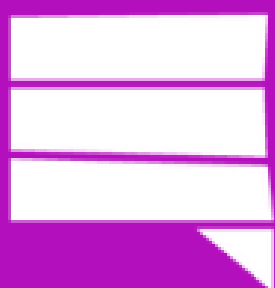


Impact Report

2022

Insights & Data



NeuroLifeNow

It's time to make your story heard

NeuroLifeNow Impact Report 2022

Insights & Data

Contents

- Health services related insights..... 2
 - Overall experience of healthcare 2
 - Number of appointments 5
 - Specialty, mode and helpfulness of delivery 8
 - Specialty..... 8
 - Mode of delivery 13
 - Helpfulness of medical appointments..... 16
 - Sought A&E/Emergency support. 20
- Mental health 23
 - Mental well-being needs met..... 23
 - Anxiety and hopelessness..... 26
- Demographics 29
 - Sample size..... 29
 - Number of conditions represented..... 30
 - Postal area 34
 - Age 39
 - Gender 41
 - Ethnicity 42

Health services related insights.

Overall experience of healthcare

For experiences of healthcare, a large proportion of the respondents (25%) answered “N/A”, suggesting they were not able to access healthcare, or did not need healthcare at time of responding.

Overall, 34% of the respondents describe their experiences to be good or very good, and about 21.8% of them describe their experiences as poor or very poor. This is equivalent to about 1 in 5 people reporting having poor or very poor experiences.

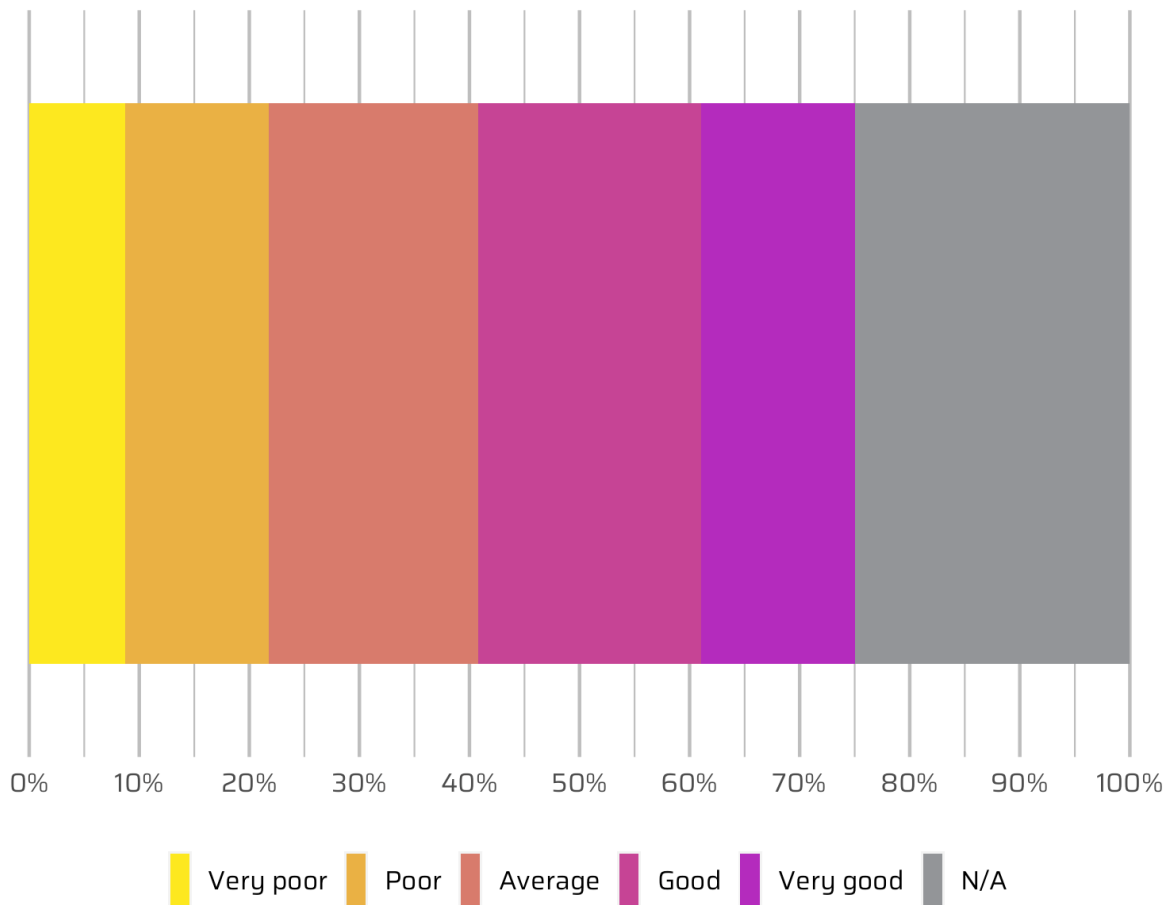


Figure 1: Experience with health services over 2022.

