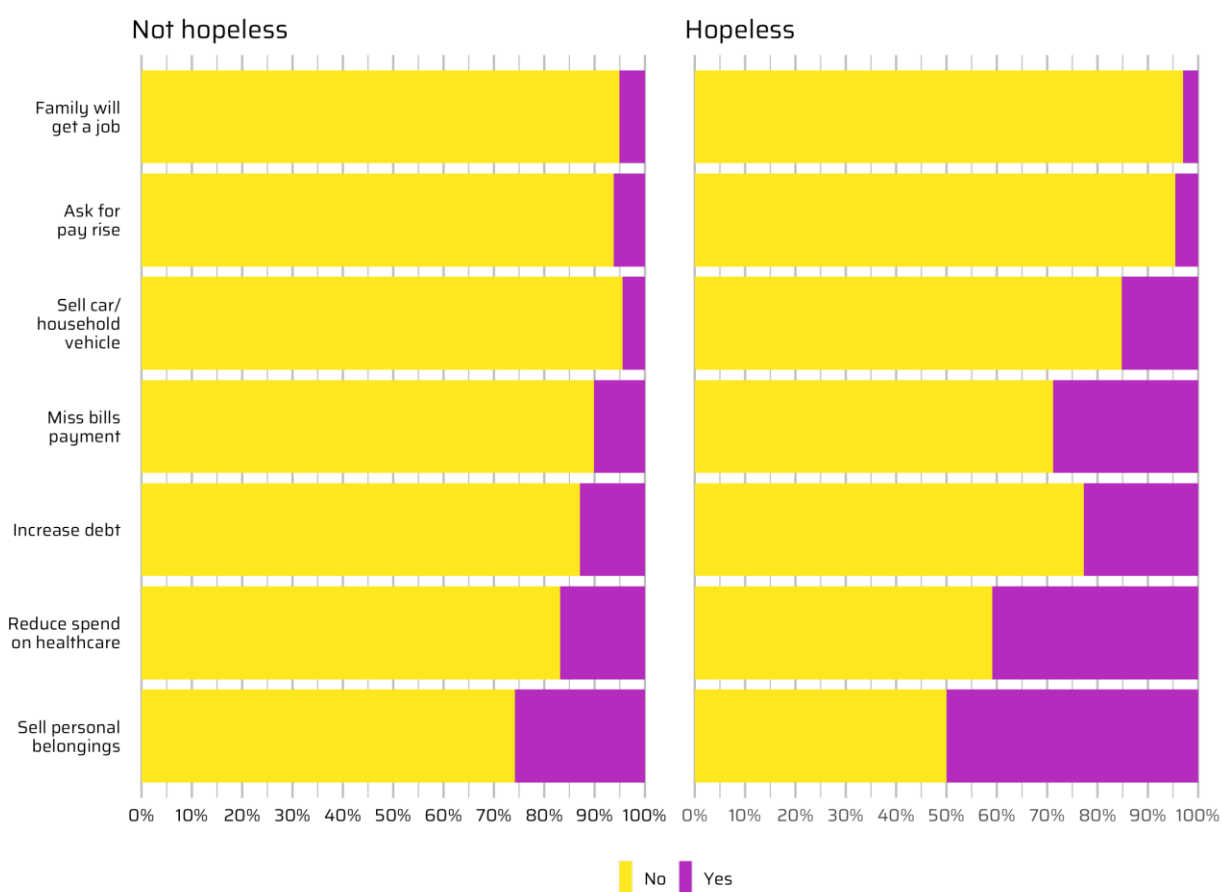


Figure 21: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they reported feelings of hopelessness.

Table 20: How respondents are coping with the cost-of-living crisis and how they vary dependent on if they reported feelings of hopelessness.

Ways of coping	Yes/No	Respondents	Percentage	Hopelessness
Family will get a job	Yes	9	5	Not hopeless
	No	169	95	
Ask for pay rise	Yes	11	6	
	No	167	94	
Sell car/ household vehicle	Yes	8	4	
	No	170	96	
Miss bills payment	Yes	18	10	
	No	160	90	

Ways of coping	Yes/No	Respondents	Percentage	Hopelessness
Increase debt	Yes	23	13	Hopeless
	No	155	87	
Reduce spend on healthcare	Yes	30	17	
	No	148	83	
Sell personal belongings	Yes	46	26	
	No	132	74	
Family will get a job	Yes	2	3	
	No	64	97	
Ask for pay rise	Yes	3	5	
	No	63	95	
Sell car/ household vehicle	Yes	10	15	
	No	56	85	
Miss bills payment	Yes	19	29	
	No	47	71	
Increase debt	Yes	15	23	
	No	51	77	
Reduce spend on healthcare	Yes	27	41	
	No	39	59	
Sell personal belongings	Yes	33	50	
	No	33	50	

Qualitative data - social care

We asked you about your experience of social care in this survey. We have created a word cloud graphic below to share with you the words most commonly used, demonstrating the shared experience of our community.

Word cloud - social care



Fig 22: Word cloud of the words used by respondents to the questions relating to social care.

Thematic analysis - social care

A thematic analysis was conducted for responses to the question, and 4 main themes emerged.

- **Theme 1: Systemic issues**
 - “Non-existent”
 - “Collapsed system”
 - Barriers to accessing social care
 - Lack of continuity
 - Overstretched system
 - Long waiting time
- **Theme 2: Positive or neutral experience**
- **Theme 3: Feeling discriminated or patronized**
- **Theme 4: Self-reliance**

Theme 1: Systemic issues

“Non-existent”

You reported that the social care system is non-existent as services are lacking, hard to reach, or not available in your area.

“... social care for those of us with these conditions is really lacking. So far I have received help with benefits, but the help stops there. There is no real care for the effects of your symptoms on your day-to-day life.”

“Social care is non-existent and help for adaptations in the home has a two year wait. I had to borrow money just to fix a door to gain access to my garden.”

“No social care is available in the district where I live.”

“I initially had a SW (Social Worker). I no longer have SW. A lot of the services are not available even if you need them. I have waited since 2019 for a wet room & bedroom on the ground floor. I have not had a shower since October 2016. I am desperate for a shower.”

“Collapsed system”

You described the system as “collapsed” due to its inability to address your needs.

“...the system has collapsed”

“It’s punishing more than it is helping now.”

“Appalling, with social services departments up and down the country incapable of recognising needs specific to people with neurological deficits.”

“The DWP assessment system is cruel designed to prevent people from claiming.”

“I have not applied for an assessment by social services as I find it too stressful and time/energy consuming.”

Barriers to accessing social care

Some of you expressed that you are not eligible for help, were never offered help, or were not sure how to access social care.

“Never been offered any.”

“My condition doesn’t fit any social care criteria that I’m aware of”

“I have had one phone call from fall services after a recent visit to A&E after a bad fall in the kitchen at home. Unfortunately, I have since moved from one health board to another to be closer to my daughter for support. I don’t know if my new health board has a similar service or how to access it.”

“I am not in receipt of social care and would not be eligible for support in my area as I’m not “critical” enough need”

“The trouble with some social care is that you must fit in a box to receive the help. If you are slightly outside of their parameters, then you do not get the help”

Lack of continuity

“My carer was not replaced when she went on maternity leave in 2019 as the agency could not find anyone ‘suitable for my needs’. Social services were not very proactive in finding a personal assistant for 8 months & then the pandemic hit.”

"Stopped having carers as they changed frequently, I'd get a really good carer built up a good rapport and they would leave for a better paid job/better hours."

"I was in receipt of social care until August 2019 when my carer left on maternity leave. The agency & social services were unable to find a replacement. Since the pandemic I have been told there is no chance of having a replacement although my needs were assessed as requiring more hours. I have been told no one suitable can be found and demand is so great that it is unlikely I will receive a care package now."

Overstretched system

"The Council is overstretched and not coping"

"The people who have been here have expressed frustration that their hands are tied by the financial restrictions imposed on them"

"Nobody is picking up DP PA jobs, agencies are run off their feet so it's tired carers by the time personal care arrives who have to skim to get to other clients as travel time is never added for them."

Long waiting time

"I have been living with bowel incontinence, due to the Autonomic Neuropathy, for four years now and am still waiting for help regarding what I can use to help me with this problem."

"I was referred by my health centre for a new assessment. I phoned them after a few weeks and was told that it takes some time to hear from them. I have now been waiting for three months while my condition grows evermore worse."

"..help for adaptations in the home has a two year wait"

"Still awaiting assessment for LA home adaptations"

Theme 2: Positive or neutral experience

Some of you reported positive or neutral experiences with the social care system.

"I have people who do my shopping, change my bedclothes and do some of my laundry which I've sourced myself."

"I have a good team available if and when I need them, although only on an ad hoc basis but I'm grateful for the support I get"

"They came out to advise me on what adaptations I would need but I had to pay £17,000 for them. They were very helpful though"

Theme 3: Feeling discriminated or patronised

Some reported feeling discriminated, patronised, or mistreated by the service providers.

"In the other area I was gas lighted that I hadn't the conditions I genuinely have and no mental health input when a MH nurse visited for around two years monitoring me for PTSD."

"I've had care needlessly removed, been gas lighted my conditions don't exist which are in my medical records. We've far less care than in 2008 yet my conditions have deteriorated hugely in that time ... we no longer feel human thanks to this."

"Judgements made by nurses and physio staff about my condition, not knowing about it and refusing to believe me"

"I feel even more isolated. I am just a jib not a human being to them."

"..they have changed the times of visits without notice, and entered my home trying to use a key from the key lock without using the doorbell"

Theme 4: Self-reliance

Some of you have taken your own initiative.

"Direct payments = choice and control"

"Waiting lists are too long, so we pay privately when required."

"I had to organise all my own social care."

"I have never received any - straight out of hospital after brain surgery and left to cope on my own - total nightmare"

"They threw back all the help in the home I had in 2016 on to me so I have to private find and fund for ten hours and even it doesn't cover what I cannot do for years. Thanks to this my elderly mum is now partially buying me some of my food. There's no earners here, no relatives to do anything and I'm still trying to get repairs done here to move in properly. It's beyond a worry, it's some kind of dystopian nightmare I cannot wake up from."

Quantitative data - social care

Social care options

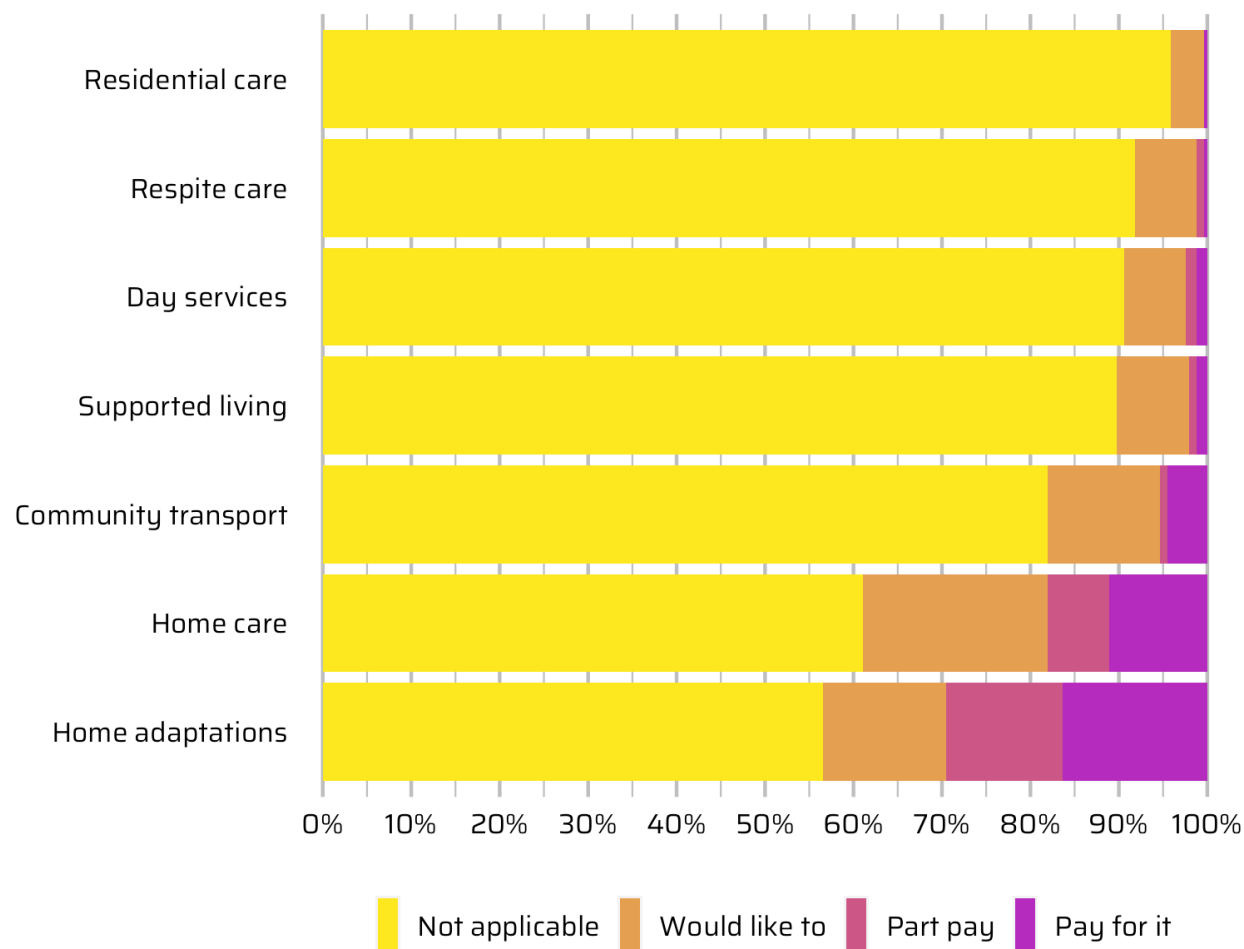


Figure 23: Type of social care services respondents are using.

Table 21: Type of social care services respondents are using.

Social care	Options	Respondents	Percentage
Residential care	Pay for it	1	0
	Part pay	0	0
	Would like to	9	4
	Not applicable	234	96
Respite care	Pay for it	1	0
	Part pay	2	1
	Would like to	17	7
	Not applicable	224	92

Social care	Options	Respondents	Percentage
Day services	Pay for it	3	1
	Part pay	3	1
	Would like to	17	7
	Not applicable	221	91
Supported living	Pay for it	3	1
	Part pay	2	1
	Would like to	20	8
	Not applicable	219	90
Community transport	Pay for it	11	5
	Part pay	2	1
	Would like to	31	13
	Not applicable	200	82
Home care	Pay for it	27	11
	Part pay	17	7
	Would like to	51	21
	Not applicable	149	61
Home adaptations	Pay for it	40	16
	Part pay	32	13
	Would like to	34	14
	Not applicable	138	57

Social care options: Do these differ among people with/without multiple neurological conditions?

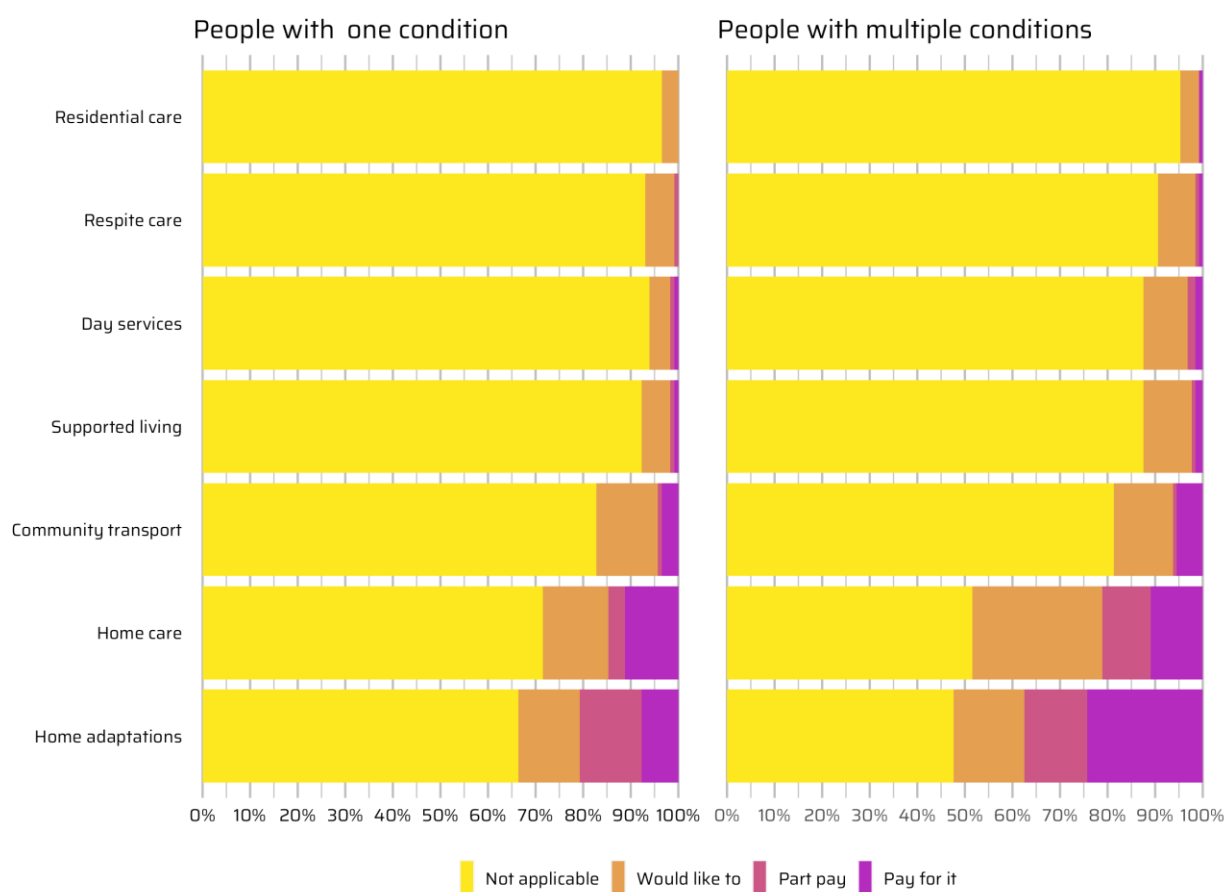


Figure 24: Type of social care services respondents are using dependent on if they have one or multiple neurological conditions.

Table 22: Type of social care services respondents are using dependent on if they have one or multiple neurological conditions.

Social care	Options	Respondents	Percentage	Number of Conditions
Residential care	Pay for it	1	1	Multiple conditions
	Part pay	0	0	
	Would like to	5	4	
	Not applicable	122	95	
Respite care	Pay for it	1	1	
	Part pay	1	1	
	Would like to	10	8	

Social care	Options	Respondents	Percentage	Number of Conditions
	Not applicable	116	91	
Day services	Pay for it	2	2	
	Part pay	2	2	
	Would like to	12	9	
	Not applicable	112	88	
Supported living	Pay for it	2	2	
	Part pay	1	1	
	Would like to	13	10	
	Not applicable	112	88	
Community transport	Pay for it	7	5	
	Part pay	1	1	
	Would like to	16	12	
	Not applicable	104	81	
Home care	Pay for it	14	11	
	Part pay	13	10	
	Would like to	35	27	
	Not applicable	66	52	
Home adaptations	Pay for it	31	24	
	Part pay	17	13	
	Would like to	19	15	
	Not applicable	61	48	
Residential care	Pay for it	0	0	One condition
	Part pay	0	0	
	Would like to	4	3	
	Not applicable	112	97	
Respite care	Pay for it	0	0	
	Part pay	1	1	
	Would like to	7	6	
	Not applicable	108	93	
Day services	Pay for it	1	1	
	Part pay	1	1	
	Would like to	5	4	
	Not applicable	109	94	
Supported living	Pay for it	1	1	
	Part pay	1	1	
	Would like to	7	6	
	Not applicable	107	92	
	Pay for it	4	3	

Social care	Options	Respondents	Percentage	Number of Conditions
Community transport	Part pay	1	1	
	Would like to	15	13	
	Not applicable	96	83	
Home care	Pay for it	13	11	
	Part pay	4	3	
	Would like to	16	14	
	Not applicable	83	72	
Home adaptations	Pay for it	9	8	
	Part pay	15	13	
	Would like to	15	13	
	Not applicable	77	66	

Social care options: Do these differ by people with co-occurring non-neurological conditions?

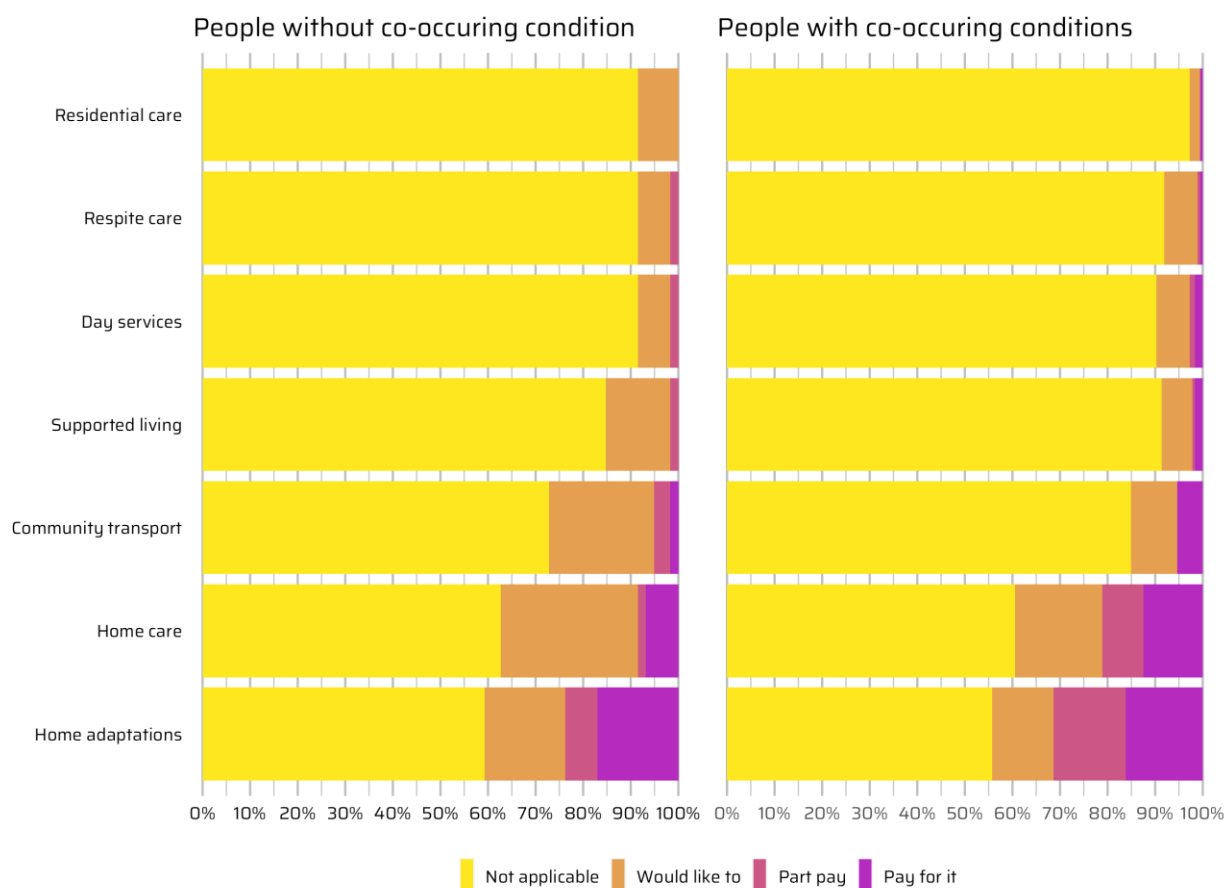


Figure 25: Type of social care services respondents are using dependent on if they have a co-occurring non-neurological condition or not.

Table 23: Type of social care services respondents are using dependent on if they have a co-occurring non-neurological condition or not.

Social care	Options	Respondents	Percentage	Co-occurring conditions
Residential care	Pay for it	0	0	Individuals without co-occurring conditions
	Part pay	0	0	
	Would like to	5	8	
	Not applicable	54	92	
Respite care	Pay for it	0	0	
	Part pay	1	2	

Social care	Options	Respondents	Percentage	Co-occurring conditions
	Would like to	4	7	
	Not applicable	54	92	
Day services	Pay for it	0	0	
	Part pay	1	2	
	Would like to	4	7	
	Not applicable	54	92	
Supported living	Pay for it	0	0	
	Part pay	1	2	
	Would like to	8	14	
	Not applicable	50	85	
Community transport	Pay for it	1	2	
	Part pay	2	3	
	Would like to	13	22	
	Not applicable	43	73	
Home care	Pay for it	4	7	
	Part pay	1	2	
	Would like to	17	29	
	Not applicable	37	63	
Home adaptations	Pay for it	10	17	
	Part pay	4	7	
	Would like to	10	17	
	Not applicable	35	59	
Residential care	Pay for it	1	1	Individuals with co-occurring conditions
	Part pay	0	0	
	Would like to	4	2	
	Not applicable	180	97	
Respite care	Pay for it	1	1	
	Part pay	1	1	
	Would like to	13	7	
	Not applicable	170	92	
Day services	Pay for it	3	2	
	Part pay	2	1	
	Would like to	13	7	
	Not applicable	167	90	
Supported living	Pay for it	3	2	
	Part pay	1	1	
	Would like to	12	6	
	Not applicable	169	91	
	Pay for it	10	5	

Social care	Options	Respondents	Percentage	Co-occurring conditions
Community transport	Part pay	0	0	
	Would like to	18	10	
	Not applicable	157	85	
Home care	Pay for it	23	12	
	Part pay	16	9	
	Would like to	34	18	
	Not applicable	112	61	
Home adaptations	Pay for it	30	16	
	Part pay	28	15	
	Would like to	24	13	
	Not applicable	103	56	

Social care options: Do these differ by age groups?

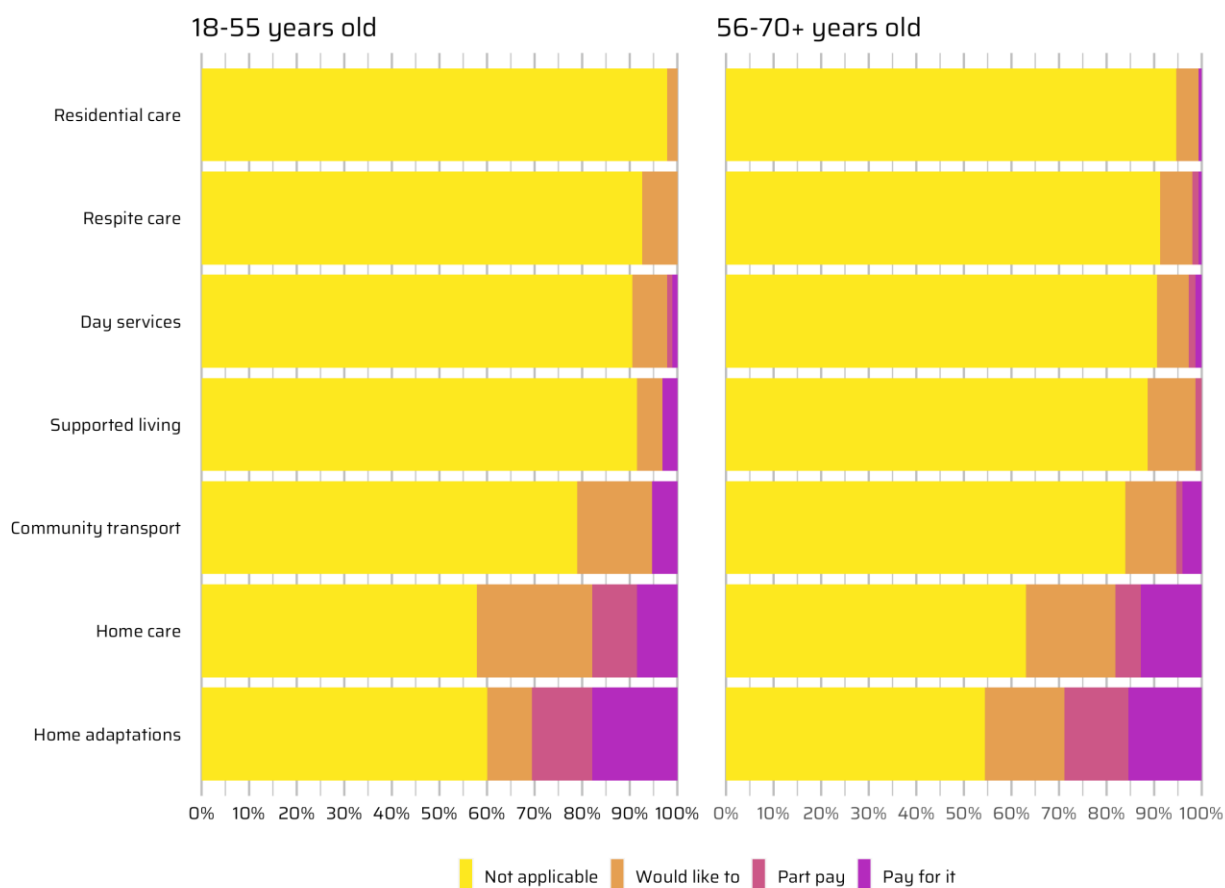


Figure 26: Type of social care services respondents are using dependent on if they have a co-occurring non-neurological condition or not.

Table 24: Type of social care services respondents are using dependent on if they have a co-occurring non-neurological condition or not.

