



January – February 2023 Report



## Foreword

As the cost-of-living crisis continues to bite, we wanted to learn more about how people affected by neurological conditions were coping. Your message was clear – you are having to choose to between heating and eating and, in some cases, forego vital healthcare.

"I now wear a woolly hat indoors instead of putting the heating on as temperature changes affect pain after surgery on my skull"

"I have emphysema in both lungs upper lobes. Since I've had to keep my heating really low I've been coughing a lot more and wheezing more."

"I struggle with energy costs, I would normally have the room temperature set to 18°c, as costs get higher I only heat the house for 4 hours per day. My asthma has got significantly worse, my MS symptoms are more troublesome. Due to the impact of my MS I don't realise when I am very cold or hot, this winter has been particularly miserable, I am fed up with always being cold."

A quarter of those who shared their experiences in January and February reduced their spend on healthcare - this included medication, personal care and transport costs. This is support that enables independent living and symptom management. The impacts are not being felt equally either - women were more likely to report worse financial wellbeing too.

## *"I rely on PIP to pay for things like swimming and physio."*

Importantly, and following calls from the neurological community and many other charities across the country, Chancellor Jeremy Hunt announced that disability benefits, including Personal Independence Payments (PIP) will increase in line with inflation from 1 April. As of January 2023, more than 400,000 people with a neurological condition currently receive PIP and will see their benefit rate rise. As this report makes all too clear, this additional financial support will help our community manage the extra costs that come with living with a condition. However, the experiences shared via NeuroLifeNow also make it clear that financial support needs to be more easily accessible and less stressful to apply for. We continue to campaign for much-needed changes to disability benefits and other forms of financial support in 2023.

The Brain & Spine Foundation neuroscience nurses are here for you, providing practical and emotional support relating to any neurological condition(s). You can get in touch for free by calling **0808 808 1000** (Mon-Fri, 9am – 4pm) or email <u>helpline@brainandspine.org.uk</u>.

Thank you so much.

Marc Smith, CEO Brain and Spine Foundation Georgina Carr, CEO Neurological Alliance (England)

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## Background

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<sup>st</sup> January – 28<sup>th</sup> February 2023.

## **Key findings**

- 363 respondents completed the January-February 2023 survey, with 81 conditions represented. The top 3 most frequently reported conditions are multiple sclerosis, dystonia, and migraine.
- The most frequent action reported in response to the cost of living increases was to reduce heating costs 65% of respondents reported to have done this.
- The most frequently reported way of coping with cost increases was selling personal belongings (35.3%), and reducing spending on healthcare (22.9%).
- More than half of respondents (55.7%) want to meet a specialist at clinic rather than speaking on phone or having home visits.
- Only 1 in 2 respondents were able to meet or speak to a specialist when they wanted to. 1 out of 10 did not see their specialist as they could not find a mutually convenient time or place.
- When people were unable to get specialist support, 4 out of 10 went without any support at all. 1% went to A&E or a walk-in clinic.
- About 2 in 3 respondents had access to medical appointments in the last eight weeks. About 3 in 4 medical appointments were found to be helpful. 4 in 10 medical appointments were with GPs.
- 7 in 10 respondents reported to feel anxious or hopeless.

## Qualitative analyses - experiences of cost-of-living rises

You were asked if there is anything else that you would like to share about you're the cost of living rises. A word cloud has been generated below to demonstrate the key and most common words used:

#### Word cloud



Figure 1: Word cloud showing key words used by respondents relating to cost-of-living increases.

## Thematic analysis

- Theme 1: Financial impacts
  - "Things are tough".
  - The cost of being disabled.

- Reduced spending.
- Theme 2: Impact on health and quality of life
  - Impact on keeping warm.
  - Impact on physical health.
  - Impact on mental health.
  - Impact on social life.
- Theme 3: More support needed
- Theme 4: Getting by

## **Theme 1: Financial impacts**

### "Things are tough"

You voiced that the situation is tough for you. You are financially stretched, cannot afford things you used to afford, and have less savings now.

"Having to return rented notability scooter as I cannot afford cost"

"I'm self-employed. Clients are cutting down on my services"

"It's becoming more difficult to afford healthy food"

"Not enough money to living on"

*"I notice every week a rise in my shopping bill."* 

"... far less being saved each month"

## The cost of being disabled.

There are increased costs of being disabled - you have to spend more for transport, medical treatment, and other equipment.

"... having to pay privately to access migraine treatment (Botox at £549 every 3 months) is expensive and should be paid for by the NHS especially as I am unable to work"

"I am still shielding from Covid due to being immune suppressed. I can only shop online. I am often paying more for products than I would if I could shop in store."

"Just that having MS and RLS always means increased costs - e.g., personal products, decent wheelchair, desperate reliefs for RLS, etc."

"I am having to make adaptations to my home and the costs are increasing"

"I live in Wales but need to pay for travel to England to see health specialist and need overnight hotel stay. A history of cancellations makes this cost more stressful when cost of living already a concern. The pressure put on myself & my husband of scenarios like travelling & accommodation costs [are] made more stressful with appointments cancelled almost every time. Not blaming overworked staff in broken systems but the situation a risk to health and well-being, marriage and-home life."

"The real cost of being disabled has rocketed.... Heating a house because you are not well enough to go out. Supermarket delivery costs money and you can't get reduced price deals."

## Reduced spending

You said that you have reduced your spending in many areas, including food, healthcare, well-being, and socialising.

"I have had to reduce the treatments I have that I have to pay privately for that I can't get on the NHS."

"I eat smaller portions and only buy meat when reduced prices"

"[I have] cut down on my weekly food shop"

"If we had not moved to a smaller house with less overheads we would have been in a very difficult position."

"Spend less on well-being e.g. massage"

".. being more selective in what I do socially"

## Theme 2: Impact on health and quality of life

**Keeping warm** 

## Many of you have struggled to keep yourself warm:

"Can't afford heating and stay in bed to keep warm, even with 6 jumpers on, joggers and 2 pairs of socks"

"I'm worried that I'm not going to be able to use my heating at all."

"Astronomically high heating costs."

"You have to make a choice between heating and eating"

"I now wear a woolly hat indoors instead of putting the heating on as temperature changes affect pain after surgery on my skull"

#### Impact on physical health

#### Your physical health has also been affected by rising prices:

"I have emphysema in both lungs upper lobes. Since I've had to keep my heating really low I've been coughing a lot more and wheezing more."

"I struggle with energy costs, I would normally have the room temperature set to 18°c, as costs get higher I only heat the house for 4 hours per day. My asthma has got significantly worse, my MS symptoms are more troublesome. Due to the impact of my MS I don't realise when I am very cold or hot, this winter has been particularly miserable, I am fed up with always being cold"

"Puts extra problems on illness e.g. I buy cheaper food [but it's] not so good health wise and less heating means more pain and spasms, increasing MS problems"

#### Impact on mental health

"Worry and anxiety about the cost of bills and food. Afraid to commit to financial decisions."

"Feel forgotten"

"[I] worry in case I can't afford to: service the car, repair the house, replace broken white goods, go to the hairdresser, buy dog food, pay more for gas/electricity, service the boiler, pay for help in the home (disabled)" *"I am just aware I need to keep warm but am scared about how much my bill will be"* 

"It's just at the back of my mind whenever I spend money."

### Impact on social life

"My scope of the world/society/friends is growing smaller. Social media helps but my eyesight is more of a problem now"

"In a crisis [where] everything [has] gone up [I] haven't got a social life – can't live a normal life...."

## Theme 3: More support needed.

## You reported that more support is needed.

".. trying to get through to public services for support e.g. DWP, NHS etc, is timeconsuming, exhausting, and demoralising, adding further stressors and strain"

"I'm disabled and don't work, and have no way to get extra money, but I'm not on any means tested benefits. I don't understand why we are not getting the same as means tested benefits."

"I still live with my parents, who are both pensioners, I hope that my Disability ESA and PIP that I receive will go up in line with inflation to help with running costs etc."

"I feel strongly that the Government has not been fair on payments for people with a disability."

"People with conditions that require electrical medical equipment are not helped at all if they are just over the line. They end up worse off as they are only just paid more but therefore have to pay for everything. This [makes] them worse off."

"I think Government help should be better targeted to those in most need."

"I received PIP, which is supposed to be an attempt to cover the extra expenses one incurs as a result of disability - no increase here to reflect the increased cost of living."

## Theme 4: Getting by

Some of you are able to get by relying on other sources of support, such as a partner, children, PIP, or pensions.

"I rely on PIP to pay for things like swimming and physio"

" I am reliant on ESA and PIP,, credit cards, and money from family."

"We have asked our young adult children (21 & 23 on minimum wage) to pay more than just board towards household costs in recent months"

"I'm reliant on PIP in addition to my wages"

## Skip prescription Lower/stop care package Borrow more money Skip meals Reduce travel (public transport) Reduce travel (car) Socialise less **Reduce** heating than usual 40% 70% 80% 90% 100% 0% 10% 20% 30% 50% 60%

Not applicable No Thought about it

#### Actions taken following increases in the cost of living.

Quantitative Data - Increase in Cost of Living

138

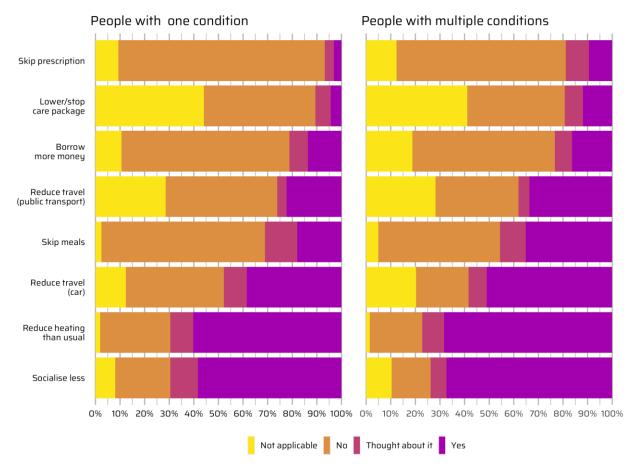
Yes

Figure 2: Actions taken following increase in the cost of living.

Changes made	Option chosen	Respondents	Percentage
	Yes	24	6.61
Chin procerintion	Thought about it	25	6.89
Skip prescription	No	274	75.48
	Not applicable	40	11.02
	Yes	31	8.54
Lower/stop	Thought about it	25	6.85
care package	No	153	42.15
	Not applicable	154	42.42
	Yes	55	15.15
Borrow	Thought about it	26	7.16
more money	No	227	62.53
	Not applicable	55	15.15
	Yes	104	28.65
Reduce travel	Thought about it	15	4.13
(public transport)	No	141	38.84
	Not applicable	103	28.37
	Yes	100	27.55
	Thought about it	42	11.57
Skip meals	No	207	57.02
	Not applicable	14	3.86
	Yes	165	45.45
Reduce travel	Thought about it	30	8.26
(car)	No	107	29.48
	Not applicable	61	16.80
	Yes	235	64.74
Reduce heating	Thought about it	33	9.09
than usual	Νο	89	24.52
	Not applicable	6	1.65
	Yes	230	63.36
Socialise less	Thought about it	31	8.54
	No	68	18.73
	Not applicable	34	9.37

Table 1: Actions taken following increase in costs of living.

# Actions taken: Does it differ among people with/without multiple neurological conditions?



*Figure 3: Actions taken following increase in costs of living among people with/without multiple neurological conditions.* 

Table 2: Actions taken following increase in costs of living among people with/without multiple neurological
conditions.

Group	Changes made	<b>Option chosen</b>	Respondents	Percentage
		Yes	19	9.41
	Elvip proscription	Thought about it	19	9.41
	Skip prescription	Νο	139	68.81
		Not applicable	25	12.38
Multiple		Yes	24	11.88
conditions	Lower/stop care package	Thought about it	15	7.43
	Lower/stop care package	Νο	80	39.60
		Not applicable	83	41.09
	Porrow more monou	Yes	33	16.34
	Borrow more money	Thought about it	14	6.93

Group	Changes made	Option chosen	Respondents	Percentage
		No	117	57.92
		Not applicable	38	18.8 <sup>-</sup>
		Yes	68	33.66
	Reduce travel (public	Thought about it	9	4.46
	transport)	No	68	33.66
		Not applicable	57	28.22
		Yes	71	35.15
		Thought about it	21	10.40
	Skip meals	No	100	49.50
		Not applicable	10	4.95
		Yes	103	50.99
		Thought about it	15	7.43
	Reduce travel (car)	No	43	21.29
		Not applicable	41	20.30
		Yes	138	68.32
		Thought about it	18	8.9
	Reduce heating than usual	No	43	21.29
		Not applicable	3	1.49
		Yes	136	67.33
		Thought about it	13	6.44
	Socialise less	No	32	15.84
		Not applicable	21	10.40
		Yes	5	3.1
		Thought about it	6	3.73
	Skip prescription	No	135	83.85
		Not applicable	15	9.32
		Yes	7	4.35
		Thought about it	10	6.2
	Lower/stop care package	No	73	45.34
		Not applicable	71	44.10
One condition		Yes	22	13.66
		Thought about it	12	7.45
Borrow more r	Borrow more money	No	110	68.32
		Not applicable	17	10.56
		Yes	36	22.36
	Reduce travel (public	Thought about it	6	3.73
	transport)	No	73	45.34
	. ,	Not applicable	46	28.5

Group	Changes made	Option chosen	Respondents	Percentage
		Yes	29	18.01
	Skip mools	Thought about it	21	13.04
	Skip meals	No	107	66.46
		Not applicable	4	2.48
		Yes	62	38.51
		Thought about it	15	9.32
	Reduce travel (car)	No	64	39.75
		Not applicable	20	12.42
		Yes	97	60.25
		Thought about it	15	9.32
	Reduce heating than usual	No	46	28.57
		Not applicable	3	1.86
		Yes	94	58.39
		Thought about it	18	11.18
	Socialise less	No	36	22.36
		Not applicable	13	8.07

# Actions taken: Does this differ by people with co-occurring non-neurological conditions?

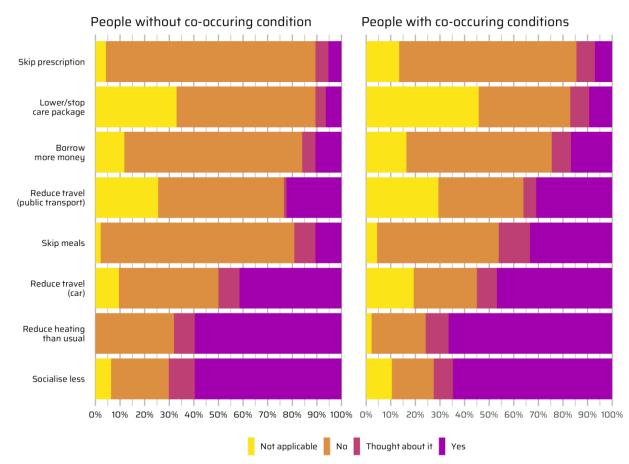


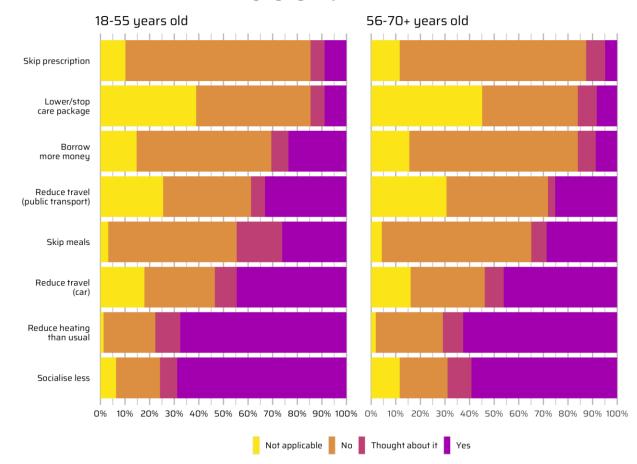
Figure 4: Actions taken following increase in costs of living among people with or without co-occurring nonneurological conditions.

Table 3: Actions taken following increase in costs of living among people with or without co-occurring nonneurological conditions.

Group	Changes made	Option chosen	Respondents	Percentage
	_	Yes	- 5	5.32
	Chip proceription	Thought about it	5	5.32
	Skip prescription	No	80	85.11
		Not applicable	4	4.26
Individuals without co-		Yes	6	6.38
occurring conditions	Lower/stop care	Thought about it	4	4.26
	package	No	53	56.38
		Not applicable	31	32.98
	Borrow more	Yes	10	10.64
	money	Thought about it	5	5.32

Group	Changes made	<b>Option chosen</b>	Respondents	Percentage
		No	68	72.34
		Not applicable	11	11.70
		Yes	21	22.34
	Reduce travel	Thought about it	1	1.06
	(public transport)	Νο	48	51.06
		Not applicable	24	25.53
		Yes	10	10.64
		Thought about it	8	8.51
	Skip meals	Νο	74	78.72
		Not applicable	2	2.13
		Yes	39	41.49
		Thought about it	8	8.51
	Reduce travel (car)	No	38	40.43
		Not applicable	9	9.57
		Yes	56	59.57
	Reduce heating	Thought about it	8	8.51
	than usual	No	30	31.91
		Not applicable	0	0.00
		Yes	56	59.57
		Thought about it	10	10.64
	Socialise less	Νο	22	23.40
		Not applicable	6	6.38
		Yes	19	7.06
		Thought about it	20	7.43
	Skip prescription	Νο	194	72.12
		Not applicable	36	13.38
		Yes	25	9.29
	Lower/stop care	Thought about it	21	7.81
	package	Νο	100	37.17
Individuals with co-occurring		Not applicable	123	45.72
conditions		Yes	45	16.73
	Borrow more	Thought about it	21	7.81
money		No	159	59.11
	Not applicable	44	16.36	
		Yes	83	30.86
	Reduce travel	Thought about it	14	5.20
	(public transport)	Νο	93	34.57
	( · · · · · · · · · · · · · · · · · · ·	Not applicable	79	29.37

Group	Changes made	Option chosen	Respondents	Percentage
		Yes	90	33.46
	T	Thought about it	34	12.64
	Skip meals	Νο	133	49.44
		Not applicable	12	4.46
		Yes	126	46.84
		Thought about it	22	8.18
	Reduce travel (car)	Νο	69	25.65
		Not applicable	52	19.33
		Yes	179	66.54
	Reduce heating	Thought about it	25	9.29
	than usual	Νο	59	21.93
		Not applicable	6	2.23
		Yes	174	64.68
	Socialise less	Thought about it	21	7.81
		Νο	46	17.10
	Not applicable	28	10.41	



#### Actions taken: Does this differ by age groups?

Figure 5: Actions taken following increase in costs of living among people in different age groups.

Table 4: Actions taken following increase in costs	of living among	people in different age groups.
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Group	Changes made	Option chosen	Respondents	Percentage
	-	Yes	14	8.92
	Skip prescription	Thought about it	9	5.73
	Skip prescription	No	118	75.16
		Not applicable	16	10.19
	Lower/stop care package	Yes	14	8.92
18-55 years old		Thought about it	9	5.73
lo-55 years olu		No	73	46.50
		Not applicable	61	38.85
		Yes	37	23.57
		Thought about it	11	7.01
	Borrow more money	No	86	54.78
		Not applicable	23	14.65

Group	Changes made	<b>Option chosen</b>	Respondents	Percentage
		Yes	52	33.12
		Thought about it	9	5.73
	Reduce travel (public transport)	No	56	35.67
		Not applicable	40	25.48
		Yes	41	26.11
		Thought about it	29	18.47
	Skip meals	No	82	52.23
		Not applicable	5	3.18
		Yes	70	44.59
		Thought about it	14	8.92
	Reduce travel (car)	No	45	28.66
		Not applicable	28	17.83
	Reduce heating than usual	Yes	106	67.52
		Thought about it	16	10.19
		No	33	21.02
		Not applicable	2	1.27
		Yes	108	68.79
		Thought about it		7.01
	Socialise less	No	28	17.83
		Not applicable	10	6.37
		Yes	10	4.85
		Thought about it	16	7.77
	Skip prescription	No	156	75.73
		Not applicable	24	
		Yes	17	8.25
		Thought about it	16	7.77
	Lower/stop care package	No	80	38.83
		Not applicable	93	45.15
		Yes	18	8.74
56-70+ years old	2	Thought about it	15	7.28
	Borrow more money	No	141	68.45
		Not applicable	32	15.53
		Yes	52	25.24
		Thought about it	6	2.91
	Reduce travel (public transport)	No	85	41.26
		Not applicable	63	30.58
		Yes	59	28.64
	Skip meals	Thought about it		6.31

Group	Changes made	Option chosen	Respondents	Percentage
		No	125	60.68
		Not applicable	9	4.37
		Yes	95	46.12
	Doduce travel (car)	Thought about it	16	7.77
	Reduce travel (car)	No	62	30.10
		Not applicable	33	16.02
		Yes	129	62.62
	Deduce besting these yours!	Thought about it	17	8.25
	Reduce heating than usual	No	56	27.18
		Not applicable	4	1.94
		Yes	122	59.22
	Socialise less	Thought about it	20	9.71
		No	40	19.42
		Not applicable	24	11.65

#### Actions taken: Does this differ by gender?

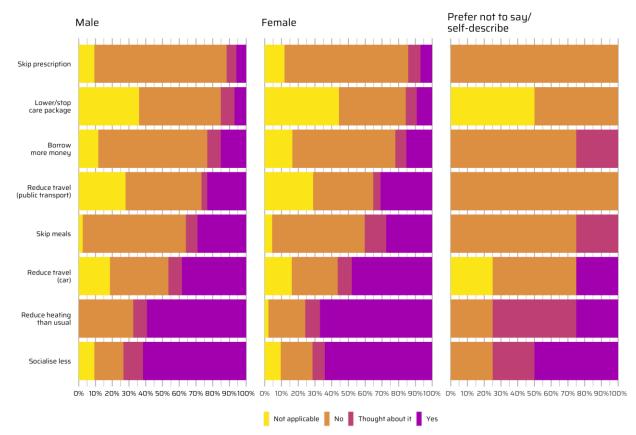


Figure 6: Actions taken following increase in costs of living among different genders.