Table 1: Experience with health services

Health services experience	Respondents	Percentage
N/A	344	25.00
Very good	192	13.95
Good	279	20.28
Average	261	18.97
Poor	180	13.08
Very poor	120	8.72

There is a trend where the percentages for “poor” or “very poor” have been steadily increasing, from just below 5% in January-February to 14.1%-21.4% in November-December.

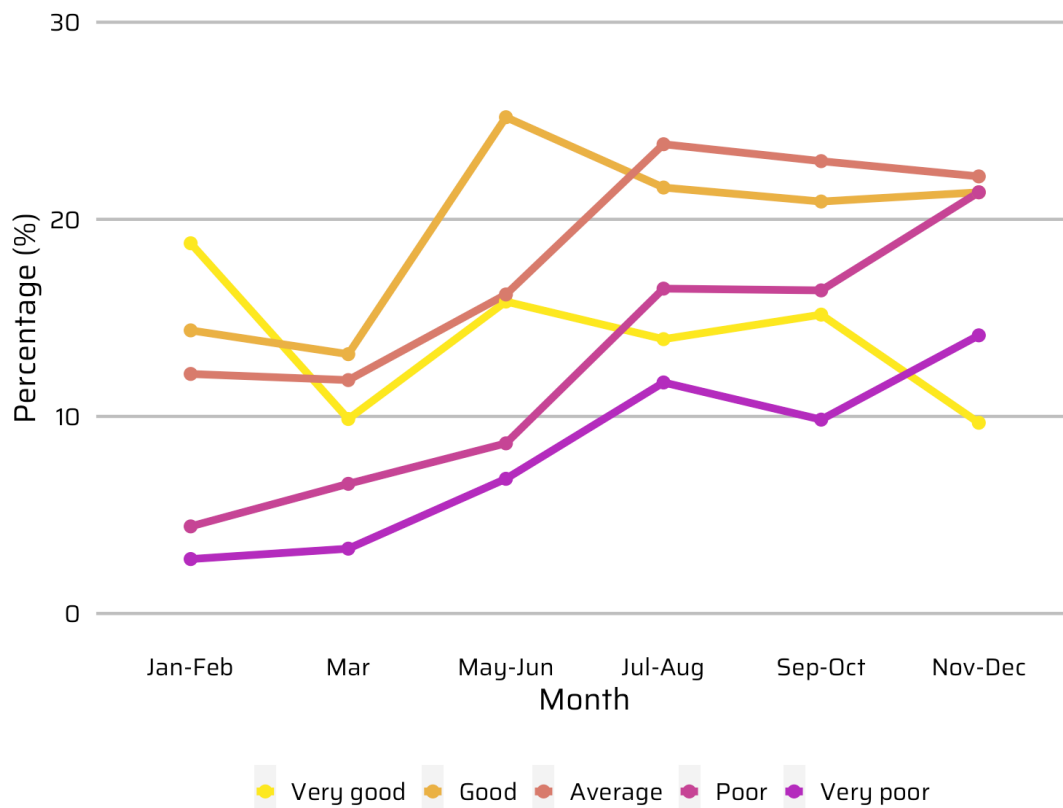


Figure 2:

Experience with health services across different months of 2022.

Table 2: Experience with health services across different months

Month	Health services experience	Respondents	Percentage
January-February	N/A	86	47.51
	Very good	34	18.78
	Good	26	14.36
	Average	22	12.15
	Poor	8	4.42
	Very poor	5	2.76
March	N/A	84	55.26
	Very good	15	9.87
	Good	20	13.16
	Average	18	11.84
	Poor	10	6.58
	Very poor	5	3.29
May-June	N/A	76	27.34
	Very good	44	15.83
	Good	70	25.18
	Average	45	16.19
	Poor	24	8.63
	Very poor	19	6.83
July-August	N/A	34	12.45
	Very good	38	13.92
	Good	59	21.61
	Average	65	23.81
	Poor	45	16.48
	Very poor	32	11.72
September-October	N/A	36	14.75
	Very good	37	15.16
	Good	51	20.90
	Average	56	22.95
	Poor	40	16.39
	Very poor	24	9.84

Month	Health services experience	Respondents	Percentage
November-December	N/A	28	11.29
	Very good	24	9.68
	Good	53	21.37
	Average	55	22.18
	Poor	53	21.37
	Very poor	35	14.11

Number of appointments

On average, 61.8% of the respondents would have had at least one medical appointments in the past 8 weeks at the time they answered the questionnaires.