Social care	Options	Respondents	Percentage	Age Group
Residential care	Pay for it	0	0	18-55 years old
	Part pay	0	0	
	Would like to	2	2	
	Not applicable	93	98	
Respite care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	7	7	
	Not applicable	88	93	
Day services	Pay for it	1	1	
	Part pay	1	1	
	Would like to	7	7	
	Not applicable	86	91	
Supported living	Pay for it	3	3	
	Part pay	0	0	
	Would like to	5	5	
	Not applicable	87	92	
Community transport	Pay for it	5	5	
	Part pay	0	0	
	Would like to	15	16	
	Not applicable	75	79	
Home care	Pay for it	8	8	
	Part pay	9	9	
	Would like to	23	24	
	Not applicable	55	58	
Home adaptations	Pay for it	17	18	
	Part pay	12	13	
	Would like to	9	9	
	Not applicable	57	60	
Residential care	Pay for it	1	1	56-70+ years old
	Part pay	0	0	
	Would like to	7	5	
	Not applicable	141	95	
Respite care	Pay for it	1	1	
	Part pay	2	1	
	Would like to	10	7	
	Not applicable	136	91	
Day services	Pay for it	2	1	

Social care	Options	Respondents	Percentage	Age Group
	Part pay	2	1	
	Would like to	10	7	
	Not applicable	135	91	
Supported living	Pay for it	0	0	
	Part pay	2	1	
	Would like to	15	10	
	Not applicable	132	89	
Community transport	Pay for it	6	4	
	Part pay	2	1	
	Would like to	16	11	
	Not applicable	125	84	
Home care	Pay for it	19	13	
	Part pay	8	5	
	Would like to	28	19	
	Not applicable	94	63	
Home adaptations	Pay for it	23	15	
	Part pay	20	13	
	Would like to	25	17	
	Not applicable	81	54	

Social care options: Do these differ by gender?

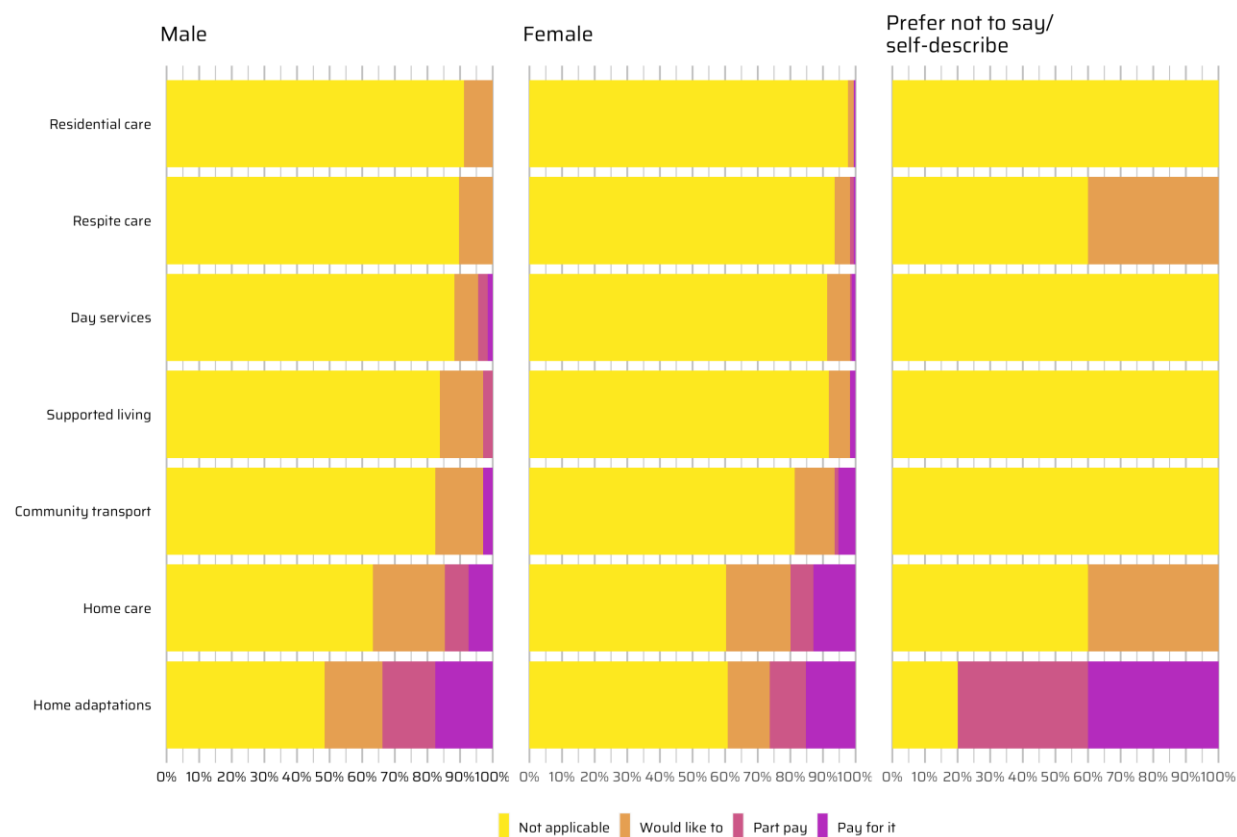


Figure 27: Type of social care services respondents are using dependent on their gender.

Table 25: Type of social care services respondents are using dependent on their gender.

Social care	Options	Respondents	Percentage	Gender
Residential care	Pay for it	0	0	Male
	Part pay	0	0	
	Would like to	6	9	
	Not applicable	62	91	
Respite care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	7	10	
	Not applicable	61	90	
Day services	Pay for it	1	1	
	Part pay	2	3	
	Would like to	5	7	

Social care	Options	Respondents	Percentage	Gender
	Not applicable	60	88	
Supported living	Pay for it	0	0	
	Part pay	2	3	
	Would like to	9	13	
	Not applicable	57	84	
Community transport	Pay for it	2	3	
	Part pay	0	0	
	Would like to	10	15	
	Not applicable	56	82	
Home care	Pay for it	5	7	
	Part pay	5	7	
	Would like to	15	22	
	Not applicable	43	63	
Home adaptations	Pay for it	12	18	
	Part pay	11	16	
	Would like to	12	18	
	Not applicable	33	49	
Residential care	Pay for it	1	1	Female
	Part pay	0	0	
	Would like to	3	2	
	Not applicable	167	98	
Respite care	Pay for it	1	1	
	Part pay	2	1	
	Would like to	8	5	
	Not applicable	160	94	
Day services	Pay for it	2	1	
	Part pay	1	1	
	Would like to	12	7	
	Not applicable	156	91	
Supported living	Pay for it	3	2	
	Part pay	0	0	

Social care	Options	Respondents	Percentage	Gender
	Would like to	11	6	
	Not applicable	157	92	
Community transport	Pay for it	9	5	
	Part pay	2	1	
	Would like to	21	12	
	Not applicable	139	81	
Home care	Pay for it	22	13	
	Part pay	12	7	
	Would like to	34	20	
	Not applicable	103	60	
Home adaptations	Pay for it	26	15	
	Part pay	19	11	
	Would like to	22	13	
	Not applicable	104	61	
Residential care	Pay for it	0	0	Prefer not to say/self-describe
	Part pay	0	0	
	Would like to	0	0	
	Not applicable	5	100	
Respite care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	2	40	
	Not applicable	3	60	
Day services	Pay for it	0	0	
	Part pay	0	0	
	Would like to	0	0	
	Not applicable	5	100	
Supported living	Pay for it	0	0	
	Part pay	0	0	
	Would like to	0	0	
	Not applicable	5	100	
	Pay for it	0	0	

Social care	Options	Respondents	Percentage	Gender
Community transport	Part pay	0	0	
	Would like to	0	0	
	Not applicable	5	100	
Home care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	2	40	
	Not applicable	3	60	
Home adaptations	Pay for it	2	40	
	Part pay	2	40	
	Would like to	0	0	
	Not applicable	1	20	

Social care options: Do these differ by employment status?

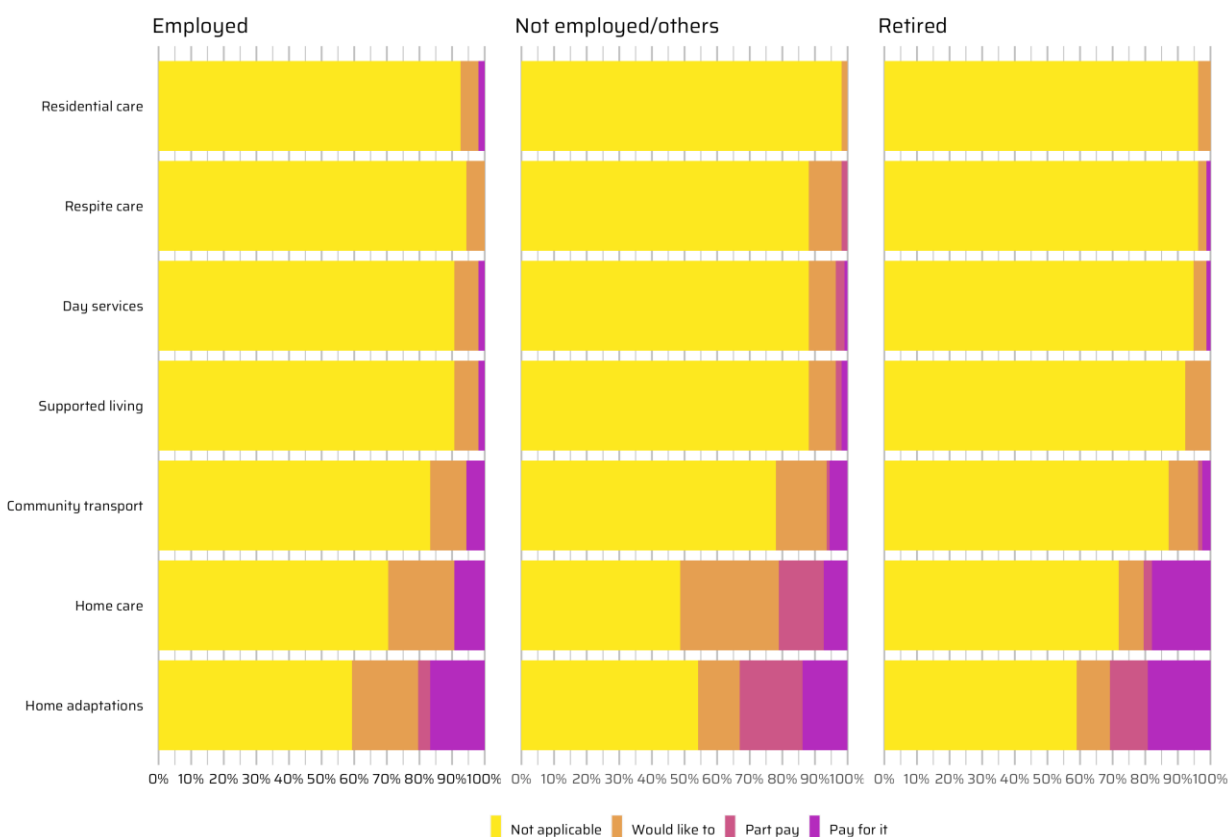


Figure 28: Type of social care services respondents are using dependent on their employment status.

Table 26: Type of social care services respondents are using dependent on their employment status.

Social care	Options	Respondents	Percentage	Employment Status
Residential care	Pay for it	1	2	Employed
	Part pay	0	0	
	Would like to	3	6	
	Not applicable	50	93	
Respite care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	3	6	
	Not applicable	51	94	
Day services	Pay for it	1	2	
	Part pay	0	0	
	Would like to	4	7	
	Not applicable	49	91	
Supported living	Pay for it	1	2	
	Part pay	0	0	
	Would like to	4	7	
	Not applicable	49	91	
Community transport	Pay for it	3	6	
	Part pay	0	0	
	Would like to	6	11	
	Not applicable	45	83	
Home care	Pay for it	5	9	
	Part pay	0	0	
	Would like to	11	20	
	Not applicable	38	70	
Home adaptations	Pay for it	9	17	
	Part pay	2	4	
	Would like to	11	20	
	Not applicable	32	59	
Residential care	Pay for it	0	0	Not employed/others
	Part pay	0	0	
	Would like to	2	2	
	Not applicable	107	98	
Respite care	Pay for it	0	0	
	Part pay	2	2	

Social care	Options	Respondents	Percentage	Employment Status
	Would like to	11	10	
	Not applicable	96	88	
Day services	Pay for it	1	1	
	Part pay	3	3	
	Would like to	9	8	
	Not applicable	96	88	
Supported living	Pay for it	2	2	
	Part pay	2	2	
	Would like to	9	8	
	Not applicable	96	88	
Community transport	Pay for it	6	6	
	Part pay	1	1	
	Would like to	17	16	
	Not applicable	85	78	
Home care	Pay for it	8	7	
	Part pay	15	14	
	Would like to	33	30	
	Not applicable	53	49	
Home adaptations	Pay for it	15	14	
	Part pay	21	19	
	Would like to	14	13	
	Not applicable	59	54	
Residential care	Pay for it	0	0	Retired
	Part pay	0	0	
	Would like to	3	4	
	Not applicable	75	96	
Respite care	Pay for it	1	1	
	Part pay	0	0	
	Would like to	2	3	
	Not applicable	75	96	
Day services	Pay for it	1	1	
	Part pay	0	0	
	Would like to	3	4	
	Not applicable	74	95	
Supported living	Pay for it	0	0	
	Part pay	0	0	
	Would like to	6	8	
	Not applicable	72	92	
Community transport	Pay for it	2	3	

Social care	Options	Respondents	Percentage	Employment Status
	Part pay	1	1	
	Would like to	7	9	
	Not applicable	68	87	
Home care	Pay for it	14	18	
	Part pay	2	3	
	Would like to	6	8	
	Not applicable	56	72	
Home adaptations	Pay for it	15	19	
	Part pay	9	12	
	Would like to	8	10	
	Not applicable	46	59	

Social care options: Do these differ by number of dependents?

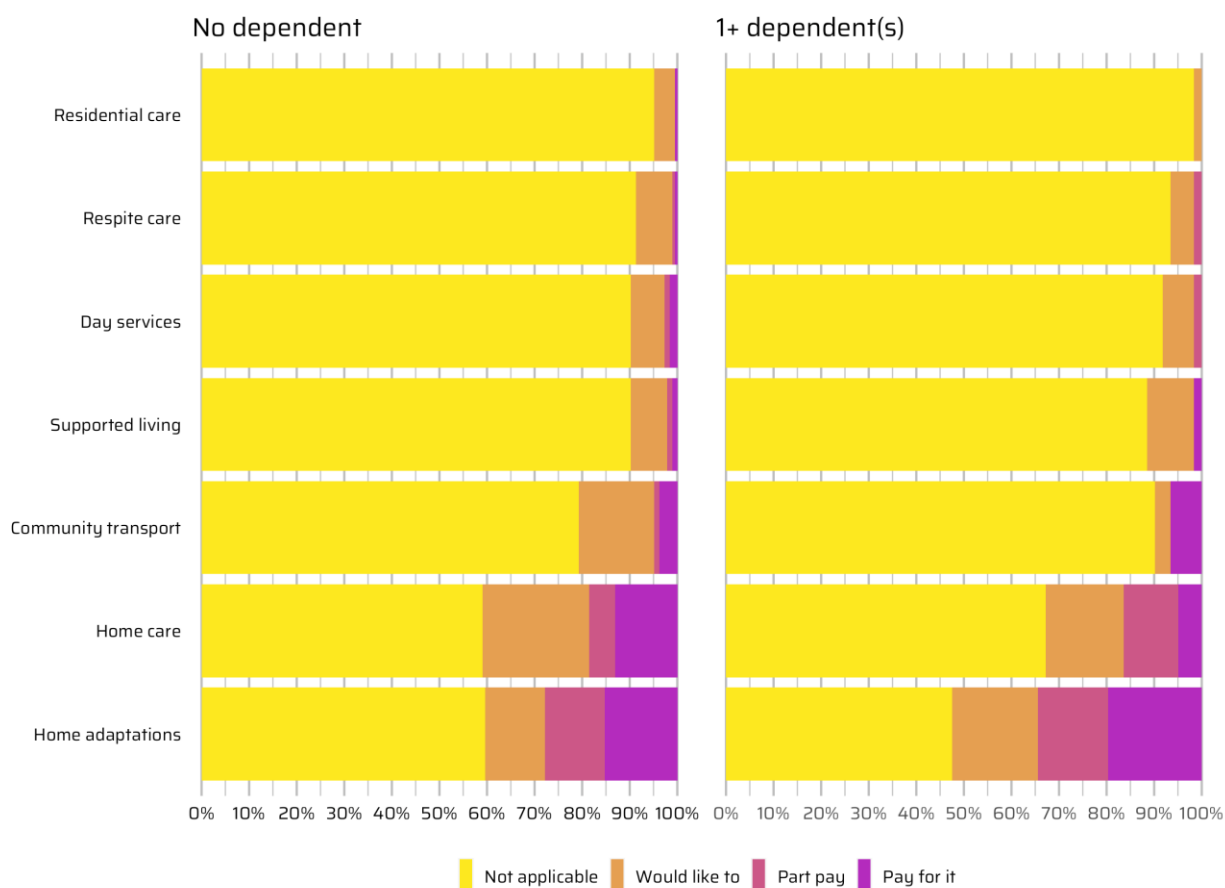


Figure 29: Type of social care services respondents are using dependent on if they have dependents or not.

Table 27 Type of social care services respondents are using dependent on if they have dependents or not.

Social care	Options	Respondents	Percentage	Number of Dependents
Residential care	Pay for it	1	1	No dependent
	Part pay	0	0	
	Would like to	8	4	
	Not applicable	174	95	
Respite care	Pay for it	1	1	
	Part pay	1	1	
	Would like to	14	8	
	Not applicable	167	91	
Day services	Pay for it	3	2	
	Part pay	2	1	
	Would like to	13	7	
	Not applicable	165	90	
Supported living	Pay for it	2	1	
	Part pay	2	1	
	Would like to	14	8	
	Not applicable	165	90	
Community transport	Pay for it	7	4	
	Part pay	2	1	
	Would like to	29	16	
	Not applicable	145	79	
Home care	Pay for it	24	13	
	Part pay	10	5	
	Would like to	41	22	
	Not applicable	108	59	
Home adaptations	Pay for it	28	15	
	Part pay	23	13	
	Would like to	23	13	
	Not applicable	109	60	
Residential care	Pay for it	0	0	1+ dependent(s)
	Part pay	0	0	
	Would like to	1	2	
	Not applicable	60	98	
Respite care	Pay for it	0	0	
	Part pay	1	2	
	Would like to	3	5	
	Not applicable	57	93	
Day services	Pay for it	0	0	

Social care	Options	Respondents	Percentage	Number of Dependents
	Part pay	1	2	
	Would like to	4	7	
	Not applicable	56	92	
Supported living	Pay for it	1	2	
	Part pay	0	0	
	Would like to	6	10	
	Not applicable	54	89	
Community transport	Pay for it	4	7	
	Part pay	0	0	
	Would like to	2	3	
	Not applicable	55	90	
Home care	Pay for it	3	5	
	Part pay	7	11	
	Would like to	10	16	
	Not applicable	41	67	
Home adaptations	Pay for it	12	20	
	Part pay	9	15	
	Would like to	11	18	
	Not applicable	29	48	

Social care options: Do these differ by extent of mental health needs met?

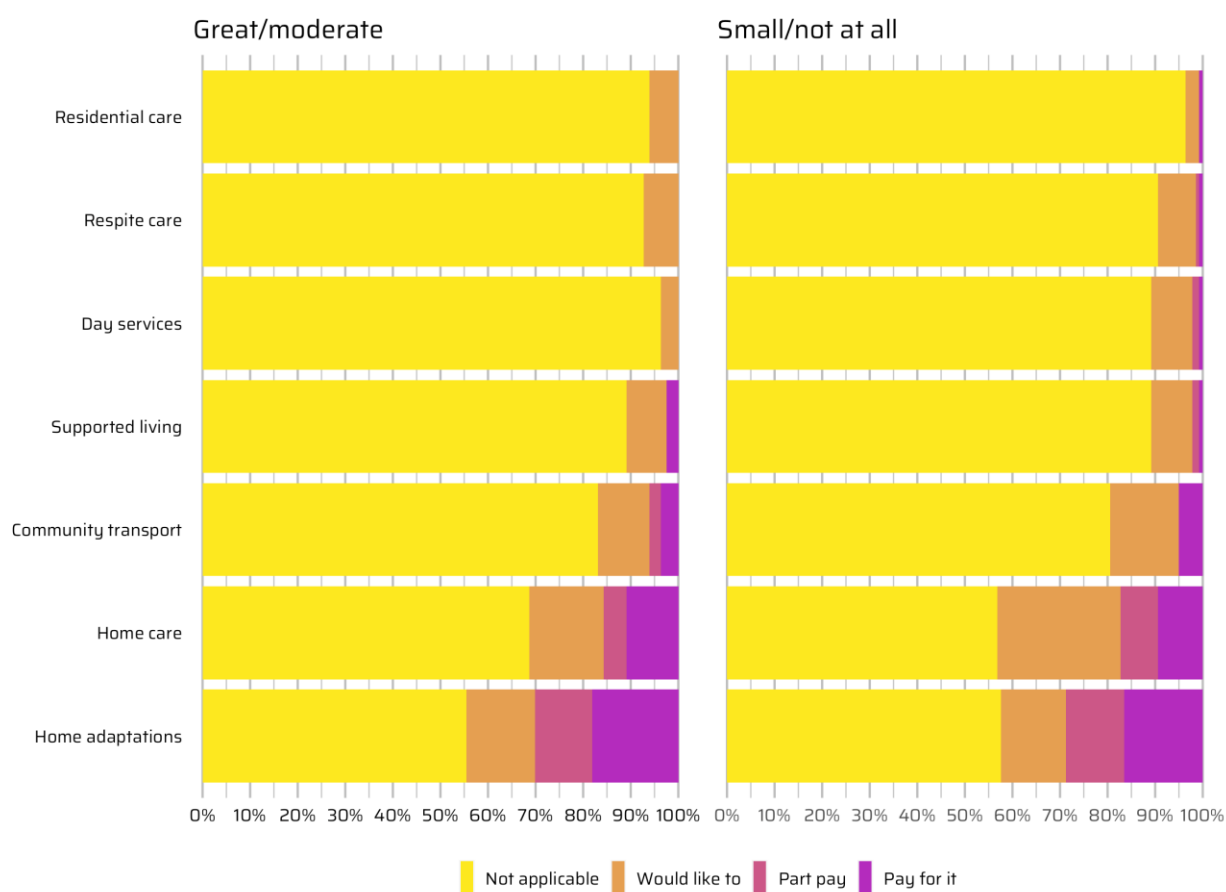


Figure 30: Type of social care services respondents are using dependent on if they have dependent on the extent their mental health needs are being met.

Table 28: Type of social care services respondents are using dependent on if they have dependent on the extent their mental health needs are being met.

Social care	Options	Respondents	Percentage	Mental Health needs
Residential care	Pay for it	0	0	Moderate/great
	Part pay	0	0	
	Would like to	5	6	
	Not applicable	78	94	
Respite care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	6	7	
	Not applicable	77	93	

Social care	Options	Respondents	Percentage	Mental Health needs
Day services	Pay for it	0	0	Not at all/small
	Part pay	0	0	
	Would like to	3	4	
	Not applicable	80	96	
Supported living	Pay for it	2	2	
	Part pay	0	0	
	Would like to	7	8	
	Not applicable	74	89	
Community transport	Pay for it	3	4	
	Part pay	2	2	
	Would like to	9	11	
	Not applicable	69	83	
Home care	Pay for it	9	11	
	Part pay	4	5	
	Would like to	13	16	
	Not applicable	57	69	
Home adaptations	Pay for it	15	18	
	Part pay	10	12	
	Would like to	12	14	
	Not applicable	46	55	
Residential care	Pay for it	1	1	
	Part pay	0	0	
	Would like to	4	3	
	Not applicable	134	96	
Respite care	Pay for it	1	1	
	Part pay	1	1	
	Would like to	11	8	
	Not applicable	126	91	
Day services	Pay for it	1	1	
	Part pay	2	1	
	Would like to	12	9	
	Not applicable	124	89	
Supported living	Pay for it	1	1	
	Part pay	2	1	
	Would like to	12	9	
	Not applicable	124	89	
Community transport	Pay for it	7	5	
	Part pay	0	0	
	Would like to	20	14	

Social care	Options	Respondents	Percentage	Mental Health needs
Home care	Not applicable	112	81	
	Pay for it	13	9	
	Part pay	11	8	
	Would like to	36	26	
	Not applicable	79	57	
Home adaptations	Pay for it	23	17	
	Part pay	17	12	
	Would like to	19	14	
	Not applicable	80	58	

Social care options: Do these differ by feeling of anxiety?

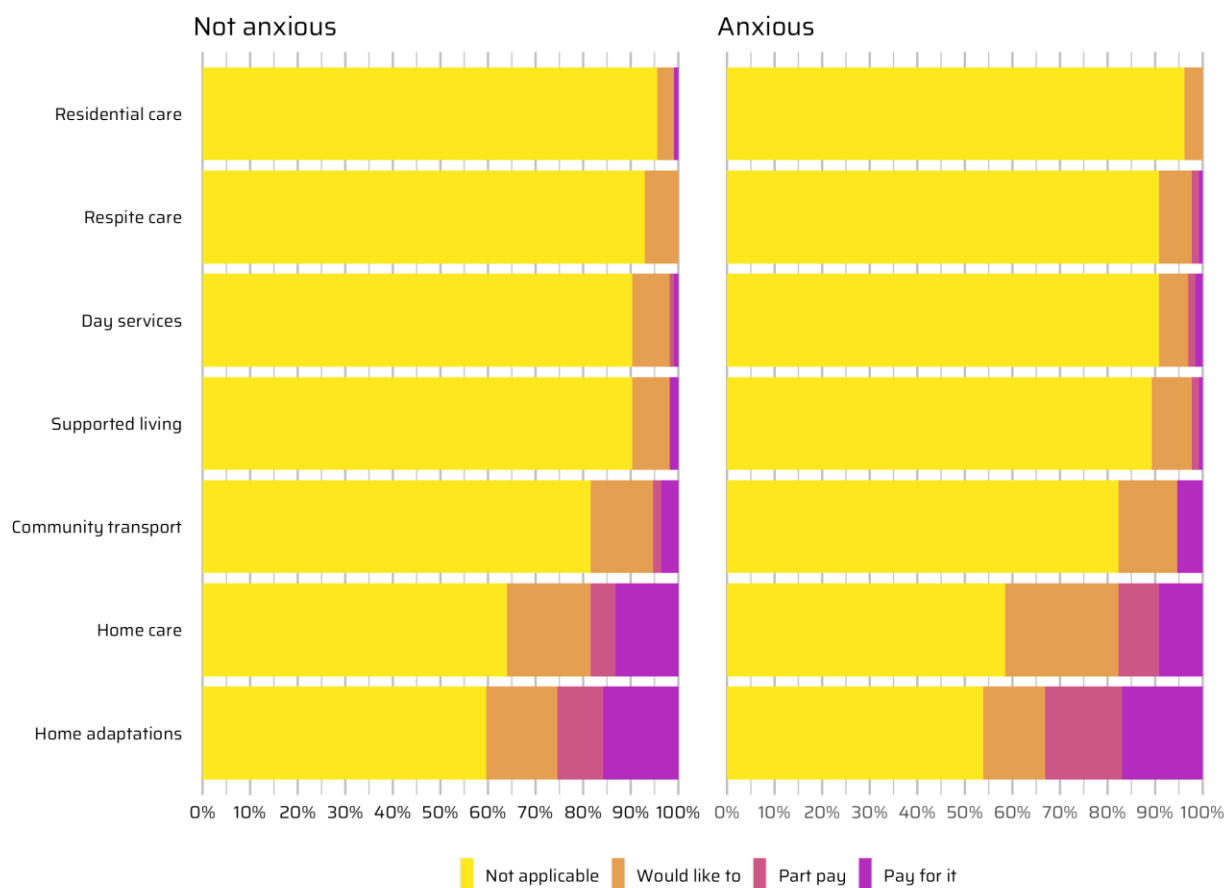


Figure 31: Type of social care services respondents are using dependent on if they have dependent on if people have reported feelings of anxiety.

Table 29: Type of social care services respondents are using dependent on if they have dependent on if people have reported feelings of anxiety.

Social care	Options	Respondents	Percentage	Anxiety
Residential care	Pay for it	1	1	Not anxious
	Part pay	0	0	
	Would like to	4	4	
	Not applicable	109	96	
Respite care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	8	7	
	Not applicable	106	93	
Day services	Pay for it	1	1	
	Part pay	1	1	
	Would like to	9	8	
	Not applicable	103	90	
Supported living	Pay for it	2	2	
	Part pay	0	0	
	Would like to	9	8	
	Not applicable	103	90	
Community transport	Pay for it	4	4	
	Part pay	2	2	
	Would like to	15	13	
	Not applicable	93	82	
Home care	Pay for it	15	13	
	Part pay	6	5	
	Would like to	20	18	
	Not applicable	73	64	
Home adaptations	Pay for it	18	16	
	Part pay	11	10	
	Would like to	17	15	
	Not applicable	68	60	
Residential care	Pay for it	0	0	Anxious
	Part pay	0	0	
	Would like to	5	4	
	Not applicable	125	96	
Respite care	Pay for it	1	1	
	Part pay	2	2	
	Would like to	9	7	
	Not applicable	118	91	
Day services	Pay for it	2	2	
	Part pay	2	2	
	Would like to	8	6	

Social care	Options	Respondents	Percentage	Anxiety
	Not applicable	118	91	
Supported living	Pay for it	1	1	
	Part pay	2	2	
	Would like to	11	8	
	Not applicable	116	89	
Community transport	Pay for it	7	5	
	Part pay	0	0	
	Would like to	16	12	
	Not applicable	107	82	
Home care	Pay for it	12	9	
	Part pay	11	8	
	Would like to	31	24	
	Not applicable	76	58	
Home adaptations	Pay for it	22	17	
	Part pay	21	16	
	Would like to	17	13	
	Not applicable	70	54	

Social care options: Do these differ by feeling of hopelessness?