Group	Changes made	<b>Option chosen</b>	Respondents	Percentage
		Yes	5	5.81
		Thought about		F 01
	Skip prescription	it	5	5.81
		No	68	79.07
		Not applicable	8	9.30
		Yes	6	6.98
		Thought about	7	0 1/
	Lower/stop care package	it	7	8.14
		No	42	48.84
		Not applicable	31	36.05
		Yes	13	15.12
		Thought about	7	8.14
	Borrow more money	it	/	0.14
		No	56	65.12
		Not applicable	10	11.63
		Yes	20	23.26
	Reduce travel (public transport)	Thought about	3	3.49
		it		2.42
Male		No	39	45.35
IVIAIC		Not applicable	24	27.91
		Yes	25	29.07
		Thought about	6	6.98
	Skip meals	it		
		No	53	61.63
		Not applicable	2	2.33
		Yes	33	38.37
		Thought about	7	8.14
	Reduce travel (car)	it	, 	0.14
		No	30	34.88
Redu		Not applicable	16	18.60
		Yes	51	59.30
		Thought about	7	8.14
	Reduce heating than usual	it	/	0.14
		No	28	32.56
		Not applicable	0	0.00
		Yes	53	61.63
	Socialise less	Thought about	10	11 ( )
		it	10	11.63

Table 5: Actions taken following increase in costs of living among different genders.

Group	Changes made	Option chosen	Respondents	Percentage
		No	15	17.44
		Not applicable	8	9.30
		Yes	19	6.96
		Thought about	20	7.33
	Skip prescription	it	20	دد./
		No	202	73.99
		Not applicable	32	11.72
		Yes	25	9.16
		Thought about	18	6.59
	Lower/stop care package	it		
		No	109	39.93
		Not applicable	121	44.32
		Yes	42	15.38
		Thought about	18	6.59
	Borrow more money	it	10	دد.ں
		No	168	61.54
		Not applicable	45	16.48
		Yes	84	30.77
	Reduce travel (public	Thought about	12	4.40
Female	transport)	it		
remale		No	98	35.90
		Not applicable	79	28.94
		Yes	75	27.47
		Thought about	35	12.82
	Skip meals	it		12.02
		No	151	55.31
		Not applicable	12	4.40
		Yes	131	47.99
		Thought about	23	8.42
	Reduce travel (car)	it	دے	0.42
		No	75	27.47
		Not applicable	44	16.12
		Yes	183	67.03
		Thought about	24	8.79
	Reduce heating than usual	it .	24	0.79
		Νο	60	21.98
		Not applicable	6	2.20
	Socialise less	Yes	175	64.10

Group	Changes made	Option chosen	Respondents	Percentage
		Thought about	20	7.33
		it	20	/.55
		No	52	19.05
		Not applicable	26	9.52
		Yes	0	0.00
		Thought about		0.00
	Skip prescription	it	0	0.00
		No	4	100.00
		Not applicable	0	0.00
		Yes	0	0.00
		Thought about	_	
	Lower/stop care package	it -	0	0.00
		Νο	2	50.00
		Not applicable	2	50.00
		Yes	0	0.00
		Thought about		
	Borrow more money	it	1	25.00
	5	Νο	3	75.00
		Not applicable	0	0.00
		Yes	0	0.00
	Reduce travel (public	Thought about		
Prefer not to		it	0	0.00
say/self-describe	transport)	No	4	100.00
		Not applicable	0	0.00
		Yes	0	0.00
		Thought about	5	0.00
	Skip meals	it	1	25.00
		No	3	75.00
		Not applicable	0	0.00
		Yes	1	25.00
		Thought about	· · ·	25.00
	Reduce travel (car)	it	0	0.00
		No	2	50.00
		Not applicable	1	25.00
		Yes	1	25.00
			I	20.00
	Poduce besting then your!	Thought about	2	50.00
	Reduce heating than usual	it		
		No	1	25.00
		Not applicable	0	0.00

Group	Changes made	Option chosen	Respondents	Percentage
		Yes	2	50.00
		Thought about	1	25.00
	Socialise less	it	I	25.00
		Νο	1	25.00
_		Not applicable	0	0.00

#### Actions taken: Does this differ by employment status?

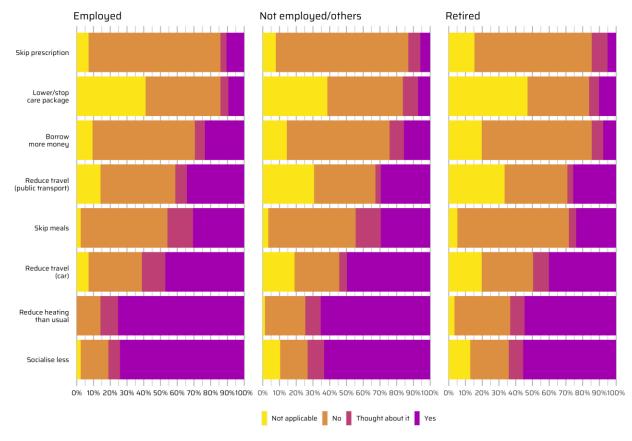


Figure 7: Actions taken following increase in costs of living among people with different employment status.

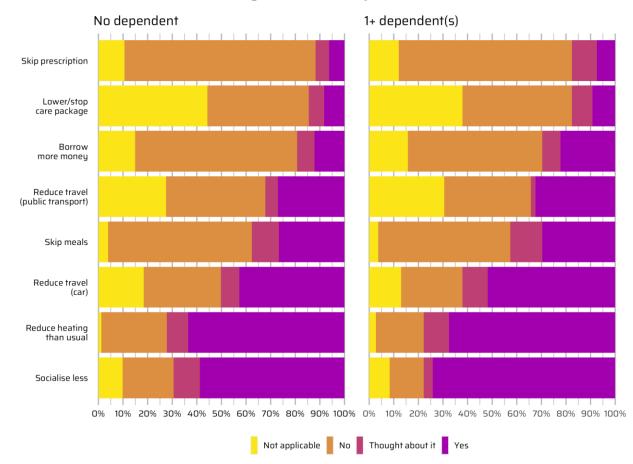
Table C. Astissant allow falles in a second in same of the income second state with sliffs and the second	
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Table 6: Actions taken following increase in costs of living among people with different emp	nogineni statas.

Group	Changes made	Option chosen	Respondents	Percentage
Employed		Yes	9	10.59
		Thought about it	3	3.53
	Skip prescription Lower/stop care package	Νο	67	78.82
		Not applicable	6	7.06
		Yes	8	9.41
		Thought about it	4	4.71

Group	Changes made	Option chosen	Respondents	Percentage
		Νο	38	44.71
		Not applicable	35	41.18
		Yes	20	23.53
		Thought about it	5	5.88
	Borrow more money	Νο	52	61.18
		Not applicable	8	9.41
		Yes	29	34.12
	Reduce travel (public	Thought about it	6	7.06
	transport)	Νο	38	44.71
		Not applicable	12	14.12
		Yes	26	30.59
		Thought about it	13	15.29
	Skip meals	Νο	44	51.76
		Not applicable	2	2.35
		Yes	40	47.06
		Thought about it	12	14.12
	Reduce travel (car)	Νο	27	31.76
		Not applicable	6	7.06
		Yes	64	75.29
	Reduce heating than	Thought about it	9	10.59
	usual	Νο	12	14.12
		Not applicable	0	0.00
		Yes	63	74.12
		Thought about it	6	7.06
	Socialise less	Νο	14	16.47
		Not applicable	2	2.35
		Yes	9	5.88
		Thought about it	11	7.19
	Skip prescription	No	121	79.08
		Not applicable	12	7.84
		Yes	11	7.19
Not		Thought about it	14	9.15
employed/others	Lower/stop care package	Νο	69	45.10
		Not applicable	59	38.56
		Yes	24	15.69
	_	Thought about it	13	8.50
	Borrow more money	Νο	94	61.44
		Not applicable	22	14.38

Group	Changes made	Option chosen	Respondents	Percentage
		Yes	45	29.41
	Reduce travel (public	Thought about it	5	3.27
	transport)	No	56	36.60
		Not applicable	47	30.72
		Yes	45	29.41
		Thought about it	23	15.03
	Skip meals	No	80	52.29
		Not applicable	5	3.27
		Yes	76	49.67
		Thought about it	7	4.58
	Reduce travel (car)	No	41	26.80
		Not applicable	29	18.95
		Yes	100	65.36
	Reduce heating than usual	Thought about it	14	9.15
		No	37	24.18
		Not applicable	2	1.31
		Yes	97	63.40
		Thought about it	15	9.80
	Socialise less	Νο	25	16.34
		Not applicable	16	10.46
		Yes	6	5.13
	Clvin procerintion	Thought about it	11	9.40
	Skip prescription	Νο	82	70.09
		Not applicable	18	15.38
		Yes	12	10.26
		Thought about it	7	5.98
	Lower/stop care package	Νο	43	36.75
		Not applicable	55	47.01
Retired		Yes	9	7.69
Renreu		Thought about it	8	6.84
	Borrow more money	Νο	77	65.81
		Not applicable	23	19.66
		Yes	30	25.64
	Reduce travel (public	Thought about it	4	3.42
	transport)	No	44	37.61
		Not applicable	39	33.33
	Chin mosts	Yes	28	23.93
	Skip meals	Thought about it	5	4.27

Group	Changes made	Option chosen	Respondents	Percentage
		No	78	66.67
	Not applicable	6	5.13	
		Yes	47	40.17
	Reduce travel (car)	Thought about it	11	9.40
		No	36	30.77
		Not applicable	23	19.66
		Yes	64	54.70
	Reduce heating than	Thought about it	10	8.55
	usual	No	39	33.33
		Not applicable	4	3.42
	Socialise less	Yes	65	55.56
		Thought about it	10	8.55
		No	27	23.08
		Not applicable	15	12.82



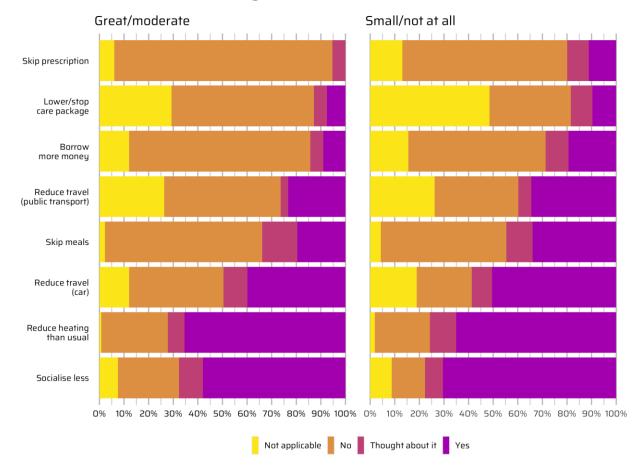
#### Actions taken: Does this differ by number of dependents?

Figure 8: Actions taken following increase in costs of living among groups with different number of dependents.

Group	Changes made	Option chosen	Respondents	Percentage
	Skip prescription	Yes	- 16	6.27
		Thought about it	14	5.49
		No	198	77.65
		Not applicable	27	10.59
	Lower/stop care package	Yes	21	8.24
No dependent		Thought about it	16	6.27
		No	105	41.18
		Not applicable	113	44.31
	Borrow more money	Yes	31	12.16
		Thought about it	18	7.06
		No	168	65.88
		Not applicable	38	14.90

Group	Changes made	<b>Option chosen</b>	Respondents	Percentage
		Yes	69	27.06
	Reduce travel (public transport)	Thought about it	13	5.10
	Reduce fravel (public fransport)	No	103	40.39
		Not applicable	70	27.45
		Yes	68	26.67
	Chin moole	Thought about it	28	10.98
		No	149	58.43
		Not applicable	10	3.92
		Yes	109	42.75
		Thought about it	19	7.45
	Reduce travel (car)	No	80	31.37
		Not applicable	47	18.43
		Yes	162	63.53
		Thought about it	22	8.63
	Reduce heating than usual	No	68	26.67
		Not applicable	3	1.18
		Yes	150	58.82
		Thought about it	27	10.59
	Socialise less	No	53	20.78
		Not applicable	25	9.80
	Skip prescription	Yes	8	7.41
		Thought about it	11	10.19
		No	76	70.37
		Not applicable	13	12.04
	Lower/stop care package	Yes	10	9.26
		Thought about it	9	8.33
		No	48	44.44
		Not applicable	41	37.96
	Borrow more money	Yes	24	22.22
1+ dependent(s)		Thought about it	8	7.41
		No	59	54.63
		Not applicable	17	15.74
	Reduce travel (public transport)	Yes	35	32.41
		Thought about it	2	1.85
		No	38	35.19
		Not applicable	33	30.56
		Yes	32	29.63
	Skip meals	Thought about it	14	12.96
		_		

Group	Changes made	Option chosen	Respondents	Percentage
		No	58	53.70
		Not applicable	4	3.70
		Yes	56	51.85
	Doduco travel (car)	Thought about it	11	10.19
	Reduce travel (car)	No	27	25.00
		Not applicable	14	12.96
		Yes	73	67.59
	Deduce besting then yous!	Thought about it	11	10.19
	Reduce heating than usual	No	21	19.44
		Not applicable	3	2.78
		Yes	80	74.07
	Socialise less	Thought about it	4	3.70
		No	15	13.89
		Not applicable	9	8.33



#### Actions taken: Does this differ by extent of mental health needs met?

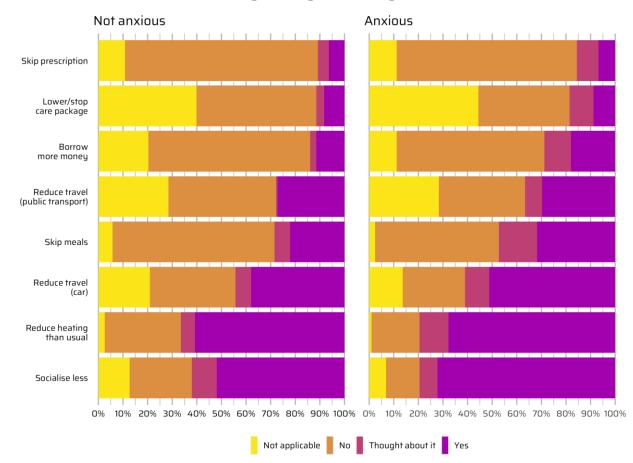
*Figure 9: Actions taken following increase in costs of living among people with different extent of mental health needs met.* 

Table 8: Actions taken following increase in costs of living among people with different extent of mental health needs met.

Group	Changes made	Option chosen	Respondents	Percentage
	Skip prescription	Yes	0	0.00
		Thought about it	7	5.26
		No	118	88.72
		Not applicable	8	6.02
	Lower/stop care package	Yes	10	7.52
Moderate/great		Thought about it	7	5.26
		No	77	57.89
		Not applicable	39	29.32
	Borrow more money	Yes	12	9.02
		Thought about it	7	5.26
		No	98	73.68

Group	Changes made	Option chosen	Respondents	Percentage
		Not applicable	16	12.03
		Yes	31	23.31
	Deduce travel (public transport)	Thought about it	4	3.01
	Reduce travel (public transport)	No	63	47.37
		Not applicable	35	26.32
		Yes	26	19.55
	Skip meals	Thought about it	19	14.29
		No	85	63.91
		Not applicable	3	2.26
		Yes	53	39.85
		Thought about it	13	9.77
	Reduce travel (car)	No	51	38.35
		Not applicable	16	12.03
		Yes	87	65.41
		Thought about it	9	6.77
	Reduce heating than usual	No	36	27.07
		Not applicable	1	0.75
		Yes	77	57.89
		Thought about it	13	9.77
	Socialise less	No	33	24.81
		Not applicable	10	7.52
		Yes	23	11.17
		Thought about it	18	8.74
	Skip prescription	No	138	66.99
		Not applicable	27	13.11
	Lower/stop care package	Yes	20	9.71
		Thought about it	18	8.74
		No	68	33.01
		Not applicable	100	48.54
Not at all/small		Yes	40	19.42
	Borrow more money	Thought about it	19	9.22
		No	115	55.83
		Not applicable	32	15.53
	Reduce travel (public transport)	Yes	71	34.47
		Thought about it	11	5.34
		No	70	33.98
		Not applicable	54	26.21
	Skip meals	Yes	70	33.98

Group	Changes made	Option chosen	Respondents	Percentage
		Thought about it	22	10.68
		No	105	50.97
		Not applicable	9	4.37
		Yes	104	50.49
		Thought about it	17	8.25
	Reduce travel (car)	No	46	22.33
	Not applicable	39	18.93	
	Yes	134	65.05	
		Yes Thought about it	22	10.68
	Reduce heating than usual	No	46	22.33
		Thought about itZNo10Not applicableYes10Thought about it10No4Not applicable3Yes13Thought about it2No4Not applicable3Yes13Thought about it2No4Not applicable3Yes14Not applicable14Yes14Thought about it2No2	4	1.94
		No10Not applicable9Yes104Thought about it1No44Not applicable39Yes134Thought about it21No44Not applicable39Yes134Thought about it21No44Not applicable44No44Not applicable44Not applicable44Not applicable44Not applicable44Not applicable44Not applicable44No24	145	70.39
			15	7.28
	Socialise less	No	28	13.59
		Not applicable	18	8.74



### Actions taken: Does this differ by feeling of anxiety?

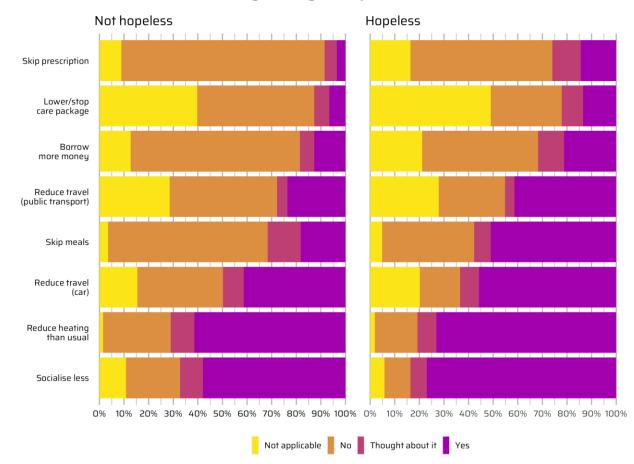
Figure 10: Actions taken following increase in costs of living among people with/without anxiety.

Group	Changes made	Option chosen	Respondents	Percentage
	Skip prescription          Skip prescription       Yes         Thought       No         Not appl       Yes         anxious       Lower/stop care package       Thought         No       No         No       No         No       No         No       No         No       No         No       No         No       Not appl	Yes	10	6.33
		Thought about it	7	4.43
	Skip prescription	No	124	78.48
Not applique l'ower/stop sare		Not applicable	17	10.76
		Yes	13	8.23
		Thought about it	5	3.16
NUI alixiuus	Lower/Stop care package	No	77	48.73
		Not applicable	63	39.87
	5	Yes	18	11.39
		Thought about it	4	2.53
	Borrow more money	No	104	65.82
		Not applicable	32	20.25

Table 9: Actions taken following increase in costs of living among people with/without anxiety.