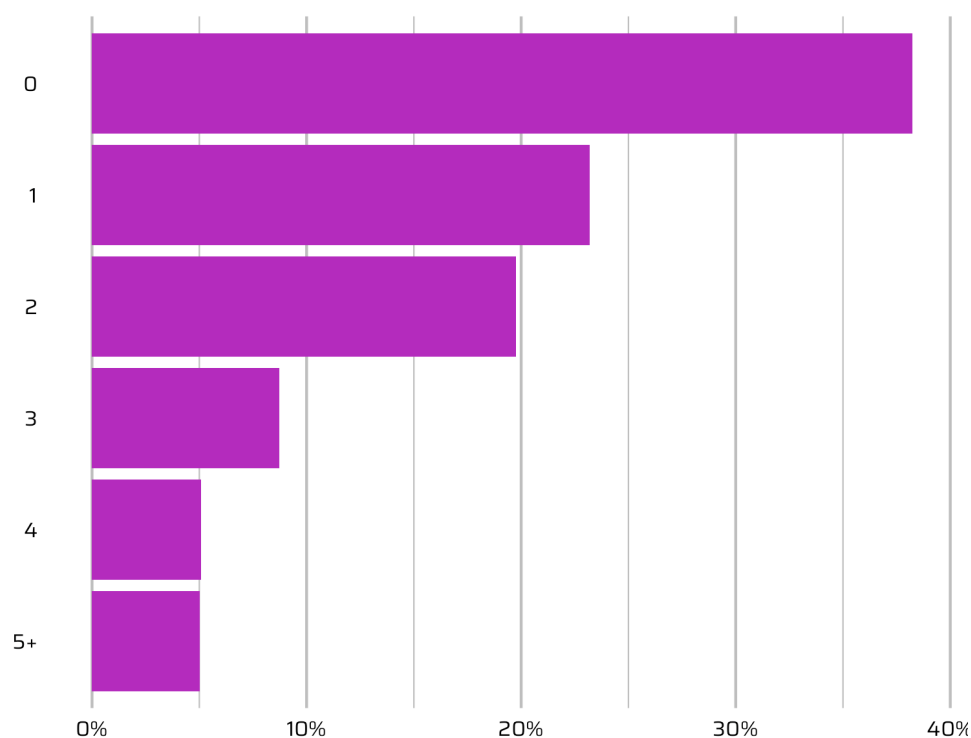


Figure 3: Number of medical appointments in the past 8 weeks at the time they answered the questionnaires.

Table 3: Number of medical appointments in the past 8 weeks

Number of appointments	Respondents	Percentage
0	526	38.23
1	319	23.18

Number of appointments	Respondents	Percentage
2	272	19.77
3	120	8.72
4	70	5.09
5+	69	5.01

For May-June, the questionnaire asked about number of medical appointments in the past 4 weeks.

The number of respondents with at least one medical appointment has increased from 48.07% in January-February to 67.34% in November-December.

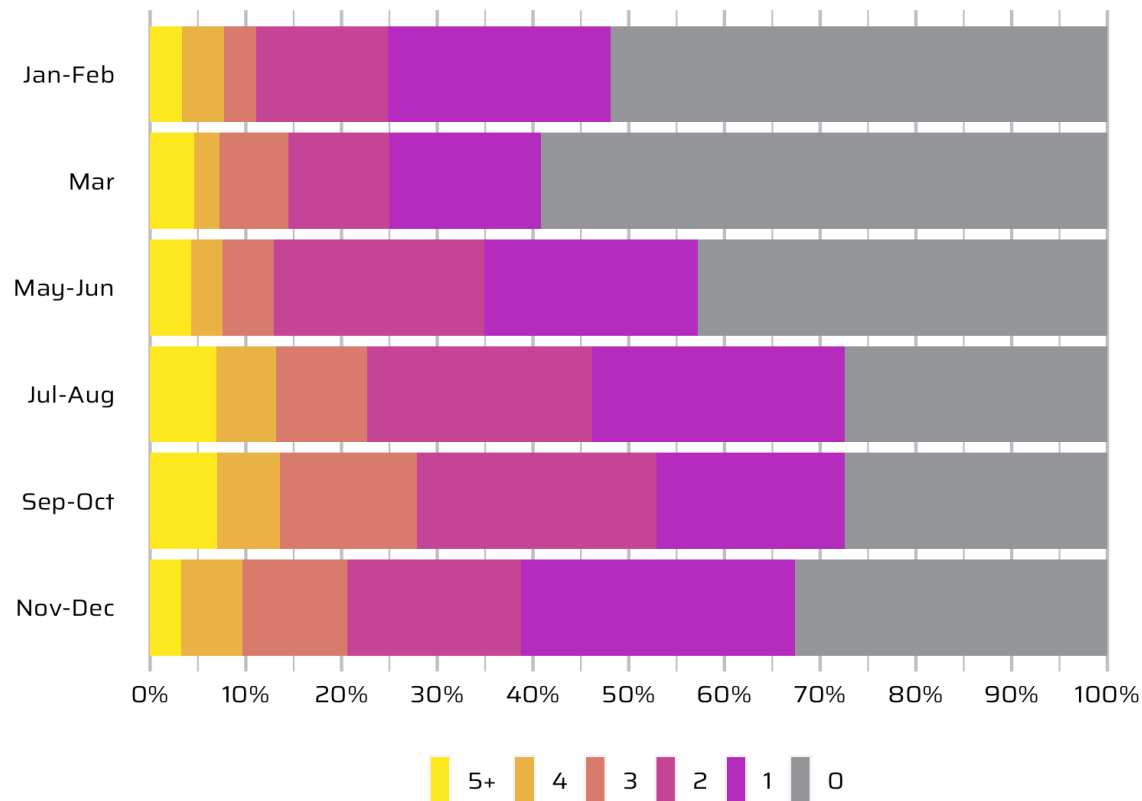


Figure 4: Number of medical appointments across the months.