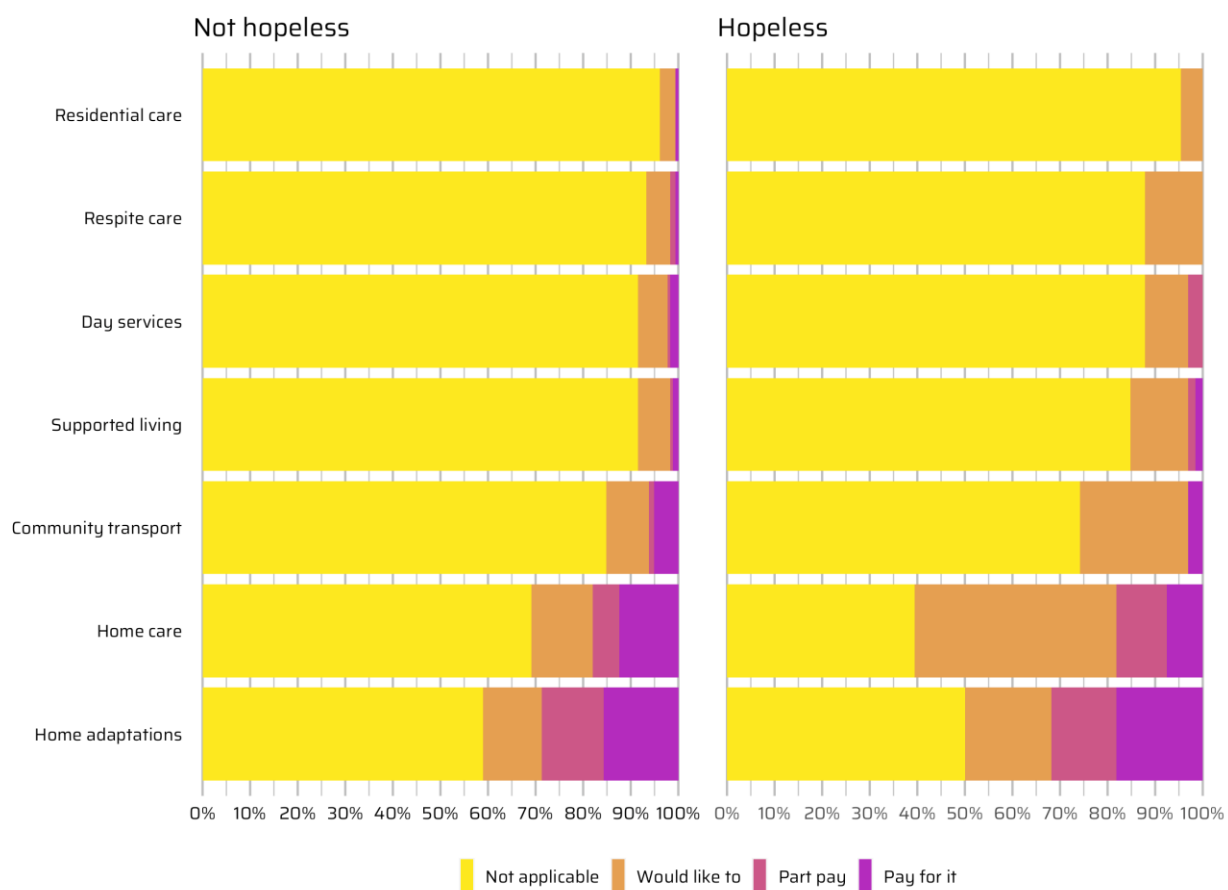


Figure 32: Type of social care services respondents are using dependent on if they have dependent on if people have reported feelings of hopelessness.

Table 30: Type of social care services respondents are using dependent on if they have dependent on if people have reported feelings of hopelessness.

Social care	Options	Respondents	Percentage	Group
Residential care	Pay for it	1	1	Not hopeless
	Part pay	0	0	
	Would like to	6	3	
	Not applicable	171	96	
Respite care	Pay for it	1	1	Not hopeless
	Part pay	2	1	
	Would like to	9	5	
	Not applicable	166	93	

Social care	Options	Respondents	Percentage	Group
Day services	Pay for it	3	2	Hopeless
	Part pay	1	1	
	Would like to	11	6	
	Not applicable	163	92	
Supported living	Pay for it	2	1	
	Part pay	1	1	
	Would like to	12	7	
	Not applicable	163	92	
Community transport	Pay for it	9	5	
	Part pay	2	1	
	Would like to	16	9	
	Not applicable	151	85	
Home care	Pay for it	22	12	
	Part pay	10	6	
	Would like to	23	13	
	Not applicable	123	69	
Home adaptations	Pay for it	28	16	
	Part pay	23	13	
	Would like to	22	12	
	Not applicable	105	59	
Residential care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	3	5	
	Not applicable	63	95	
Respite care	Pay for it	0	0	
	Part pay	0	0	
	Would like to	8	12	
	Not applicable	58	88	
Day services	Pay for it	0	0	
	Part pay	2	3	
	Would like to	6	9	
	Not applicable	58	88	
Supported living	Pay for it	1	2	
	Part pay	1	2	
	Would like to	8	12	
	Not applicable	56	85	
Community transport	Pay for it	2	3	
	Part pay	0	0	
	Would like to	15	23	

Social care	Options	Respondents	Percentage	Group
	Not applicable	49	74	
Home care	Pay for it	5	8	
	Part pay	7	11	
	Would like to	28	42	
	Not applicable	26	39	
Home adaptations	Pay for it	12	18	
	Part pay	9	14	
	Would like to	12	18	
	Not applicable	33	50	

Quantitative data – mental health

Extent Mental Health Needs Met

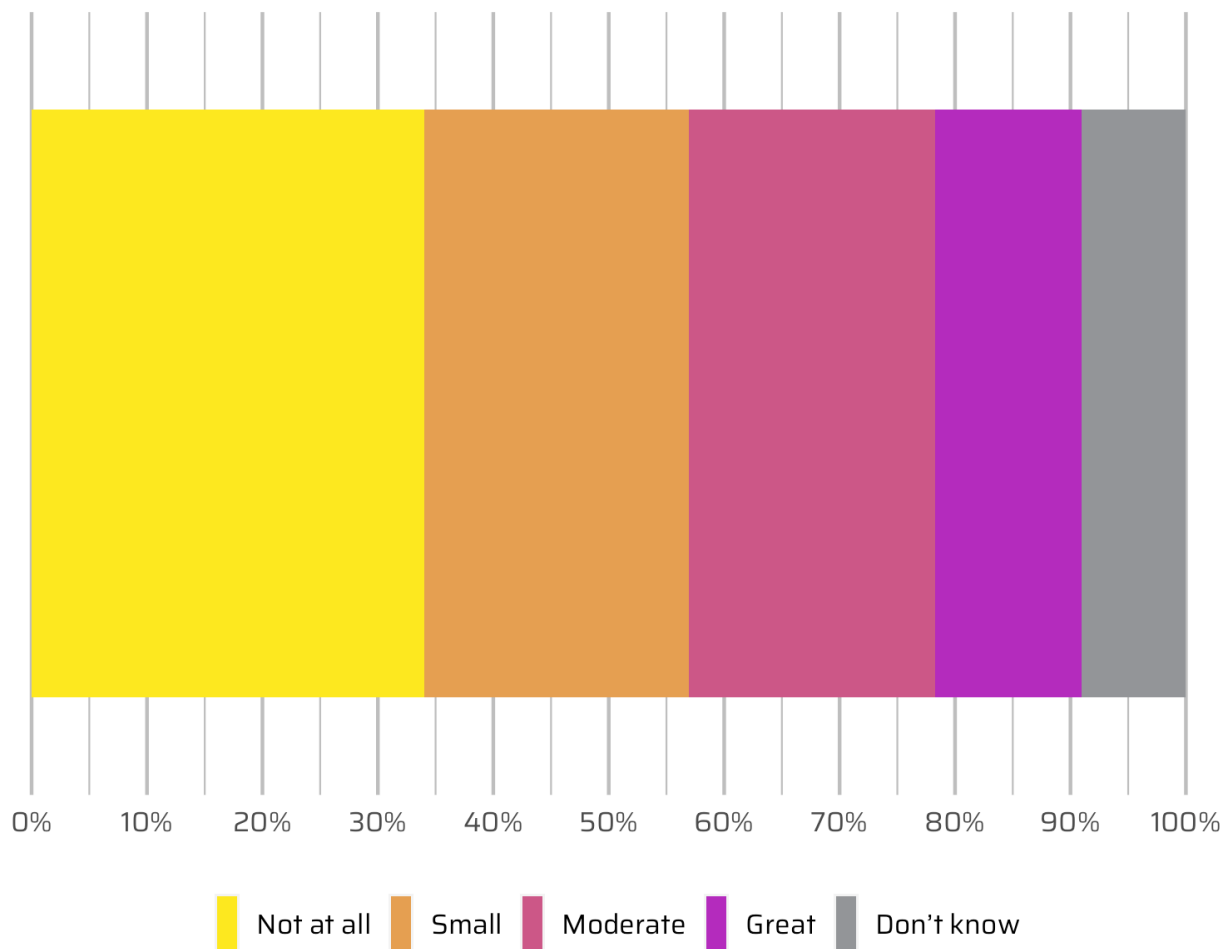


Figure 33: Extent respondents stated their mental health needs are being met.

Table 31: Extent respondents stated their mental health needs are being met.

Extent	Respondents	Percentage
Great	31	13
Moderate	52	21
Small	56	23
Not at all	83	34
Don't know	22	9

Gender: Extent Mental Health Needs Met

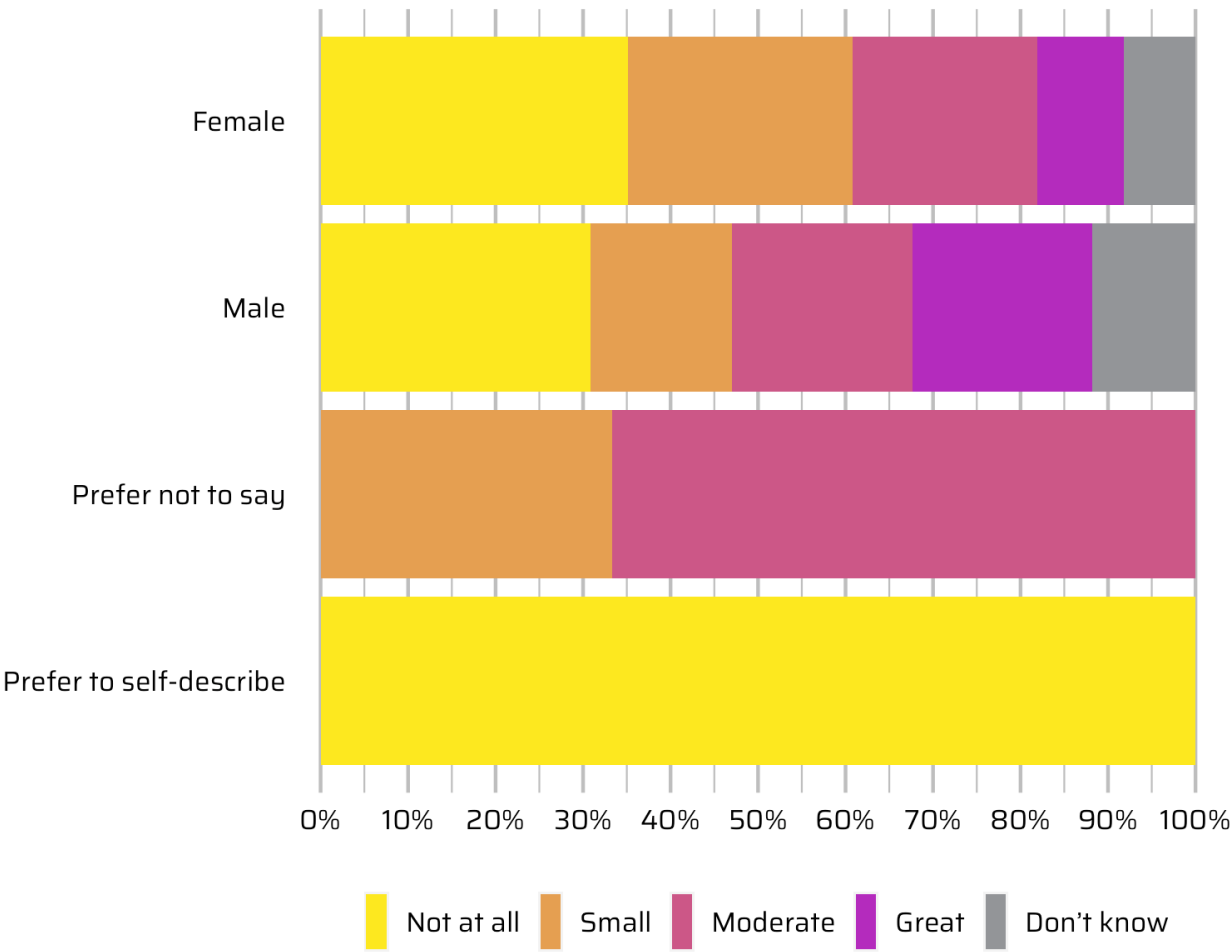


Figure 34: Extent respondents stated their mental health needs are being met broken down by gender.

Table 32: Extent respondents stated their mental health needs are being met broken down by gender.

Gender	Extent	Respondents	Percentage
Female	Great	17	10
	Moderate	36	21
	Small	44	26
	Not at all	60	35
	Don't know	14	8
Male	Great	14	21
	Moderate	14	21
	Small	11	16

Gender	Extent	Respondents	Percentage
	Not at all	21	31
	Don't know	8	12
Prefer not to say	Great	0	0
	Moderate	2	67
	Small	1	33
	Not at all	0	0
	Don't know	0	0
Prefer to self-describe	Great	0	0
	Moderate	0	0
	Small	0	0
	Not at all	2	100
	Don't know	0	0

Employment Status: Extent Mental Health Needs Met

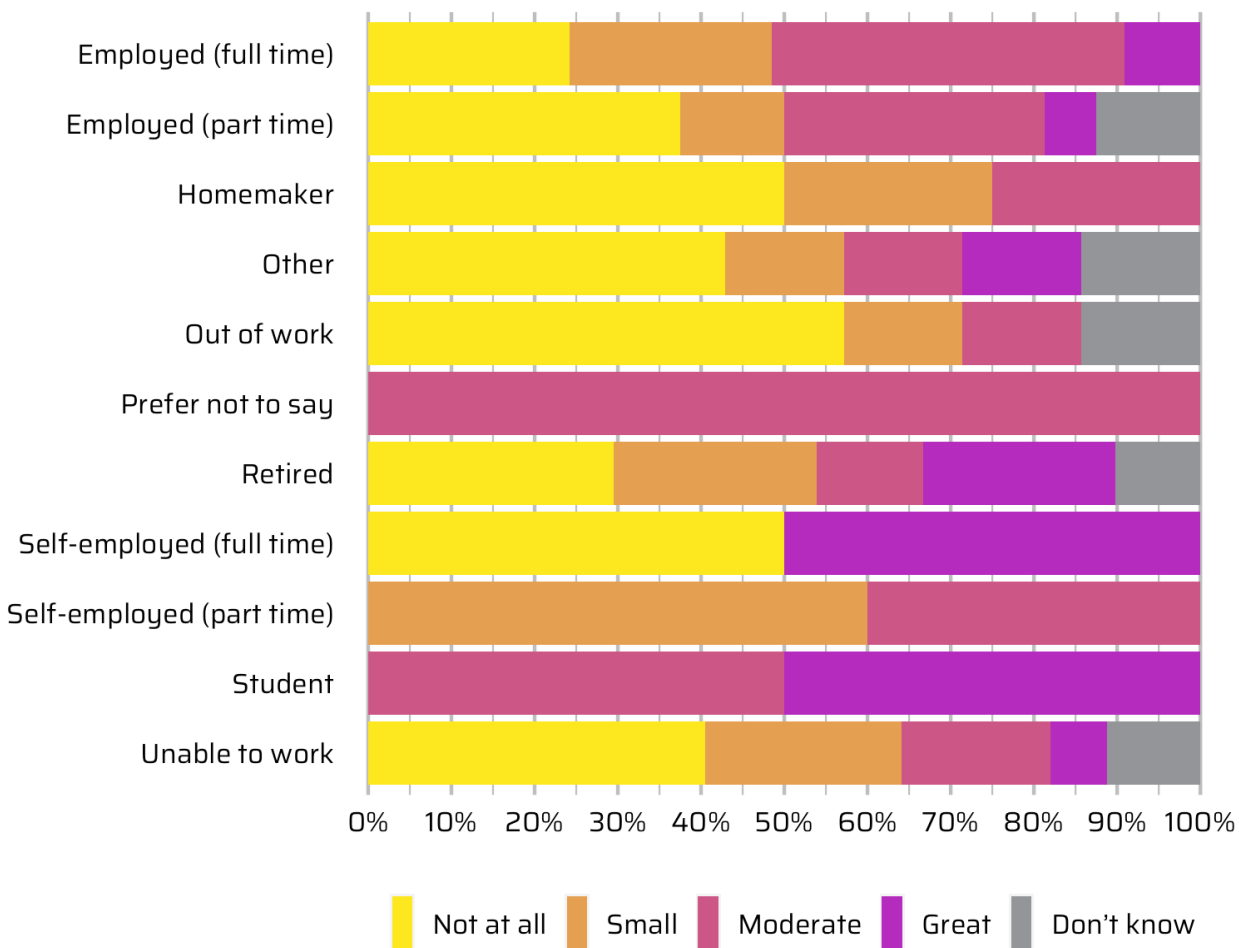


Figure 35: Extent respondents stated their mental health needs are being met broken down by employment status.

Table 33: Extent respondents stated their mental health needs are being met broken down by employment status.

Employment Status	Extent	Respondents	Percentage
Employed (full time)	Great	3	9
	Moderate	14	42
	Small	8	24
	Not at all	8	24
	Don't know	0	0
Employed (part time)	Great	1	6
	Moderate	5	31
	Small	2	12
	Not at all	6	38
	Don't know	2	12
Homemaker	Great	0	0
	Moderate	1	25
	Small	1	25
	Not at all	2	50
	Don't know	0	0
Other	Great	1	14
	Moderate	1	14
	Small	1	14
	Not at all	3	43
	Don't know	1	14
Out of work	Great	0	0
	Moderate	1	14
	Small	1	14
	Not at all	4	57
	Don't know	1	14
Prefer not to say	Great	0	0
	Moderate	1	100
	Small	0	0

Employment Status	Extent	Respondents	Percentage
	Not at all	0	0
	Don't know	0	0
Retired	Great	18	23
	Moderate	10	13
	Small	19	24
	Not at all	23	29
	Don't know	8	10
Self-employed (full time)	Great	1	50
	Moderate	0	0
	Small	0	0
	Not at all	1	50
	Don't know	0	0
Self-employed (part time)	Great	0	0
	Moderate	2	40
	Small	3	60
	Not at all	0	0
	Don't know	0	0
Student	Great	1	50
	Moderate	1	50
	Small	0	0
	Not at all	0	0
	Don't know	0	0
Unable to work	Great	6	7
	Moderate	16	18
	Small	21	24
	Not at all	36	40
	Don't know	10	11

Number of Dependents: Extent Mental Health Needs Met

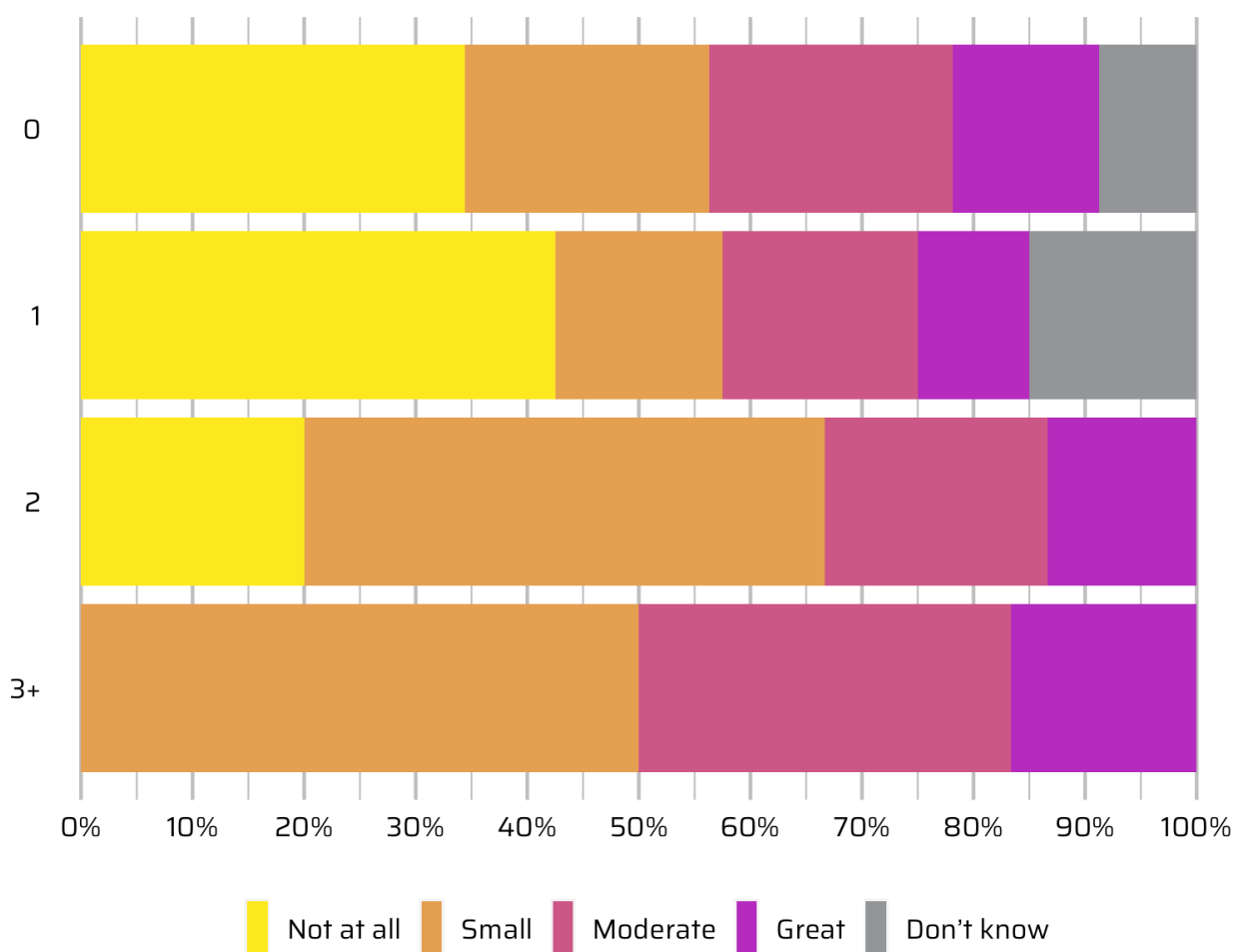


Figure 36: Extent respondents stated their mental health needs are being met broken down by if the respondents had dependents or not.

Table 34: Extent respondents stated their mental health needs are being met broken down by if the respondents had dependents or not.

Dependents	Extent	Respondents	Percentage
0	Great	24	13
	Moderate	40	22
	Small	40	22
	Not at all	63	34
	Don't know	16	9
1	Great	4	10
	Moderate	7	18
	Small	6	15

Dependents	Extent	Respondents	Percentage
2	Not at all	17	42
	Don't know	6	15
	Great	2	13
	Moderate	3	20
	Small	7	47
	Not at all	3	20
3+	Don't know	0	0
	Great	1	17
	Moderate	2	33
	Small	3	50
	Not at all	0	0
	Don't know	0	0

Anxious or Hopeless Feeling: Extent Mental Health Needs Met

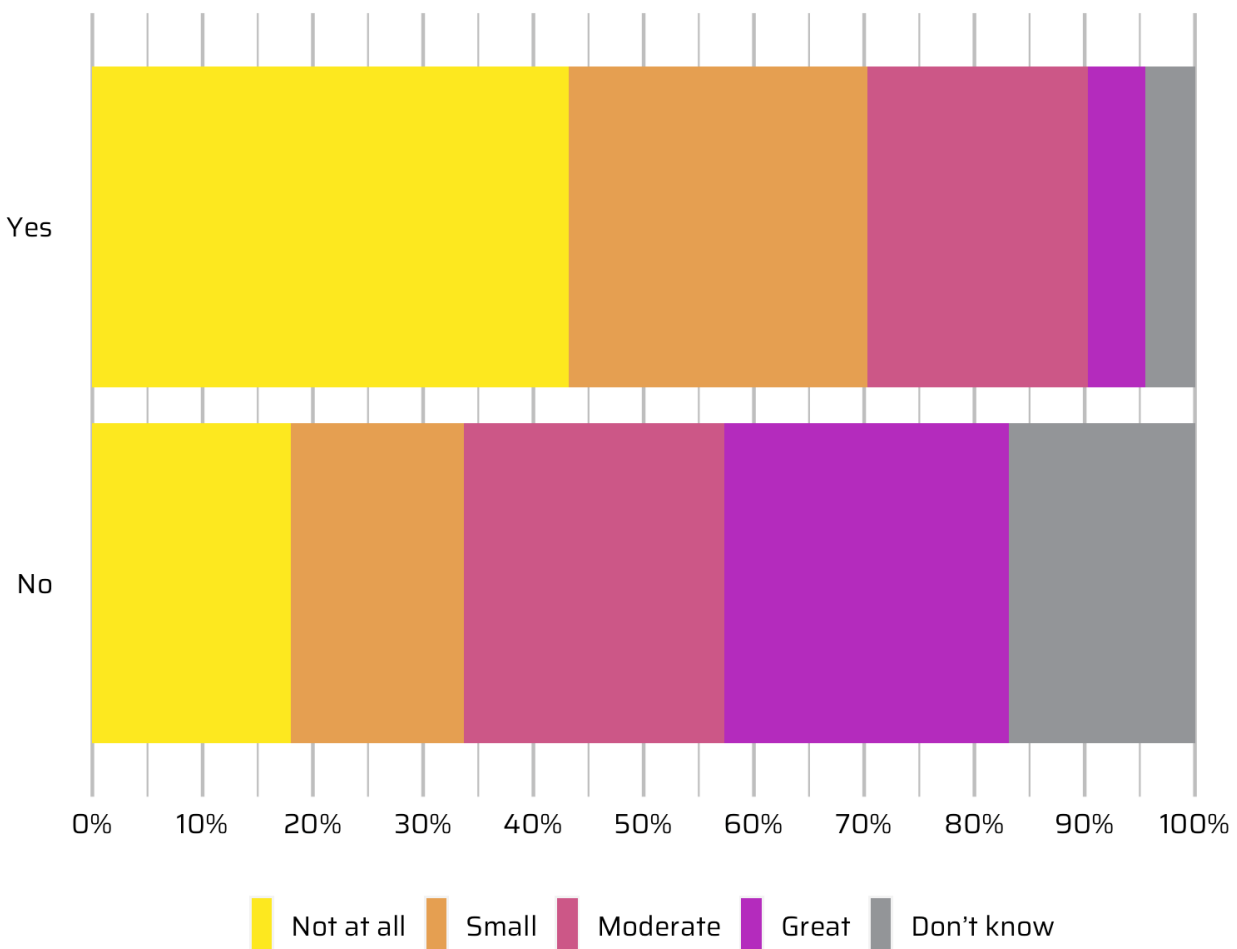


Figure 37: Extent respondents stated their mental health needs are being met broken down by if the respondent reported feeling hopeless or anxious.

Table 35: Extent respondents stated their mental health needs are being met broken down by if the respondent reported feeling hopeless or anxious.

Anxious or Hopeless	Extent	Respondents	Percentage
Yes	Great	8	5
	Moderate	31	20
	Small	42	27
	Not at all	67	43
	Don't know	7	5
No	Great	23	26
	Moderate	21	24
	Small	14	16
	Not at all	16	18
	Don't know	15	17

Age: Extent Mental Health Needs Met

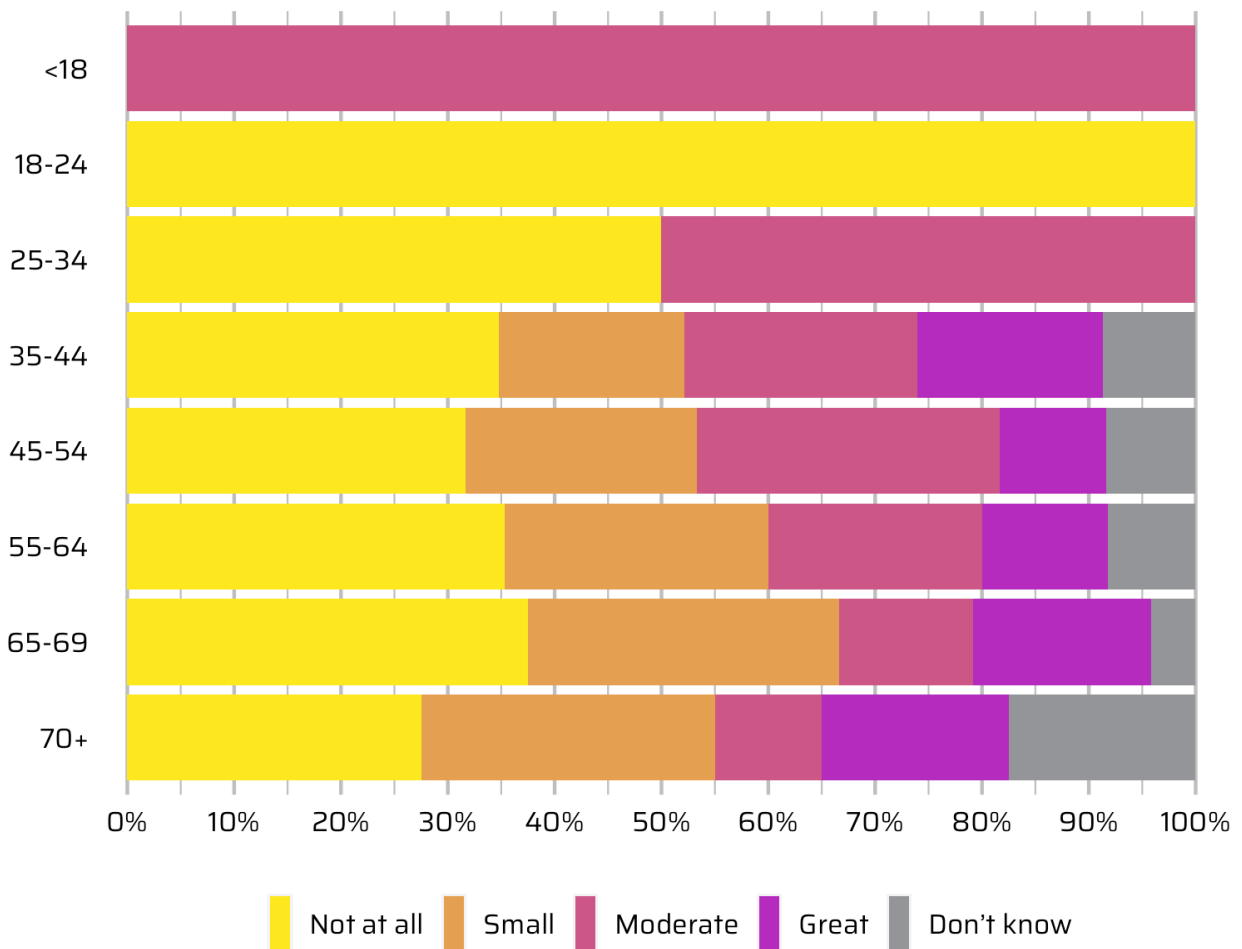


Figure 38: Extent respondents stated their mental health needs are being met broken down by age group.