Group	Changes made	Option chosen	Respondents	Percentage
		Yes	43	27.22
	Doduce travel (public trapenert)	Thought about it	1	0.63
	Reduce travel (public transport)	No	69	43.67
		Not applicable	45	28.48
		Yes	35	22.15
		Thought about it	10	6.33
	Skip meals	No	104	65.82
		Not applicable	9	5.70
		Yes	60	37.9
		Thought about it	10	6.3
	Reduce travel (car)	No	55	34.8
		Not applicable	33	20.89
		Yes	96	60.76
		Thought about it	9	5.70
	Reduce heating than usual	No	49	31.0
		Not applicable	4	2.53
		Yes	82	51.9
	Socialise less	Thought about it	16	10.1
		No	40	25.3
		Not applicable	20	12.60
		Yes	14	6.8
		Thought about it	18	8.78
	Skip prescription	No	150	73.1
		Not applicable	23	11.2
		Yes	18	8.7
		Thought about it	20	9.70
Reduce l Socialise Skip pres Lower/st Anxious Borrow r	Lower/stop care package	No	76	37.0
		Not applicable	91	44.39
		Yes	37	18.05
Anxious		Thought about it	22	10.7
	Borrow more money	No	123	60.00
		Not applicable	23	11.22
		Yes	61	29.76
		Thought about it	14	6.8
	Reduce travel (public transport)	No	72	35.1
		Not applicable	58	28.29
		Yes	65	31.7
	Skin meals	Thought about it		51.7

Group	Changes made	Option chosen	Respondents	Percentage
		No	103	50.24
		Not applicable	5	2.44
		Yes	105	51.22
	Doduce travel (car)	Thought about it	20	9.76
Reduce f	Reduce travel (car)	No	52	25.37
		Not applicable	28	13.66
		Yes	139	67.80
		Thought about it	24	11.71
	Reduce heating than usual	No	40	19.51
		Not applicable	2	0.98
		Yes	148	72.20
		Thought about it	15	7.32
	Socialise less	No	28	13.66
		Not applicable	14	6.83



### Actions taken: Does this differ by feeling of hopelessness?

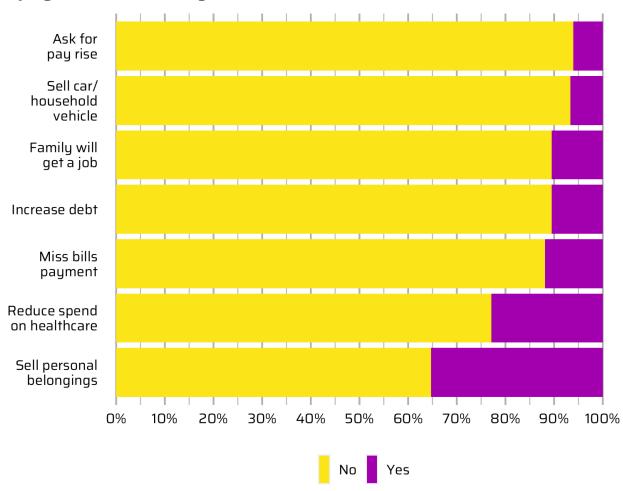
Figure 11: Actions taken following increase in costs of living among people with/without feeling of hopelessness.

Table 10: Actions taken following increase in costs of living among people with/without feeling of hopelessness.

Group	Changes made	Option chosen	Respondents	Percentage
		Yes	9	3.47
	Chin processintion	escription Yes Thought about it No Not applicable Yes Thought about it No Not applicable Yes Yes Thought about it No Not applicable Yes	13	5.02
	Skip prescription	Νο	214	82.63
		Not applicable	23	8.88
		Yes	17	6.56
Not hopeless	lower/stop save paskage	re package Not applicable 2: Yes 1 Thought about it 16 No 12:	16	6.18
	Lower/stop care package	Νο	123	47.49
		Not applicable	103	39.77
		Yes	33	12.74
	Borrow more money	Thought about it	15	5.79
		No	178	68.73

Group	Changes made	Option chosen	Respondents	Percentage
		Not applicable	33	12.74
		Yes	61	23.55
		Thought about it	11	4.25
	Reduce travel (public transport)	Νο	113	43.63
		Not applicable	74	28.57
		Yes	47	18.15
		Thought about it	35	13.51
	Skip meals	No	168	64.86
		Not applicable	9	3.47
		Yes	107	41.31
		Thought about it	22	8.49
	Reduce travel (car)	No	90	34.75
		Not applicable	40	15.44
		Yes	159	61.39
		Thought about it	25	9.65
	Reduce heating than usual	No	71	27.41
		Not applicable	4	1.54
		Yes	150	57.92
		Thought about it	24	9.27
	Socialise less	No		22.01
		Not applicable	28	10.81
		Yes	15	14.42
		Thought about it		11.54
	Skip prescription	No	60	57.69
		Not applicable	17	16.35
		Yes	14	13.46
		Thought about it	9	8.65
	Lower/stop care package	No	30	28.85
		Not applicable	51	49.04
Hopeless		Yes	22	21.15
		Thought about it	11	10.58
	Borrow more money	No	49	47.12
		Not applicable	22	21.15
		Yes	43	41.35
		Thought about it	4	3.85
	Reduce travel (public transport)	No		26.92
		Not applicable	29	27.88
	Skip meals	Yes	53	50.96

Group	Changes made	Option chosen	Respondents	Percentage
		Thought about it	7	6.73
		No	39	37.50
		Not applicable	5	4.81
		Yes	58	55.77
	Doduce travel (car)	Thought about it	8	7.69
Redu	Reduce travel (car)	No	17	16.35
		Not applicable	21	20.19
		Yes	76	73.08
	Doduce booting than usual	Thought about it	8	7.69
	Reduce heating man usual		18	17.31
		Not applicable	2	1.92
		Yes	80	76.92
		Thought about it	7	6.73
	500181158 1855	No	11	10.58
	Yes Socialise less		6	5.77



### Coping with cost-of-living crisis (overall)

Figure 12: Ways of coping with cost-of-living crisis (overall).

Table 11: Ways of coping with cost-of-living crisis (overall).

Ways of coping	Yes/No	Respondents	Percentage
Family will get a job	Yes	38	10.47
Family will get a job	No	325	89.53
Ask for	Yes	22	6.06
pay rise	No	341	93.94
Sell car/ household vehicle	Yes	24	6.61
	No	339	93.39
Miss bills	Yes	43	11.85
payment	No	320	88.15
Increase debt	Yes	38	10.47
	No	325	89.53
Reduce spend on healthcare	Yes	83	22.87

Ways of coping	Yes/No	Respondents	Percentage
	No	280	77.13
	Yes	128	35.26
Sell personal belongings	No	235	64.74

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

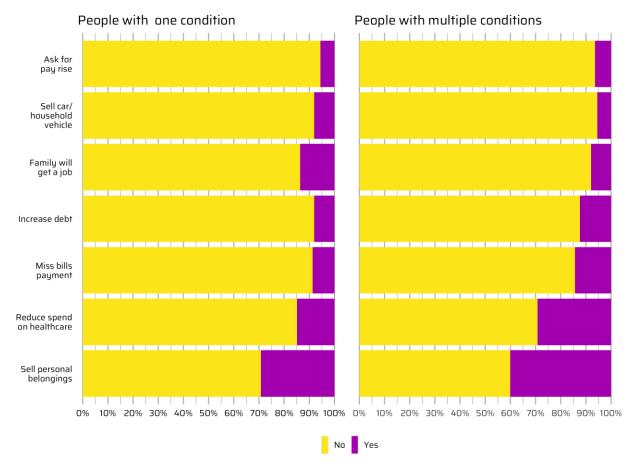


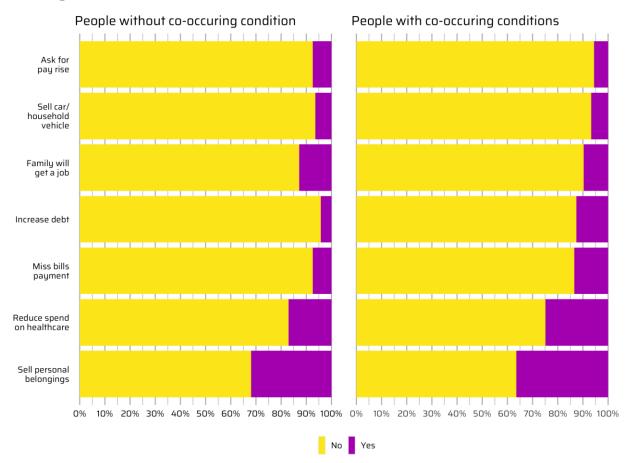
Figure 13: Ways of coping with cost-of-living crisis among people with/without multiple neurological conditions.

Table 12: Ways of coping with cost-of-living crisis among people with/without multiple neurological conditions.

Group	Ways of coping	Yes/No	Respondents	Percentage
	Family will get a job 🛛 🚽	Yes	- 16	7.92
		No	186	92.08
Multiple conditions	Ask for pay rise	Yes	13	6.44
		No	189	93.56
		Yes	11	5.45

Group	Ways of coping	Yes/No	Respondents	Percentage
	Sell car/ household vehicle	No	191	94.55
	Miss bills payment	Yes	29	14.36
	Miss bills payment	No	173	85.64
	Increase debt	Yes	25	12.38
		No	177	87.62
	Reduce spend on healthcare	Yes	59	29.21
	Reduce spend on nearmcare	No	143	70.79
	Sell personal belongings	Yes	81	40.10
		No	121	59.90
	Family will get a job	Yes	22	13.66
		No	139	86.34
	Ask for pay rise	Yes	9	5.59
		No	152	94.41
	Sell car/ household vehicle	Yes	13	8.07
		No	148	91.93
One condition	Miss bills payment	Yes	14	8.70
One condition		No	147	91.30
	Increase debt	Yes	13	8.07
		No	148	91.93
	Poduce creation bealthcare	Yes	24	14.91
	Reduce spend on healthcare	No	137	85.09
	Sell personal belongings	Yes	47	29.19
		No	114	70.81

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

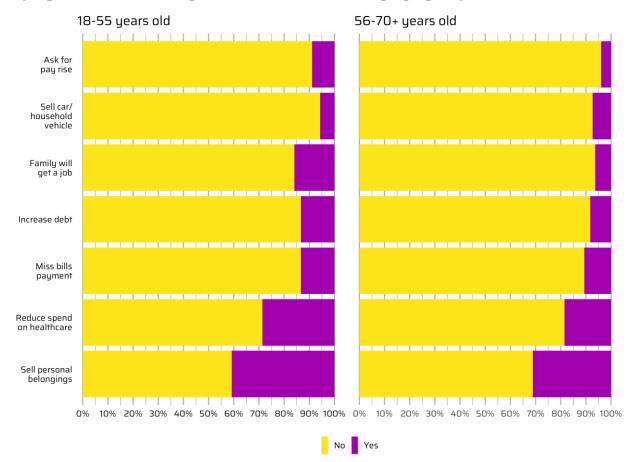


*Figure 14: Ways of coping with cost-of-living crisis among people with/without co-occurring non-neurological conditions.* 

Table 13: Ways of coping with cost-of-living crisis among people with/without co-occurring non-neurological conditions.

Group	Ways of coping	Yes/No	Respondents	Percentage
Individuals without co-occurring	Family will get a job	Yes	12	12.77
	Family will get a job	No	82	87.23
	Ask for pay rise	Yes	7	7.45
		No	87	92.55
	Sell car/ household	Yes	6	6.38
conditions	Sell car/ household vehicle	No	88	93.62
	Miss hills noumant	Yes	7	7.45
	Miss bills payment	No	87	92.55
		Yes	4	4.26
	Increase debt	No	90	95.74

Group	Ways of coping	Yes/No	Respondents	Percentage
	Reduce spend on	Yes	16	17.02
	healthcare	No	78	82.98
	Sell personal	Yes	30	31.91
	belongings	No	64	68.09
	Family will get a job	Yes	26	9.67
	Family will get a jub	No	243	90.33
	Ask for pay rise	Yes	15	5.58
		No	254	94.42
	Sell car/ household	Yes	18	6.69
	vehicle	No	251	93.31
Individuals with co-occurring	Miss bills payment	Yes	36	13.38
conditions		No	233	86.62
		Yes	34	12.64
	Increase debt	No	235	87.36
	Reduce spend on	Yes	67	24.91
	healthcare	No	202	75.09
	Sell personal	Yes	98	36.43
	belongings	No	171	63.57



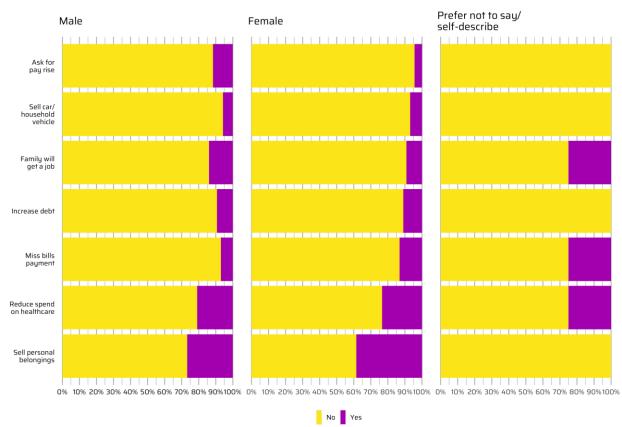
### Coping with cost-of-living crisis: Does this differ by age groups?

Figure 15: Ways of coping with cost-of-living crisis among people in different age groups.

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Table 14: Ways of coping	with cost-of-living crisis am	ong people in different age groups.

Group	Ways of coping	Yes/No	Respondents	Percentage
	Family will got a job	Yes	25	15.92
	Family will get a job	No	132	84.08
	Ask for pay rise	Yes	14	8.92
		No	143	91.08
	Sell car/ household	Yes	9	5.73
18-55 years old	vehicle	No	148	94.27
	Miss bills payment	Yes	21	13.38
		No	136	86.62
	Increase debt	Yes	21	13.38
		No	136	86.62
	Doduco coord on boolthcoro	Yes	45	28.66
	Reduce spend on healthcare	No	112	71.34

Group	Ways of coping	Yes/No	Respondents	Percentage
	Coll porconal belongings	Yes	64	40.76
	Sell personal belongings	No	93	59.24
	Family will get a job	Yes	13	6.31
		No	193	93.69
	Ask for pay rise	Yes	8	3.88
		No	198	96.12
	Sell car/ household vehicle	Yes	15	7.28
		No	191	92.72
	Miss bills payment	Yes	22	10.68
56-70+ years old		No	184	89.32
	Increase debt	Yes	17	8.25
		No	189	91.75
	Reduce spend on healthcare	Yes	38	18.45
		No	168	81.55
		Yes	64	31.07
	Sell personal belongings	No	142	68.93

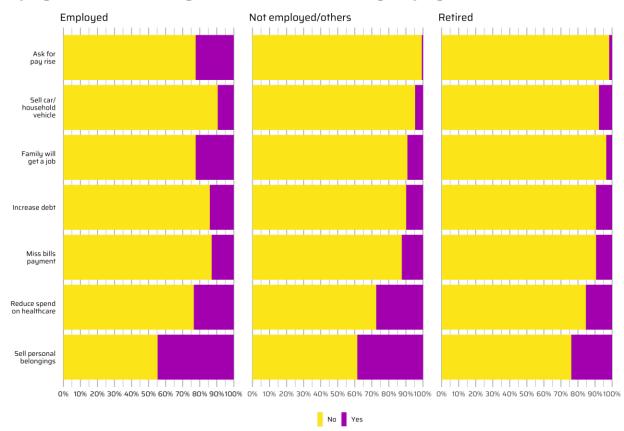


## Coping with cost-of-living crisis: Does this differ by sex?

Figure 16: Ways of coping with cost-of-living crisis among different sexes.

Ways of coping	Yes/No	Respondents	Percentage
Family will get a job	Yes	12	13.95
Failing will ger a job	No	74	86.05
Ask for pouriso	Yes	10	11.63
Ask for pay rise	No	76	88.37
Sell car/ household	Yes	5	5.81
vehicle	No	81	94.19
Miss bills payment	Yes	6	6.98
	No	80	93.02
Increase debt	Yes	8	9.30
	No	78	90.70
Reduce spend on	Yes	18	20.93
healthcare	No	68	79.07
	Yes	23	26.74
Sell personal belongings	No	63	73.26
	Family will get a job Ask for pay rise Sell car/ household vehicle Miss bills payment Increase debt Reduce spend on	YesFamily will get a jobYesNoYesAsk for pay riseYesNoSell car/ householdYesvehicleNoMiss bills paymentYesMoYesIncrease debtYesNoYesReduce spend on healthcareYesSell personal belongingsYes	$ \begin{array}{c c c c c } \hline & Yes & 12 \\ \hline No & 74 \\ \hline No & 74 \\ \hline No & 74 \\ \hline No & 76 \\ \hline Sell car/ household & Yes & 5 \\ \hline vehicle & No & 81 \\ \hline Miss bills payment & \hline Yes & 6 \\ \hline No & 80 \\ \hline No & 80 \\ \hline Increase debt & \hline Yes & 8 \\ \hline No & 78 \\ \hline Reduce spend on & Yes & 18 \\ \hline healthcare & No & 68 \\ \hline Sell personal belongings & \hline Yes & 23 \\ \hline \end{array} $

Group	Ways of coping	Yes/No	Respondents	Percentage
	En seite seitt wert nich	Yes	25	9.16
	Family will get a job	No	248	90.84
		Yes	12	4.40
	Ask for pay rise	No	261	95.60
	Sell car/ household	Yes	19	6.96
	vehicle	No	254	93.04
		Yes	36	13.19
Female	Miss bills payment	No	237	86.81
		Yes	30	10.99
	Increase debt	No	243	89.01
	Reduce spend on	Yes	64	23.44
	healthcare	No	209	76.56
	Sell personal belongings	Yes	105	38.46
		No	168	61.54
	Family will get a job	Yes	1	25.00
		No	3	75.00
	Ask for pay rise	Yes	0	0.00
		No	4	100.00
	Sell car/ household	Yes	0	0.00
	vehicle	No	4	100.00
Prefer not to say/self-		Yes	1	25.00
describe	Miss bills payment	No	3	75.00
		Yes	0	0.00
	Increase debt	No	4	100.00
	Reduce spend on	Yes	1	25.00
	healthcare	No	3	75.00
		Yes	0	0.00
	Sell personal belongings	No	4	100.00



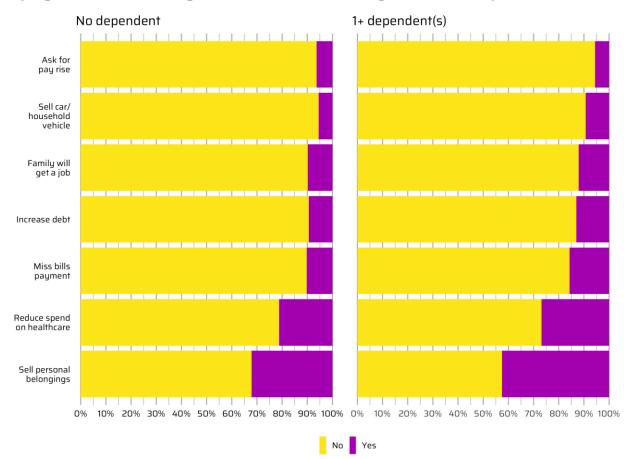
### Coping with cost-of-living crisis: Does this differ by employment status?

Figure 17: Ways of coping with cost-of-living crisis among different employment statuses.

Group	Ways of coping	Yes/No	Respondents	Percentage
	Family will get a job	Yes	19	22.35
Employed	Family will get a job	No	66	77.65
	Ack for pourise	Yes	19	22.35
	Ask for pay rise	No	66	77.65
	Sell car/ household	Yes	8	9.41
	vehicle	No	77	90.59
	Miss hills pourpopt	Yes	11	12.94
	Miss bills payment	No	74	87.06
	Increase debt	Yes	12	14.12
		No	73	85.88
	Reduce spend on healthcare	Yes	20	23.53
		No	65	76.47
		Yes	38	44.71
	Sell personal belongings	No	47	55.29

Table 16: Ways of coping with cost-of-living crisis among different employment statuses.