Table 4: Number of medical appointments across months.

Month	Number of appointments	Respondents	Percentage
January-February	0	94	51.93
	1	42	23.20

Month	Number of appointments	Respondents	Percentage
	2	25	13.81
	3	6	3.31
	4	8	4.42
	5+	6	3.31
March	0	90	59.21
	1	24	15.79
	2	16	10.53
	3	11	7.24
	4	4	2.63
	5+	7	4.61
May-June	0	119	42.81
	1	62	22.30
	2	61	21.94
	3	15	5.40
	4	9	3.24
	5+	12	4.32
July-August	0	75	27.47
	1	72	26.37
	2	64	23.44
	3	26	9.52
	4	17	6.23
	5+	19	6.96
September-October	0	67	27.46
	1	48	19.67
	2	61	25.00
	3	35	14.34
	4	16	6.56
	5+	17	6.97
November-December	0	81	32.66
	1	71	28.63
	2	45	18.15

Month	Number of appointments	Respondents	Percentage
	3	27	10.89
	4	16	6.45
	5+	8	3.23

Specialty, mode and helpfulness of delivery

Specialty

Overall, the most seen health professional for medical appointments are the GPs (37.7%), followed by specialist nurses (20.4%) and neurologists (15.2%).

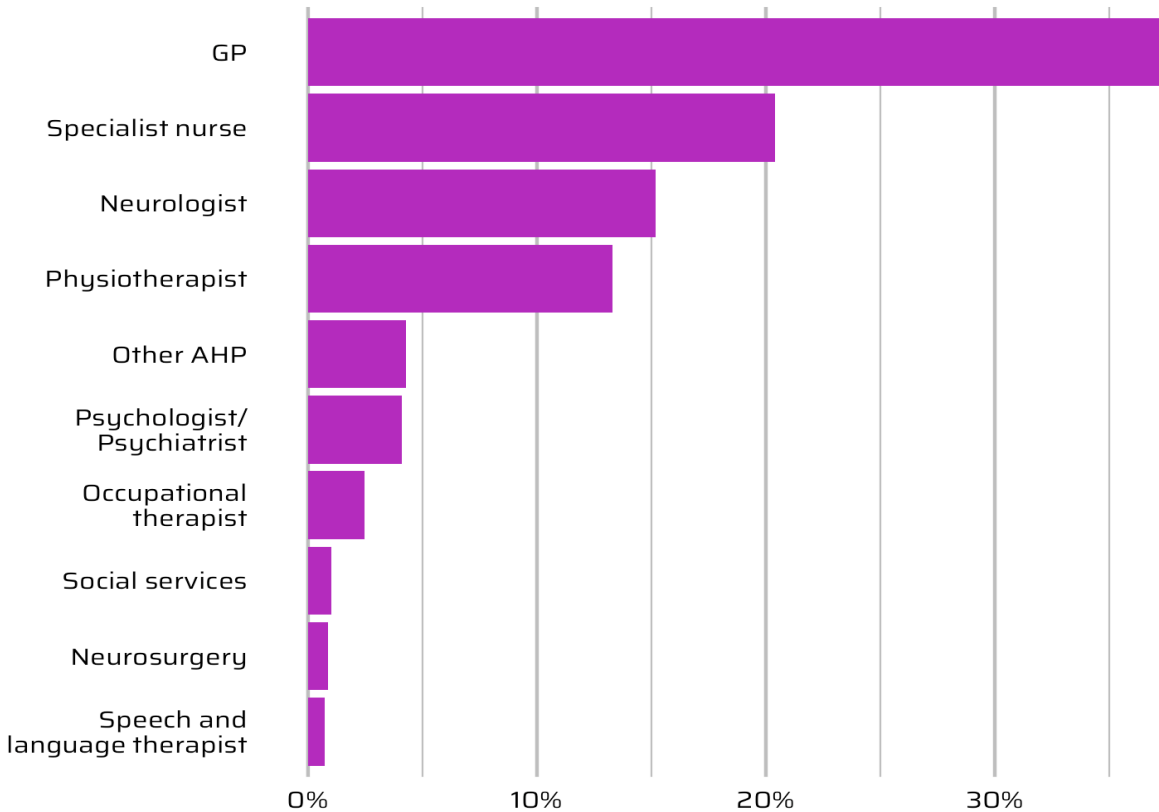


Figure 5: Specialty of the medical appointments held in the last 8 weeks at the time they answered the questionnaires.

Table 5: Specialty of the medical appointments held in the last 8 weeks at the time they answered the questionnaires.

Specialty	Respondents	Percentage
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Specialty	Respondents	Percentage
GP	561	37.65
Specialist nurse	304	20.40
Neurologist	226	15.17
Physiotherapist	198	13.29
Other Allied Health Professional (AHP)	64	4.30
Psychologist/ Psychiatrist	61	4.09
Occupational therapist	37	2.48
Social services	15	1.01
Neurosurgery	13	0.87
Speech and language therapist	11	0.74

This trend for GPs seems to increase after March, from 4. On the other hand, we can observe decrease in percentages for specialist nurse, neurologist, and physiotherapist.