Table 36: Extent respondents stated their mental health needs are being met broken down by age group.

Age	Extent	Respondents	Percentage
<18	Great	0	0
	Moderate	1	100
	Small	0	0
	Not at all	0	0
	Don't know	0	0
18-24	Great	0	0
	Moderate	0	0
	Small	0	0

Age	Extent	Respondents	Percentage
	Not at all	1	100
	Don't know	0	0
25-34	Great	0	0
	Moderate	5	50
	Small	0	0
	Not at all	5	50
	Don't know	0	0
35-44	Great	4	17
	Moderate	5	22
	Small	4	17
	Not at all	8	35
	Don't know	2	9
45-54	Great	6	10
	Moderate	17	28
	Small	13	22
	Not at all	19	32
	Don't know	5	8
55-64	Great	10	12
	Moderate	17	20
	Small	21	25
	Not at all	30	35
	Don't know	7	8
65-69	Great	4	17
	Moderate	3	12
	Small	7	29
	Not at all	9	38
	Don't know	1	4
70+	Great	7	18
	Moderate	4	10
	Small	11	28
	Not at all	11	28
	Don't know	7	18

Anxious or Hopeless Feeling

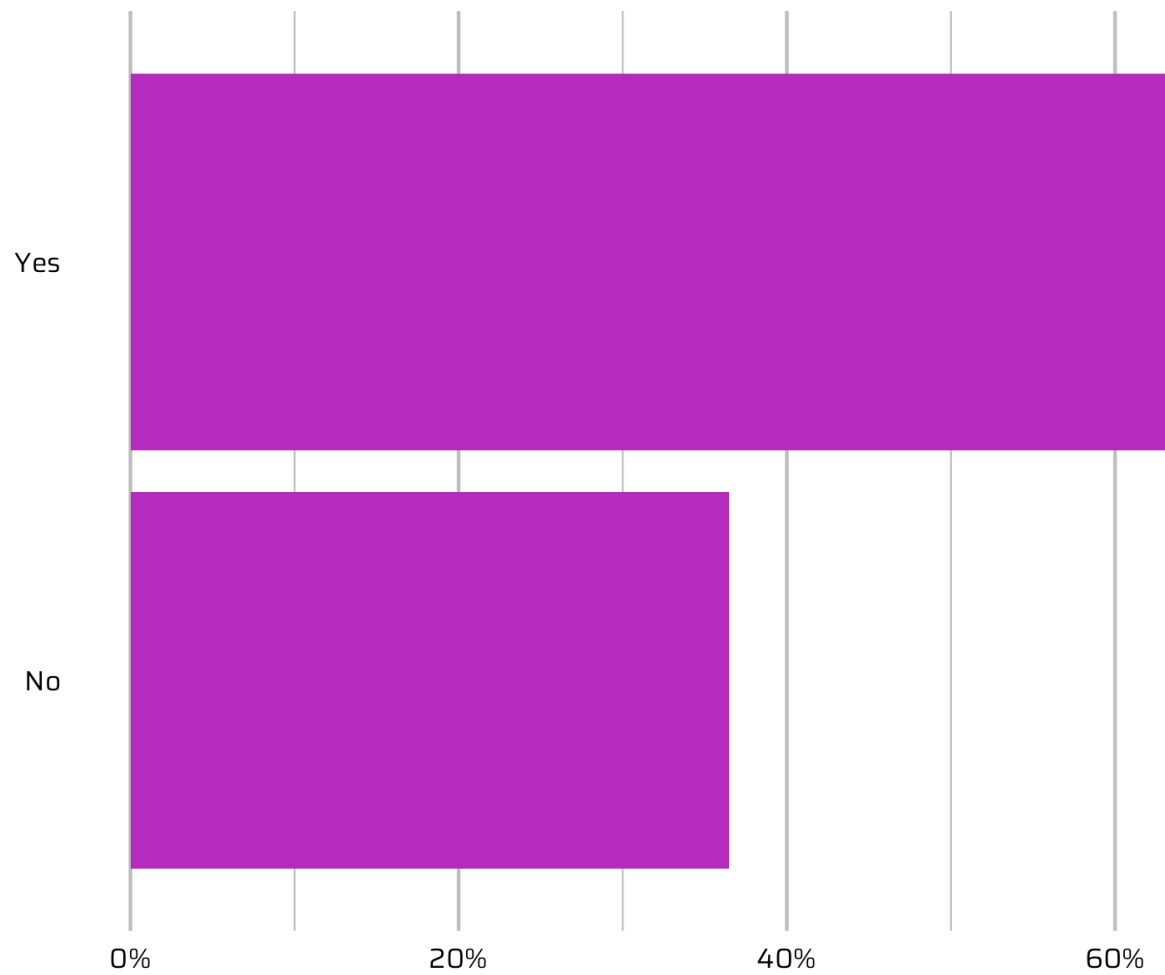


Figure 39: Respondents reporting if they are feeling anxious or hopeless.

Table 37: Respondents reporting if they are feeling anxious or hopeless.

Anxious or Hopeless	Respondents	Percentage
Yes	155	64
No	89	36

Employment Status: Anxious or Hopeless Feeling

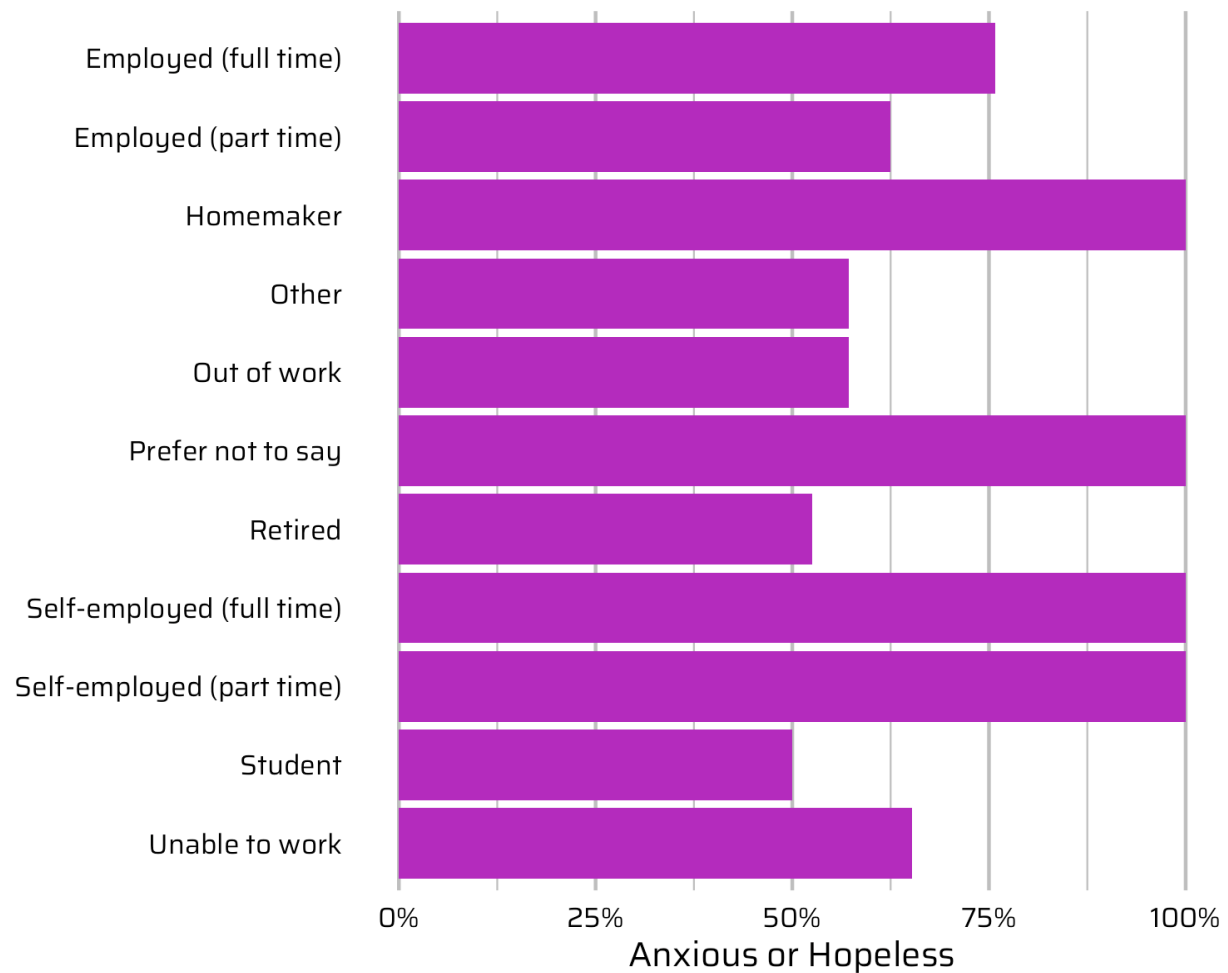


Figure 40: Respondents reporting if they are feeling anxious or hopeless broken down by employment status.

Table 38: Respondents reporting if they are feeling anxious or hopeless broken down by employment status.

Employment Status	Anxious or Hopeless	Respondents	Percentage
Employed (full time)	Yes	25	76
	No	8	24
Employed (part time)	Yes	10	62
	No	6	38
Homemaker	Yes	4	100
	No	0	0
Other	Yes	4	57
	No	3	43

Employment Status	Anxious or Hopeless	Respondents	Percentage
Out of work	Yes	4	57
	No	3	43
Prefer not to say	Yes	1	100
	No	0	0
Retired	Yes	41	53
	No	37	47
Self-employed (full time)	Yes	2	100
	No	0	0
Self-employed (part time)	Yes	5	100
	No	0	0
Student	Yes	1	50
	No	1	50
Unable to work	Yes	58	65
	No	31	35

Quantitative data - Sought emergency support

Frequency NHS A&E/Emergency Support Sought

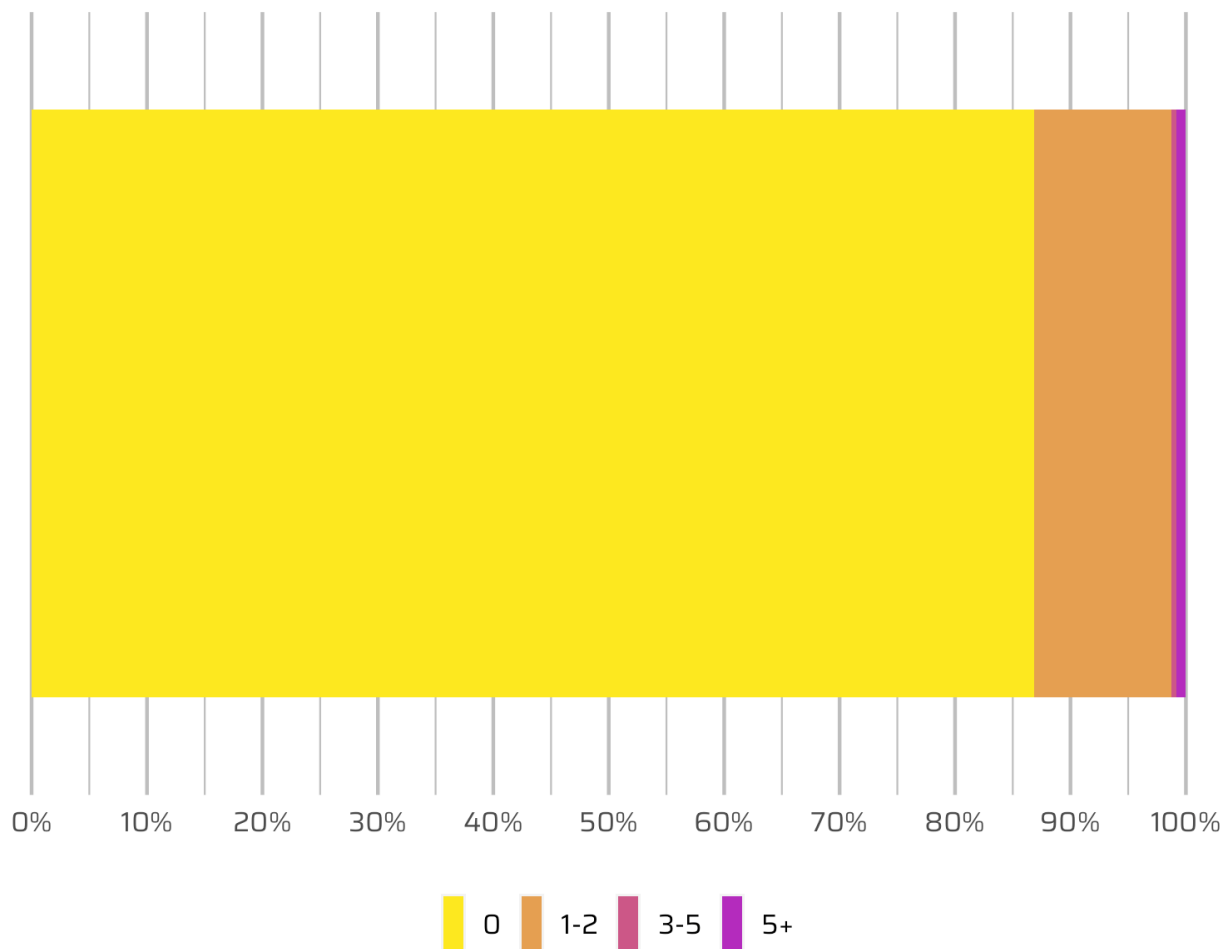


Figure 41: The frequency respondents sought NHS A&E or Emergency Support.

Table 39: The frequency respondents sought NHS A&E or Emergency Support.

Frequency	Respondents	Percentage
5+	2	1
3-5	1	0
1-2	29	12
0	212	87

Gender: Frequency NHS A&E/Emergency Support Sought

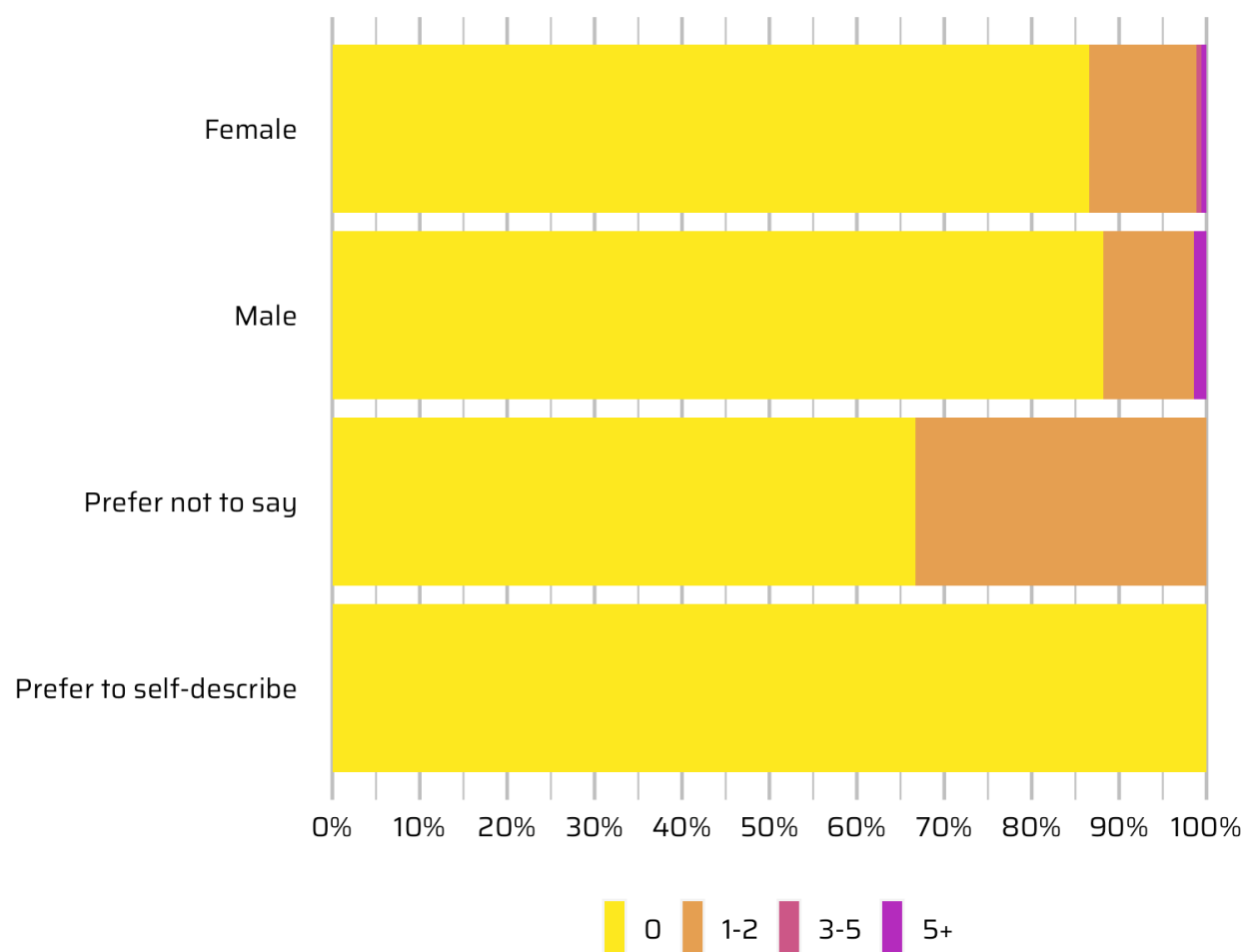


Figure 42: The frequency respondents sought NHS A&E or Emergency Support broken down by gender.

Table 40: The frequency respondents sought NHS A&E or Emergency Support broken down by gender.

Gender	Frequency	Respondents	Percentage
Female	5+	1	1
	3-5	1	1
	1-2	21	12
	0	148	87
Male	5+	1	1
	3-5	0	0
	1-2	7	10
	0	60	88

Gender	Frequency	Respondents	Percentage
Prefer not to say	5+	0	0
	3-5	0	0
	1-2	1	33
	0	2	67
Prefer to self-describe	5+	0	0
	3-5	0	0
	1-2	0	0
	0	2	100

Employment Status: Frequency NHS A&E/Emergency Support Sought

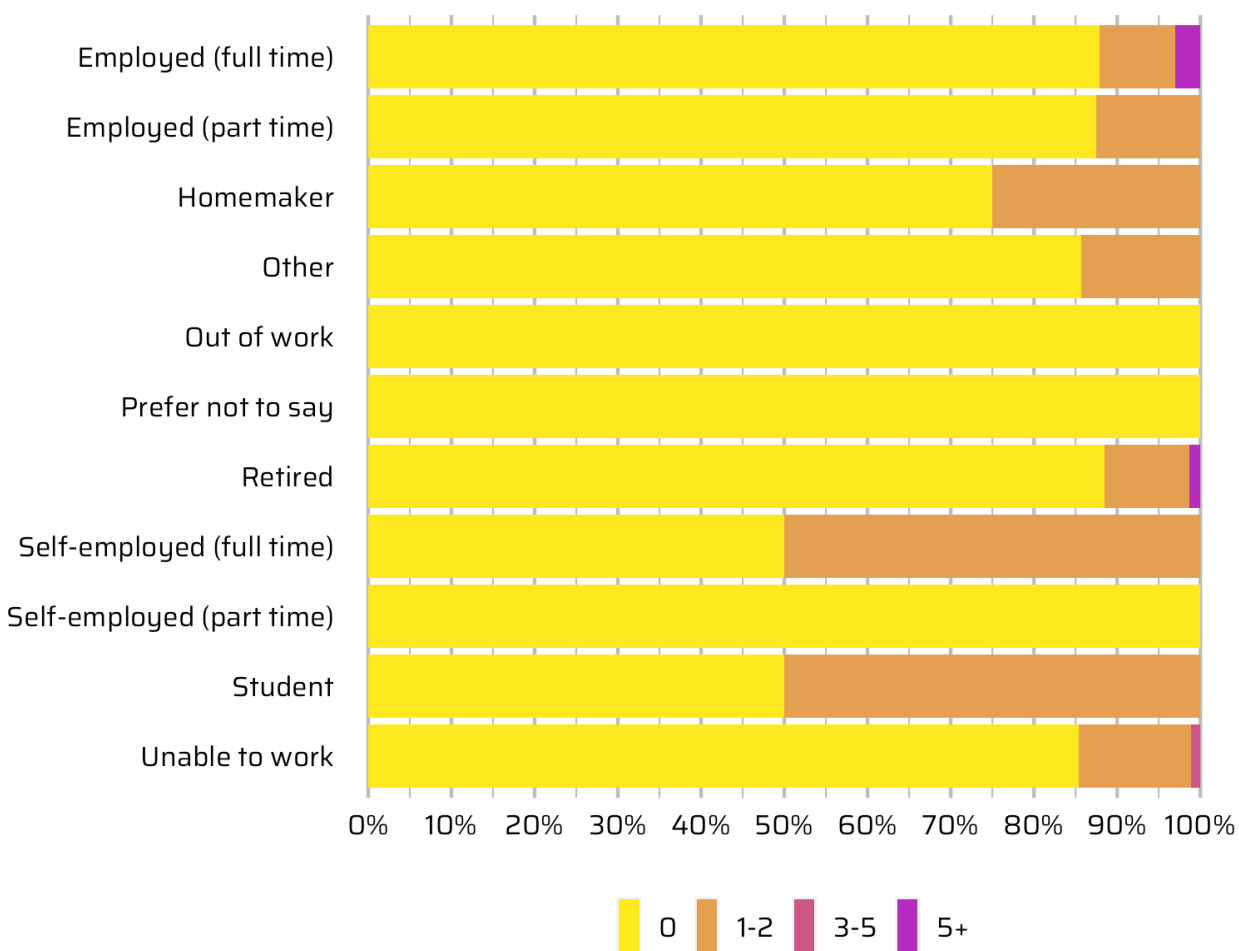


Figure 43: The frequency respondents sought NHS A&E or Emergency Support broken down by employment status.

Table 41: the frequency respondents sought NHS A&E or Emergency Support broken down by employment status.

Employment Status	Frequency	Respondents	Percentage
Employed (full time)	5+	1	3
	3-5	0	0
	1-2	3	9
	0	29	88
Employed (part time)	5+	0	0
	3-5	0	0
	1-2	2	12
	0	14	88
Homemaker	5+	0	0
	3-5	0	0
	1-2	1	25
	0	3	75
Other	5+	0	0
	3-5	0	0
	1-2	1	14
	0	6	86
Out of work	5+	0	0
	3-5	0	0
	1-2	0	0
	0	7	100
Prefer not to say	5+	0	0
	3-5	0	0
	1-2	0	0
	0	1	100
Retired	5+	1	1
	3-5	0	0
	1-2	8	10
	0	69	88
Self-employed (full time)	5+	0	0
	3-5	0	0
	1-2	1	50
	0	1	50
Self-employed (part time)	5+	0	0
	3-5	0	0
	1-2	0	0
	0	5	100
Student	5+	0	0

Employment Status	Frequency	Respondents	Percentage
	3-5	0	0
	1-2	1	50
	0	1	50
Unable to work	5+	0	0
	3-5	1	1
	1-2	12	13
	0	76	85

Number of Dependents: Frequency NHS A&E/Emergency Support Sought

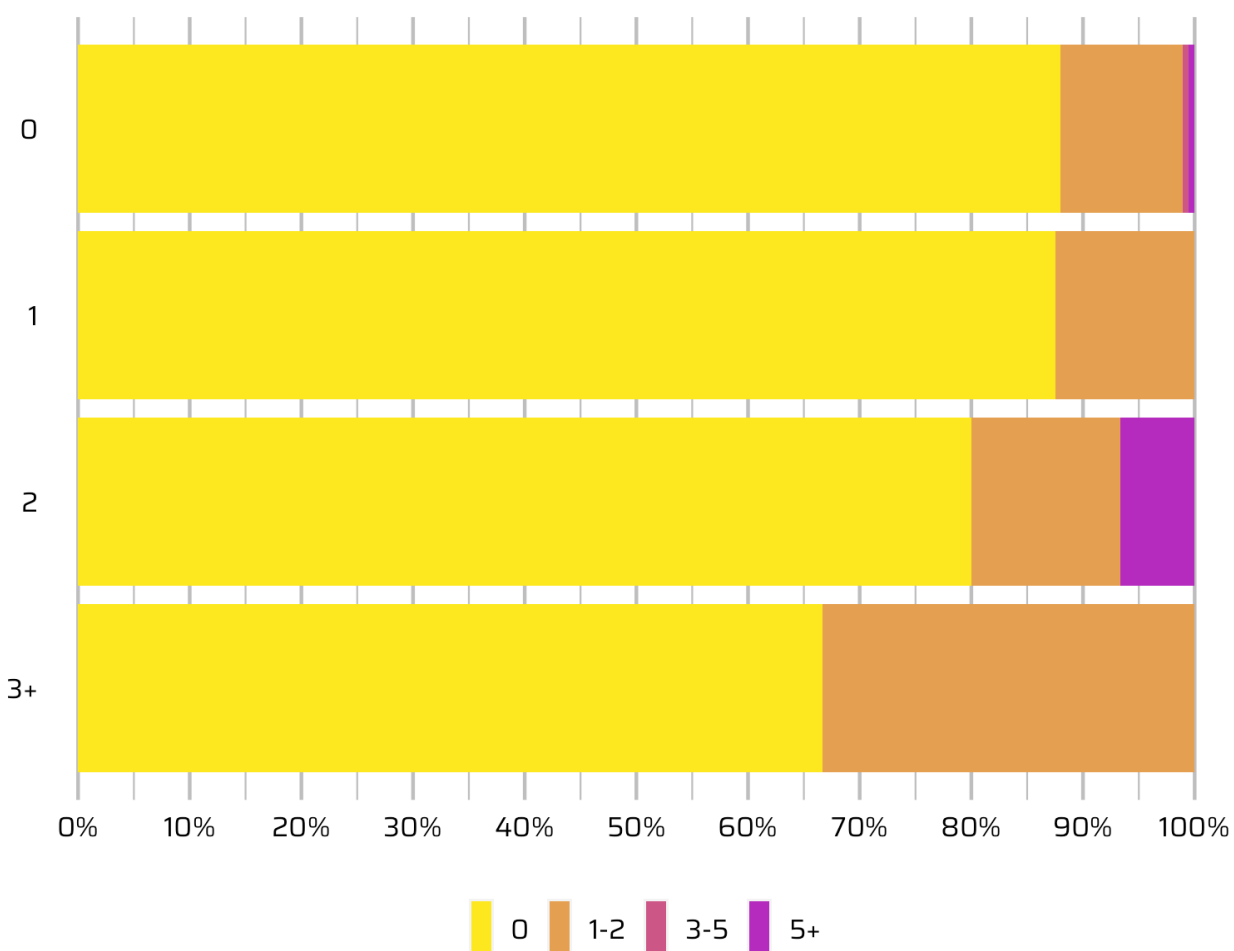


Figure 44: The frequency respondents sought NHS A&E or Emergency Support broken down by the number of dependents the respondents have.

Table 42: The frequency respondents sought NHS A&E or Emergency Support broken down by the number of dependents the respondents have.