Group	Ways of coping	Yes/No	Respondents	Percentage
	Family will get a job	Yes	14	9.15
		No	139	90.85
	Ack for pourico	Yes	1	0.65
	Ask for pay rise	No	152	99.35
	Sell car/ household	Yes	7	4.58
	vehicle	No	146	95.42
	NA:	Yes	19	12.42
Not employed/others	Miss bills payment	No	134	87.58
	Increase debt	Yes	15	9.80
		No	138	90.20
	Reduce spend on healthcare	Yes	42	27.45
		No	111	72.55
	Sell personal belongings	Yes	59	38.56
		No	94	61.44
	Family will get a job	Yes	4	3.42
		No	113	96.58
	۸ - I. f	Yes	2	1.71
	Ask for pay rise	No	115	98.29
	Sell car/ household	Yes	9	7.69
	vehicle	No	108	92.31
Dativad		Yes	11	9.40
Retired	Miss bills payment	No	106	90.60
		Yes	11	9.40
	Increase debt	No	106	90.60
		Yes	18	15.38
	Reduce spend on healthcare	No	99	84.62
	<b>C</b> -II	Yes	28	23.93
	Sell personal belongings	No	89	76.07



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

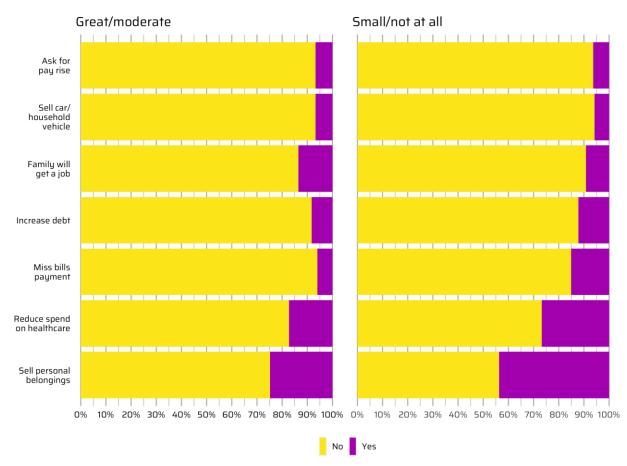
*Figure 18: Ways of coping with cost-of-living crisis among people with/without dependents.* 

	Table 17: Ways of coping with	h cost-of-living crisis among	people with/without dependents.
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Group	Ways of coping	Yes/No	Respondents	Percentage
	Family will got a job	Yes	- 25	9.80
	Family will get a job	No	230	90.20
	Ask for pay rise	Yes	16	6.27
		No	239	93.73
No dependent	Sell car/ household vehicle	Yes	14	5.49
		No	241	94.51
	Miss bills payment	Yes	26	10.20
		No	229	89.80
	Increase debt	Yes	24	9.41
		No	231	90.59
	Reduce spend on healthcare	Yes	54	21.18
	Reduce Spend On Nealincare	No	201	78.82

Group	Ways of coping	Yes/No	Respondents	Percentage
		Yes	82	32.16
	Sell personal belongings	No	173	67.84
	Family will get a job	Yes	13	12.04
		No	95	87.96
	Ask for pay rise	Yes	6	5.56
		No	102	94.44
1+ dependent(s)	Sell car/ household vehicle	Yes	10	9.26
		No	98	90.74
	Miss bills payment	Yes	17	15.74
		No	91	84.26
	Increase debt	Yes	14	12.96
		No	94	87.04
		Yes	29	26.85
	Reduce spend on healthcare	No	79	73.15
		Yes	46	42.59
	Sell personal belongings	No	62	57.41

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



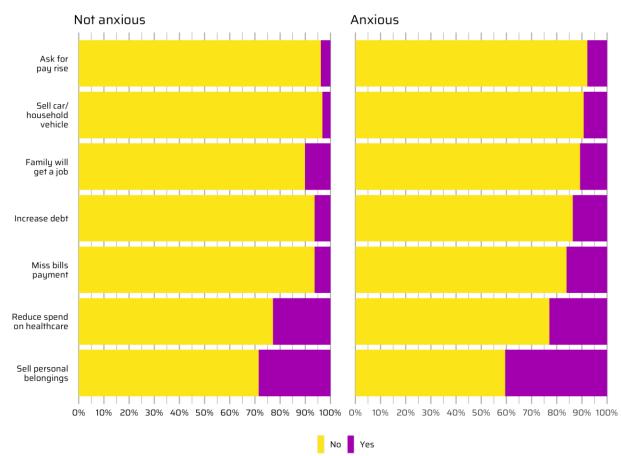
*Figure 19: Ways of coping with cost-of-living crisis among people with different extent of mental health needs met.* 

 Table 18: Ways of coping with cost-of-living crisis among people with different extent of mental health needs

 met.

Group	Ways of coping	Yes/No	Respondents	Percentage
	- Family will got a job	Yes	- 18	13.53
	Family will get a job	No	115	86.47
	Ack for pourico	Yes	9	6.77
	Ask for pay rise	No	124	93.23
Modorato/groat	Sell car/ household	Yes	9	6.77
Moderate/great	vehicle	No	124	93.23
	Micc hills noumant	Yes	8	6.02
	Miss bills payment	No	125	93.98
	Increase debt	Yes	11	8.27
		No	122	91.73

Group	Ways of coping	Yes/No	Respondents	Percentage
	Reduce spend on healthcare	Yes	23	17.29
		No	110	82.71
	Sell personal belongings	Yes	33	24.81
	No	No	100	75.19
	Family will get a job	Yes	19	9.22
		No	187	90.78
	Ask for pay rise	Yes	13	6.31
		No	193	93.69
	Sell car/ household	Yes	12	5.83
	vehicle	No	194	94.17
Not at all/small	Miss bills payment	Yes	31	15.05
	Miss bills pagilielli	No	175	84.95
	Increase debt	Yes	25	12.14
		No	181	87.86
	Reduce spend on healthcare	Yes	55	26.70
		No	151	73.30
	Sell personal belongings	Yes	90	43.69
		No	116	56.31



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

Figure 20: Ways of coping with cost-of-living crisis among people with/without feeling of anxiety.

Group	Ways of coping	Yes/No	Respondents	Percentage
	Family will get a job	Yes	16	10.13
		No	142	89.87
		Yes	6	3.80
	Ask for pay rise	No	152	96.20
	Sell car/ household	Yes	5	3.16
Not anxious	vehicle	No	153	96.84
NUI alixiuus		Yes	10	6.33
	Miss bills payment	No	148	93.67
	Increase debt	Yes	10	6.33
	Increase debi	No	148	93.67
		Yes	36	22.78
	Reduce spend on healthcare	No	122	77.22

Group	Ways of coping	Yes/No	Respondents	Percentage
	Sell personal belongings	Yes	45	28.48
	Sell personal belongings	No	113	71.52
	Family will get a job	Yes	22	10.73
	Farmy winger a job	No	183	89.27
	<b>A</b> -1, <b>f</b> - ,	Yes	16	7.80
	Ask for pay rise	No	189	92.20
	Sell car/ household	Yes	19	9.27
A	vehicle	No	186	90.73
	Miss hills noumont	Yes	33	16.10
Anxious	Miss bills payment	No	172	83.90
	Increase debt	Yes	28	13.66
	Increase debi	No	177	86.34
	Deduce creater healthcare	Yes	47	22.93
	Reduce spend on healthcare	No	158	77.07
	Coll porconal balangings	Yes	83	40.49
	Sell personal belongings	No	122	59.51

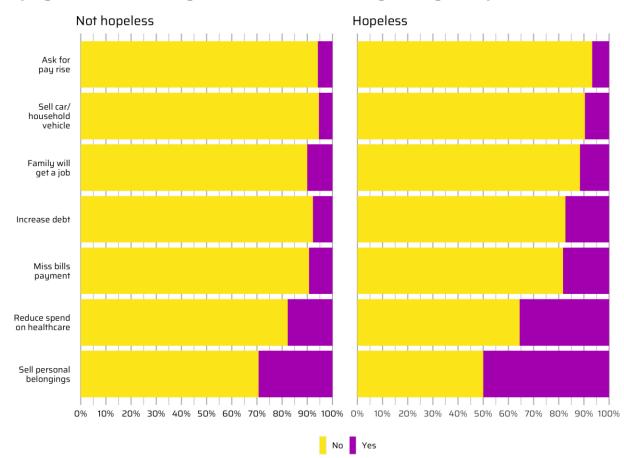




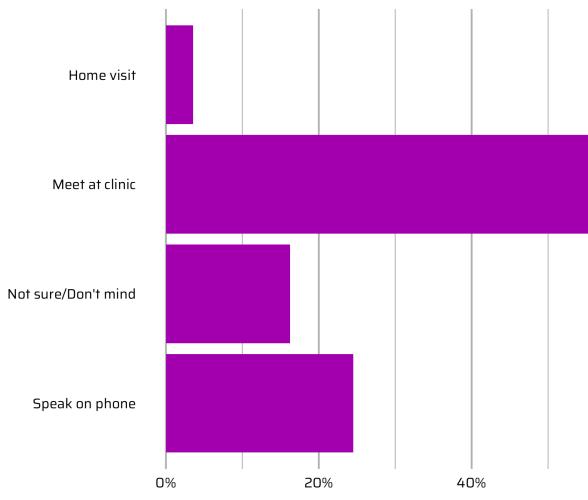
Figure 21: Ways of coping with cost-of-living crisis among people with/without feeling of hopelessness.

Group	Ways of coping	Yes/No	Respondents	Percentage
		Yes	26	10.04
	Family will get a job	No	233	89.96
	Ask for pay rise	Yes	15	5.79
	Ask for pay lise	No	244	94.21
	Sell car/ household	Yes	14	5.41
	vehicle	No	245	94.59
Not hopeless	Miss bills payment	Yes	24	9.27
		No	235	90.73
	Increase debt	Yes	20	7.72
	increase debi	No	239	92.28
		Yes	46	17.76
	Reduce spend on healthcare	No Yes No Yes	213	82.24

Table 20: Ways of coping with cost-of-living crisis among people with/without feeling of hopelessness.

Group	Ways of coping	Yes/No	Respondents	Percentage
	Coll porconal bolongiage	Yes	76	29.34
	Sell personal belongings	No	183	70.66
	Family will got a job	Yes	12	11.54
	Family will get a job	No	92	88.46
	Ack for pourico	Yes	7	6.73
	Ask for pay rise	No	97	93.27
	Sell car/ household	Yes	10	9.62
	vehicle	No	94	90.38
	Miss hills noumant	Yes	19	18.27
Hopeless	Miss bills payment	No	85	81.73
		Yes	18	17.31
	Increase debt	No	86	82.69
		Yes	37	35.58
	Reduce spend on healthcare	No	67	64.42
	Coll porconal holongiana	Yes	52	50.00
	Sell personal belongings	No	52	50.00

# **Meeting specialists**



# Purpose wanting to meet/speak to a specialist.

Figure 22: Purpose of seeing or speaking to a specialist.

Table 21: Purpose wanting to see or speak to a specialist.

Purpose of meeting specialist	Respondents	Percentage
Home visit	- 13	3.58
Meet at clinic	202	55.65
Not sure/Don't mind	59	16.25
Speak on phone	89	24.52

# Able to meet/speak to a specialist.

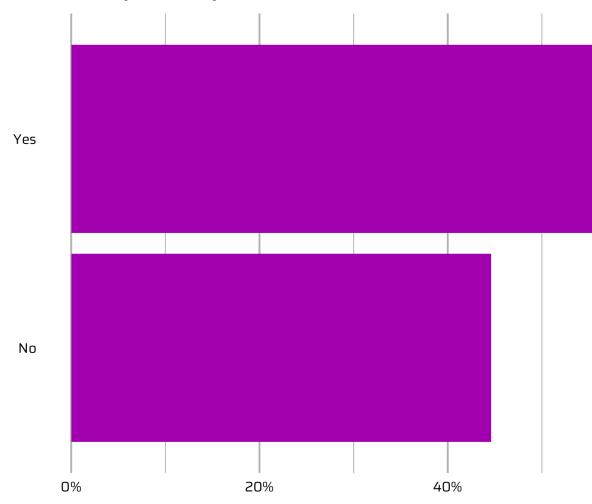


Figure 23: Whether respondents were able to meet or speak to a specialist.

Table 22: Whether respondents were able to meet or speak to a specialist.

Able to meet/speak to a specialist	Respondents	Percentage
Yes	201	55.37
No	162	44.63

# Convenience of meeting a specialist

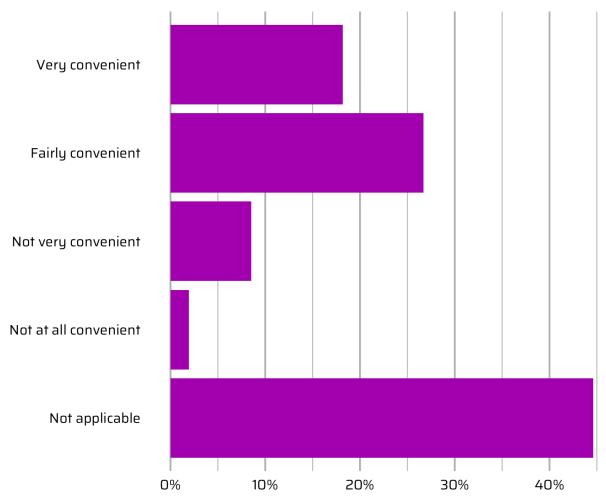
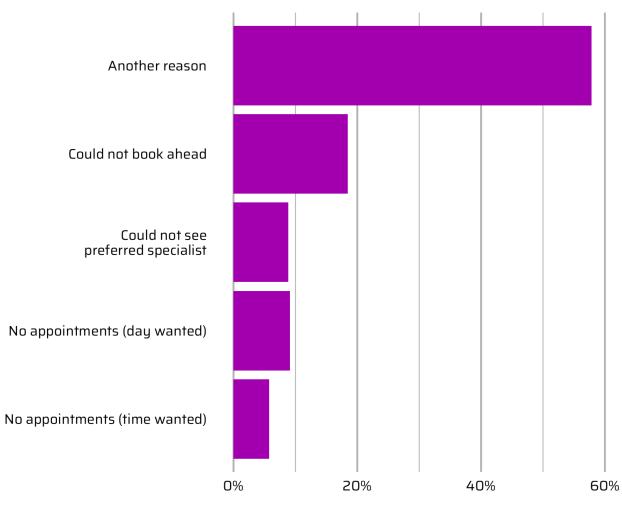


Figure 24: Convenience of meeting a specialist.

Table 23: Convenience of meeting a specialist.

Convenience	Respondents	Percentage
Very convenient	66	18.18
Fairly convenient	97	26.72
Not very convenient	31	8.54
Not at all convenient	7	1.93
Not applicable	162	44.63



### Reasons of not getting an appointment or a convenient one

Figure 25: Reasons of not getting an appointment or a convenient one.

Table 24: Reasons of not getting an appointment or a convenient one.

Reason not getting appointment	Respondents	Percentage
Another reason	210	57.85
Could not book ahead	67	18.46
Could not see preferred specialist	32	8.82
No appointments (day wanted)	33	9.09
No appointments (time wanted)	21	5.79

# Action taken following not getting an appointment/not offered a convenient one.

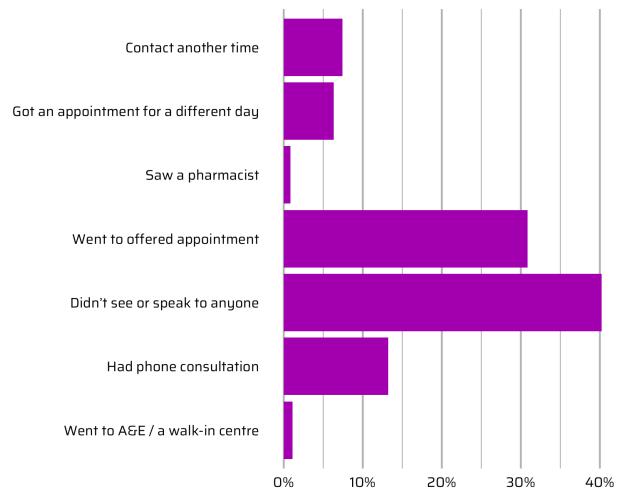


Figure 26: Action taken following not getting an appointment/not offered a convenient one.

Table 25: Action taken following not getting an appointment/not offered a convenient one.

Action taken	Respondents	Percentage
Contact another time	27	7.44
Got an appointment for a different day	23	6.34
Saw a pharmacist	3	0.83
Went to offered appointment	112	30.85
Didn't see or speak to anyone	146	40.22
Had phone consultation	48	13.22
Went to A&E / a walk-in centre	4	1.10

# Purpose of meeting a specialist to whether one is able to meet/speak to a specialist.

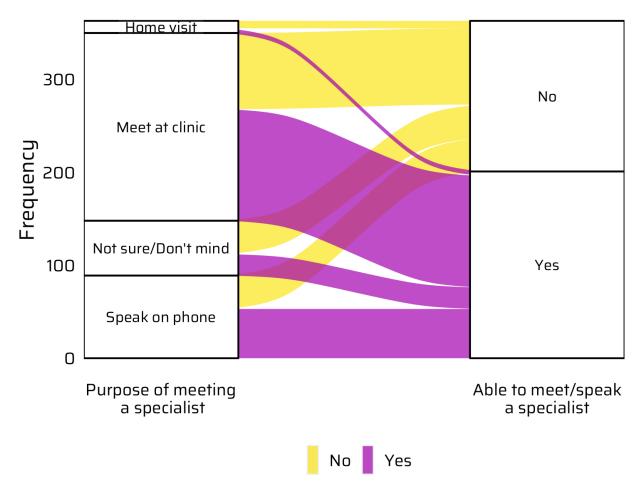
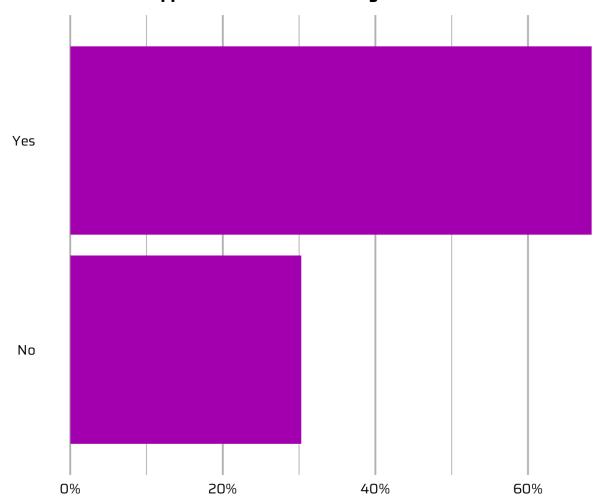


Figure 27: Flow diagram showing purpose of meeting a specialist and whether one is able to meet/speak to a specialist.

Table 26: Purpose of meeting a specialist and whether one is able to meet/speak to a specialist.

Purpose of meeting specialist	Able to meet/speak to a specialist	Frequency	Percentage
Home visit	Νο	8	2.20
	Yes	5	1.38
Meet at clinic	Νο	82	22.59
	Yes	120	33.06
Not sure/Don't mind	Νο	36	9.92
	Yes	23	6.34
Speak on phone	Νο	36	9.92
	Yes	53	14.60

# **Medical appointments**



# Access to medical appointments in the last eight weeks

Figure 28: Access to medical appointments in the last eight weeks.

Appointments	Respondents	Percentage
Yes	248	68.32
No	110	30.30

# Number of medical appointments

Figure 29: Number of medical appointments in the last eight weeks.

Table 28: Number of medical appointments in th	e last eight weeks.
	-

Number of appointments	Respondents	Percentage
6+	15	4.13
5	6	1.65
4	23	6.34
3	44	12.12
2	63	17.36
1	92	25.34
0	120	33.06

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.

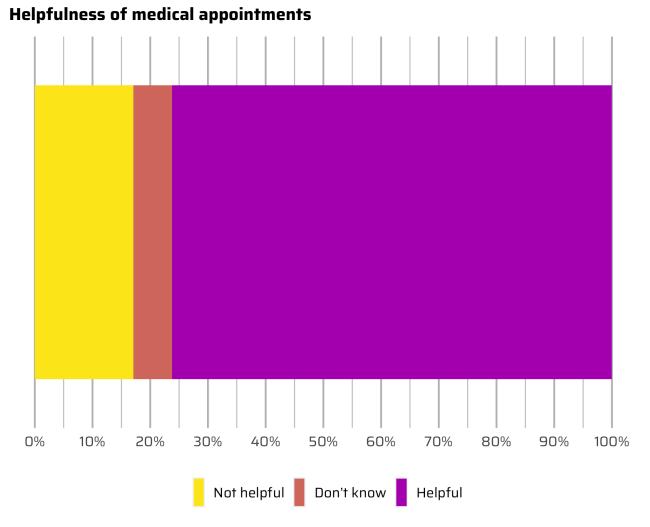


Figure 30: Helpfulness of medical appointments held in the last eight weeks.