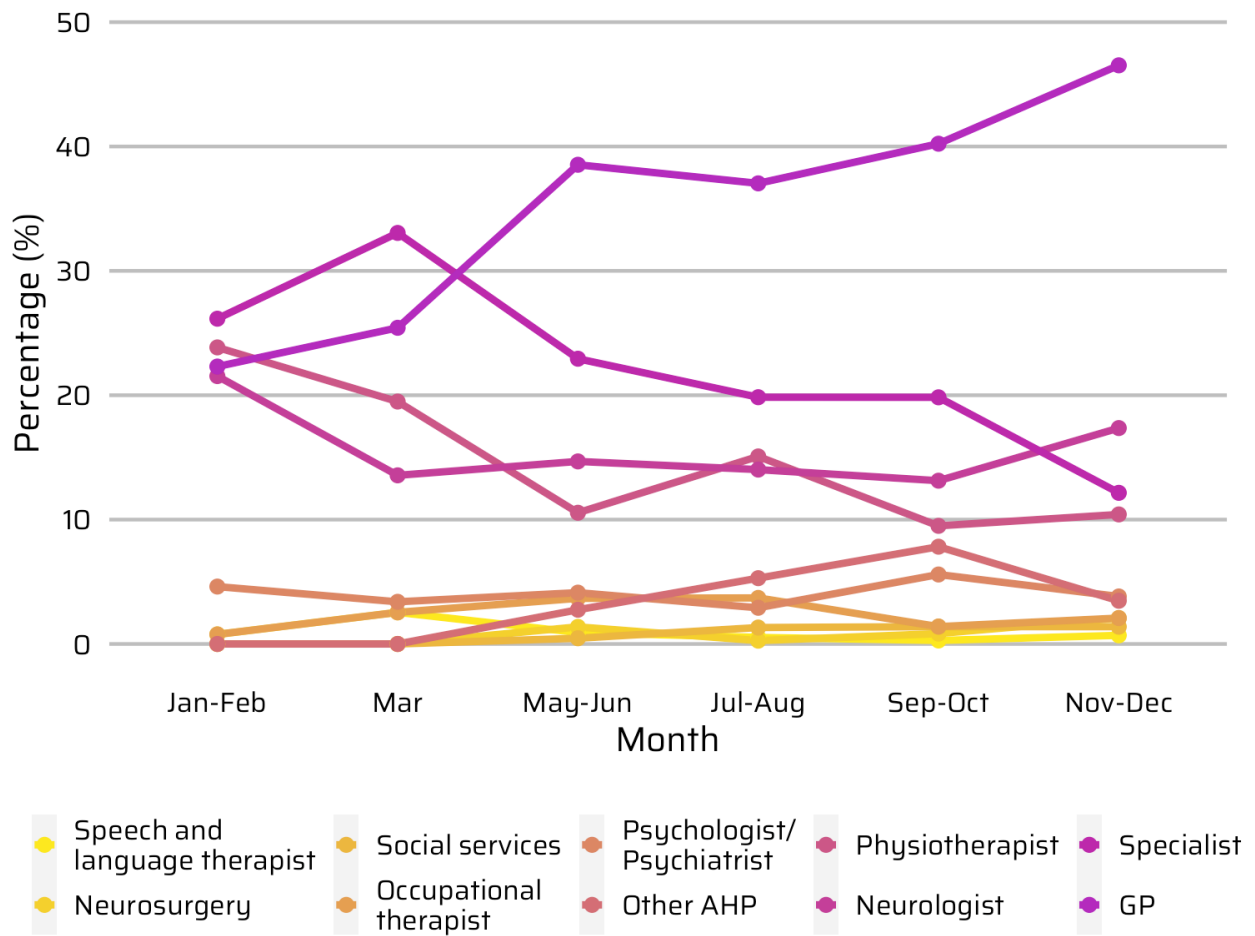


Figure 6: Specialty of the medical appointments held in the last 8 weeks at the time they answered the questionnaires. across months.

Table 6: Specialty of the medical appointments held in the last 8 weeks at the time they answered the questionnaires across months.

Month	Specialty	Respondents	Percentage
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Month	Specialty	Respondents	Percentage
January-February	Speech and language therapist	1	0.77
	Neurosurgery	0	0.00
	Social services	0	0.00
	Occupational therapist	1	0.77
	Psychologist / Psychiatrist	6	4.62
	Other Allied Health Professional	0	0.00
	Physiotherapist	31	23.85
	Neurologist	28	21.54
	Specialist nurse	34	26.15
	GP	29	22.31
March	Speech and language therapist	3	2.54
	Neurosurgery	0	0.00
	Social services	0	0.00
	Occupational therapist	3	2.54
	Psychologist / Psychiatrist	4	3.39
	Other Allied Health Professional	0	0.00
	Physiotherapist	23	19.49
	Neurologist	16	13.56
	Specialist nurse	39	33.05
	GP	30	25.42
May-June	Speech and language therapist	2	0.92
	Neurosurgery	3	1.38
	Social services	1	0.46
	Occupational therapist	8	3.67
	Psychologist / Psychiatrist	9	4.13
	Other Allied Health Professional	6	2.75
	Physiotherapist	23	10.55
	Neurologist	32	14.68
	Specialist nurse	50	22.94
	GP	84	38.53
July-August	Speech and language therapist	2	0.53