Dependents	Frequency	Respondents	Percentage
0	5+	1	1
	3-5	1	1
	1-2	20	11
	0	161	88
1	5+	0	0
	3-5	0	0
	1-2	5	12
	0	35	88
2	5+	1	7
	3-5	0	0
	1-2	2	13
	0	12	80
3+	5+	0	0
	3-5	0	0
	1-2	2	33
	0	4	67

Anxious or Hopeless Feeling: Frequency NHS A&E/Emergency Support Sought

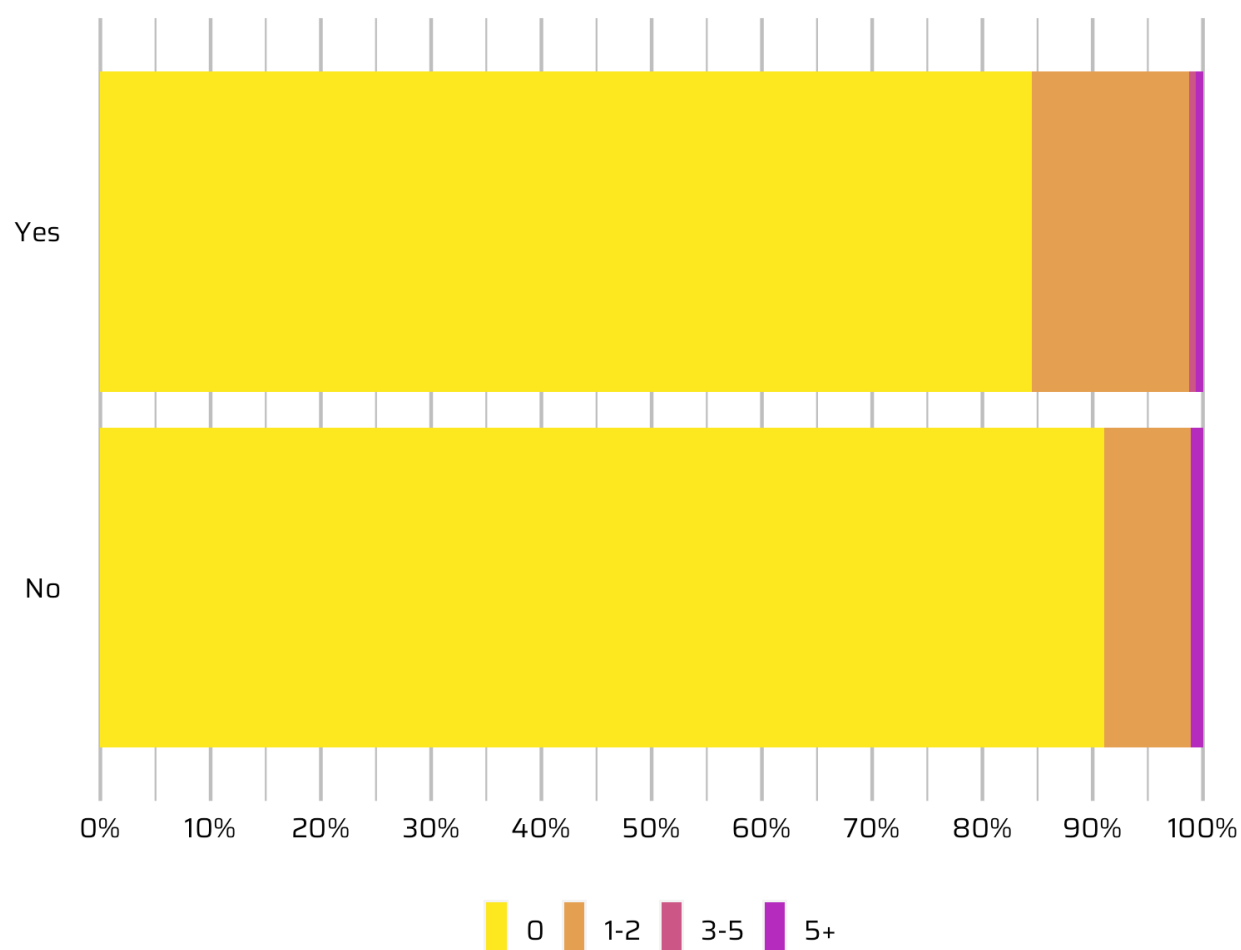


Figure 45: The frequency respondents sought NHS A&E or Emergency Support broken down by if they reported feeling anxious or hopeless.

Table 43: The frequency respondents sought NHS A&E or Emergency Support broken down by if they reported feeling anxious or hopeless.

Anxious or Hopeless	Frequency	Respondents	Percentage
Yes	5+	1	1
	3-5	1	1
	1-2	22	14
	0	131	85
No	5+	1	1
	3-5	0	0
	1-2	7	8

Anxious or Hopeless	Frequency	Respondents	Percentage
	0	81	91

Age: Frequency NHS A&E/Emergency Support Sought

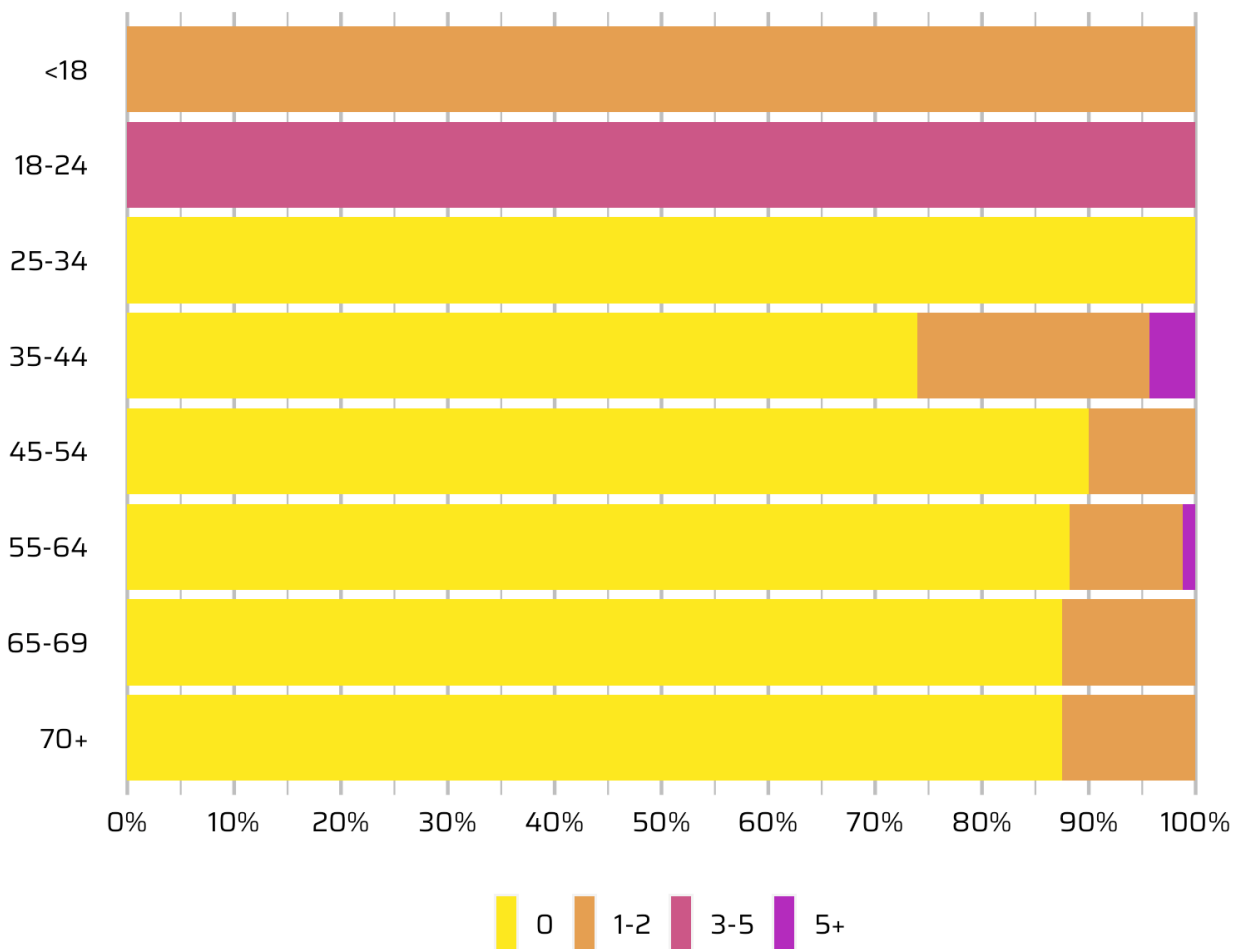


Figure 46: The frequency respondents sought NHS A&E or Emergency Support broken down by age group.

Table 44: The frequency respondents sought NHS A&E or Emergency Support broken down by age group

Age	Frequency	Respondents	Percentage
<18	5+	0	0
	3-5	0	0
	1-2	1	100
	0	0	0

Age	Frequency	Respondents	Percentage
18-24	5+	0	0
	3-5	1	100
	1-2	0	0
	0	0	0
25-34	5+	0	0
	3-5	0	0
	1-2	0	0
	0	10	100
35-44	5+	1	4
	3-5	0	0
	1-2	5	22
	0	17	74
45-54	5+	0	0
	3-5	0	0
	1-2	6	10
	0	54	90
55-64	5+	1	1
	3-5	0	0
	1-2	9	11
	0	75	88
65-69	5+	0	0
	3-5	0	0
	1-2	3	12
	0	21	88
70+	5+	0	0
	3-5	0	0
	1-2	5	12
	0	35	88

Quantitative data - Experience of care and support accessed

Treatment, Care, or Support Accessed

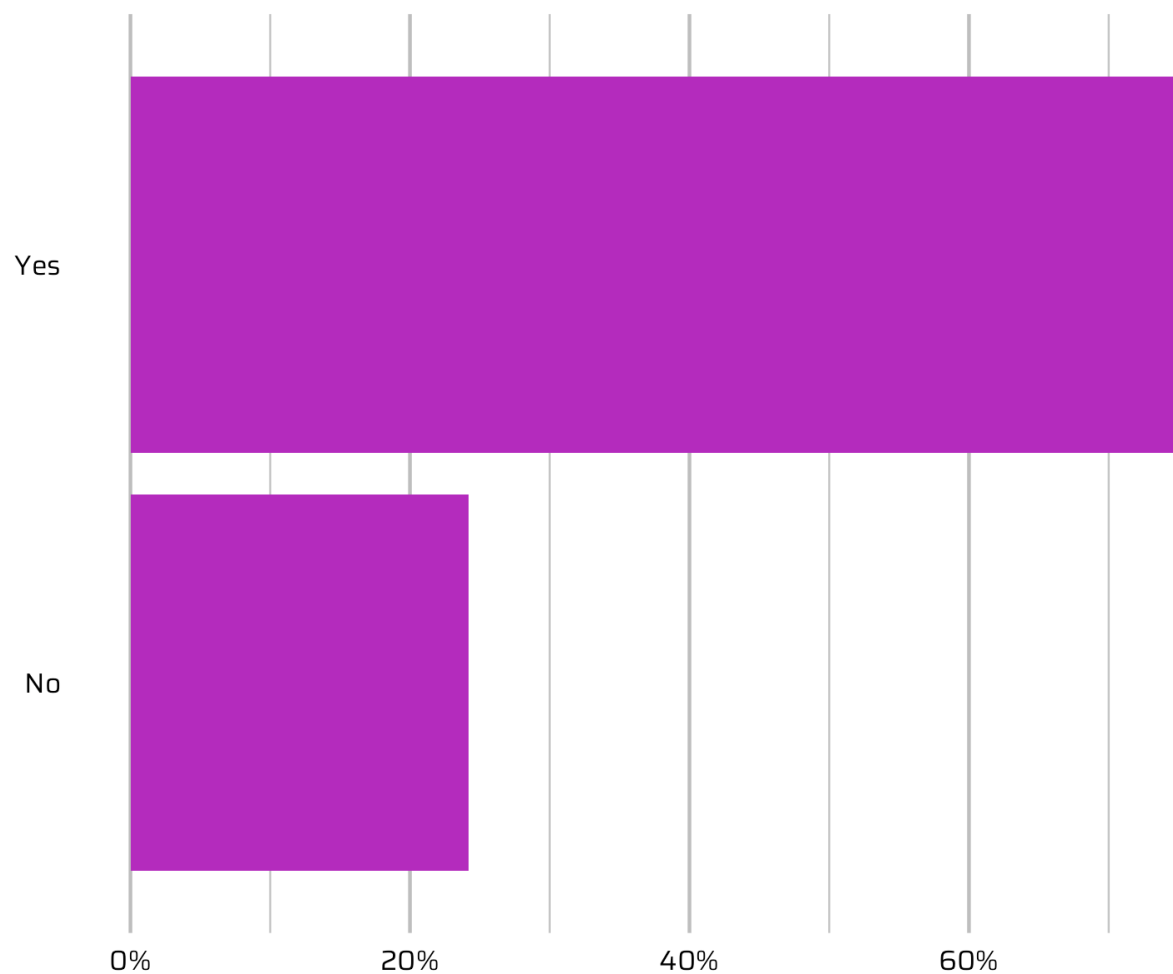


Figure 47: Respondents that reported accessing treatment, care and support services.

Table 45: Respondents that reported accessing treatment, care and support services.

Access	Respondents	Percentage
Yes	182	75
No	59	24
NA	3	1

Experience Overall

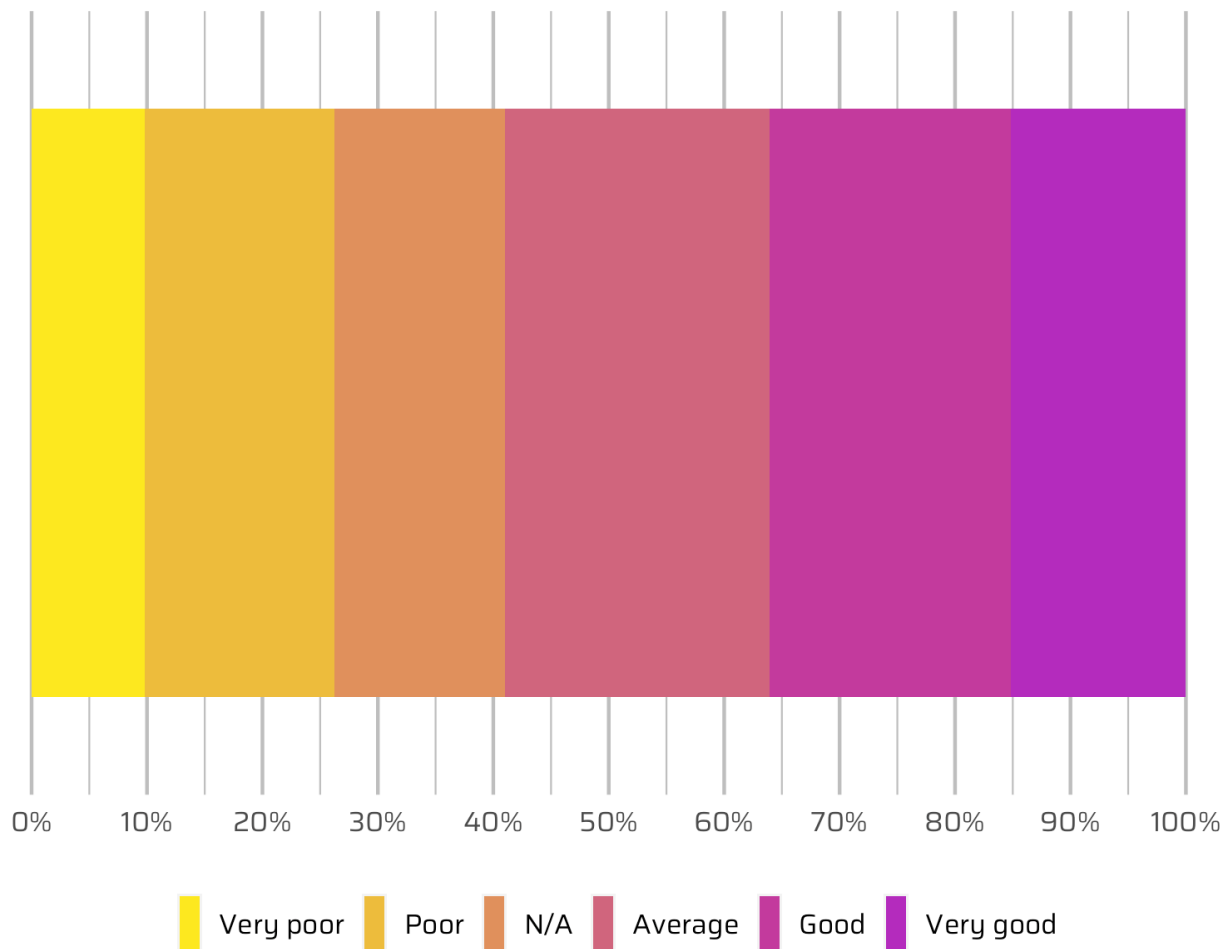


Figure 48: Overall experience of those respondents that reported accessing treatment, care, and support services.

Table 46: Overall experience of those respondents that reported accessing treatment, care, and support services.

Experience	Respondents	Percentage
Very good	37	15
Good	51	21
Average	56	23
N/A	36	15
Poor	40	16
Very poor	24	10

Gender: Experience Overall

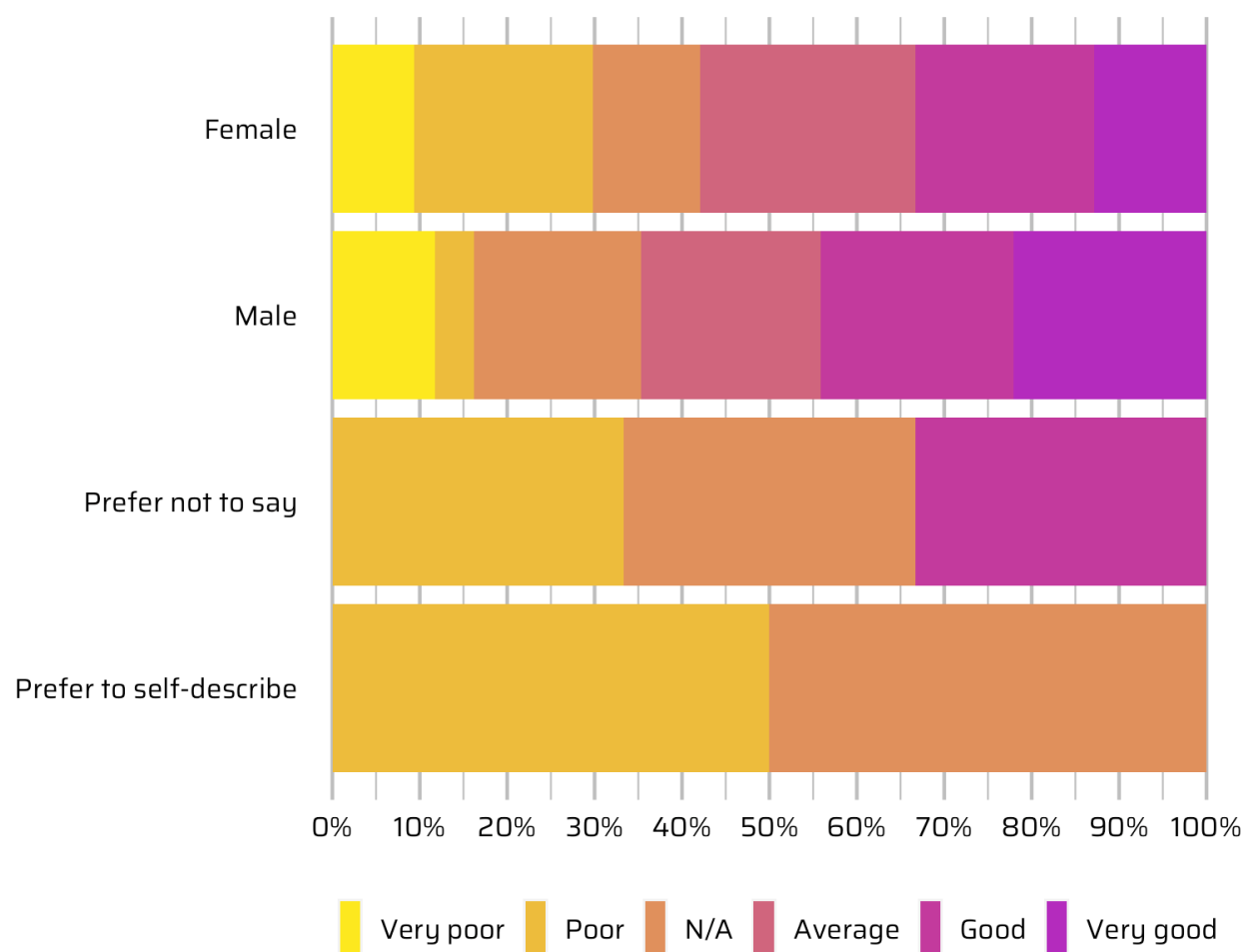


Figure 49: Overall experience of those respondents that reported accessing treatment, care, and support services broken down by gender.

Table 47: Overall experience of those respondents that reported accessing treatment, care, and support services broken down by gender.

Gender	Experience	Respondents	Percentage
Female	Very good	22	13
	Good	35	20
	Average	42	25
	N/A	21	12
	Poor	35	20
	Very poor	16	9
Male	Very good	15	22
	Good	15	22

Gender	Experience	Respondents	Percentage
	Average	14	21
	N/A	13	19
	Poor	3	4
	Very poor	8	12
Prefer not to say	Very good	0	0
	Good	1	33
	Average	0	0
	N/A	1	33
	Poor	1	33
	Very poor	0	0
Prefer to self-describe	Very good	0	0
	Good	0	0
	Average	0	0
	N/A	1	50
	Poor	1	50
	Very poor	0	0

Employment Status: Experience Overall

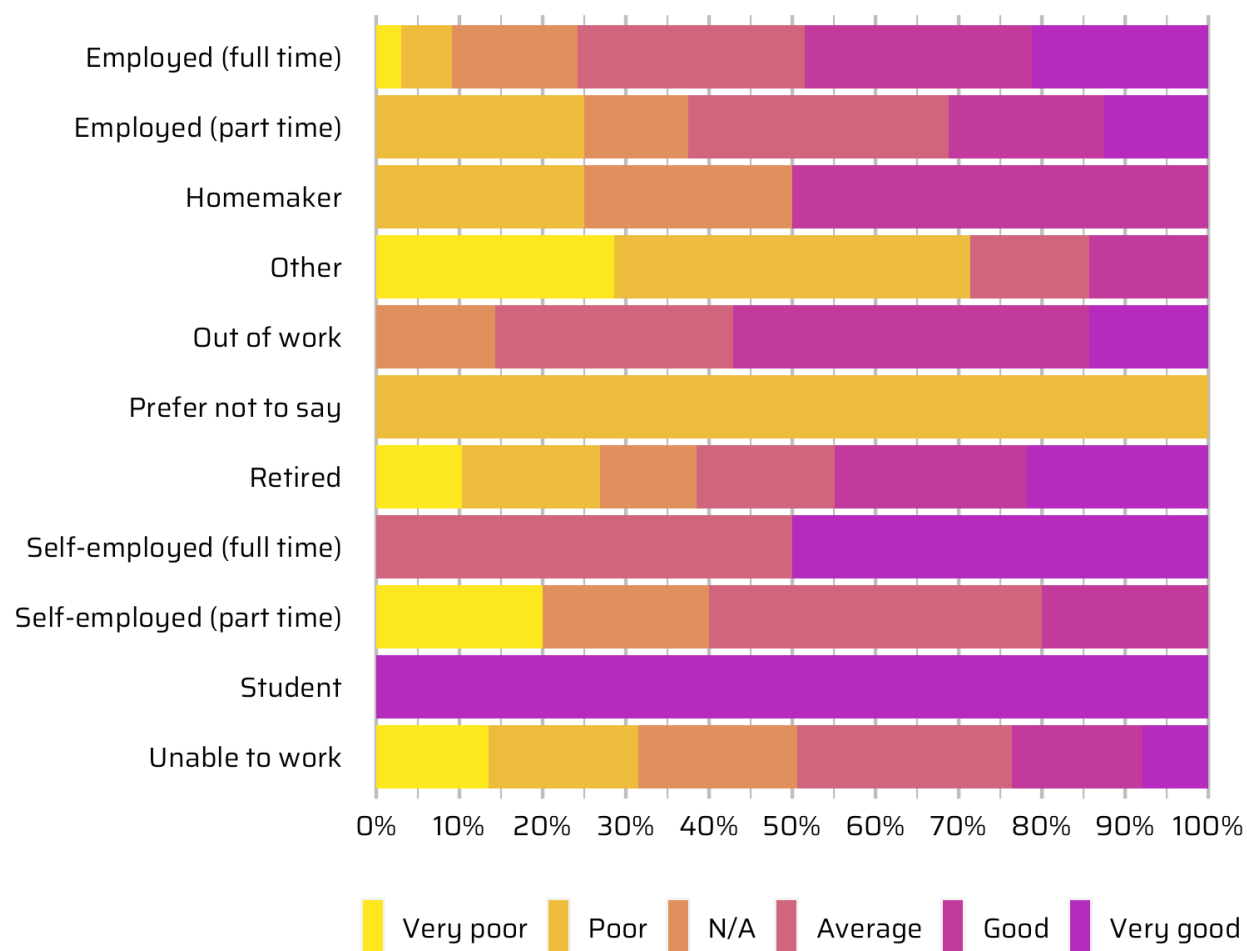


Figure 50: Overall experience of those respondents that reported accessing treatment, care, and support services broken down by employment status.

Table 48: Overall experience of those respondents that reported accessing treatment, care, and support services broken down by employment status.

Employment Status	Experience	Respondents	Percentage
Employed (full time)	Very good	7	21
Employed (full time)	Good	9	27
	Average	9	27
	N/A	5	15
	Poor	2	6
	Very poor	1	3
Employed (part time)	Very good	2	12
	Good	3	19

Employment Status	Experience	Respondents	Percentage
	Average	5	31
	N/A	2	12
	Poor	4	25
	Very poor	0	0
Homemaker	Very good	0	0
	Good	2	50
	Average	0	0
	N/A	1	25
	Poor	1	25
	Very poor	0	0
Other	Very good	0	0
	Good	1	14
	Average	1	14
	N/A	0	0
	Poor	3	43
	Very poor	2	29
Out of work	Very good	1	14
	Good	3	43
	Average	2	29
	N/A	1	14
	Poor	0	0
	Very poor	0	0
Prefer not to say	Very good	0	0
	Good	0	0
	Average	0	0
	N/A	0	0
	Poor	1	100
	Very poor	0	0
Retired	Very good	17	22
	Good	18	23
	Average	13	17
	N/A	9	12
	Poor	13	17
	Very poor	8	10
Self-employed (full time)	Very good	1	50
	Good	0	0
	Average	1	50
	N/A	0	0
	Poor	0	0

Employment Status	Experience	Respondents	Percentage
Self-employed (part time)	Very poor	0	0
	Very good	0	0
	Good	1	20
	Average	2	40
	N/A	1	20
	Poor	0	0
	Very poor	1	20
Student	Very good	2	100
	Good	0	0
	Average	0	0
	N/A	0	0
	Poor	0	0
	Very poor	0	0
Unable to work	Very good	7	8
	Good	14	16
	Average	23	26
	N/A	17	19
	Poor	16	18
	Very poor	12	13

Number of Dependents: Experience Overall

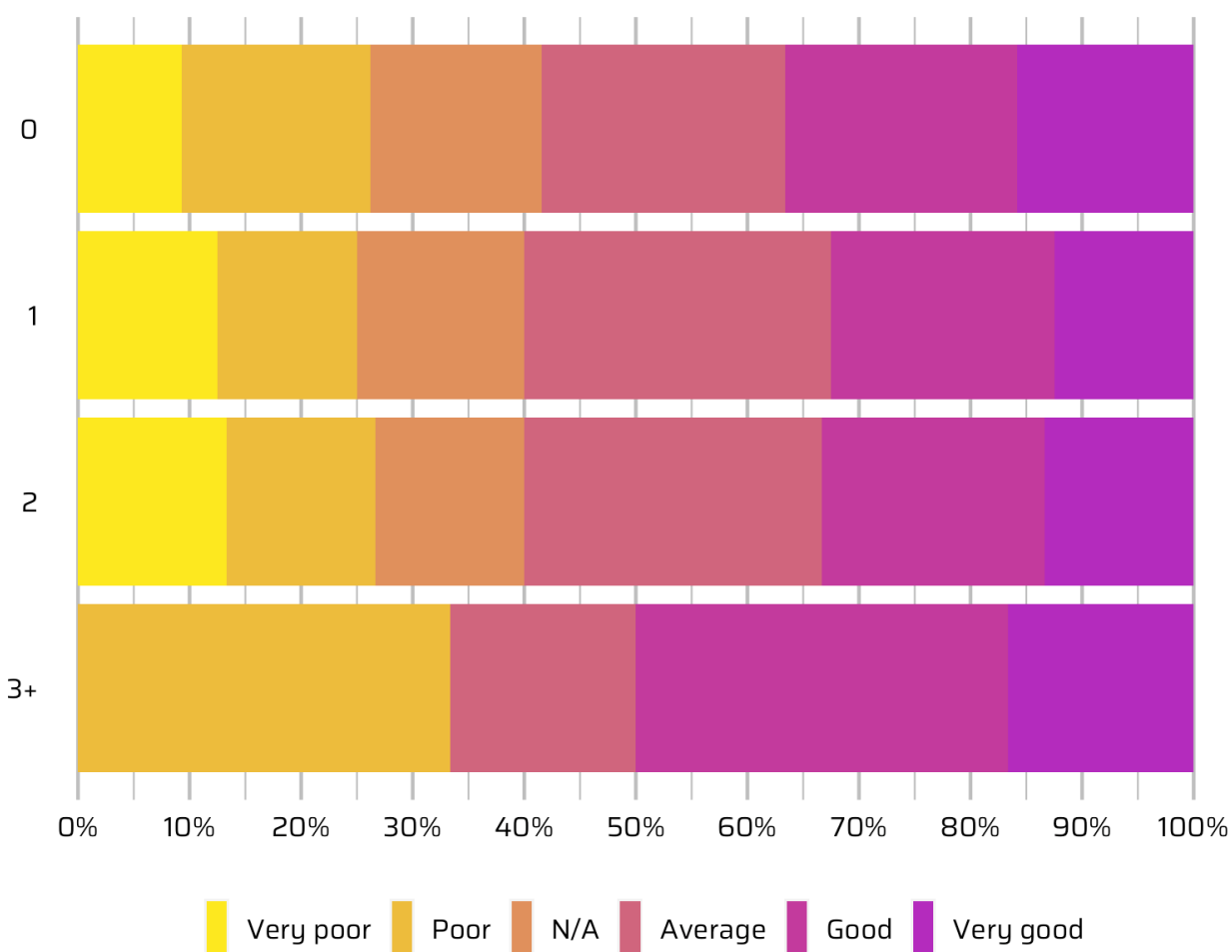


Figure 51: Overall experience of those respondents that reported accessing treatment, care, and support services broken down by number dependents.