Table 29: Helpfulness of medical appointments held in the last eight weeks.

Helpfulness	Observations	Percentage
Helpful	455	76.21
Don't know	40	6.70
Not helpful	102	17.09

### Specialty of medical appointments

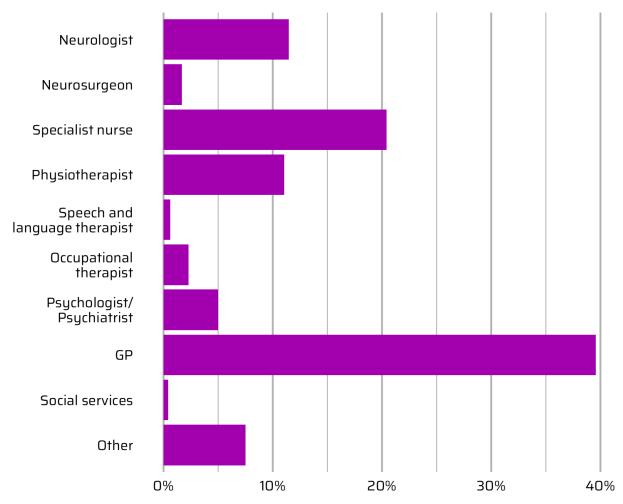
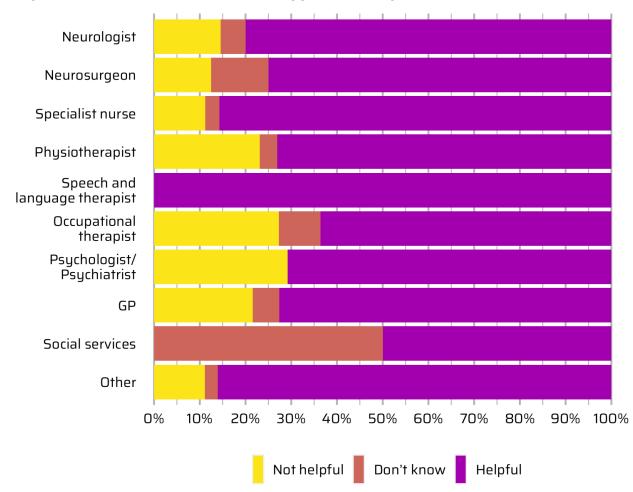


Figure 31: Specialty of the medical appointments held in the last eight weeks.

Table 30: Specialty of the medical appointments held in the last eight weeks.

Specialty	Observations	Percentage
Neurologist	55	11.46
Neurosurgeon	8	1.67
Specialist nurse	98	20.42
Physiotherapist	53	11.04
Speech and language therapist	3	0.62
Occupational therapist	11	2.29
Psychologist/Psychiatrist	24	5.00
GP	190	39.58
Social services	2	0.42
Other	36	7.50



### Helpfulness of the different medical appointment specialisms

Figure 32: Helpfulness of the different specialisms for medical appointments held in the last eight weeks.

Specialty	Helpfulness	Observations	Percentage
	Helpful	44	80.00
Neurologist	Don't know	3	5.45
	Not helpful	8	14.55
	Helpful	6	75.00
Neurosurgeon	Don't know	1	12.50
	Not helpful	1	12.50
	Helpful	84	85.71

Don't know

Not helpful

Don't know

Helpful

Table 31: Helpfulness of the different specialisms for medical appointments held in the last eight weeks.

Specialist nurse

**Physiotherapist** 

138

3.06

11.22

73.08

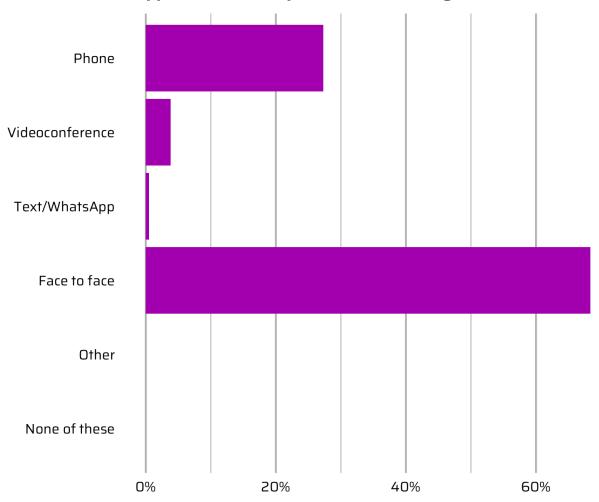
3.85

3

11

38

Specialty	Helpfulness	Observations	Percentage
	Not helpful	12	23.08
	Helpful	3	100.00
Speech and language therapist	Don't know	0	0.00
	Not helpful	0	0.00
	Helpful	7	63.64
Occupational therapist	Don't know	1	9.09
	Not helpful	3	27.27
	Helpful	17	70.83
Psychologist/Psychiatrist	Don't know	0	0.00
	Not helpful	7	29.17
	Helpful	138	72.63
GP	Don't know	11	5.79
	Not helpful	41	21.58
	Helpful	1	50.00
Social services	Don't know	1	50.00
	Not helpful	0	0.00
	Helpful	31	86.11
Other	Don't know	1	2.78
	Not helpful	4	11.11

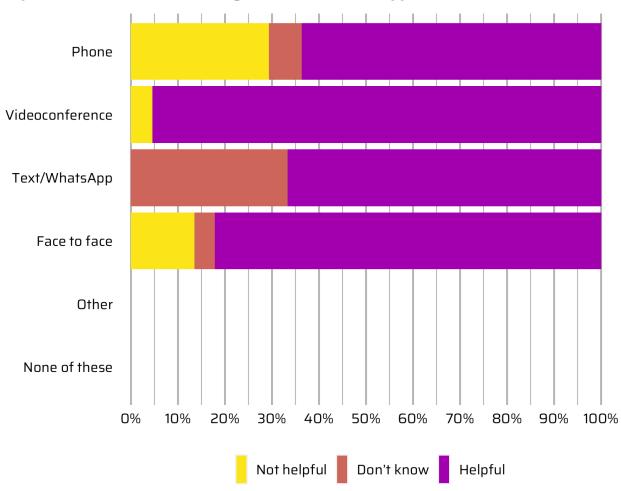


# Mode of medical appointments completed in the last eight weeks.

Figure 33: Mode by which medical appointments were held in the last 8 weeks.

Table 32: Mode by which medical appointments were held in the last 8 weeks.

Mode	Observations	Percentage
Phone	157	27.30
Videoconference	22	3.83
Text/WhatsApp	3	0.52
Face to face	393	68.35
Other	0	0.00
None of these	0	0.00



## Helpfulness of different delivery modes of medical appointments

*Figure 34: Helpfulness of the different modes of delivery for medical appointments held in the last eight weeks.* 

Table 33: Helpfulness of the different modes of delivery for medical appointments held in the last eight weeks.

Mode	Helpfulness	Observations	Percentage
	Helpful	100	63.69
Phone	Don't know	11	7.01
	Not helpful	46	29.30
	Helpful	21	95.45
Videoconference	Don't know	0	0.00
	Not helpful	1	4.55
	Helpful	2	66.67
Text/WhatsApp	Don't know	1	33.33
	Not helpful	0	0.00
Face to face	Helpful	323	82.19

Mode	Helpfulness	Observations	Percentage
	Don't know	17	4.33
	Not helpful	53	13.49
	Helpful	0	NaN
Other	Don't know	0	NaN
	Not helpful	0	NaN
	Helpful	0	NaN
None of these	Don't know	0	NaN
	Not helpful	0	NaN

# **Mental health**

# Feeling anxious or hopeless

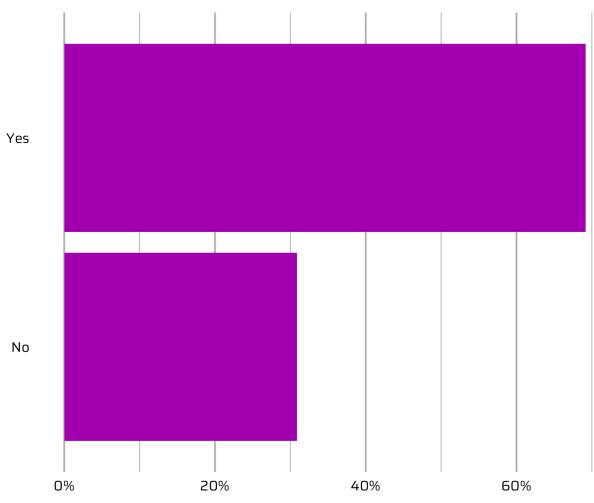
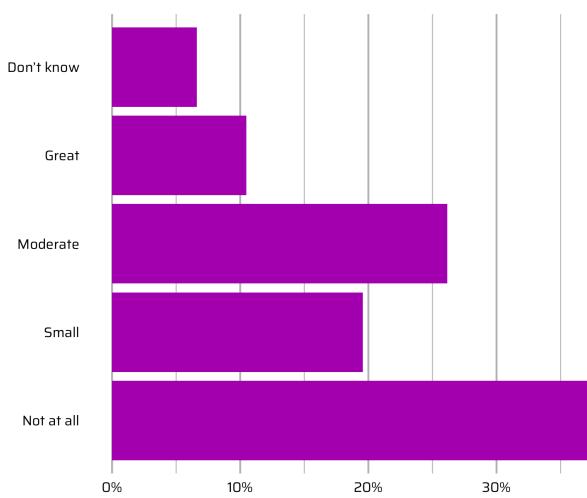


Figure 35: Respondents that reported feeling anxious or hopeless.

Anxious or Hopeless	Respondents	Percentage	
Yes	251	69.15	
No	112	30.85	

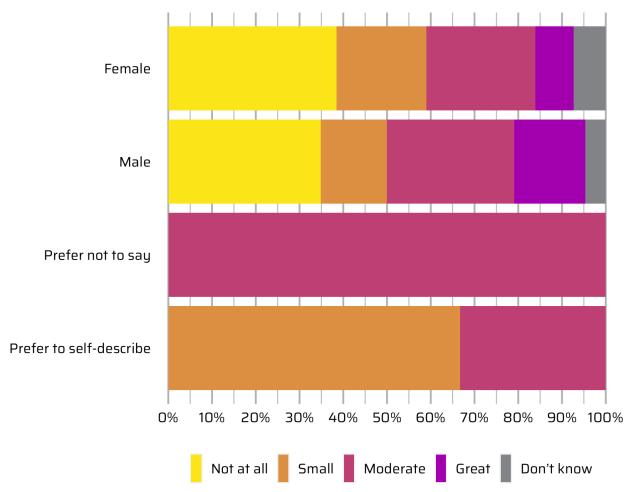


#### Extent mental health needs are met.

Figure 36: Extent respondents reported their mental health needs were being met.

Table 35: Extent respondents reported their mental health needs were being met.

Mental health needs	Respondents	Percentage
Don't know	24	6.61
Great	38	10.47
Moderate	95	26.17
Small	71	19.56
Not at all	135	37.19



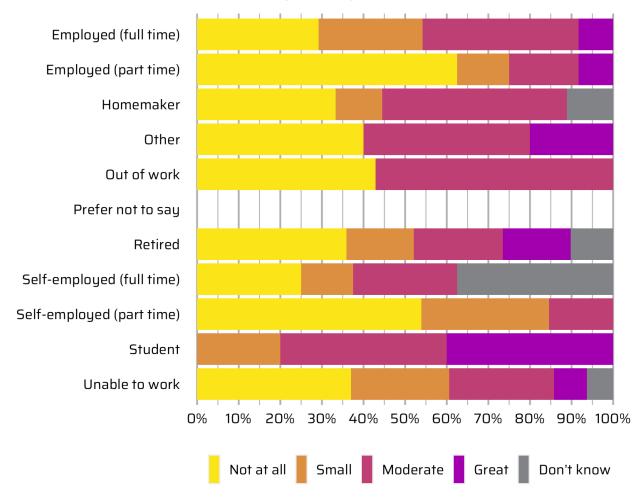
## Extent mental health needs met by gender.

Figure 37: Extent respondents reported their mental health needs were being met, broken down by gender.

Gender	Mental health needs	Respondents	Percentage
	Great	24	8.79
	Moderate	68	24.91
Female	Small	56	20.51
	Not at all	105	38.46
	Don't know	20	7.33
Male	Great	14	16.28
	Moderate	25	29.07
	Small	13	15.12
	Not at all	30	34.88
	Don't know	4	4.65
Prefer not to say	Great	0	0.00

Gender	Mental health needs	Respondents	Percentage
	Moderate	1	100.00
	Small	0	0.00
	Not at all	0	0.00
	Don't know	0	0.00
Prefer to self-describe	Great	0	0.00
	Moderate	1	33.33
		2	66.67
	Not at all	0	0.00
	Don't know	0	0.00

## Extent mental health needs met by employment status.

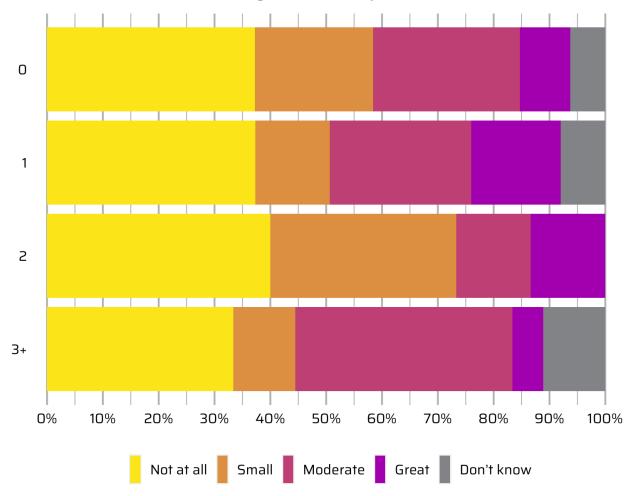


*Figure 38: Extent respondents reported their mental health needs were being met, broken down by employment status.* 

Employment Status	Mental health needs	Respondents	Percentage
	Great	4	8.3
	Moderate	18	37.50
Employed (full time)	Small	12	25.00
	Not at all	14	29.1
	Don't know	0	0.00
	Great	2	8.3
	Moderate	4	16.6
Employed (part time)	Small	3	12.50
	Not at all	15	62.50
	Don't know	0	0.0
	Great	0	0.0
	Moderate	4	44.4
Homemaker	Small	1	
	Not at all	3	33.3
	Don't know	1	11.1
	Great	1	20.0
	Moderate	2	40.0
Other	Small	0	0.0
	Not at all	2	40.0
	Don't know	0	0.0
	Great	0	0.0
	Moderate	4	57.1
Out of work	Small	0	0.0
	Not at all	3	42.8
	Don't know	0	0.0
	Great	0	Nal
	Moderate	0	Nal
Prefer not to say	Small	0	Nal
	Not at all	0	Nal
	Don't know	0	Nal
	Great	19	16.24
	Moderate	25	21.3
Retired	Small	19	16.2
	Not at all	42	35.90
	Don't know	12	10.20
Self-employed (full time)	Great	0	0.00

Table 37: Extent respondents reported their mental health needs were being met, broken down by employment status.

Employment Status	Mental health needs	Respondents	Percentage
	Moderate	2	25.00
	Small	1	12.50
	Not at all	2	25.00
	Don't know	3	37.50
	Great	0	0.00
	Moderate	2	15.38
Self-employed (part time)	Small	4	30.77
	Not at all	7	53.85
	Don't know	0	0.00
	Great	2	40.00
	Moderate	2	40.00
Student	Small	1	20.00
	Not at all	0	0.00
	Don't know	0	0.00
	Great	10	7.87
	Moderate	32	25.20
Unable to work	Small	30	23.62
	Not at all	47	37.01
	Don't know	8	6.30



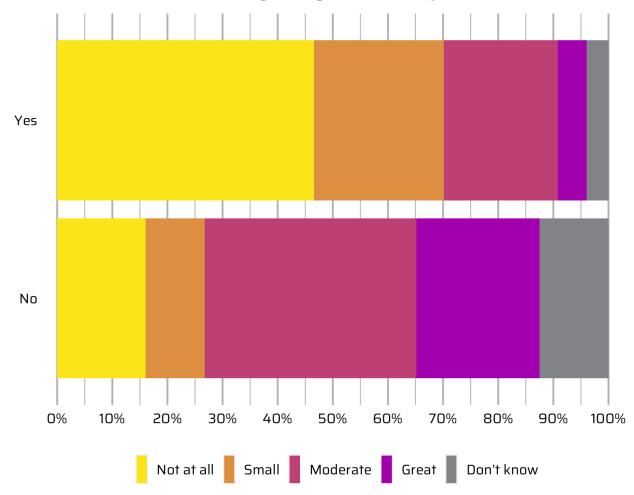
### Extent mental health needs met by number of dependents.

*Figure 39: Extent respondents reported their mental health needs were being met, broken down by number of dependents.* 

Table 38: Extent respondents reported their mental health needs were being met, broken down by number of dependents.

Dependents	Mental health needs	Respondents	Percentage
	Great	23	9.02
	Moderate	67	26.27
0	Small	54	21.18
	Not at all	95	37.25
	Don't know	16	6.27
	Great	12	16.00
1	Moderate	19	25.33
I	Small	10	13.33
	Not at all	28	37.33

Dependents	Mental health needs	Respondents	Percentage
	Don't know	6	8.00
	Great	2	13.33
	Moderate	2	13.33
2	Small	5	33.33
	Not at all	6	40.00
	Don't know	0	0.00
	Great	1	5.56
	Moderate	7	38.89
3+	Small	2	11.11
	Not at all	6	33.33
	Don't know	2	11.11

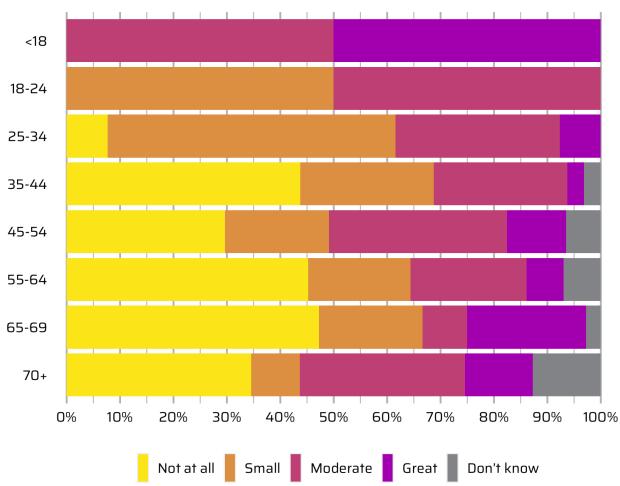


## Extent mental health needs met by feeling anxious or hopeless.

Figure 40: Extent respondents reported their mental health needs were being met, broken down by if they also reported feeling anxious or hopeless.

Table 39: Extent respondents reported their mental health needs were being met, broken down by if they also reported feeling anxious or hopeless.

Anxious or hopeless	Mental health needs	Respondents	Percentage
	Great	13	5.18
	Moderate	52	20.72
Yes	Small	59	23.51
	Not at all	117	46.61
	Don't know	10	3.98
	Great	25	22.32
	Moderate	43	38.39
No	Small	12	10.71
	Not at all	18	16.07
	Don't know	14	12.50



## Extent mental health needs met by age.

Figure 41: Extent respondents reported their mental health needs were being met, broken down by age group. Table 40: Extent respondents reported their mental health needs were being met, broken down by age group.