Month	Specialty	Respondents	Percentage
	Neurosurgery	1	0.26
	Social services	5	1.32
	Occupational therapist	14	3.70
	Psychologist / Psychiatrist	11	2.91
	Other Allied Health Professional	20	5.29
	Physiotherapist	57	15.08
	Neurologist	53	14.02
	Specialist nurse	75	19.84
	GP	140	37.04
September- October	Speech and language therapist	1	0.28
	Neurosurgery	3	0.84
	Social services	5	1.40
	Occupational therapist	5	1.40
	Psychologist / Psychiatrist	20	5.59
	Other Allied Health Professional	28	7.82
	Physiotherapist	34	9.50
	Neurologist	47	13.13
	Specialist nurse	71	19.83
November- December	GP	144	40.22
	Speech and language therapist	2	0.69
	Neurosurgery	6	2.08
	Social services	4	1.39
	Occupational therapist	6	2.08
	Psychologist / Psychiatrist	11	3.82
	Other Allied Health Professional	10	3.47
	Physiotherapist	30	10.42
	Neurologist	50	17.36
Specialist nurse	35	12.15	
	GP	134	46.53

Mode of delivery

The most used mode of delivery is face-to-face appointments (67.0%), followed by phone appointments (29.75%). Almost 2 of every 3 appointments are face-to-face.

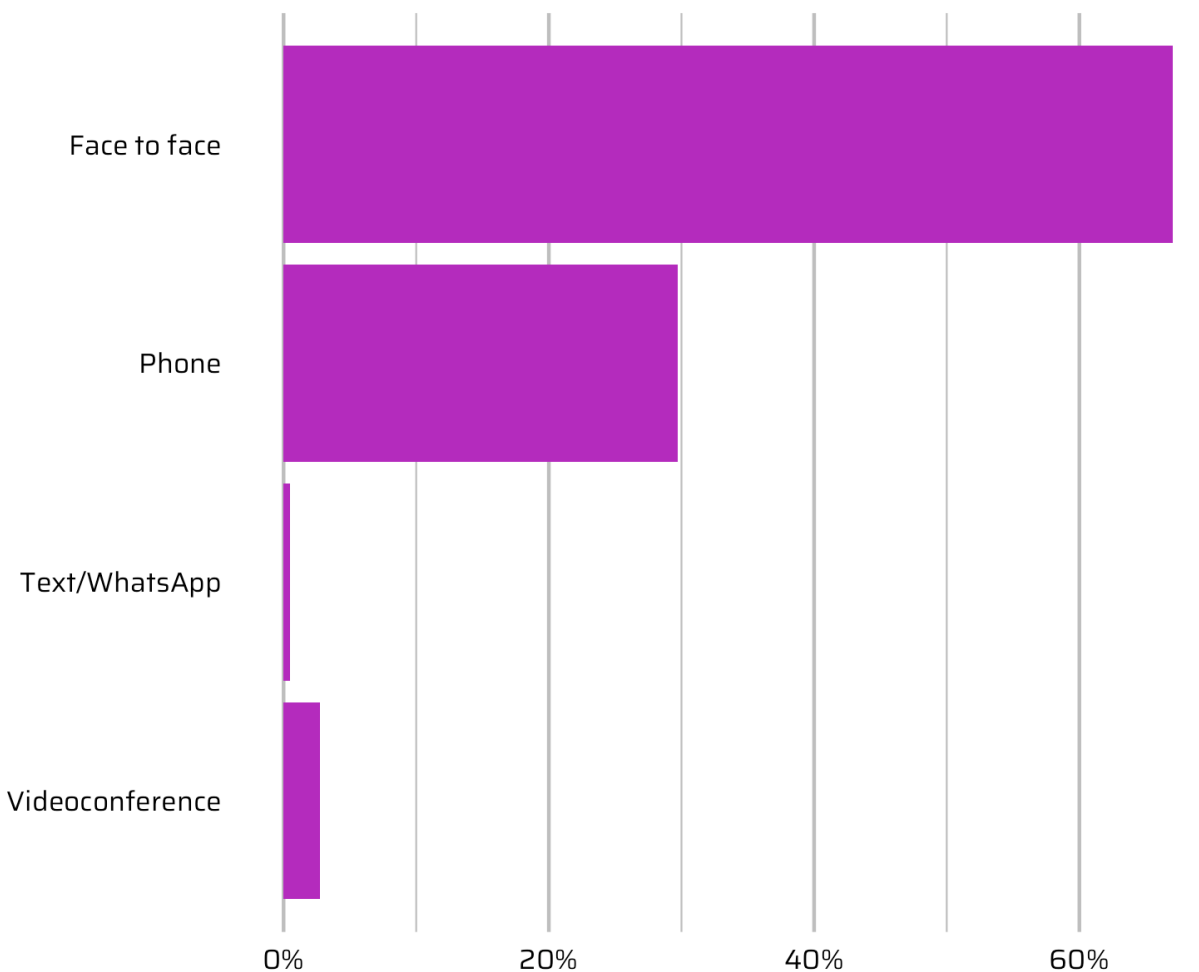


Figure 7: Mode by which medical appointments were held in the last 8 weeks at the time they answered the questionnaires.