Table 49: Overall experience of those respondents that reported accessing treatment, care, and support services broken down by number dependents.

Dependents	Experience	Respondents	Percentage
0	Very good	29	16
	Good	38	21
	Average	40	22
	N/A	28	15
	Poor	31	17
	Very poor	17	9
1	Very good	5	12
	Good	8	20

Dependents	Experience	Respondents	Percentage
	Average	11	28
	N/A	6	15
	Poor	5	12
	Very poor	5	12
2	Very good	2	13
	Good	3	20
	Average	4	27
	N/A	2	13
	Poor	2	13
	Very poor	2	13
3+	Very good	1	17
	Good	2	33
	Average	1	17
	N/A	0	0
	Poor	2	33
	Very poor	0	0

Anxious or Hopeless Feeling: Experience Overall

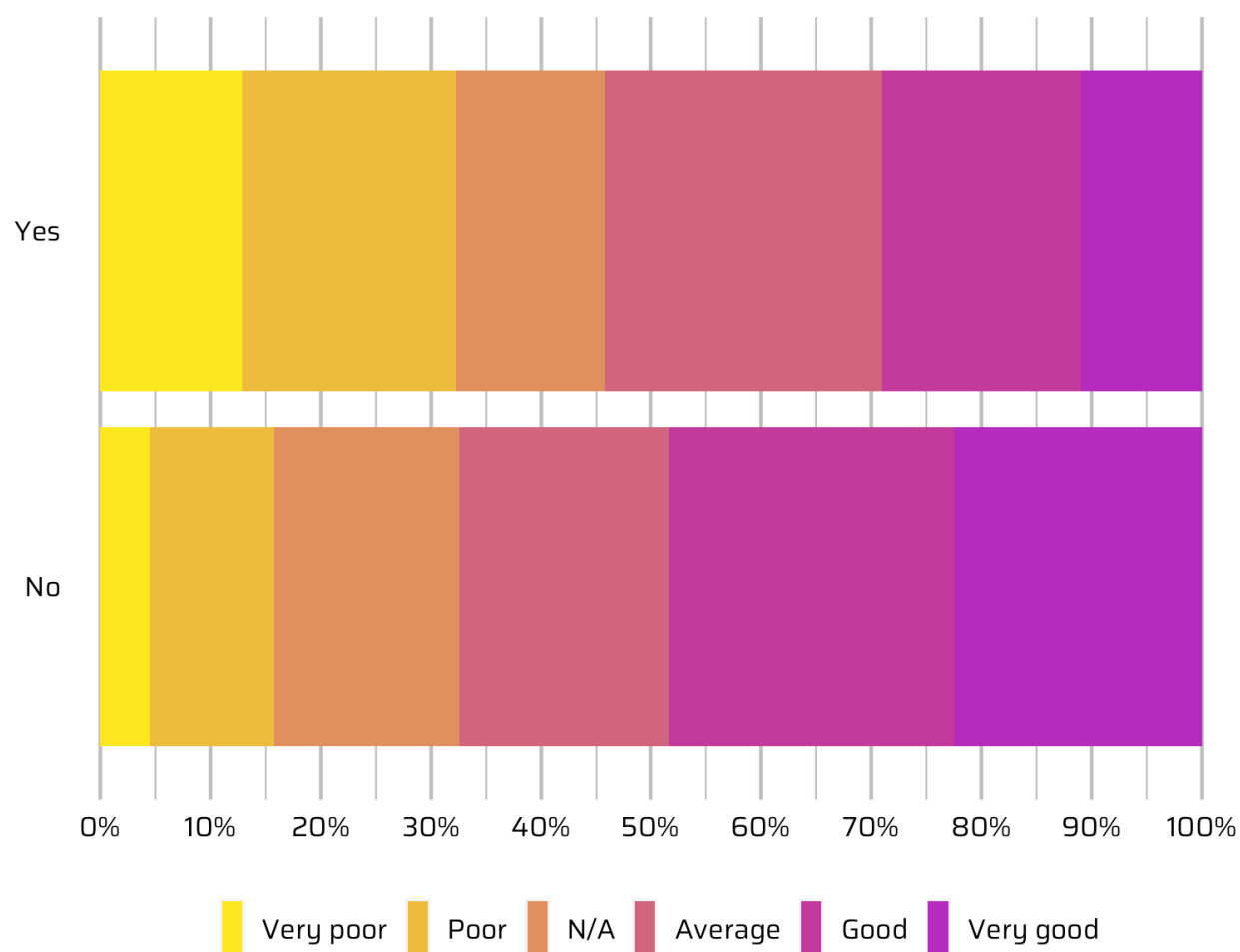


Figure 52: Overall experience of those respondents that reported accessing treatment, care, and support services split by if the person reported feeling anxious or hopeless.

Table 50: Overall experience of those respondents that reported accessing treatment, care, and support services split by if the person reported feeling anxious or hopeless.

Anxious or Hopeless	Experience	Respondents	Percentage
Yes	Very good	17	11
	Good	28	18
	Average	39	25
	N/A	21	14
	Poor	30	19
	Very poor	20	13
No	Very good	20	22
	Good	23	26

Anxious or Hopeless	Experience	Respondents	Percentage
	Average	17	19
	N/A	15	17
	Poor	10	11
	Very poor	4	4

Age: Experience Overall

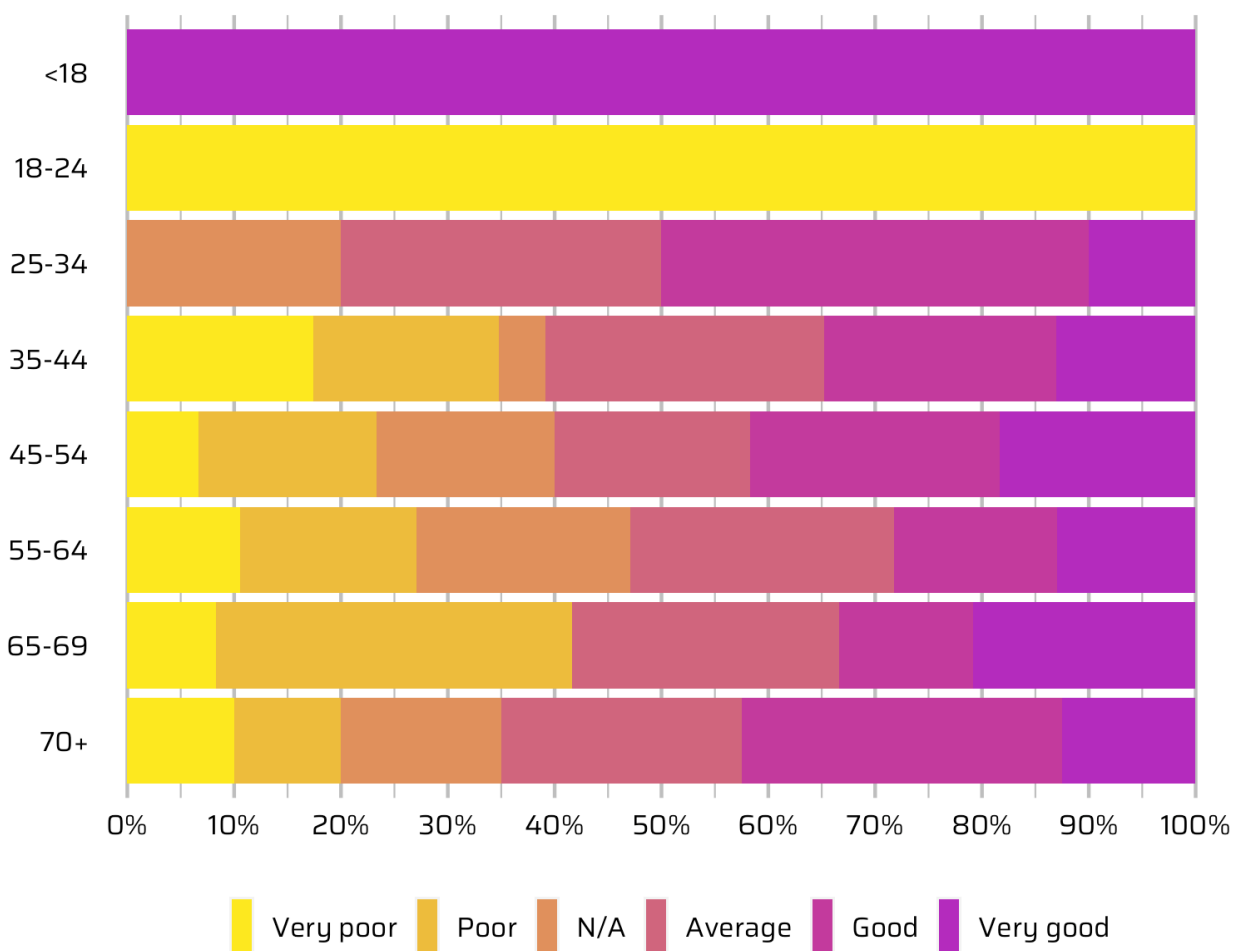


Figure 53: Overall experience of those respondents that reported accessing treatment, care, and support services broken down by age group.

Table 51: Overall experience of those respondents that reported accessing treatment, care, and support services broken down by age group.

Age	Experience	Respondents	Percentage
<18	Very good	1	100

Age	Experience	Respondents	Percentage
	Good	0	0
	Average	0	0
	N/A	0	0
	Poor	0	0
	Very poor	0	0
18-24	Very good	0	0
	Good	0	0
	Average	0	0
	N/A	0	0
	Poor	0	0
	Very poor	1	100
25-34	Very good	1	10
	Good	4	40
	Average	3	30
	N/A	2	20
	Poor	0	0
	Very poor	0	0
35-44	Very good	3	13
	Good	5	22
	Average	6	26
	N/A	1	4
	Poor	4	17
	Very poor	4	17
45-54	Very good	11	18
	Good	14	23
	Average	11	18
	N/A	10	17
	Poor	10	17
	Very poor	4	7
55-64	Very good	11	13
	Good	13	15
	Average	21	25
	N/A	17	20
	Poor	14	16
	Very poor	9	11
65-69	Very good	5	21
	Good	3	12
	Average	6	25
	N/A	0	0

Age	Experience	Respondents	Percentage
70+	Poor	8	33
	Very poor	2	8
	Very good	5	12
	Good	12	30
	Average	9	22
	N/A	6	15
	Poor	4	10
	Very poor	4	10

Number of Medical Appointments

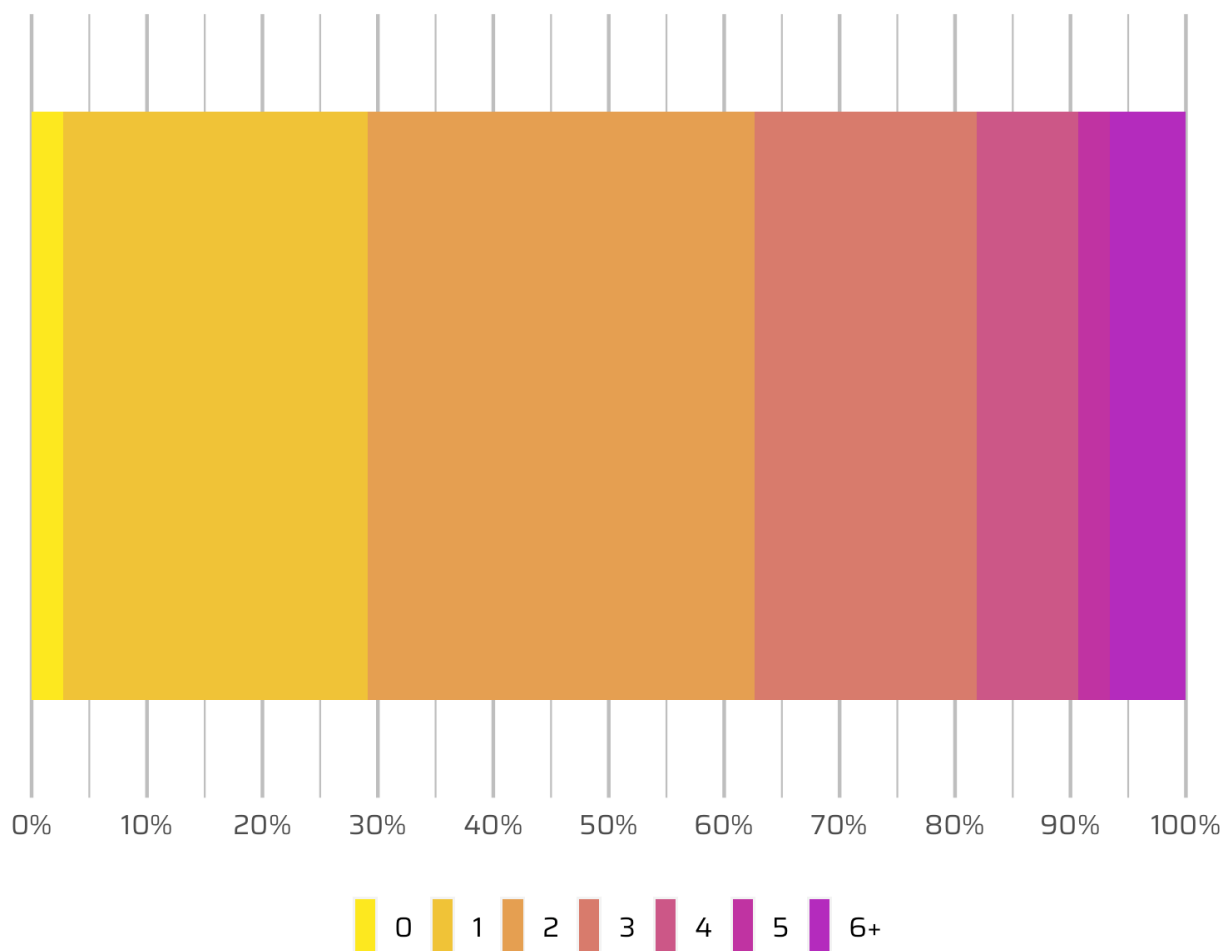


Figure 54: Number of medical appointments respondents had.

Table 52: Number of medical appointments respondents had.

Number	Respondents	Percentage
6+	12	7
5	5	3
4	16	9
3	35	19
2	61	34
1	48	26
0	5	3

Quantitative data – Medical Appointments

Nota bene: The basis for the percentages in this section is the number of observations as opposed to the number of respondents. A single respondent may have had multiple medical appointments and thus multiple observations.

Helpfulness Medical Appointments

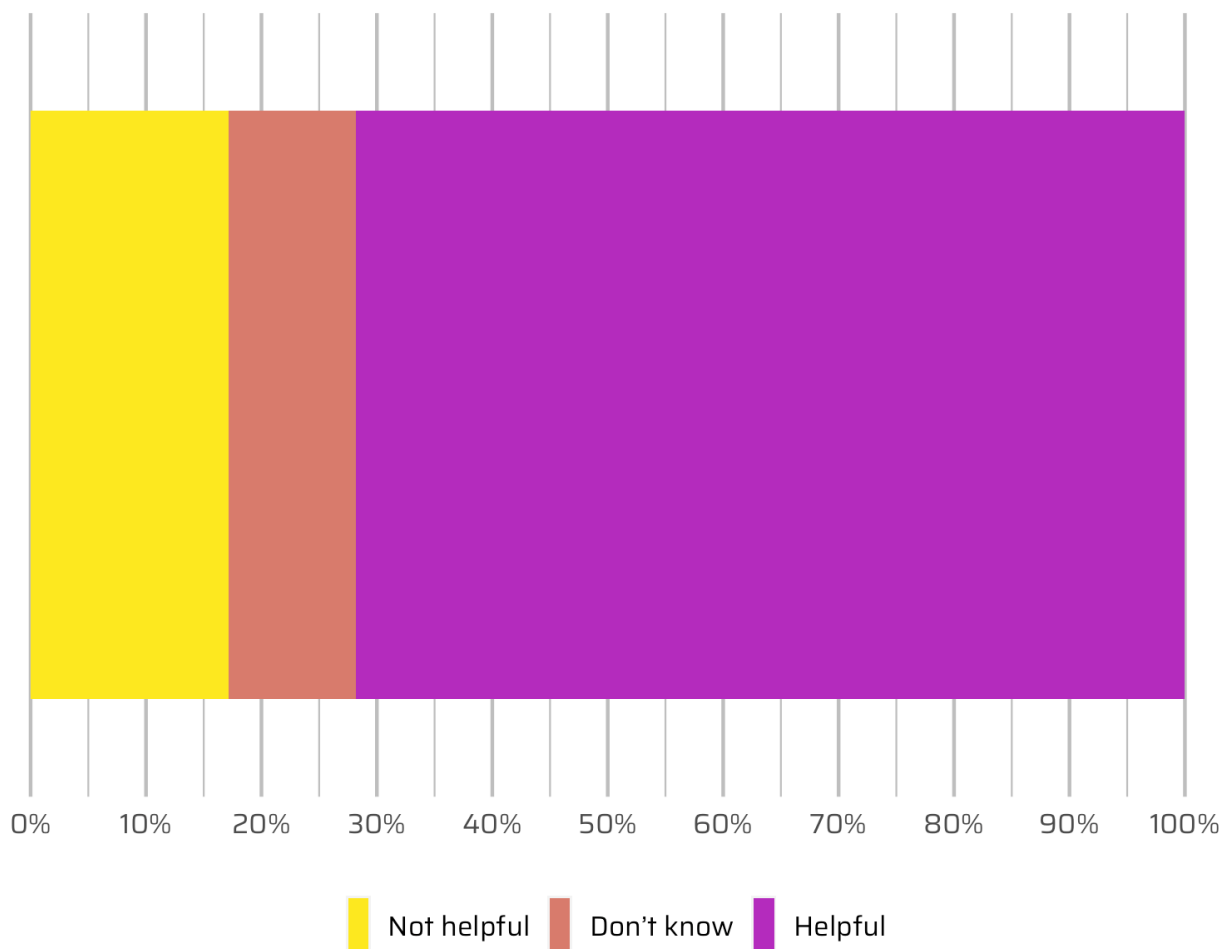


Figure 55: Helpfulness of the appointments attended by respondents.

Table 53: Helpfulness of the appointments attended by respondents.

Helpfulness	Observations	Percentage
Helpful	326	72
Don't know	50	11
Not helpful	78	17

Specialty of appointment

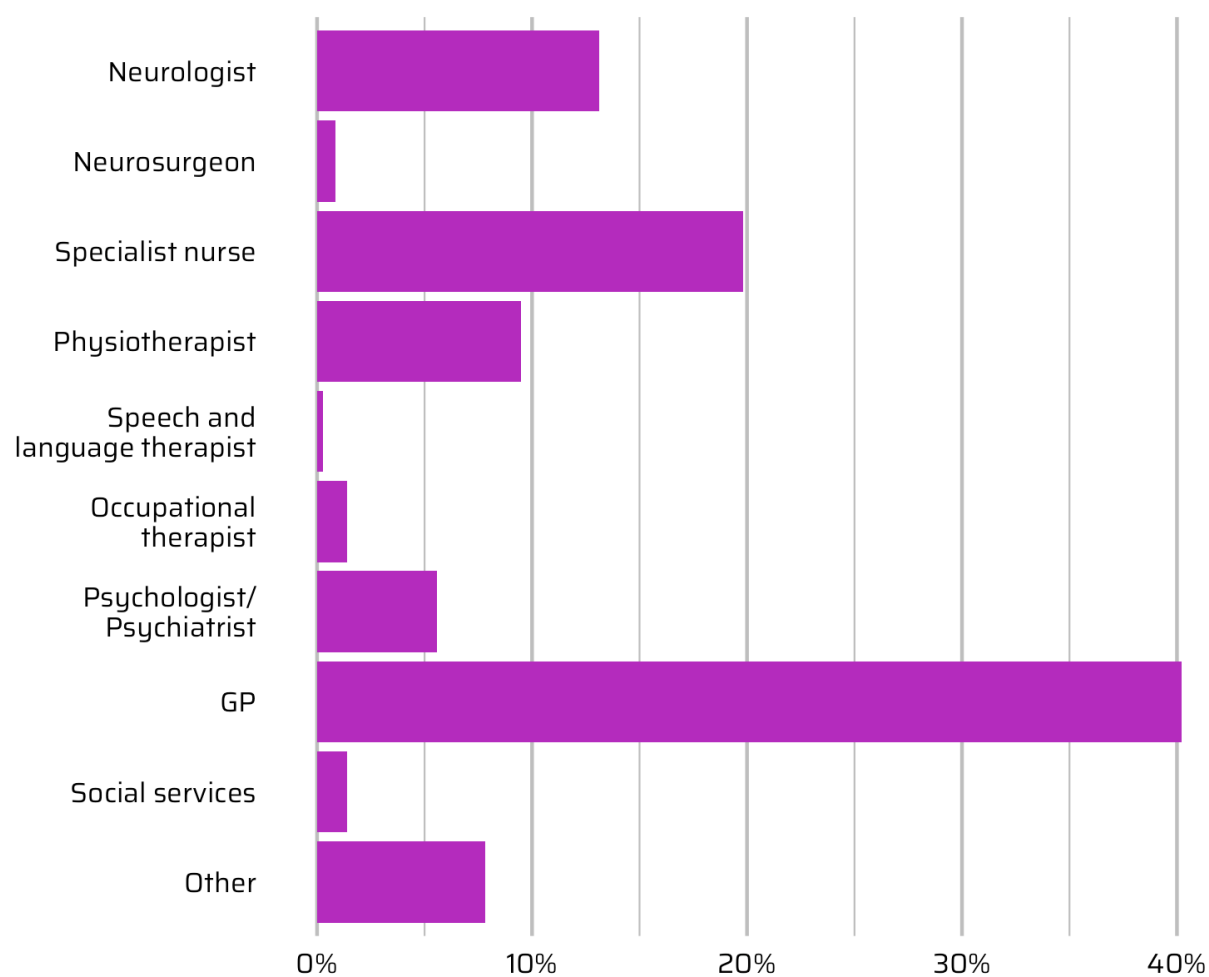


Figure 56: Specialty of appointment held.

Table 54: Specialty of appointment held.

Specialty	Observations	Percentage
Neurologist	47	13

Specialty	Observations	Percentage
Neurosurgeon	3	1
Specialist nurse	71	20
Physiotherapist	34	9
Speech and language therapist	1	0
Occupational therapist	5	1
Psychologist/Psychiatrist	20	6
GP	144	40
Social services	5	1
Other	28	8

Specialty: Helpfulness Medical Appointment

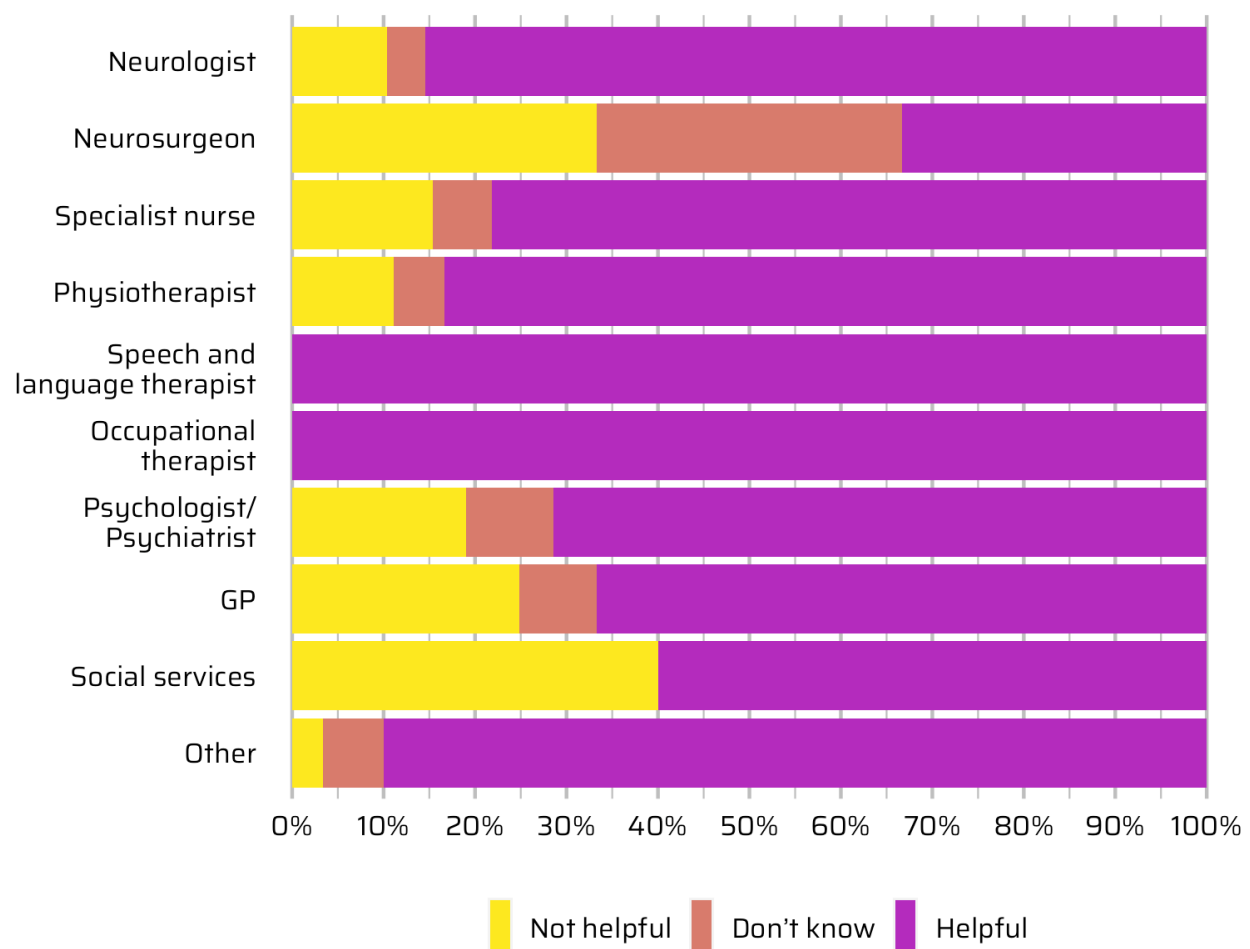


Figure 57: Helpfulness of appointment broken down broken down by specialty of the appointment.

Table 55: Helpfulness of appointment broken down broken down by specialty of the appointment.

Specialty	Helpfulness	Observations	Percentage
Neurologist	Helpful	41	85
	Don't know	2	4
	Not helpful	5	10
Neurosurgeon	Helpful	1	33
	Don't know	1	33
	Not helpful	1	33
Specialist nurse	Helpful	61	78
	Don't know	5	6
	Not helpful	12	15
Physiotherapist	Helpful	30	83
	Don't know	2	6
	Not helpful	4	11
Speech and language therapist	Helpful	1	100
	Don't know	0	0
	Not helpful	0	0
Occupational therapist	Helpful	5	100
	Don't know	0	0
	Not helpful	0	0
Psychologist/Psychiatrist	Helpful	15	71
	Don't know	2	10
	Not helpful	4	19
GP	Helpful	102	67
	Don't know	13	8
	Not helpful	38	25
Social services	Helpful	3	60
	Don't know	0	0
	Not helpful	2	40
Other	Helpful	27	90
	Don't know	2	7
	Not helpful	1	3

Mode of Appointment Delivery

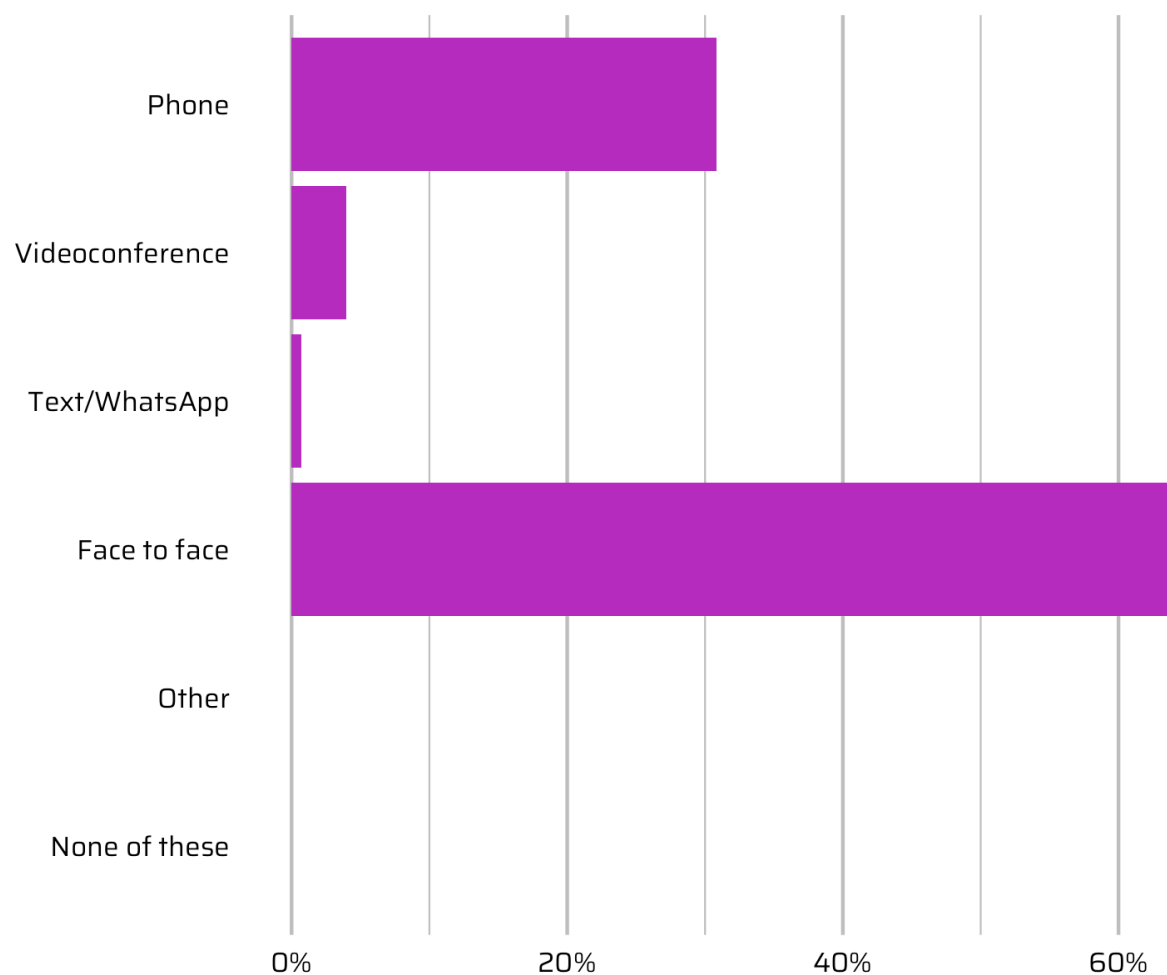


Figure 58: Mode by which appointments were delivered.