Age	Mental health needs	Respondents	Percentage
	Great	- 1	50.00
	Moderate	1	50.00
<18	Small	0	0.00
	Not at all	0	0.00
	Don't know	0	0.00
	Great	0	0.00
	Moderate	1	50.00
18-24	Small	1	50.00
	Not at all	0	0.00
	Don't know	0	0.00

Age	Mental health needs	Respondents	Percentage
	Great	1	7.69
	Moderate	4	30.77
25-34	Small	7	53.85
	Not at all	1	7.69
	Don't know	0	0.00
	Great	1	3.12
	Moderate	8	25.00
35-44	Small	8	25.00
	Not at all	14	43.75
	Don't know	1	3.12
	Great	12	11.11
	Moderate	36	33.33
45-54	Small	21	19.44
	Not at all	32	29.63
	Don't know	7	6.48
	Great	8	6.96
	Moderate	25	21.74
55-64	Small	22	19.13
	Not at all	52	45.22
	Don't know	8	6.96
	Great	8	22.22
	Moderate	3	8.33
65-69	Small	7	19.44
	Not at all	17	47.22
	Don't know	1	2.78
	Great	7	12.73
	Moderate	17	30.91
70+	Small	5	9.09
	Not at all	19	34.55
	Don't know	7	12.73

# Extent mental health needs met by diagnosed with multiple neurological conditions.

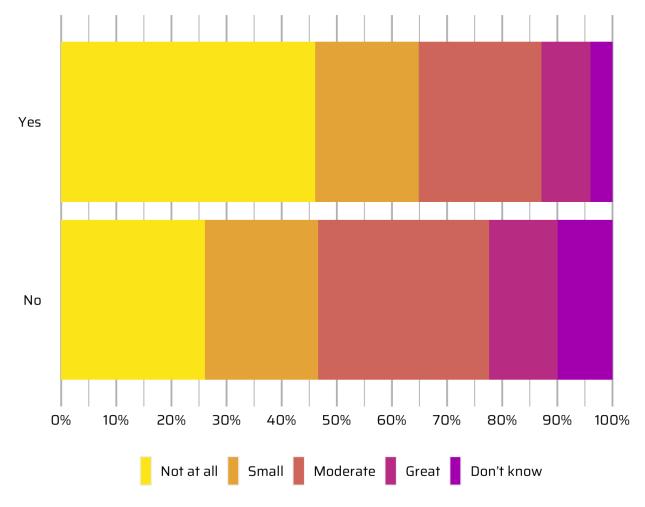


Figure 42: Extent respondents reported their mental health needs were being met, broken down by them being diagnosed with multiple neurological conditions.

Table 41: Extent respondents reported their mental health needs were being met, broken down by them being diagnosed with multiple neurological conditions.

Multiple	Mental health needs	Respondents	Percentage
	Great	18	8.91
	Moderate	45	22.28
Yes	Small	38	18.81
	Not at all	93	46.04
	Don't know	8	3.96
	Great	20	12.42
No	Moderate	50	31.06
	Small	33	20.50

Multiple	Mental health needs	Respondents	Percentage
	Not at all	42	26.09
	Don't know	16	9.94

# Frequency NHS A&E/Emergency services were sought

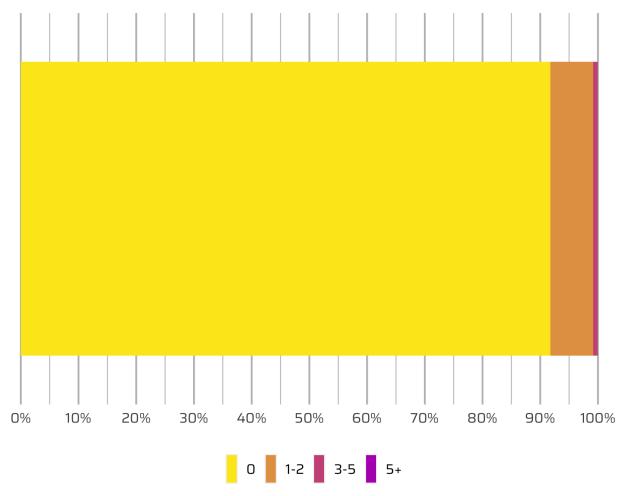
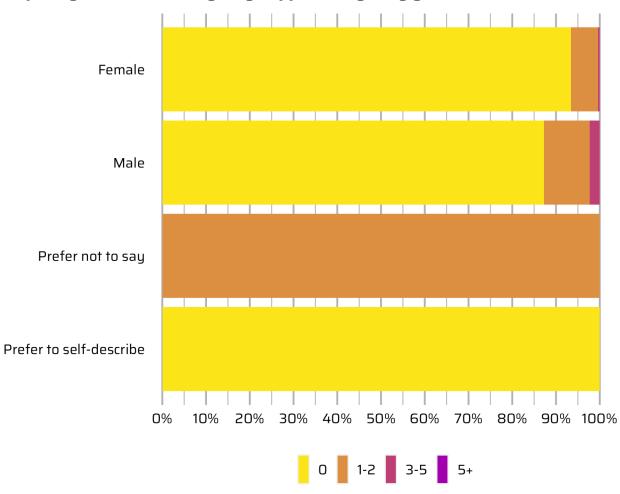


Figure 43: Frequency that NHS A&E or emergencies services were sort in the last eight weeks.

 	were sort in the last eight weeks.

A&E Frequency	Respondents	Percentage
5+	0	0.00
3-5	3	0.83
1-2	27	7.44
0	333	91.74



## Frequency NHS A&E/emergency support sought by gender.

Figure 44: Frequency that NHS AGE or emergencies services were sort in the last 8 weeks broken down by gender of respondents.

	-	-	-
Gender	A&E Frequency	Respondents	Percentage
	5+	0	0.00
Female	3-5	1	0.37
remaie	1-2	17	6.23
	0	255	93.41
	5+	0	0.00
Male	3-5	2	2.33
Male	1-2	9	10.47
	0	75	87.21
Prefer not to say	5+	0	0.00

Table 43: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by gender of respondents.

Gender	A&E Frequency	Respondents	Percentage
	3-5	0	0.00
	1-2	1	100.00
	0	0	0.00
	5+	0	0.00
Prefer to self-describe	3-5	0	0.00
Prefer to self-describe	1-2	0	0.00
	0	3	100.00

## Frequency NHS A&E/emergency support sought by employment status

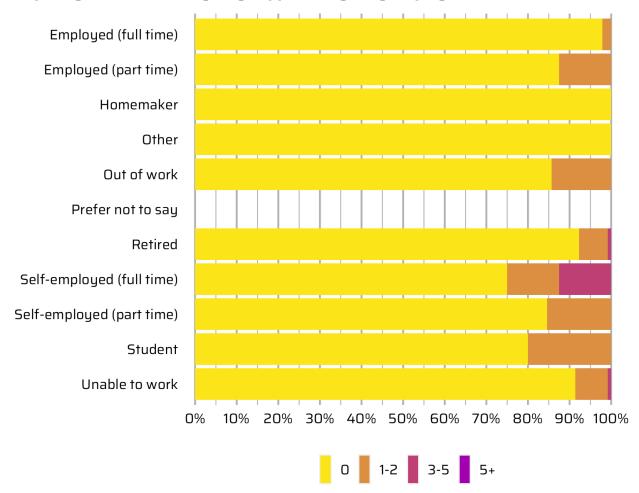


Figure 45: Frequency that NHS AGE or emergencies services were sort in the last 8 weeks broken down by employment status.

Employment status	A&E Frequency	Respondents	Percentage
	5+	0	0.00
Employed (full time)	3-5	0	0.00
Employed (full time)	1-2	1	2.08
	0	47	97.92
	5+	0	0.00
Employed (part time)	3-5	0	0.00
Employed (part time)	1-2	3	12.50
	0	21	87.50
	5+	0	0.00
Homemaker	3-5	0	0.00
numemaker	1-2	0	0.00
	0	9	100.00
	5+	0	0.00
Other	3-5	0	0.00
Other	1-2	0	0.00
	0	5	100.00
	5+	0	0.00
Out of work	3-5	0	0.00
OUT OF WORK	1-2	1	14.29
	0	6	85.7
	5+	0	NaN
Drafar pat to call	3-5	0	NaN
Prefer not to say	1-2	0	NaN
	0	0	NaN
	5+	0	0.00
Datirad	3-5	1	0.85
Retired	1-2	8	6.84
	0	108	92.3
	5+	0	0.00
Folf amplaued (full time)	3-5	1	12.50
Self-employed (full time)	1-2	1	12.50
	0	6	75.00
	5+	0	0.00
Colf amplaured (next time)	3-5	0	0.00
Self-employed (part time)	1-2	2	15.38
	0	11	84.62

Table 44: Frequency that NHS A&E or emergencies services were sort in the last 8 weeks broken down by employment status.

Employment status	A&E Frequency	Respondents	Percentage
	5+	0	0.00
Student	3-5	0	0.00
Siudeni	1-2	1	20.00
	0	4	80.00
Unable to work	5+	0	0.00
	3-5	1	0.79
	1-2	10	7.87
	0	116	91.34

Frequency NHS A&E/emergency support sought by number of dependents.

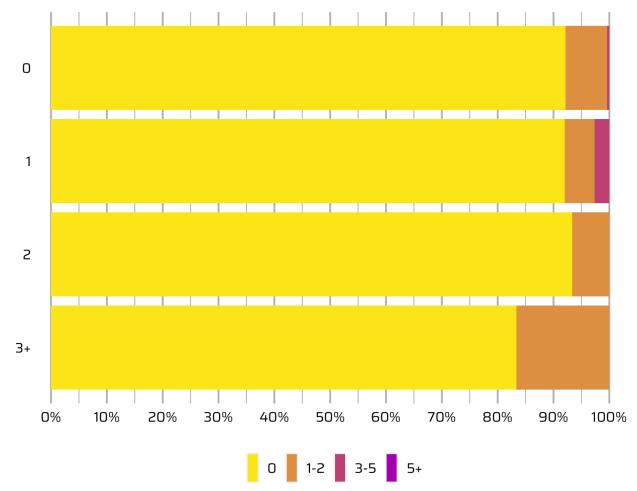


Figure 46: Frequency that NHS A&E or emergencies services were sought in the last eight weeks broken down by number of dependents.

Dependents	A&E Frequency	Respondents	Percentage
	5+	0	0.00
Ο	3-5	1	0.39
U	1-2	19	7.45
	0	235	92.16
	5+	0	0.00
1	3-5	2	2.67
I	1-2	4	5.33
	0	69	92.00
	5+	0	0.00
2	3-5	0	0.00
2	1-2	1	6.67
	0	14	93.33
	5+	0	0.00
3+	3-5	0	0.00
	1-2	3	16.67
	0	15	83.33

Table 45: Frequency that NHS AGE or emergencies services were sought in the last eight weeks broken down by number of dependents.

# Frequency NHS A&E/emergency support sought by feeling anxious or hopeless.

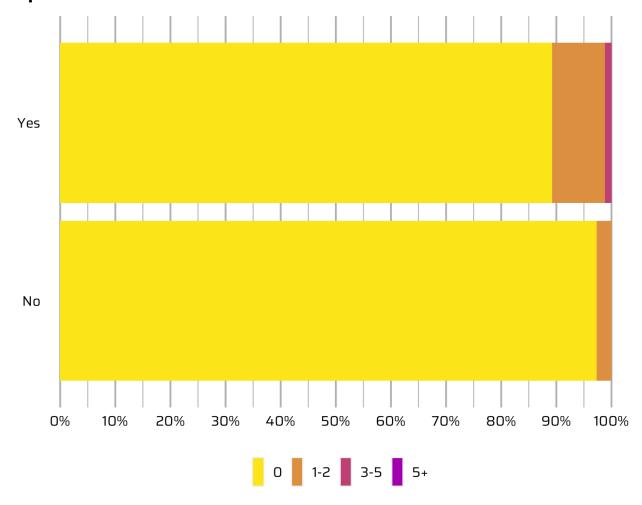
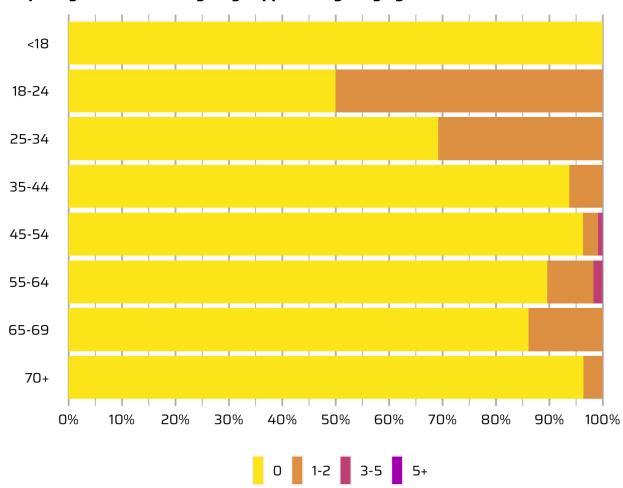


Figure 47: Frequency that NHS A&E or emergencies services were sought in the last eight weeks broken down by reporting feeling anxious or hopeless.

Table 46: Frequency that NHS A&E or emergencies services were sought in the last eight weeks broken down by reporting feeling anxious or hopeless.

Anxious or hopeless	A&E Frequency	Respondents	Percentage
	5+	0	0.00
	3-5	3	1.20
	1-2	24	9.56
	0	224	89.24
No	5+	0	0.00
	3-5	0	0.00
	1-2	3	2.68
	0	109	97.32



#### Frequency NHS A&E/emergency support sought by age

Figure 48: Frequency that NHS A&E or emergencies services were sought in the last eight weeks broken down by age.

Table 47: Frequency that NHS AGE or emergencies services were sought in the last eight weeks broken down by age.

Age	A&E Frequency	Respondents	Percentage
	5+	0	0.00
<18	3-5	0	0.00
<10	1-2	0	0.00
	0	2	100.00
	5+	0	0.00
18-24	3-5	0	0.00
10-24	1-2	1	50.00
	0	1	50.00
25-34		0	0.00

Age	A&E Frequency	Respondents	Percentage
	3-5	0	0.00
	1-2	4	30.77
	0	9	69.23
	5+	0	0.00
35-44	3-5	0	0.00
55-44	1-2	2	6.25
	0	30	93.75
	5+	0	0.00
45-54	3-5	1	0.93
45-54	1-2	3	2.78
	0	104	96.30
	5+	0	0.00
55-64	3-5	2	1.74
55-64	1-2	10	8.70
	0	103	89.57
	5+	0	0.00
65-69	3-5	0	0.00
69-69	1-2	5	13.89
	0	31	86.11
	5+	0	0.00
70+	3-5	0	0.00
/U+	1-2	2	3.64
	0	53	96.36

Frequency NHS A&E/emergency support sought by multiple neurological conditions.

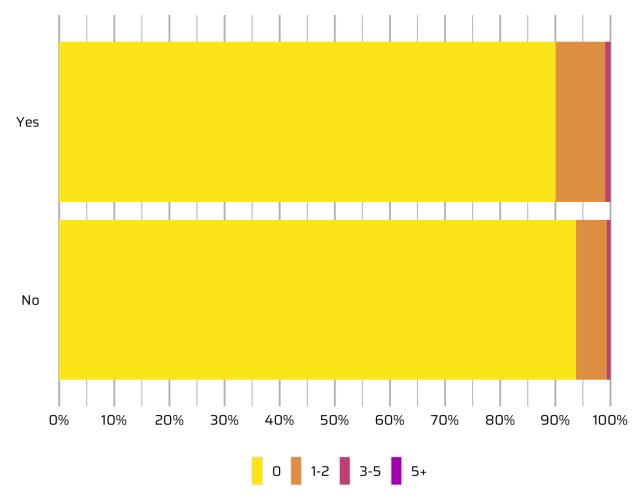


Figure 49: Frequency that NHS A&E or emergencies services were sought in the last eight weeks broken down by being diagnosed with multiple conditions.

Table 48: Frequency that NHS AGE or emergencies services were sought in the last eight weeks broken down by being diagnosed with multiple conditions.

Multiple	A&E Frequency	Respondents	Percentage
	5+	0	0.00
	3-5	2	0.99
165	1-2	18	8.91
	0	182	90.10
	5+	0	0.00
N	3-5	1	0.62
INU	1-2	9	5.59
	0	151	93.79

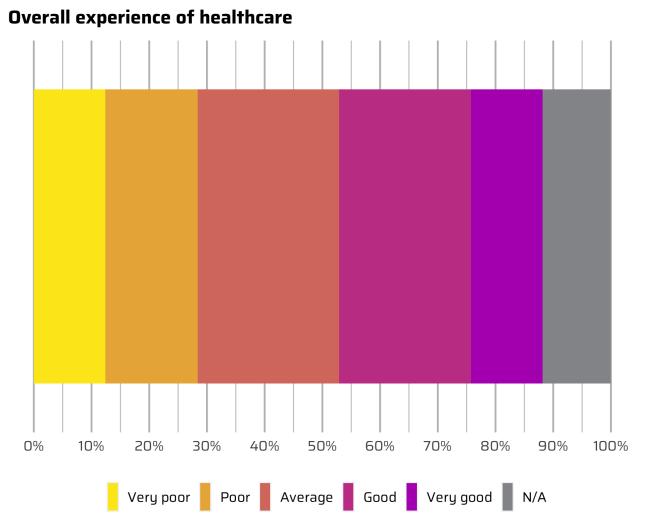
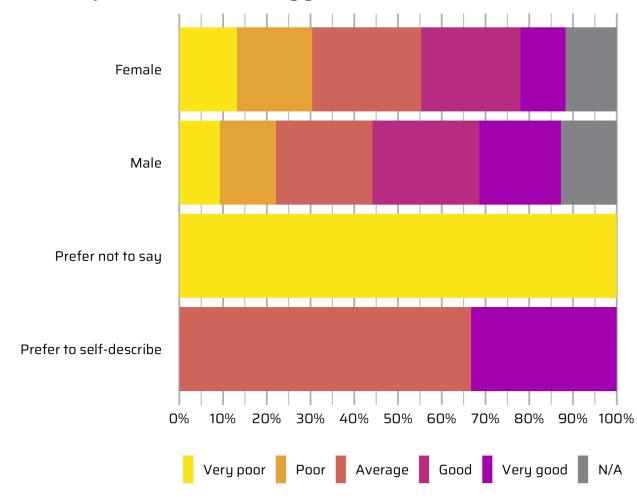


Figure 50: Overall experience of healthcare reported by respondents.

		<i>c</i> , , , ,		
Table 49: Overal	l evnerience i	nt healthcare	renorted hu	resnondents
$1001C \pm 0.01010$		oj neunnune	reported by	respondents.

Experience	Respondents	Percentage
N/A	43	11.85
Very good	45	12.40
Good	83	22.87
Average	89	24.52
Poor	58	15.98
Very poor	45	12.40



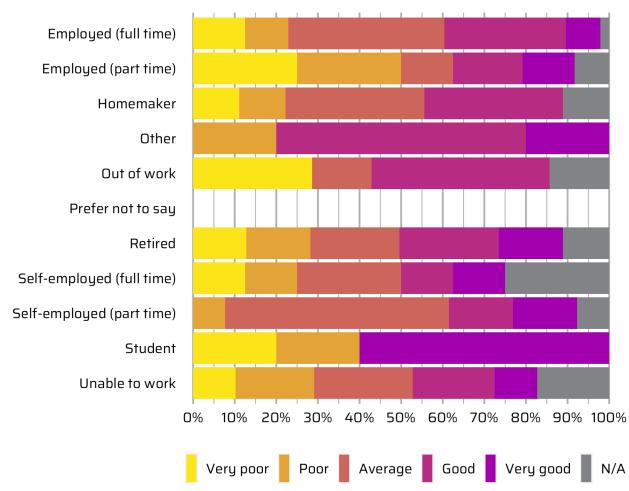
## Overall experience of healthcare by gender

Figure 51: Respondents overall experience of healthcare broken down by gender.

Gender	Experience	Respondents	Percentage
	N/A	32	11.72
	Very good	28	10.26
Famala	Good	62	22.71
Female	Average	68	24.91
	Poor	47	17.22
	Very poor	36	13.19
	N/A	11	12.79
Male	Very good	16	18.60
	Good	21	24.42
	Average	19	22.09
	Poor	11	12.79

Table 50: Respondents overall experience of healthcare broken down by gender.

Gender	Experience	Respondents	Percentage
	Very poor	8	9.30
	N/A	0	0.00
	Very good	0	0.00
Drofor pot to cou	Good	0	0.00
Prefer not to say	Average	0	0.00
	Poor	0	0.00
	Very poor	1	100.00
	N/A	0	0.00
	Very good	1	33.33
Ductou to colf docouilos	Good	0	0.00
Prefer to self-describe	Average	2	66.67
	Poor	0	0.00
	Very poor	0	0.00



## Overall experience of healthcare by employment status

Figure 52: Respondents overall experience of healthcare broken down by employment status.