Table 7: Mode by which medical appointments were held in the last 8 weeks at the time they answered the questionnaires.

Mode	Respondents	Percentage
Face to face	1,183	67.03
Phone	525	29.75
Video conference	48	2.72
Text/WhatsApp	9	0.51

There seems to be no drastic change in trends of using different mode of deliveries.

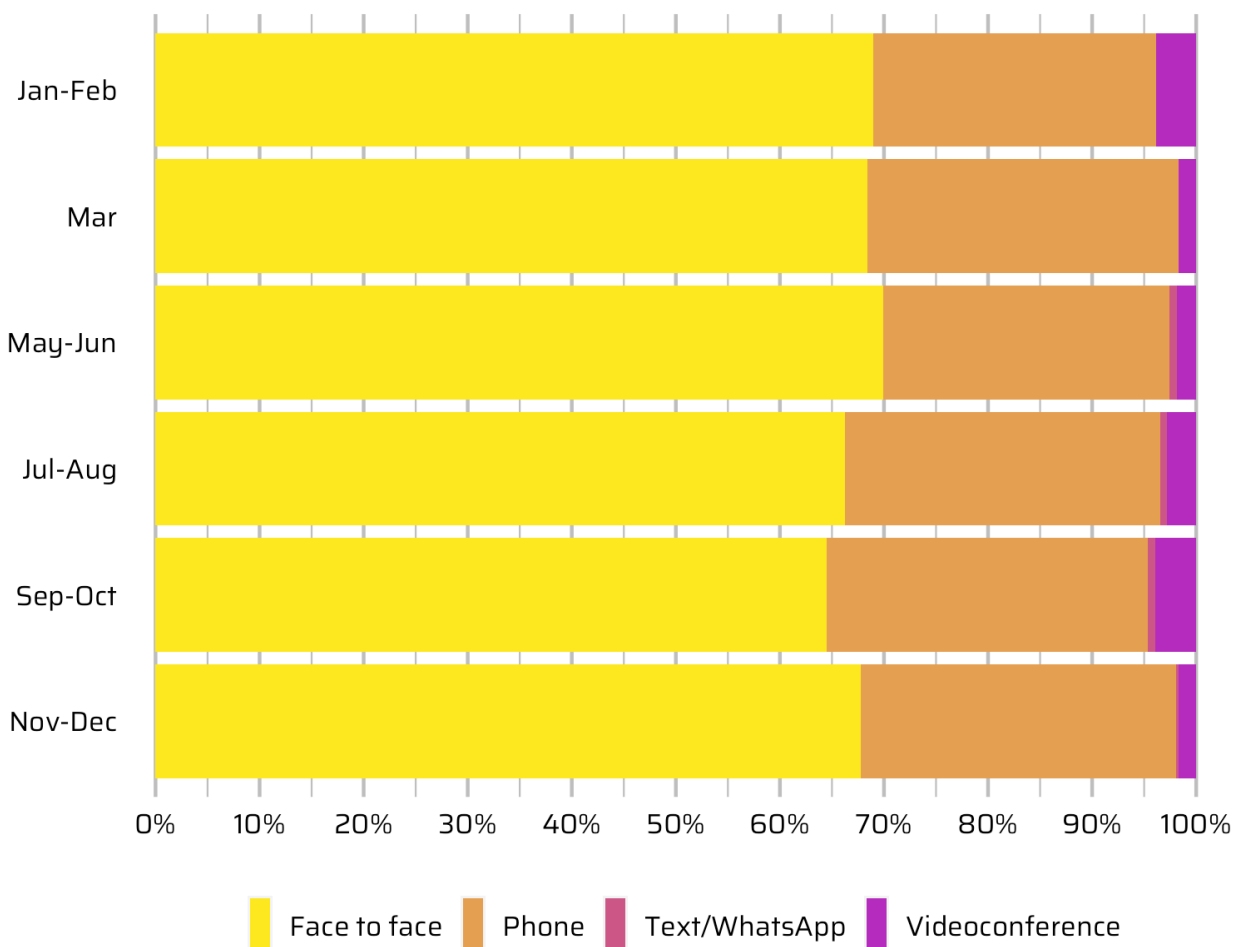


Table 8: Mode by which medical appointments were held in the last 8 weeks at the time they answered the questionnaires across months.

Table 8: Mode by which medical appointments were held in the last 8 weeks at the time they answered the questionnaires across months.