Table 56: Mode by which appointments were delivered.

Mode	Observations	Percentage
Phone	133	31
Videoconference	17	4
Text/WhatsApp	3	1
Face to face	278	65
Other	0	0
None of these	0	0

Mode of Delivery: Helpfulness Medical Appointment

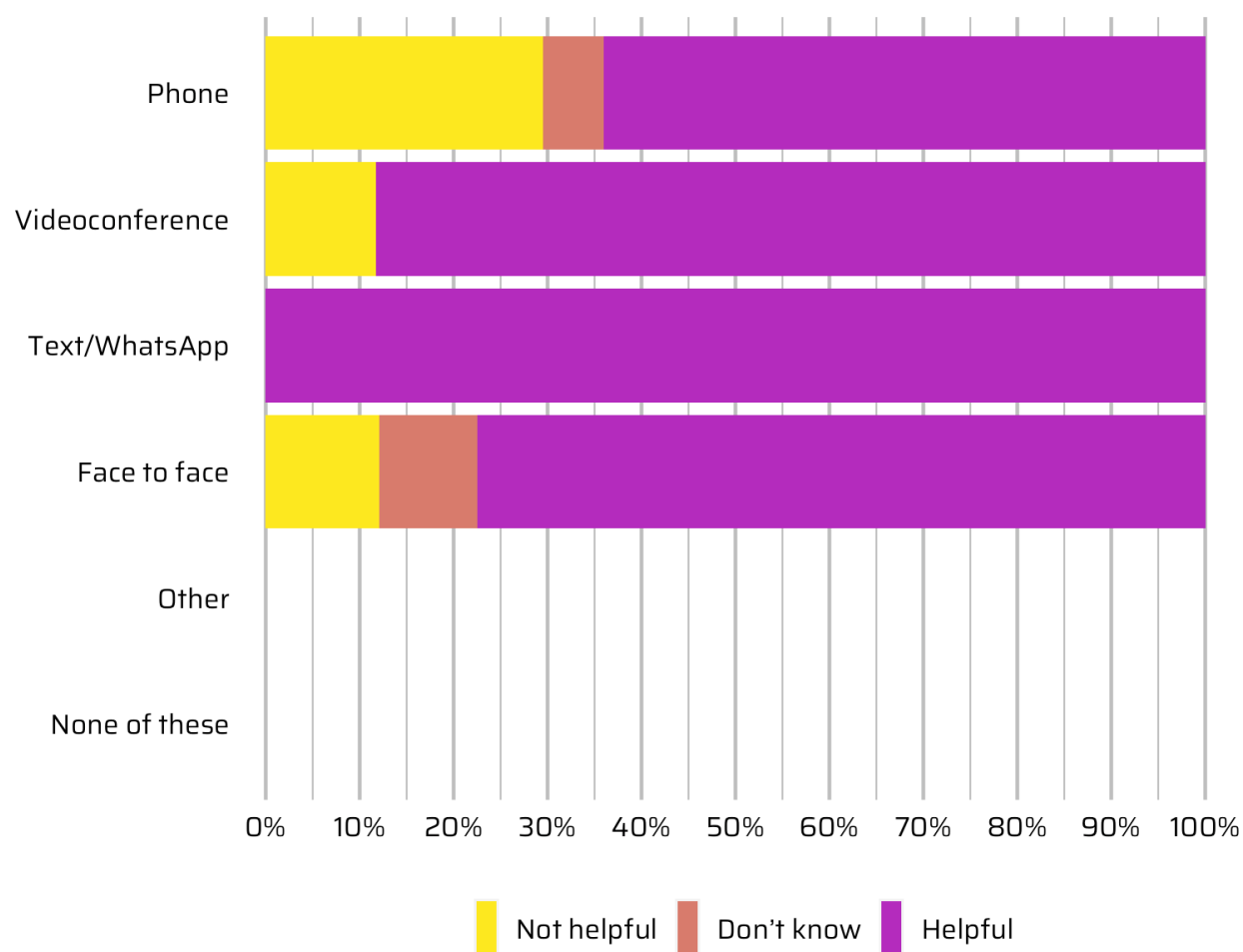


Figure 59: Helpfulness of appointment broken down broken down by how the appointment was delivered.

Table 57: Helpfulness of appointment broken down broken down by how the appointment was delivered.

Mode of Delivery	Helpfulness	Observations	Percentage
Phone	Helpful	89	64
	Don't know	9	6
	Not helpful	41	29
Videoconference	Helpful	15	88
	Don't know	0	0
	Not helpful	2	12
Text/WhatsApp	Helpful	3	100
	Don't know	0	0

Mode of Delivery	Helpfulness	Observations	Percentage
	Not helpful	0	0
Face to face	Helpful	230	77
	Don't know	31	10
	Not helpful	36	12
Other	Helpful	0	0
	Don't know	0	0
	Not helpful	0	0
None of these	Helpful	0	0
	Don't know	0	0
	Not helpful	0	0

Demographics

Sample

Total number of respondents: 244

Neurological Condition

Nota bene: A single respondent may have multiple neurological conditions, therefore for this analysis the number of respondents per condition do not add up to the total number of respondents and the percentages do not add up to 100%.

A total of 128 respondents, equating to 52% of respondents, indicated that they have multiple (i.e., more than one) neurological conditions. In total, there are 74 conditions reported.

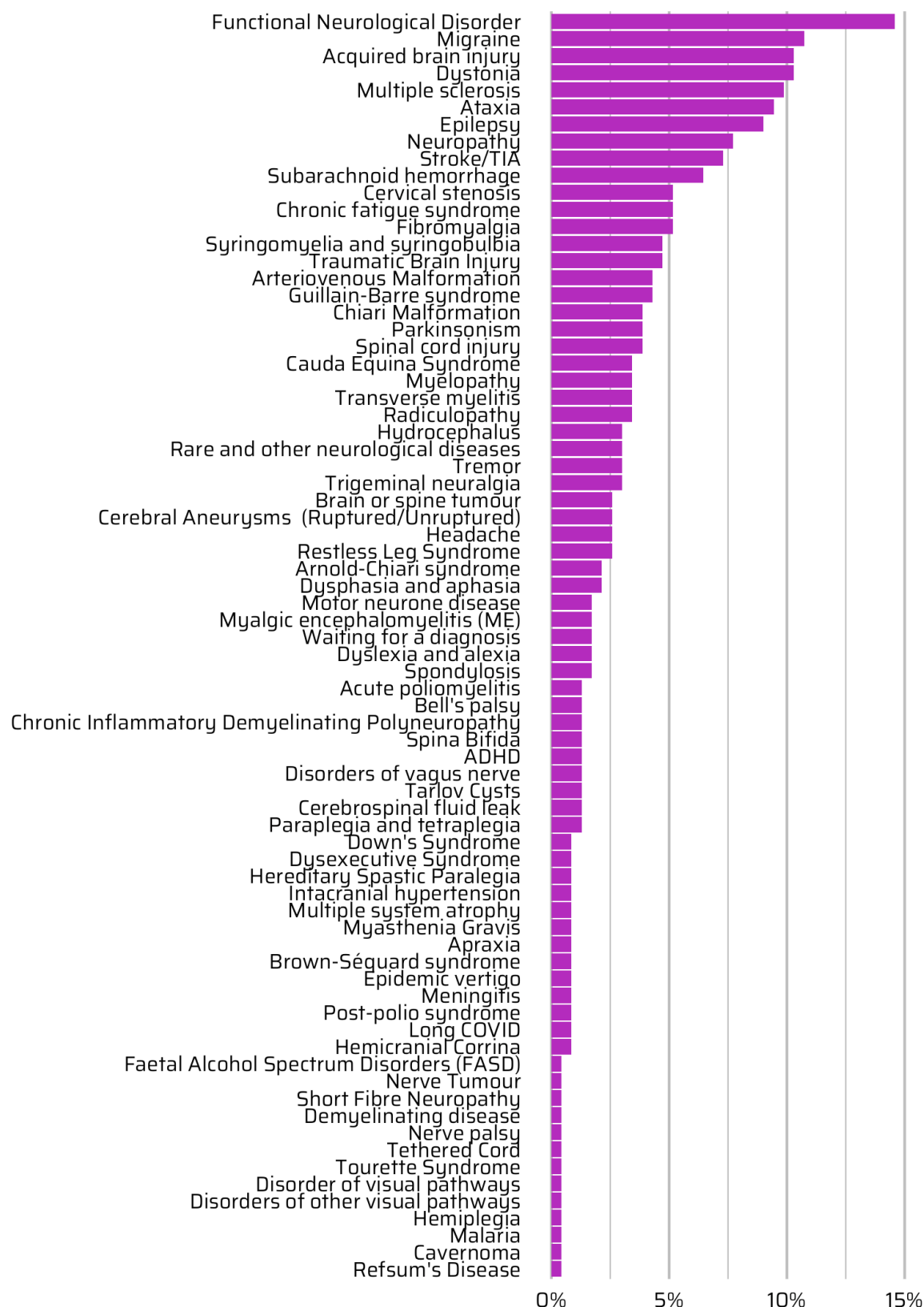


Figure 60: Neurological Conditions that respondents are diagnosed with.

Table 58: Neurological Conditions that respondents are diagnosed with.

Condition	Respondents	Percentage
Functional Neurological Disorder	34	15
Migraine	25	11
Acquired brain injury	24	10
Dystonia	24	10
Multiple sclerosis	23	10
Ataxia	22	9
Epilepsy	21	9
Neuropathy	18	8
Stroke/TIA	17	7
Subarachnoid hemorrhage	15	6
Cervical stenosis	12	5
Chronic fatigue syndrome	12	5
Fibromyalgia	12	5
Syringomyelia and syringobulbia	11	5
Traumatic Brain Injury	11	5
Arteriovenous Malformation	10	4
Guillain-Barre syndrome	10	4
Chiari Malformation	9	4
Parkinsonism	9	4
Spinal cord injury	9	4
Cauda Equina Syndrome	8	3
Myelopathy	8	3
Transverse myelitis	8	3
Radiculopathy	8	3
Hydrocephalus	7	3
Rare and other neurological diseases	7	3
Tremor	7	3
Trigeminal neuralgia	7	3
Brain or spine tumour	6	3
Cerebral Aneurysms (Ruptured/Unruptured)	6	3
Headache	6	3
Restless Leg Syndrome	6	3
Arnold-Chiari syndrome	5	2
Dysphasia and aphasia	5	2
Motor neurone disease	4	2
Myalgic encephalomyelitis (ME)	4	2
Waiting for a diagnosis	4	2
Dyslexia and alexia	4	2

Condition	Respondents	Percentage
Spondylosis	4	2
Acute poliomyelitis	3	1
Bell's palsy	3	1
Chronic Inflammatory Demyelinating Polyneuropathy	3	1
Spina Bifida	3	1
ADHD	3	1
Disorders of vagus nerve	3	1
Tarlov Cysts	3	1
Cerebrospinal fluid leak	3	1
Paraplegia and tetraplegia	3	1
Down's Syndrome	2	1
Dysexecutive Syndrome	2	1
Hereditary Spastic Paralegia	2	1
Intacranial hypertension	2	1
Multiple system atrophy	2	1
Myasthenia Gravis	2	1
Apraxia	2	1
Brown-Séquard syndrome	2	1
Epidemic vertigo	2	1
Meningitis	2	1
Post-polio syndrome	2	1
Long COVID	2	1
Hemicranial Corrina	2	1
Faetal Alcohol Spectrum Disorders (FASD)	1	0
Nerve Tumour	1	0
Short Fibre Neuropathy	1	0
Demyelinating disease	1	0
Nerve palsy	1	0
Tethered Cord	1	0
Tourette Syndrome	1	0
Disorder of visual pathways	1	0
Disorders of other visual pathways	1	0
Hemiplegia	1	0
Malaria	1	0
Cavernoma	1	0
Refsum's Disease	1	0

Age of diagnosis

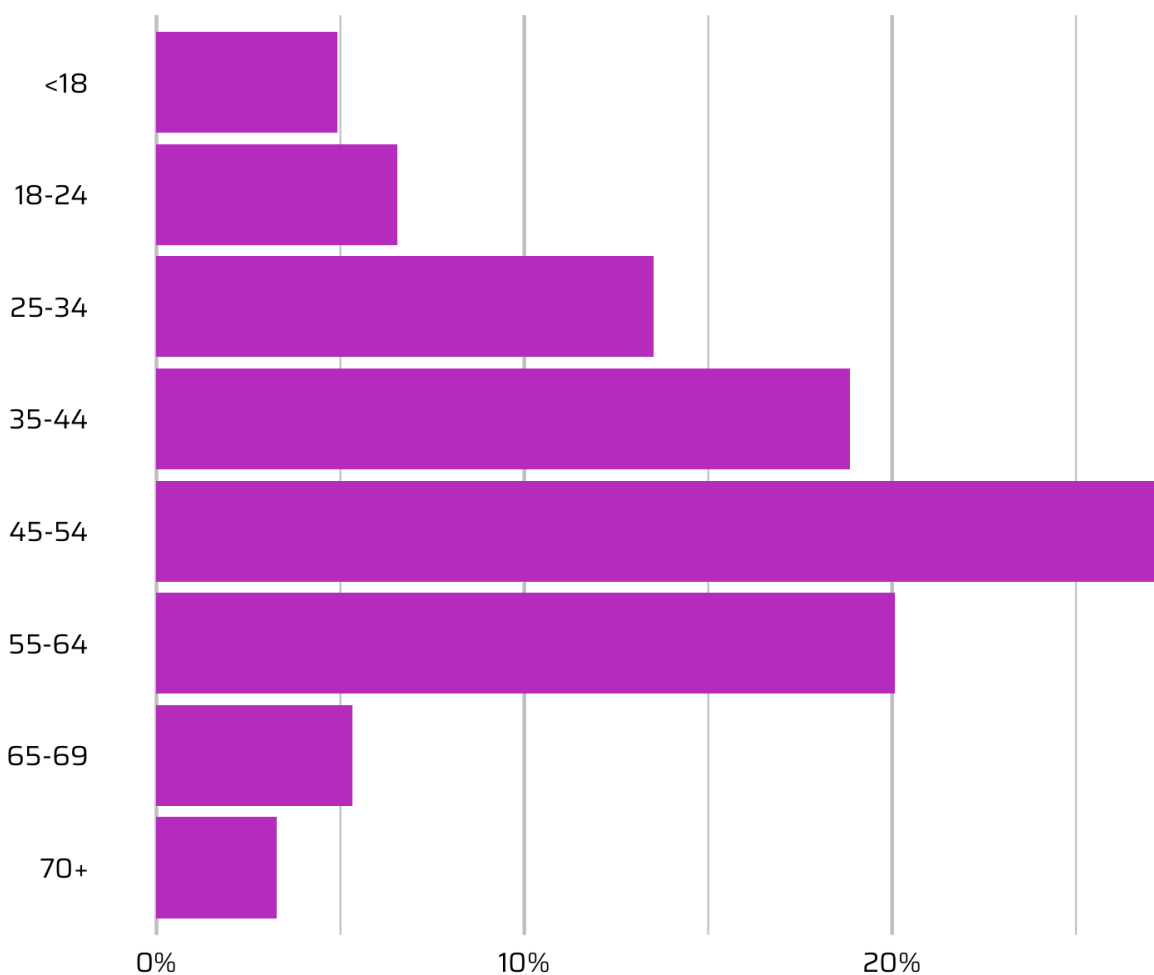


Figure 61: Age respondents when they were first diagnosed.

Table 59: Age respondents when they were first diagnosed.

Age when diagnosed	Respondents	Percentage
<18	12	5
18-24	16	7
25-34	33	14
35-44	46	19
45-54	67	27
55-64	49	20
65-69	13	5
70+	8	3

Number of non-neurological co-occurring conditions

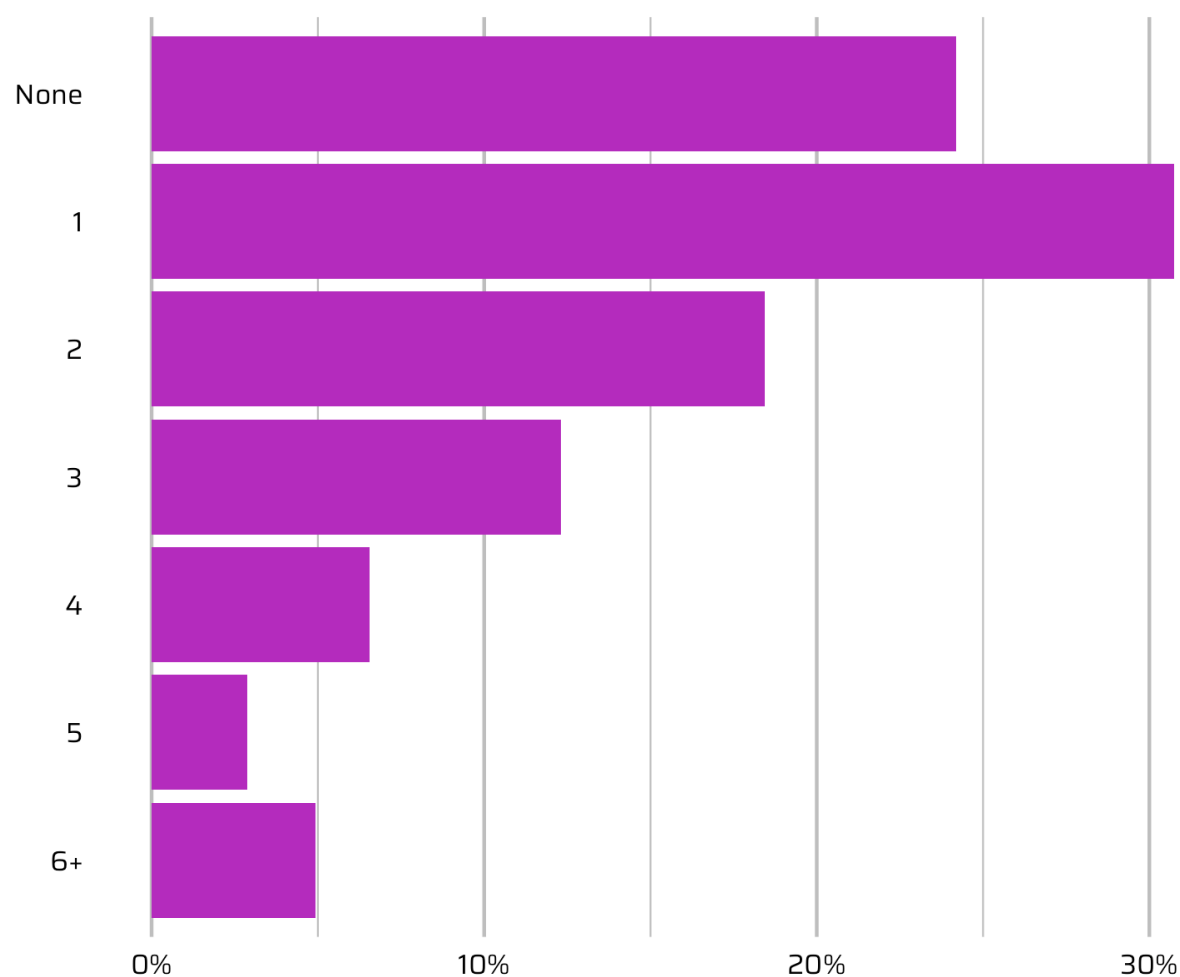


Figure 62: Number of non-neurological conditions that respondents are diagnosed with that co-occur with their neurological condition(s).

Table 60: Number of non-neurological conditions that respondents are diagnosed with that co-occur with their neurological condition(s).

Co-occurring Conditions	Respondents	Percentage
None	59	24
1	75	31
2	45	18
3	30	12
4	16	7
5	7	3
6+	12	5

Gender

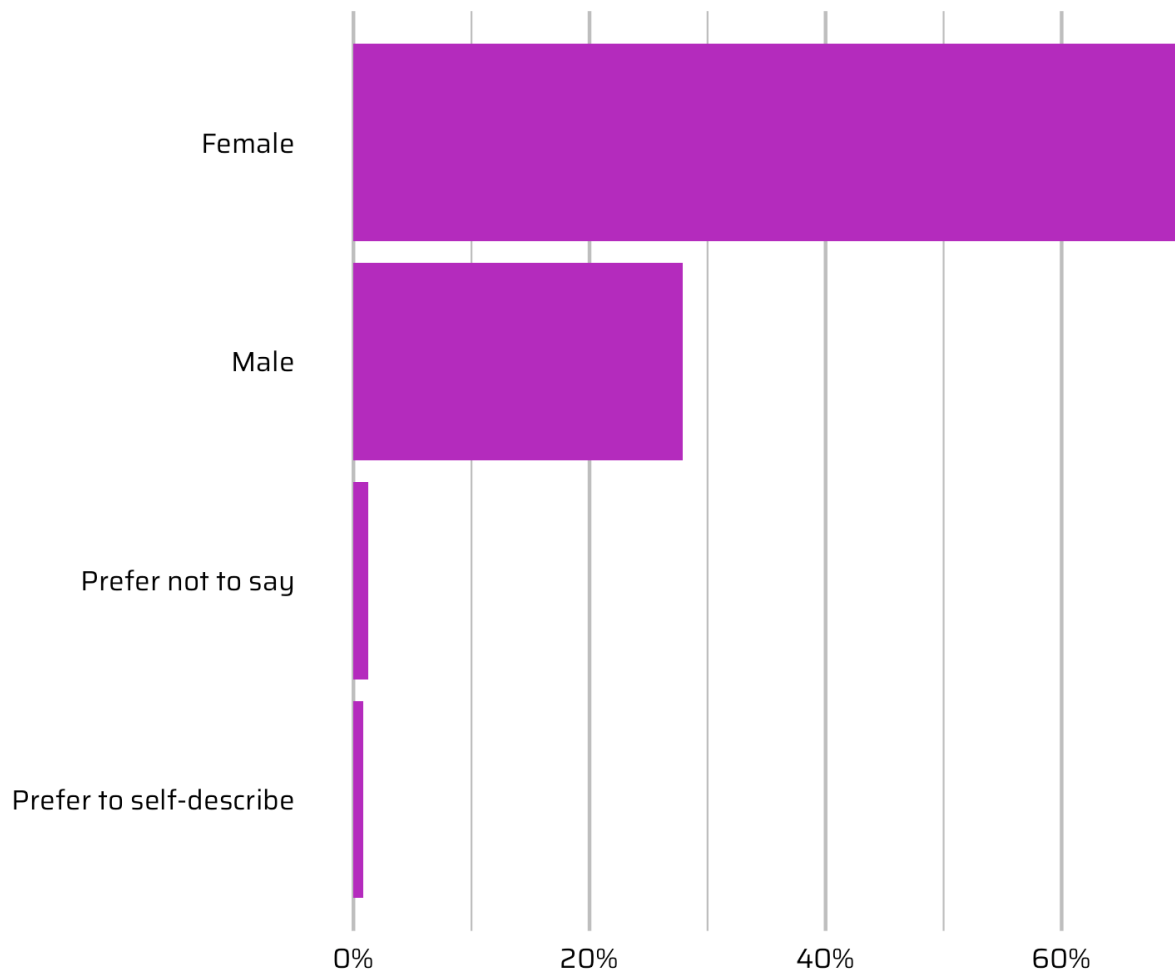


Figure 63: Gender of respondents.

Table 61: Gender of respondents.

Gender	Respondents	Percentage
Female	171	70
Male	68	28
Prefer not to say	3	1
Prefer to self-describe	2	1

Age

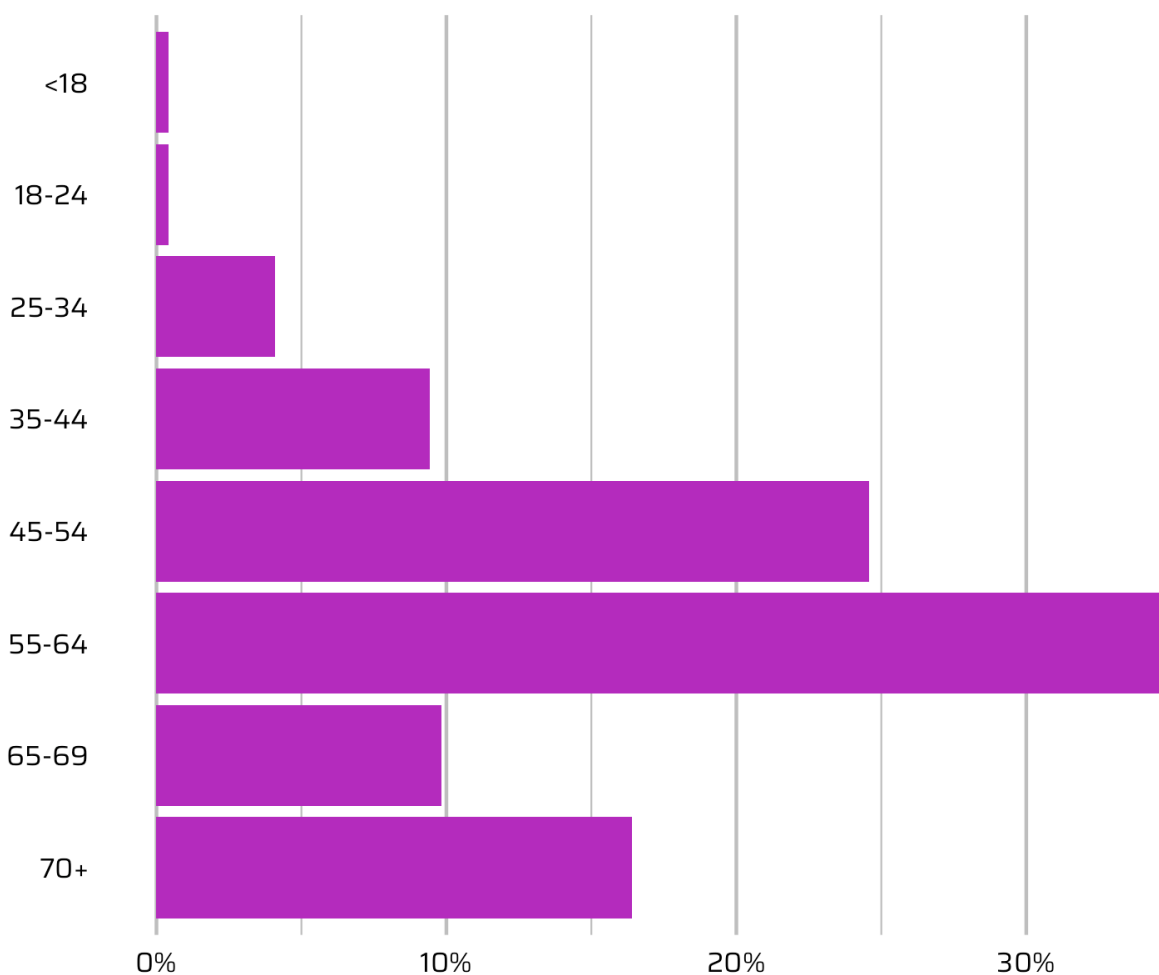


Figure 64: Age group of respondents.

Table 62: Age group of respondents.