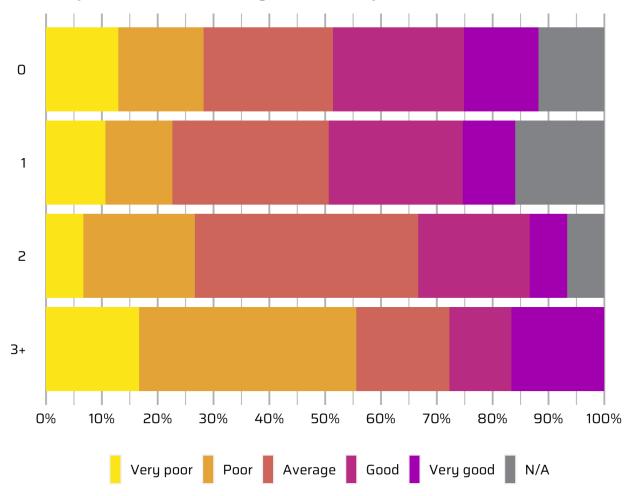
Employment status	Experience	Respondents	Percentage
	N/A	1	2.08
	Very good	4	8.33
Employed (full time)	Good	14	29.17
Employed (full time)	Average	18	37.50
	Poor	5	10.42
	Very poor	6	12.50
Employed (part time)	N/A	2	8.33
	Very good	3	12.50
	Good	4	16.67
	Average	3	12.50
	Poor	6	25.00

Table F1: Deceedants everal	l experience of healthcare broke.	a down hu amployment status
- 10018 51. RESUUNDENTS OVERDI		H GUVVH DU EHHDIDUHHEHH STULUS.

Employment status	Experience	Respondents	Percentage
	Very poor	6	25.00
	N/A	1	11.11
	Very good	0	0.00
	Good	3	33.33
Homemaker	Average	3	33.33
	Poor	1	11.1
	Very poor	1	11.1
	N/A	0	0.00
	Very good	1	20.00
	Good	3	60.00
Other	Average	0	0.00
	Poor	1	20.00
	Very poor	0	0.00
	N/A	1	14.29
	Very good	0	0.00
	Good	3	42.86
Out of work	Average	1	14.29
	Poor	0	0.00
	Very poor	2	28.5
	N/A	0	Nal
	Very good	0	Nal
	Good	0	Nal
Prefer not to say	Average	0	Nal
	Poor	0	Nal
	Very poor	0	Nal
	N/A	13	
	Very good	18	15.38
	Good	28	23.9
Retired	Average	25	21.3
	Poor	18	15.38
	Very poor	15	12.82
	N/A	2	25.00
	Very good	1	12.50
	Good	1	12.50
Self-employed (full time)	Average	2	25.00
	Poor	1	12.50
	Very poor	1	12.50
Self-employed (part time)	N/A	1	7.69

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Employment status	Experience	Respondents	Percentage
	Very good	2	15.38
	Good	2	15.38
	Average	7	53.85
	Poor	1	7.69
	Very poor	0	0.00
	N/A	0	0.00
	Very good	3	60.00
Student	Good	0	0.00
Siuueili	Average	0	0.00
	Poor	1	20.00
	Very poor	1	20.00
	N/A	22	17.32
	Very good	13	10.24
Unable to work	Good	25	19.69
	Average	30	23.62
	Poor	24	18.90
	Very poor	13	10.24



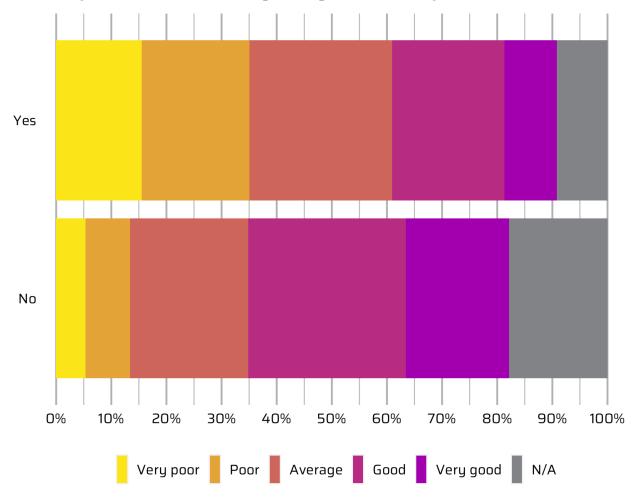
## Overall experience of healthcare by number of dependents

Figure 53: Respondents overall experience of healthcare broken down by number of dependents.

Dependents	Experience	Respondents	Percentage
	N/A	30	11.76
	Very good	34	13.33
0	Good	60	23.53
U	Average	59	23.14
	Poor	39	15.29
	Very poor	33	12.94
	N/A	12	16.00
	Very good	7	9.33
1	Good	18	24.00
	Average	21	28.00
	Poor	9	12.00

Table 52: Respondents overall experience of healthcare broken down by number of dependents.

Dependents	Experience	Respondents	Percentage
	Very poor	8	10.67
	N/A	1	6.67
	Very good	1	6.67
7	Good	3	20.00
2	Average	6	40.00
	Poor	3	20.00
	Very poor	1	6.67
	N/A	0	0.00
	Very good	3	16.67
7	Good	2	11.11
3+	Average	3	16.67
	Poor	7	38.89
	Very poor	3	16.67



## Overall experience of healthcare by feeling anxious or hopeless.

*Figure 54: Respondents overall experience of healthcare broken down by reporting feeling anxious or hopeless.* 

Table 53: Respondents overall experience of healthcare broken down by reporting feeling anxious or hopeless.

, ,		21	2, 2
Anxious or hopeless	Experience	Respondents	Percentage
	N/A	23	9.16
	Very good	24	9.56
Yes	Good	51	20.32
162	Average	65	25.90
	Poor	49	19.52
	Very poor	39	15.54
	N/A	20	17.86
Νο	Very good	21	18.75
NU	Good	32	28.57
	Average	24	21.43

Anxious or hopeless	Experience	Respondents	Percentage
	Poor	9	8.04
	Very poor	6	5.36

### Overall experience of healthcare by age.

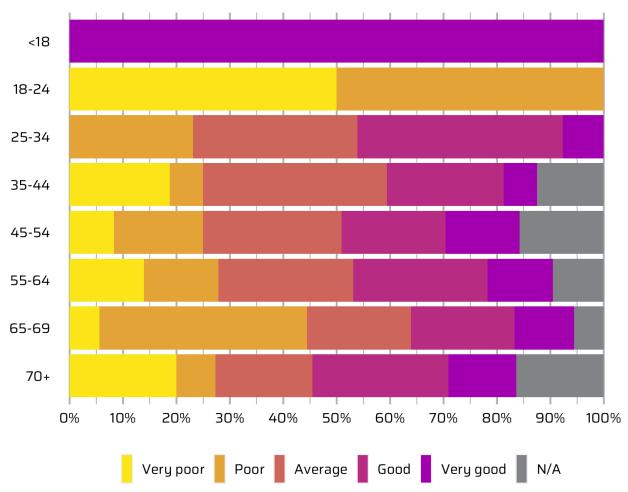


Figure 55: Respondents overall experience of healthcare broken down by age.

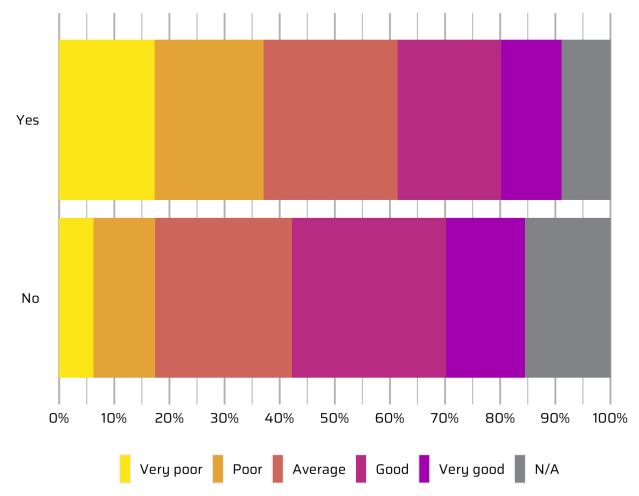
Age	Experience	Respondents	Percentage
	N/A	0	0.00
	Very good	2	100.00
<u>~</u> 18	Good	0	0.00
<10	Average	0	0.00
	Poor	0	0.00
	Very poor	0	0.00

Table 54: Respondents overall experience of healthcare broken down by age.

Age	Experience	Respondents	Percentage
	N/A	0	0.00
	Very good	0	0.00
10 74	Good	0	0.00
18-24	Average	0	0.00
	Poor	1	50.00
	Very poor	1	50.00
	N/A	0	0.00
	Very good	1	7.69
	Good	5	38.46
25-34	Average	4	30.77
	Poor	3	23.08
	Very poor	0	0.00
	N/A	4	12.50
	Very good	2	6.25
	Good	7	21.88
35-44	Average	11	34.38
	Poor	2	6.25
	Very poor	6	18.75
	N/A	17	15.74
	Very good	15	13.89
	Good	21	19.44
45-54	Average	28	25.93
	Poor	18	16.67
	Very poor	9	8.33
	N/A	11	9.57
	Very good	14	12.17
/	Good	29	25.22
55-64	Average	29	25.22
	Poor	16	13.91
	Very poor	16	13.91
	N/A	2	5.56
	Very good	4	11.11
65-69	Good	7	19.44
	Average	7	19.44
	Poor	14	38.89

Age	Experience	Respondents	Percentage
	Very poor	2	5.56
70+	N/A	9	16.36
	Very good	7	12.73
	Good	14	25.45
	Average	10	18.18
	Poor	4	7.27
	Very poor	11	20.00

Overall experience of healthcare by multiple neurological conditions



*Figure 56: Respondents overall experience of healthcare broken down by if they were diagnosed with multiple neurological conditions.* 

Table 55: Respondents overall experience of healthcare broken down by if they were diagnosed with multiple neurological conditions.

Multiple	Experience	Respondents	Percentage
	N/A	- 18	8.91
	Very good	22	10.89
Yes	Good	38	18.81
res	Average	49	24.26
	Poor	40	19.80
	Very poor	35	17.33
	N/A	25	15.53
No	Very good	23	14.29
	Good	45	27.95
	Average	40	24.84
	Poor	18	11.18
	Very poor	10	6.21

## **Demographics**

#### Sample size

Total number of respondents: 363

### **Neurological conditions**

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 202 respondents, equating to 56% of respondents, indicated that they have multiple (i.e., more than one) neurological conditions. In total, there are 81 conditions reported.

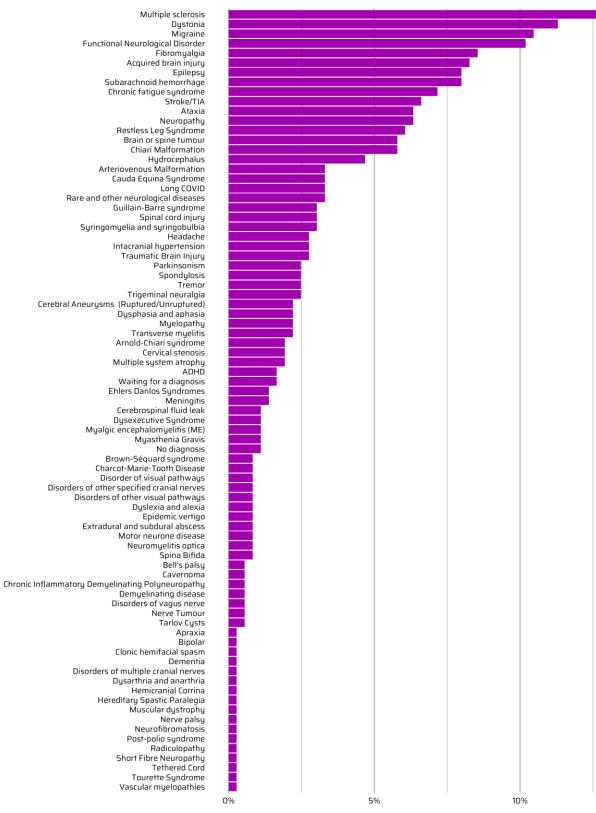


Figure 57: Neurological conditions respondents reported to be diagnosed with.

Table CC. Neuroleasical	ditione	receedente	recerted to	he diagonad with
Table 56: Neurological d	()()()()()()())	$r \mu \varsigma n n n n \mu \mu n r \varsigma$	r e n n r e n n r	<u>NE NUMBER WULL</u>
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Condition	Respondents	Percentage
Multiple sclerosis	46	12.67
Dystonia	41	11.29
Migraine	38	10.47
Functional Neurological Disorder	37	10.19
Fibromyalgia	31	8.54
Acquired brain injury	30	8.26
Epilepsy	29	7.99
Subarachnoid hemorrhage	29	7.99
Chronic fatigue syndrome	26	7.16
Stroke/TIA	24	6.61
Ataxia	23	6.34
Neuropathy	23	6.34
Restless Leg Syndrome	22	6.06
Brain or spine tumour	21	5.79
Chiari Malformation	21	5.79
Hydrocephalus	17	4.68
Arteriovenous Malformation	12	3.31
Cauda Equina Syndrome	12	3.31
Long COVID	12	3.31
Rare and other neurological diseases	12	3.31
Guillain-Barre syndrome	11	3.03
Spinal cord injury	11	3.03
Syringomyelia and syringobulbia	11	3.03
Headache	10	2.75
Intacranial hypertension	10	2.75
Traumatic Brain Injury	10	2.75
Parkinsonism	9	2.48
Spondylosis	9	2.48
Tremor	9	2.48
Trigeminal neuralgia	9	2.48
Cerebral Aneurysms (Ruptured/Unruptured)	8	2.20
Dysphasia and aphasia	8	2.20
Myelopathy	8	2.20
Transverse myelitis	8	2.20
Arnold-Chiari syndrome	7	1.93
Cervical stenosis	7	1.93
Multiple system atrophy	7	1.93
ADHD	6	1.65
Waiting for a diagnosis	6	1.65

Condition	Respondents	Percentage
Ehlers Danlos Syndromes	5	1.38
Meningitis	5	1.38
Cerebrospinal fluid leak	4	1.10
Dysexecutive Syndrome	4	1.10
Myalgic encephalomyelitis (ME)	4	1.10
Myasthenia Gravis	4	1.10
No diagnosis	4	1.10
Brown-Séquard syndrome	3	0.83
Charcot-Marie-Tooth Disease	3	0.83
Disorder of visual pathways	3	0.83
Disorders of other specified cranial nerves	3	0.83
Disorders of other visual pathways	3	0.83
Dyslexia and alexia	3	0.83
Epidemic vertigo	3	0.83
Extradural and subdural abscess	3	0.83
Motor neurone disease	3	0.83
Neuromyelitis optica	3	0.83
5pina Bifida	3	0.83
3ell's palsy	2	0.55
Tavernoma	2	0.55
Chronic Inflammatory Demyelinating Polyneuropathy	2	0.55
Demyelinating disease	2	0.55
Disorders of vagus nerve	2	0.55
Nerve Tumour	2	0.55
Tarlov Cysts	2	0.55
Apraxia	1	0.28
Bipolar	1	0.28
Ilonic hemifacial spasm	1	0.28
Dementia	1	0.28
Disorders of multiple cranial nerves	1	0.28
Dysarthria and anarthria	1	0.28
Hemicranial Corrina	1	0.28
lereditary Spastic Paralegia	1	0.28
Auscular dystrophy	1	0.28
Nerve palsy	1	0.28
Neurofibromatosis	1	0.28
Post-polio syndrome	1	0.28
Radiculopathy	1	0.28
Short Fibre Neuropathy	1	0.28
Fethered Cord	1	0.28

Condition	Respondents	Percentage
Tourette Syndrome	1	0.28
Vascular myelopathies	1	0.28

# Age at diagnosis

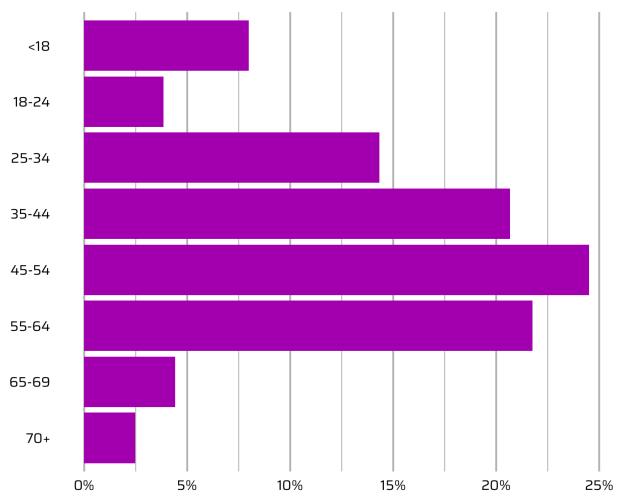


Figure 58: Age of respondents when they were first diagnosed with a neurological condition.

Table 57: Age of respondents		finet elimente e e e el contele e	
- ו מחום 5 /י ממם חד rachnnante	M/non thou M/oro :	ת המותח הבמח האודה ה	- מסוורמומורמו במממודומת
	VVIICII LIICU VVCIC	וווסנ טוטעווטסכט אונוו ט	

Age when diagnosed	Respondents	Percentage
<18	29	7.99
18-24	14	3.86
25-34	52	14.33
35-44	75	20.66
45-54	89	24.52
55-64	79	21.76
65-69	16	4.41

Age when diagnosed	Respondents	Percentage
70+	9	2.48

Multiple neurological conditions

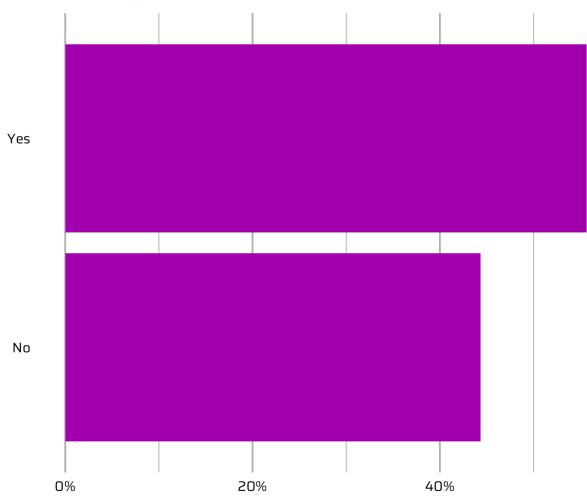
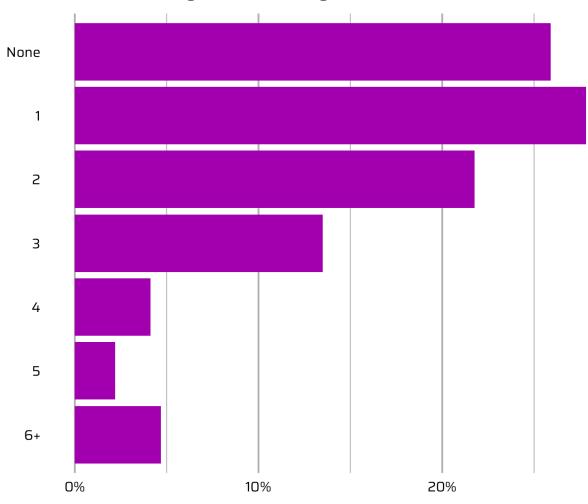


Figure 59: Respondents diagnosed with multiple neurological conditions or not.

Table 58: Respondents diagnosed with multiple neurological conditions or not.

Multiple	Respondents	Percentage
Yes	202	55.65
No	161	44.35



# Number of non-neurological co-occurring conditions

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

<b>Co-occurring Conditions</b>	Respondents	Percentage
None	94	25.90
1	101	27.82
2	79	21.76
3	49	13.50
4	15	4.13
5	8	2.20
6+	17	4.68

Table 59: Number of non-neurological conditions that respondents are diagnosed with that co- occur with their neurological condition(s).

# Gender

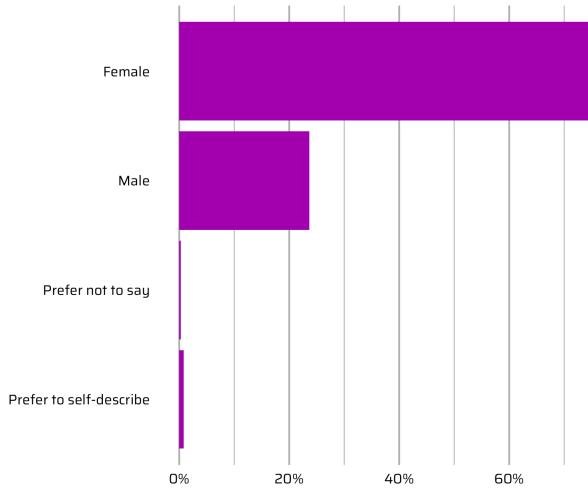


Figure 61: Gender of respondents.

Table 60: Gender of respondents.