Age	Respondents	Percentage
<18	1	0
18-24	1	0
25-34	10	4
35-44	23	9
45-54	60	25
55-64	85	35
65-69	24	10
70+	40	16

Ethnicity

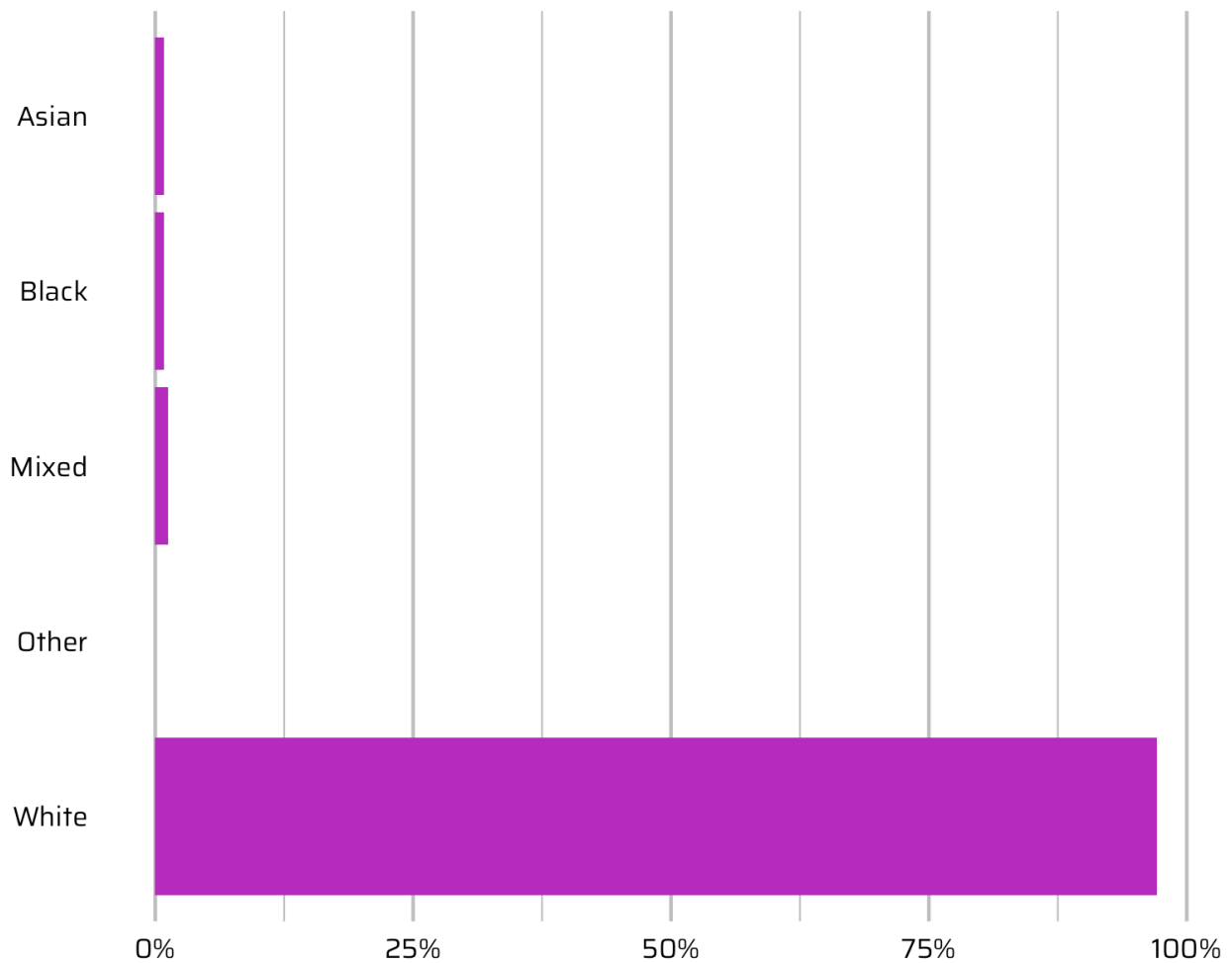


Figure 65: Number of non-neurological conditions that respondents are diagnosed with that co-occur with their neurological condition(s).

Table 63: Number of non-neurological conditions that respondents are diagnosed with that co-occur with their neurological condition(s).

Ethnicity	Respondents	Percentage
Asian	2	1
Black	2	1
Mixed	3	1
Other	0	0
White	237	97

Location of respondents

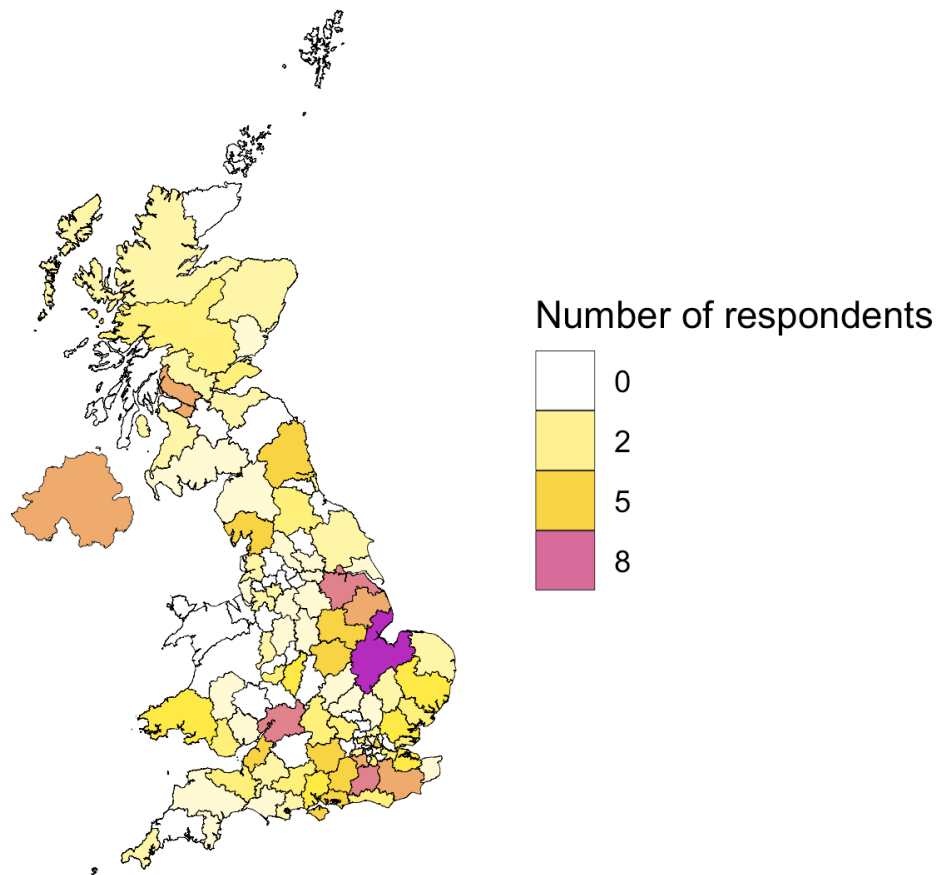


Figure 66: Location of respondents.

Table 64: Location of respondents.

Area Name	Postal Area	Number of respondents
Peterborough	PE	9
Doncaster	DN	7
Gloucester	GL	7
Redhill	RH	7
Glasgow	G	6
Kingston upon Thames	KT	6
Lincoln	LN	6
Tonbridge	TN	6
Northern Ireland	BT	6
Bristol	BS	5

Area Name	Postal Area	Number of respondents
London - E	E	5
Guildford	GU	5
Lancaster	LA	5
Leicester	LE	5
Newcastle upon Tyne	NE	5
Nottingham	NG	5
Portsmouth	PO	5
Reading	RG	5
Birmingham	B	4
Chelmsford	CM	4
Ipswich	IP	4
Medway	ME	4
Swansea	SA	4
Southampton	SO	4
Brighton	BN	3
Cardiff	CF	3
Colchester	CO	3
Croydon	CR	3
Dartford	DA	3
Darlington	DL	3
Dudley	DY	3
Harrow	HA	3
Hemel Hempstead	HP	3
Kirkcaldy	KY	3
Oxford	OX	3
Perth	PH	3
Salisbury	SP	3
Southend-on-Sea	SS	3
Taunton	TA	3
Aberdeen	AB	2
Bath	BA	2
Bournemouth	BH	2
Cambridge	CB	2
Edinburgh	EH	2
Enfield	EN	2
Falkirk	FK	2
Outer Hebrides	HS	2
Inverness	IV	2
Kilmarnock	KA	2
Manchester	M	2

Area Name	Postal Area	Number of respondents
Norwich	NR	2
Preston	PR	2
Sunderland	SR	2
Telford	TF	2
Truro	TR	2
Twickenham	TW	2
Warrington	WA	2
York	YO	2
Bradford	BD	1
Carlisle	CA	1
Canterbury	CT	1
Dundee	DD	1
Derby	DE	1
Dumfries and Galloway	DG	1
Dorchester	DT	1
Exeter	EX	1
Hull	HU	1
Liverpool	L	1
Llandrindod Wells	LD	1
Leeds	LS	1
Milton Keynes	MK	1
London - N	N	1
Northampton	NN	1
Newport	NP	1
London - NW	NW	1
Sheffield	S	1
London - SE	SE	1
Stevenage	SG	1
Stockport	SK	1
Sutton	SM	1
Stoke-on-Trent	ST	1
Torquay	TQ	1
Wakefield	WF	1
St Albans	AL	0
Blackburn	BB	0
Bolton	BL	0
Bromley	BR	0
Chester	CH	0
Coventry	CV	0
Crewe	CW	0

Area Name	Postal Area	Number of respondents
Durham	DH	0
London - EC	EC	0
The Fylde	FY	0
Huddersfield	HD	0
Harrogate	HG	0
Hereford	HR	0
Halifax	HX	0
Ilford	IG	0
Kirkwall	KW	0
Llandudno	LL	0
Luton	LU	0
Motherwell	ML	0
Oldham	OL	0
Paisley	PA	0
Plymouth	PL	0
Romford	RM	0
Slough	SL	0
Swindon	SN	0
London - SW	SW	0
Shrewsbury	SY	0
Teviotdale	TD	0
Teeside	TS	0
Uxbridge	UB	0
London - W	W	0
London - WC	WC	0
Watford	WD	0
Wigan	WN	0
Worcester	WR	0
Walsall	WS	0
Wolverhampton	WV	0
Lerwick	ZE	0

NB: 7 respondents did not provide a UK-based postcode (or did not provide one) and are hence not included in this map and table.

Employment Status

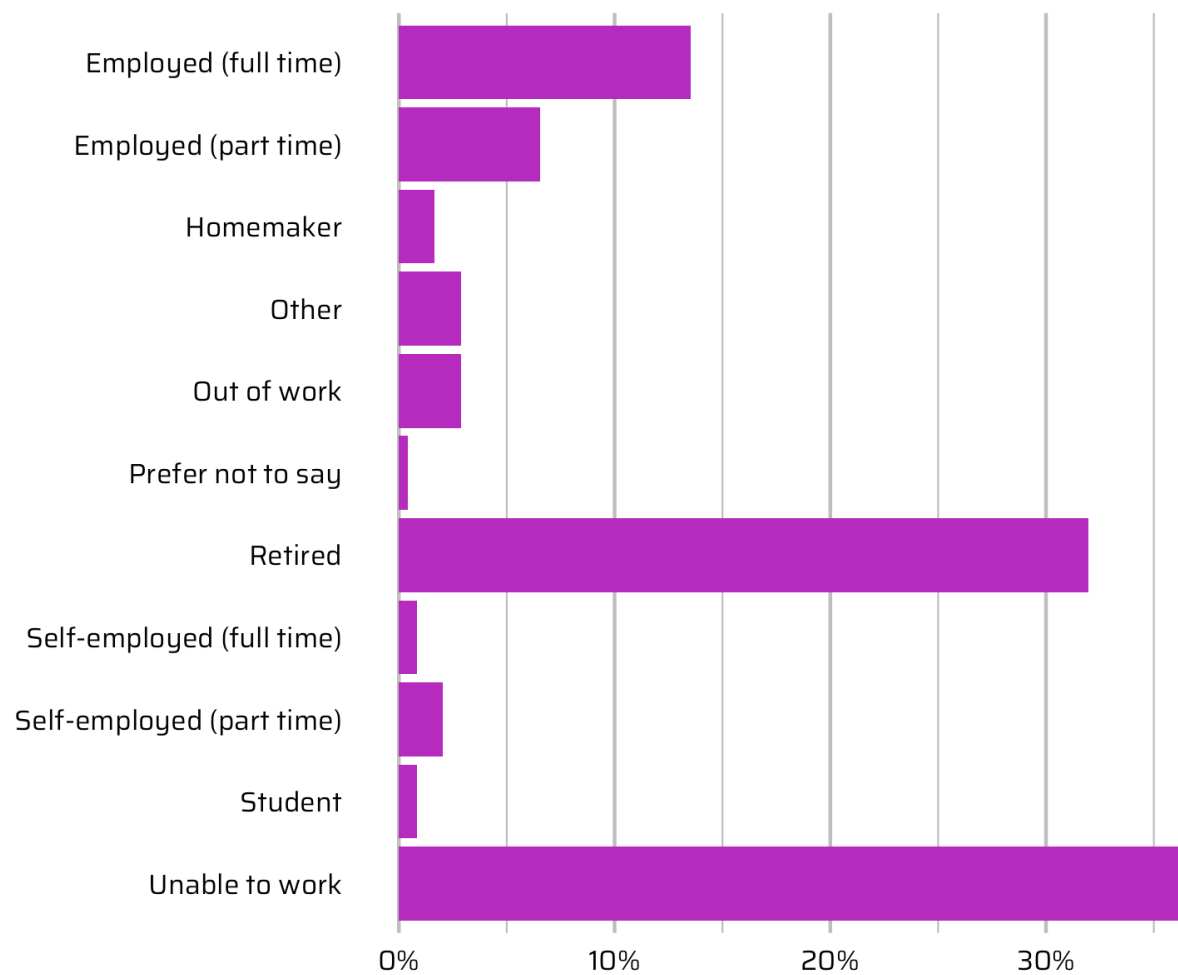


Figure 67: Employment status of respondents.

Table 65: Employment status of respondents.

Employment Status	Respondents	Percentage
Employed (full time)	33	14
Employed (part time)	16	7
Homemaker	4	2
Other	7	3
Out of work	7	3
Prefer not to say	1	0
Retired	78	32
Self-employed (full time)	2	1
Self-employed (part time)	5	2
Student	2	1

Employment Status	Respondents	Percentage
Unable to work	89	36

Number of dependents

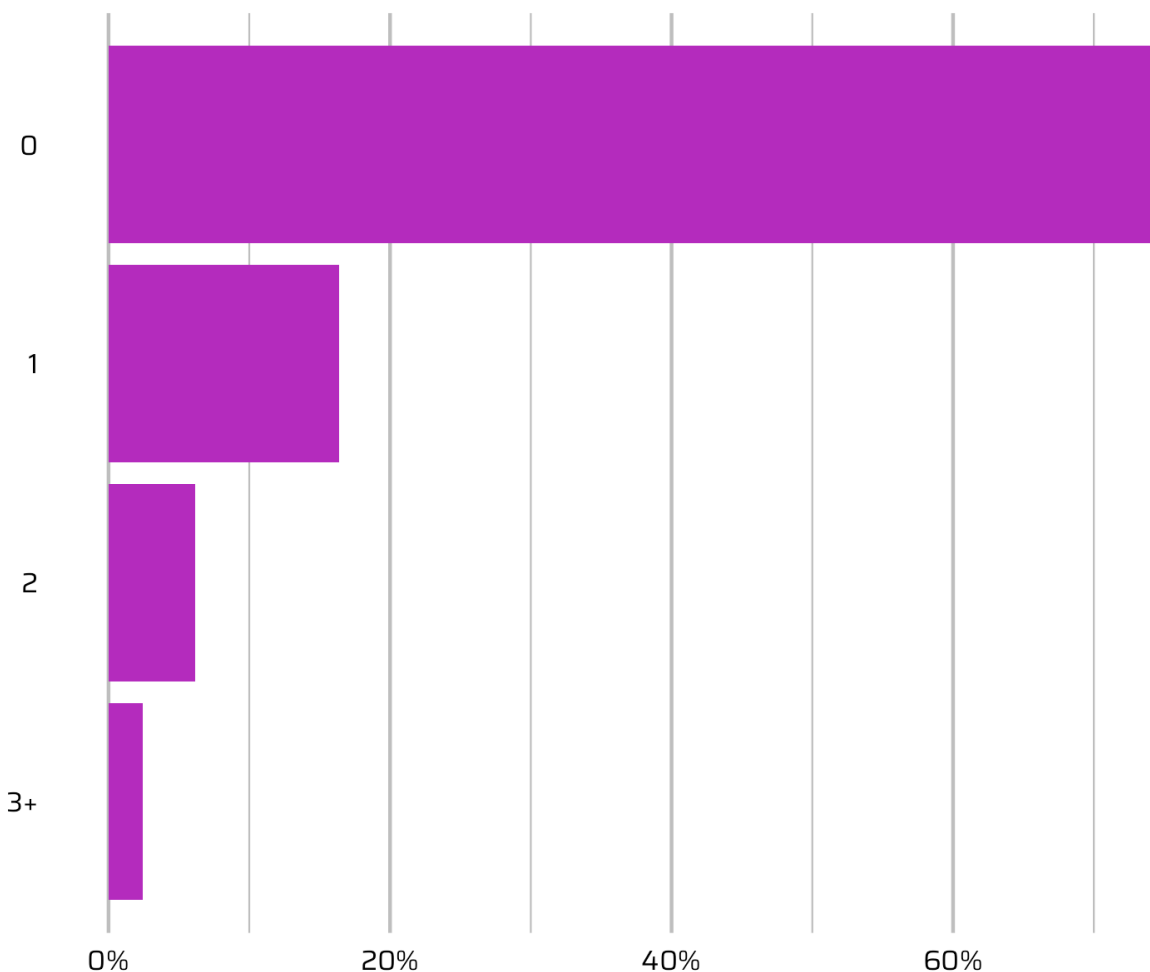


Figure 68: Number of dependents of respondents.

Table 66: Number of dependents of respondents.

Dependents	Respondents	Percentage
0	183	75
1	40	16
2	15	6
3+	6	2

Source

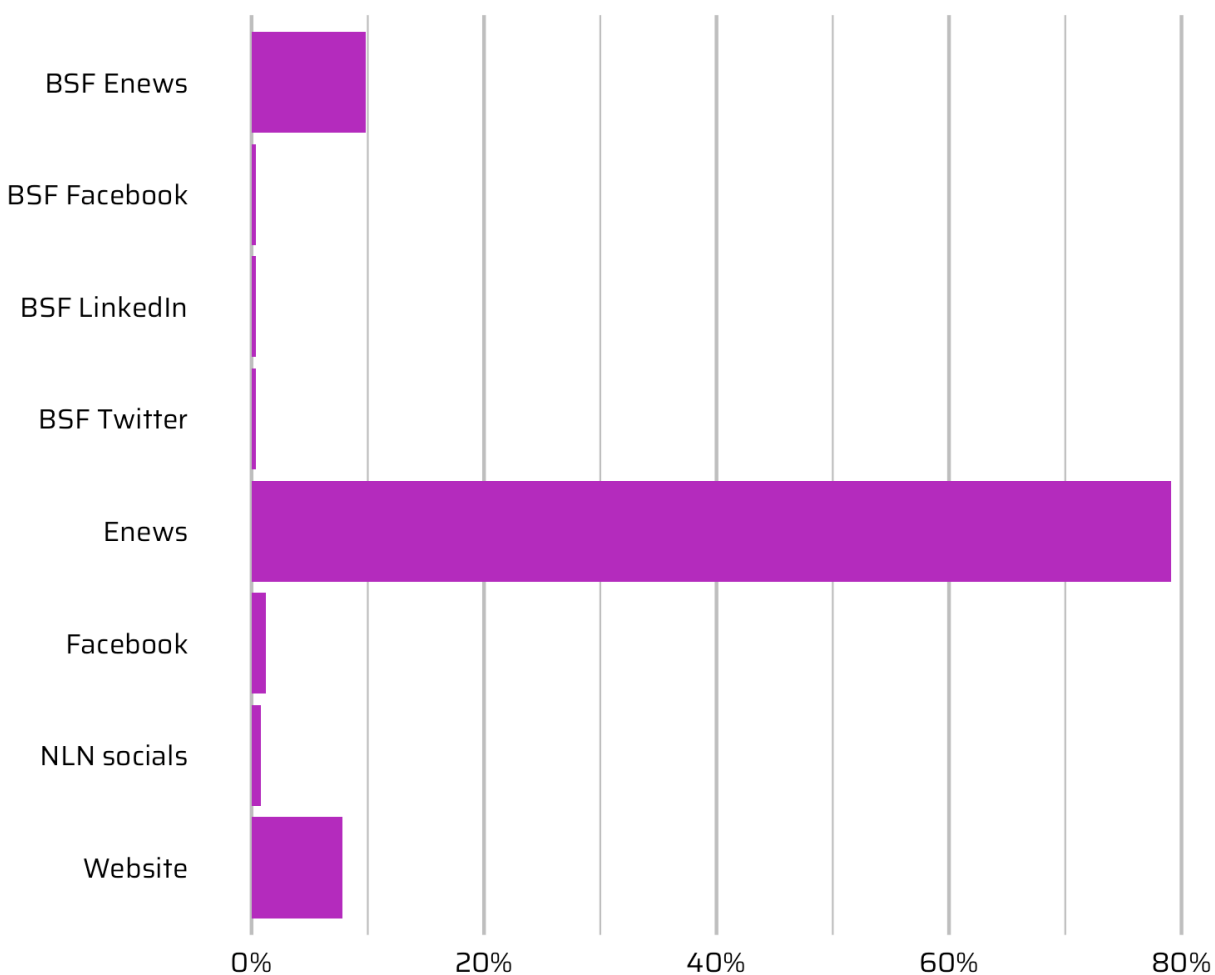


Figure 69: Where respondents are coming to the survey from.

Table 67: Where respondents are coming to the survey from.

Source	Respondents	Percentage
Brain & Spine Foundation E-Newsletter	24	10
Brain & Spine Foundation Facebook	1	0
Brain & Spine Foundation LinkedIn	1	0
Brain & Spine Foundation Twitter	1	0
NeuroLifeNow E-Newsletter	193	79
NeuroLifeNow Facebook	3	1
NeuroLifeNow Socials	2	1
NeuroLifeNow Website	19	8

Appendix A – Survey Questions

Question	Response options		
Are you filling in this questionnaire for yourself?	Yes	No	
Which year were you diagnosed with your primary neurological condition?	Free text		
About your condition(s)			
Please tell us your first neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a second neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a third neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a fourth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		
Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No	
Please tell us a fifth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms		

Do you have any other neurological condition(s) and/or symptoms you would like to add?	Yes	No		
Please tell us a sixth neurological condition and/or symptom you have.	See Appendix B for a list of conditions and symptoms			
Do you live with conditions other than your neurological condition(s)? If so, how many:	None	1	2	3
	4	5	6+	
About your current financial wellbeing				
Thinking about since the start of the year, which of the following actions, if any, have you taken in response to the rising cost of living?	I have done this.	I have thought about this but not done it.	I have not done this.	Not Applicable
	<i>For the list below select on the above scale.</i>			
	Gone out socially less than you would have			
	Skipped a prescription			
	Lowered or stopped your care package			
	Reduced travel by car			
	Reduced travel by public transport			
	Not turned on the heating when you normally would have			
	Borrowed more money			
Over the next six months, which of the following, if any, do you expect to do as a result of rising cost of living?	Miss a payment on household bills	Take out a loan/increase personal debt	Members of my household will get a new job	Sell a car/household vehicle
	Ask for a pay rise	Sell personal belongings	Reduce spend on health or care (i.e. prescription costs or social care)	
Is there anything else that you would like to share about your experiences of increasing cost of living?	Free text			
Your experiences of social care				
Are you receiving any of the following sources of social care and support?	Yes & I pay for it	Yes & I part pay for this	No but I would like to	N/A
	<i>For the list below select on the above scale.</i>			
	Home care (e.g. help in your home)			

	Residential care (e.g. living in a care home).			
	Home adaptations			
	Community transport			
	Supported living			
	Respite care			
	Day services (e.g. attending day centre)			
In your own words, please tell us about your experiences of social care?	Free text			
About your recent experiences of care and support.				
Overall, how would you describe your experience of health or care in the last eight weeks?	Very good	Good	Average	Poor
	Very Poor	N/A		
How many times have you sought A&E/emergency support from the NHS as a result of your neurological condition in the last eight weeks?	None	1-2 times	3-5 times	5 or more times
Have you had any medical appointments (including remote appointments) in the last eight weeks?	Yes	No	Don't Know	
How many medical appointments have you had in the last eight weeks?	0	1	2	3
	4	5	6+	
Who was your first medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/ Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your first medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your first medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your second medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist

	Occupational Therapist	Psychologist/ Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your second medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your second medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your third medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/ Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your third medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your third medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your fourth medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/ Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your fourth medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your fourth medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your fifth medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/ Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your fifth medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face

	Other			
How helpful was your fifth medical appointment?	It was helpful	It was not helpful	Don't Know	
Who was your sixth medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and Language Therapist
	Occupational Therapist	Psychologist/ Psychiatrist	GP	Social Services
	Neurosurgery	Other AHP	Other	
How was your sixth medical appointment delivered?	Phone	Videoconference	Via text/WhatsApp	Face to face
	Other			
How helpful was your sixth medical appointment?	It was helpful	It was not helpful	Don't Know	
To what extent do you feel your mental wellbeing needs are being met?	To a great extent	To a moderate extent	To a small extent	Not at all
	Don't Know			
Which of the following describes how you feel at the moment?	Calm	Well supported	Anxious	Hopeless
	Lonely			
About you				
What year were you born?	Free text			
To which of these ethnic groups do you belong?	White British	White Irish	Any other White background	White and Black Caribbean
	White and Asian	Any other mixed background	Indian	Pakistani
	Bangladeshi	Any other Asian background	Caribbean	African
	Any other Black background	Chinese	Any other ethnic background	
What is your gender?	Male	Female	Prefer to self-describe	Prefer not to say
What best describes your employment status?	Employed (full time)	Employed (part time)	Self-employed (full-time)	Self-employed (part-time)
	Homemaker	Student	Out of work	Unable to work

	Retired	Prefer not to say	Other	
How many dependents live with you?	1	2	3	4
	5	6+		
Communicating with you.				
What is your first name?	Free text			
What is your surname?	Free text			
What is your Email Address?	Free text			
What is the first line of your address?	Free text			
What is your postcode?	Free text			

Appendix B – List of Neurological Symptoms & Conditions

Acquired brain injury	Hemicranial Corrina	Stroke/TIA
Acute poliomyelitis	Hemiplegia	Subacute sclerosing panencephalitis
ADHD	Hereditary Spastic Paralegia	Subarachnoid hemorrhage
Agnosia	Huntington's disease	Syringomyelia and syringobulbia
Amoebic brain abscess	Hydrocephalus	Tarlov Cysts
Apraxia	Hydromyelia	Tethered Cord
Arnold-Chiari syndrome	Intracranial hypertension	Tourette Syndrome
Arteriovenous Malformation	Intracranial abscess and granuloma	Toxic encephalopathy
Ataxia	Intracranial and intraspinal abscess and granuloma in diseases classified elsewhere	Toxoplasma meningoencephalitis
Bell's palsy	Intracranial and intraspinal phlebitis and thrombophlebitis	Transverse myelitis
Bipolar	Intracranial and intraspinal phlebitis and thrombophlebitis	Traumatic Brain Injury
Brain or spine tumour	Intraspinal abscess and granuloma	Tremor
Brown-Séquard syndrome	Kennedy's disease	Trigeminal neuralgia
Cauda Equina Syndrome	Leukoencephalitis	Tuberculous meningitis
Cavernoma	Long COVID	Vascular myelopathies
Cerebral Aneurysms (Ruptured/Unruptured)	Malaria	Waiting for a diagnosis
Cerebral cysts	Melkersson's syndrome	Postzoster neuralgia
Cerebrospinal fluid leak	Meningeal tuberculoma	Progressive multifocal leukoencephalopathy
Cervical stenosis	Meningitis	Rabies

Chagas' disease	Migraine	Radiculopathy
Charcot-Marie-Tooth Disease	Motor neurone disease	Rare and other neurological diseases
Chiari Malformation	Multiple sclerosis	Rare and other neurological diseases
Chronic fatigue syndrome	Multiple system atrophy	Refsum's Disease
Clonic hemifacial spasm	Muscular dystrophy	Restless Leg Syndrome
Cranial nerve disorder	Myalgic encephalomyelitis (ME)	Short Fibre Neuropathy
Creutzfeldt-Jakob disease	Myasthenia Gravis	Spina Bifida
Cysticercosis of central nervous system	Mycoses	Spinal cord injury
Dementia	Myelopathy	Spinal muscular atrophy
Demyelinating disease	Myopathy	Split Cord
Disorder of visual pathways	Myositis	Spondylosis
Disorders of hypoglossal nerve	Myotonic disorders	Stroke/TIA
Disorders of multiple cranial nerves	Narcolepsy and cataplexy	Subacute sclerosing panencephalitis
Disorders of olfactory nerve	Nerve palsy	Subarachnoid hemorrhage
Disorders of optic chiasm	Nerve Tumour	Syringomyelia and syringobulbia
Disorders of other specified cranial nerves	Neurofibromatosis	Tarlov Cysts
Disorders of other visual pathways	Neuromyelitis optica	Tethered Cord
Disorders of vagus nerve	Neuropathy	Tourette Syndrome
Disorders of visual cortex	No diagnosis	Toxic encephalopathy
Down's Syndrome	Optic atrophy	Toxoplasma meningoencephalitis
Dysarthria and anarthria	Papilloedema	Transverse myelitis
Dyslexia and alexia	Paraplegia and tetraplegia	Traumatic Brain Injury
Dysphasia and aphasia	Parkinsonism	Tremor
Dystonia	Post-polio syndrome	Trigeminal neuralgia
Eaton-Lambert syndrome	Postzoster neuralgia	Tuberculous meningitis

Ehlers Danlos Syndromes	Progressive multifocal leukoencephalopathy	Vascular myelopathies
Encephalitis	Rabies	Waiting for a diagnosis
Epidemic vertigo	Radiculopathy	Tourette Syndrome
Epilepsy	Rare and other neurological diseases	Toxic encephalopathy
Extradural and subdural abscess	Rare and other neurological diseases	Toxoplasma meningoencephalitis
Extrapyramidal disorder	Refsum's Disease	Transverse myelitis
Facial myokymia	Restless Leg Syndrome	Traumatic Brain Injury
Faetal Alcohol Spectrum Disorders (FASD)	Short Fibre Neuropathy	Tremor
Fibromyalgia	Spina Bifida	Trigeminal neuralgia
Functional Neurological Disorder	Spinal cord injury	Tuberculous meningitis
Geniculate ganglionitis	Spinal muscular atrophy	Vascular myelopathies
Guillain-Barre syndrome	Split Cord	Waiting for a diagnosis
Headache	Spondylosis	