Gender	Respondents	Percentage
Female	273	75.21
Male	86	23.69
Prefer not to say	1	0.28
Prefer to self-describe	3	0.83

## **Sexual orientation**

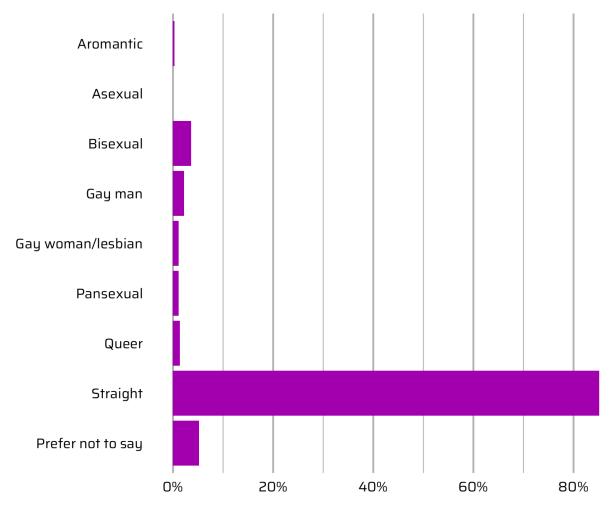


Figure 62: Sexual orientation of respondents.

Table 61: Sexual orientation of respondents.

Sexual orientation	Respondents	Percentage
Aromantic	- 1	0.28
Asexual	0	0.00
Bisexual	13	3.58
Gay man	8	2.20
Gay woman/lesbian	4	1.10
Pansexual	4	1.10
Queer	5	1.38
Straight	309	85.12
Prefer not to say	19	5.23

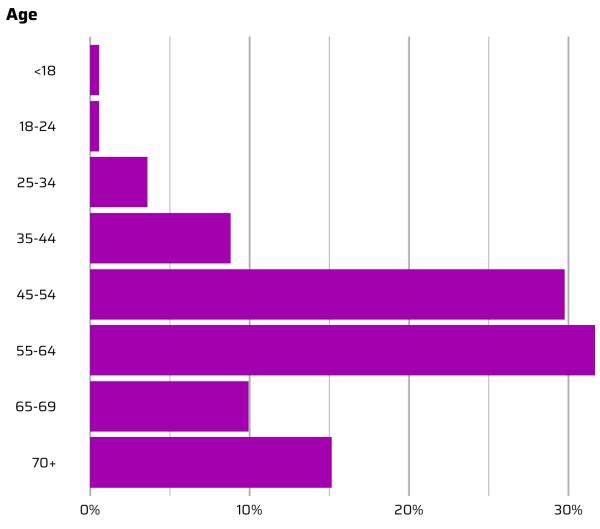


Figure 63: Age of respondents.

#### Table 62: Age of respondents.

Age	Respondents	Percentage
<18	2	0.55
18-24	2	0.55
25-34	13	3.58
35-44	32	8.82
45-54	108	29.75
55-64	115	31.68
65-69	36	9.92
70+	55	15.15

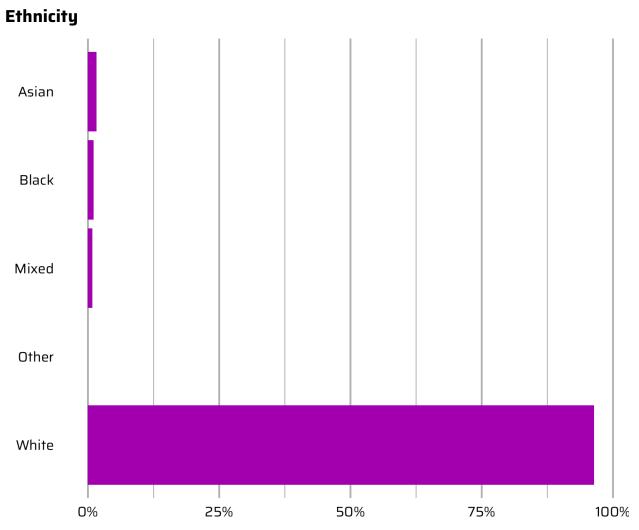


Figure 64: Ethnicity of respondents.

Table 63: Ethnicity of respondents.

Ethnicity	Respondents	Percentage
Asian	6	1.65
Black	4	1.10
Mixed	3	0.83
Other	0	0.00
White	350	96.42

# Location of respondents

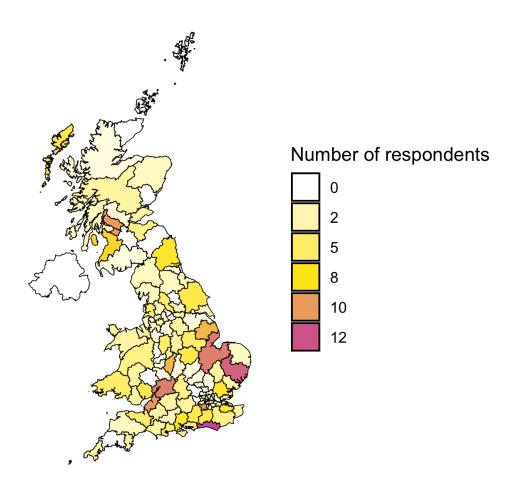


Figure 65: Location of respondents.

Table 64 Location of respondents.

Area Name	Postal Area	Number of respondents
Brighton	BN	13
lpswich	IP	12
Gloucester	GL	11
Peterborough	PE	11
Bristol	BS	10
Glasgow	G	10
Kingston upon Thames	КТ	10
Birmingham	В	9
Lincoln	LN	9
Kilmarnock	KA	8
Chelmsford	CM	7

Area Name	Postal Area	Number of respondents
Medway	ME	7
Newcastle upon Tyne	NE	7
Southampton	SO	7
Guildford	GU	6
Outer Hebrides	HS	6
Leicester	LE	6
Newport	NP	6
Redhill	RH	6
York	YO	6
Bradford	BD	5
Bournemouth	BH	5
Nottingham	NG	5
Preston	PR	5
Swansea	SA	5
Stoke-on-Trent	ST	5
Taunton	ТА	5
Edinburgh	EH	4
Oxford	OX	4
Portsmouth	PO	4
Shrewsbury	SY	4
Tonbridge	TN	4
Bath	BA	3
Cambridge	СВ	3
Cardiff	CF	3
Chester	СН	3
Colchester	CO	3
Canterbury	СТ	3
Derby	DE	3
Dorchester	DT	3
London - E	E	3
Harrow	HA	3
Kirkcaldy	KY	3
Llandrindod Wells	LD	3
Llandudno	LL	3
Manchester	М	3
Perth	PH	3
Reading	RG	3
Sheffield	S	3
Swindon	SN	3
London - SW	SW	3

Area Name	Postal Area	Number of respondents
Torquay	TQ	3
Truro	TR	3
Twickenham	TW	3
Wakefield	WF	3
Walsall	WS	3
Aberdeen	AB	2
Blackburn	BB	2
Bolton	BL	2
Carlisle	CA	2
Croydon	CR	2
Dartford	DA	2
Darlington	DL	2
Exeter	EX	2
Hull	HU	2
Liverpool	L	2
Lancaster	LA	2
Leeds	LS	2
London - N	Ν	2
Norwich	NR	2
Paisley	PA	2
London - SE	SE	2
Salisbury	SP	2
Southend-on-Sea	SS	2
Teeside	TS	2
London - W	W	2
Warrington	WA	2
Bromley	BR	1
Coventry	CV	1
Crewe	CW	1
Dumfries and Galloway	DG	1
Durham	DH	1
Doncaster	DN	1
Dudley	DY	1
Enfield	EN	1
Falkirk	FK	1
Inverness	IV	1
Luton	LU	1
Milton Keynes	МК	1
Northampton	NN	1
London - NW	NW	1

Area Name	Postal Area	Number of respondents
Oldham	OL	- 1
Stevenage	SG	1
Stockport	SK	1
Sunderland	SR	1
Uxbridge	UB	1
Worcester	WR	1
Wolverhampton	WV	1
St Albans	AL	0
Dundee	DD	0
London - EC	EC	0
The Fylde	FY	0
Huddersfield	HD	0
Harrogate	HG	0
Hemel Hempstead	HP	0
Hereford	HR	0
Halifax	HX	0
llford	IG	0
Kirkwall	КW	0
Motherwell	ML	0
Plymouth	PL	0
Romford	RM	0
Slough	SL	0
Sutton	SM	0
Teviotdale	TD	0
Telford	TF	0
London - WC	WC	0
Watford	WD	0
Wigan	WN	0
Lerwick	ZE	0
Northern Ireland	ВТ	0

NB: 6 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**

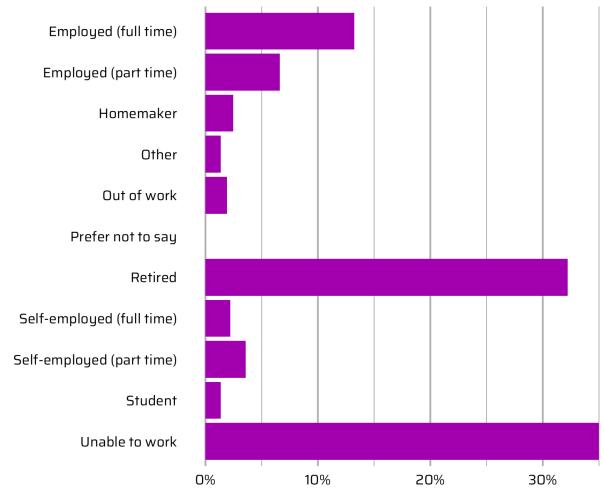


Figure 66: Employment status of respondents.

Table 65: Employment status of respondents.

Employment Status	Respondents	Percentage
Employed (full time)	48	13.22
Employed (part time)	24	6.61
Homemaker	9	2.48
Other	5	1.38
Out of work	7	1.93
Prefer not to say	0	0.00
Retired	117	32.23
Self-employed (full time)	8	2.20
Self-employed (part time)	13	3.58
Student	5	1.38
Unable to work	127	34.99

# Number of dependents

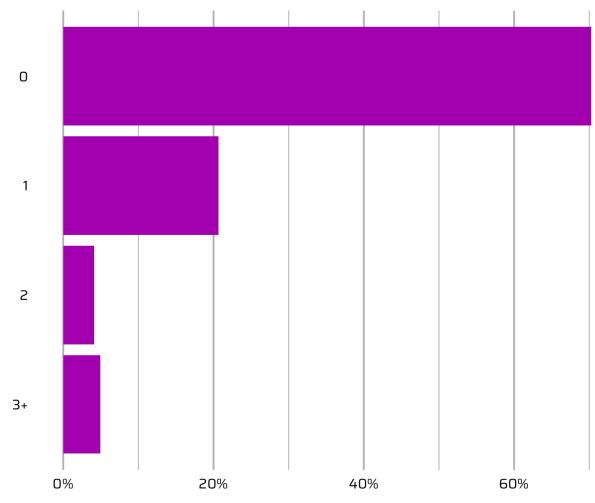


Figure 67: Number of dependents of respondents.

Table 66: Number of dependents of respondents.

Dependents	Respondents	Percentage
0	255	70.25
1	75	20.66
2	15	4.13
3+	18	4.96

# **Receiving care or support**

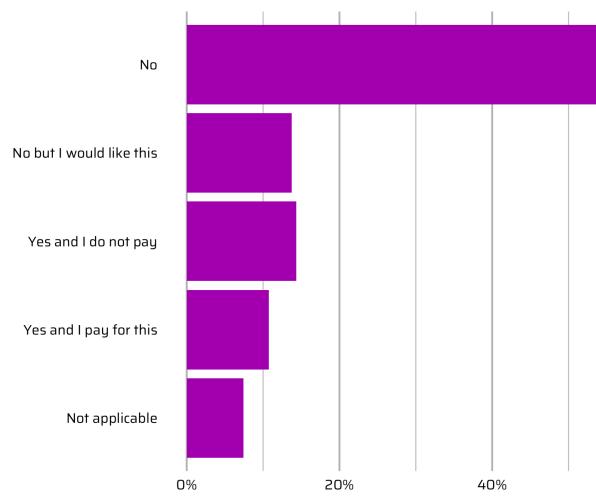


Figure 68: Number of respondents that receive care and support.

Table 67: Number of respondents that receive care and support.

Home care/support	Respondents	Percentage
No	195	53.72
No but I would like this	50	13.77
Yes and I do not pay	52	14.33
Yes and I pay for this	39	10.74
Not applicable	27	7.44

# Appendix A – Survey Questions

Question	Response options			
Are you filling in this questionnaire for yourself?	Yes	No		
About your condition(s)				
Which year were you diagnosed with your primary neurological condition?	Free text			
Which year were you diagnosed with your primary neurological condition?	Free text	Free text		
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	Νο		
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		mptoms	
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)	Yes	No				
and/or symptoms you would like to add?						
Please tell us a sixth neurological condition and/or	See Appendix B for a	list of a	conditions and syr	nptoms		
symptom you have.						
Do you live with conditions other than your	None	1		2		3
neurological condition(s)? If so, how many:	4	5		6+		
About your current financial wellbeir	g					
Which of the following actions, if any, have you	Choose one of the fo	low for	each:			
taken in response to the rising cost-of-living?	I have done this / I ha	ive thou	ught about this bu	t not done it	/ I have no	t done this
	Skip meals		Gone out sociall	ally less than Skipped a presc		prescription
		you		you would have		
	Lowered or stopped your		Reduced travel by car		Reduced travel by public	
	care package				transport	
	Not turned on the heating		Borrowed more money			
	when you normally would					
	have					
Over the next six months, which of the following, if	Miss payment on Take out a loan/increase		increase	Members of my househo		
any, do you expect to do because of rising cost-of-	household bills p		personal debt		will get a	new job
living?	Sell a car/household	ell a car/household Ask for a pay rise		e	Sell personal belongings	
	vehicle					
	Reduce spend on hea	alth or	Not applicable			
	care (i.e. prescription	costs				
	or social care)					
Is there anything else that you would like to share	Free text					
about your experiences of increasing cost-of-living?						
About your recent experiences of tre	atment and sup	oort.				
Overall, how would you describe your experience of	Very good	Good		Average		Poor
health or care in the last eight weeks?	Very Poor	N/A				

Last time you wanted to see or speak to a specialist	See a specialist at	Speak to a specialist	Have someone visit	I didn't mind /
about your neurological condition, what did you	the clinic	on the phone	me at my home	wasn't sure
want to do?				what I wanted
Were you about to speak to or see a specialist?	Yes	Νο		
How convenient was the appointment you were	Very convenient	Fairly convenient	Not very convenient	Not at all
able to get?				convenient
If you were not able to get an appointment or the	There weren't any	There weren't any	I could not see my	I could not book
appointment you were offered wasn't convenient,	appointments for	appointments for the	preferred specialist	ahead
why was that?	the day.	time I wanted		
	Another reason			
Please tell us the reason why you could not get an	Free text	·		
appointment or were not offered a convenient one.				
What did you do on that occasion?	Went to the	Got an appointment	Had a consultation	Went to A&E / a
	appointment I was	for a different day	over the phone	walk-in centre
	offered			
	Saw a pharmacist	Decided a contact my	Didn't see or speak	
		specialist another	to anyone	
		time		
How many times have you sought A&E/emergency	None	1-2 times	3-5 times	5 or more times
support from the NHS as a result of your				
neurological condition in the last eight weeks?				
Have you had any medical appointments (including	Yes	No	Don't Know	
remote appointments) in the last eight weeks?				
How many medical appointments have you had in	0	1	2	3
the last eight weeks?	4	5	6+	
Who was your first medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and
				Language
				Therapist

	Occupational	Psychologist/	GP	Social Services
	Therapist	Psychiatrist		
	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	Psychologist/	GP	Social Services
	Therapist	Psychiatrist		
	Neurosurgery	Other AHP	Other	
How was your second medical appointment	Phone	Videoconference	Via text/WhatsApp	Face to face
delivered?	Other			
How helpful was your second medical	It was helpful	It was not helpful	Don't Know	
appointment?				
Who was your third medical appointment with?	Neurologist	Specialist Nurse	Physiotherapist	Speech and
				Language
				Therapist
	Occupational	Psychologist/	GP	Social Services
	Therapist	Psychiatrist		
	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	Psychologist/	GP	Social Services
	Therapist	Psychiatrist		
	Neurosurgery	Other AHP	Other	·
How was your fourth medical appointment	Phone	Videoconference	Via text/WhatsApp	Face to face
delivered?	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	Psychologist/	GP	Social Services
	Therapist	Psychiatrist		
	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	Psychologist/	GP	Social Services
	Therapist	Psychiatrist		
	Neurosurgery	Other AHP	Other	
How was your sixth medical appointment	Phone	Videoconference	Via text/WhatsApp	Face to face
delivered?	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	To a great extent	To a moderate extent	To a small extent	Not at all
needs are being met?	Don't Know			
Which of the following describes how you feel at	Calm	Well supported	Anxious	Hopeless
the moment?	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 Caribean	
	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 is your sexual orientation?	Aromantic	Asexual	Bisexual	Gay man	
	Gay woman/lesbian	Pansexual	Queer	Straight (heterosexual)	
	Prefer not to say	Other		1	
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+			
Do you receive any care or support at home for your	Yes and I pay for	Yes and I do not pay	No but I would like	No	
day-to-day life?	this		this		
	Not applicable				
Communicating with you.					
What is your first name?	Free text				

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# Appendix B – List of Neurological Symptoms & Conditions

Acquired brain injury	Dystonia	Myotonic disorders
Acute poliomyelitis	Eaton-Lambert syndrome	Narcolepsy and cataplexy
ADHD	Ehlers Danlos Syndromes	Nerve palsy
Agnosia	Encephalitis	Nerve Tumour
Amoebic brain abscess	Epidemic vertigo	Neurofibromatosis
Apraxia	Epilepsy	Neuromyelitis optica
Arnold-Chiari syndrome	Extradural and subdural abscess	Neuropathy
Arteriovenous Malformation	Extrapyramidal disorder	No diagnosis
Ataxia	Facial myokymia	Optic atrophy
Bell's palsy	Faetal Alcohol Spectrum Disorders	Papilloedema
	(FASD)	
Bipolar	Fibromyalgia	Paraplegia and tetraplegia
Brain or spine tumour	Functional Neurological Disorder	Parkinsonism
Brown-Séquard syndrome	Geniculate ganglionitis	Peripheral Neuropathy
Cauda Equina Syndrome	Guillain-Barre syndrome	Post-polio syndrome
Cavernoma	Headache	Postzoster neuralgia
Cerebral Aneurysms	Hemicranial Corrina	Progressive multifocal
(Ruptured/Unruptured)		leukoencephalopathy
Cerebral cysts	Hemiplegia	Rabies
Cerebrospinal fluid leak	Hereditary Spastic Paralegia	Radiculopathy
Cervical stenosis	Huntington's disease	Rare and other neurological diseases

Chagas' disease	Hydrocephalus	Refsum's Disease
Charcot-Marie-Tooth Disease	Hydromyelia	Restless Leg Syndrome
Chiari Malformation	Intacranial hypertension	Short Fibre Neuropathy
Chronic fatigue syndrome	Intracranial abscess and granuloma	Spina Bifida
Chronic Inflammatory Demyelinating	Intracranial and intraspinal abscess	Spinal cord injury
Polyneuropathy	and granuloma in diseases classified	
	elsewhere	
Clonic hemifacial spasm	Intracranial and intraspinal phlebitis	Spinal muscular atrophy
	and thrombophlebitis	
Cranial nerve disorder	Intraspinal abscess and granuloma	Split Cord
Creutzfeldt-Jakob disease	Kennedy's disease	Spondylosis
Cysticercosis of central nervous	Leukoencephalitis	Stroke/TIA
system		
Dementia	Long COVID	Subacute sclerosing panencephalitis
Demyelinating disease	Malaria	Subarachnoid hemorrhage
Disorder of visual pathways	Melkersson's syndrome	Syringomyelia and syringobulbia
Disorders of hypoglossal nerve	Meningeal tuberculoma	Tarlov Cysts
Disorders of multiple cranial nerves	Meningitis	Tethered Cord
Disorders of olfactory nerve	Migraine	Tourette Syndrome
Disorders of optic chiasm	Motor neurone disease	Toxic encephalopathy
Disorders of other specified cranial	Multiple sclerosis	Toxoplasma meningoencephalitis
nerves		
Disorders of other visual pathways	Multiple system atrophy	Transverse myelitis

Disorders of vagus nerve	Muscular dystrophy	Traumatic Brain Injury
Disorders of visual cortex	Myalgic encephalomyelitis (ME)	Tremor
Down's Syndrome	Myasthenia Gravis	Trigeminal neuralgia
Dysarthria and anarthria	Mycoses	Tuberculous meningitis
Dysexecutive Syndrome	Myelopathy	Vascular myelopathies
Dyslexia and alexia	Myopathy	Waiting for a diagnosis
Dysphasia and aphasia	Myositis	