Month	Mode	Respondents	Percentage
January- February	Videoconference	5	3.88
	Text/WhatsApp	0	0.00
	Phone	35	27.13

Month	Mode	Respondents	Percentage
March	Face to face	89	68.99
	Videoconference	2	1.71
	Text/WhatsApp	0	0.00
	Phone	35	29.91
	Face to face	80	68.38
May-June	Videoconference	5	1.86
	Text/WhatsApp	2	0.74
	Phone	74	27.51
July-August	Face to face	188	69.89
	Videoconference	13	2.81
	Text/WhatsApp	3	0.65
	Phone	140	30.30
	Face to face	306	66.23
September- October	Videoconference	17	3.94
	Text/WhatsApp	3	0.70
	Phone	133	30.86
November- December	Face to face	278	64.50
	Videoconference	6	1.68
	Text/WhatsApp	1	0.28
	Phone	108	30.25
	Face to face	242	67.79

Helpfulness of medical appointments.

Overall, 70.8% of the medical appointments were found to be helpful. In other words, about 5 in 7 medical appointments were found to be helpful.

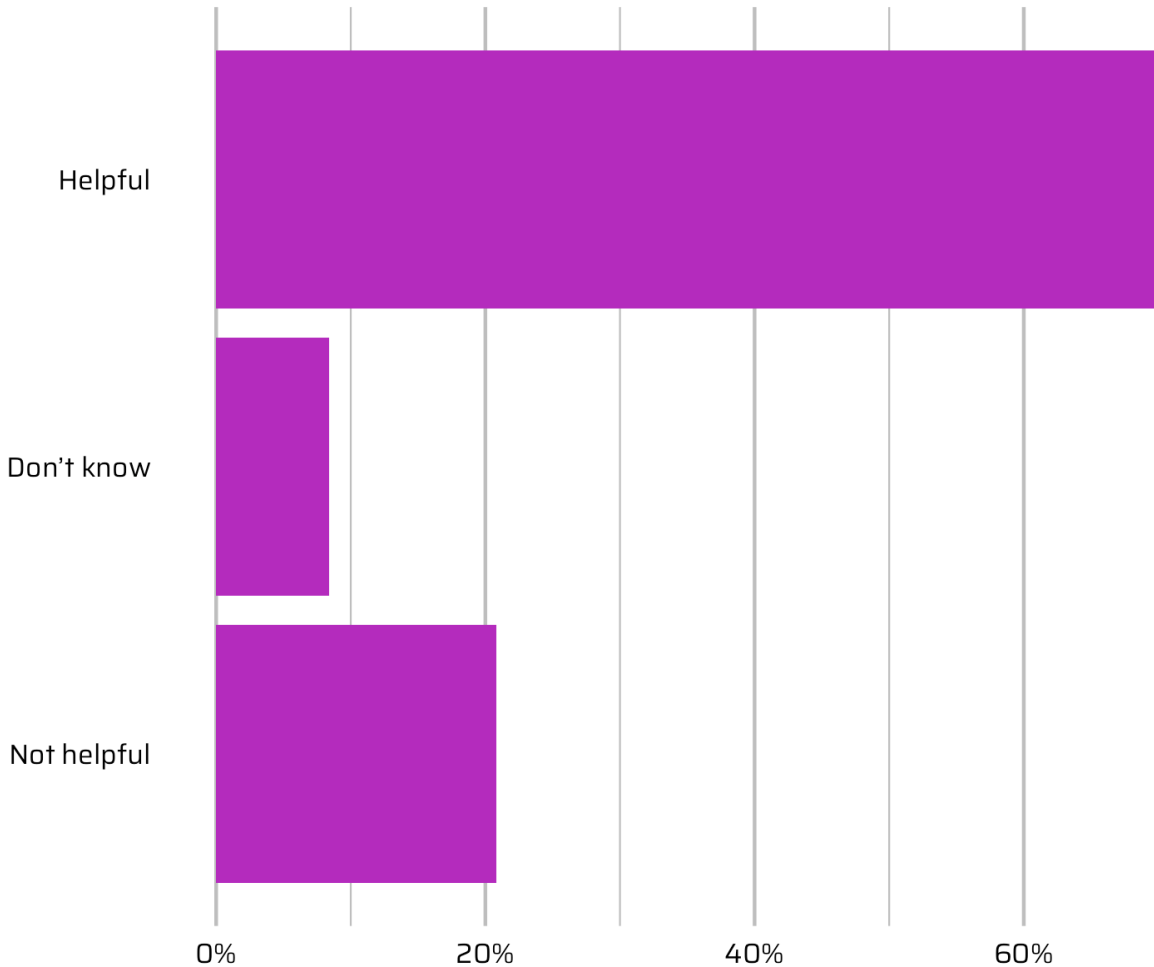


Figure 9: Helpfulness of the medical appointments in the past 8 weeks at the time they answered the questionnaires.

Table 9: Helpfulness of the medical appointments in the past 8 weeks at the time they answered the questionnaires.

Helpfulness	Respondents	Percentage
Helpful	1,281	70.81

Helpfulness	Respondents	Percentage
Don't know	152	8.40
Not helpful	376	20.78

However, there is a trend where the proportion of medical appointments found to be helpful is decreasing, whereas the proportion of medical appointments found to be not helpful is steadily increasing over time.

In January-February, the percentage of medical appointments found to be not helpful was 9.4%, but in November-December, the percentage went up to 28.7%.

In other words, about 1 in 10 medical appointments were found to be not helpful in January-February, but this number tripled to about 3 in 10 medical appointments in November-December.

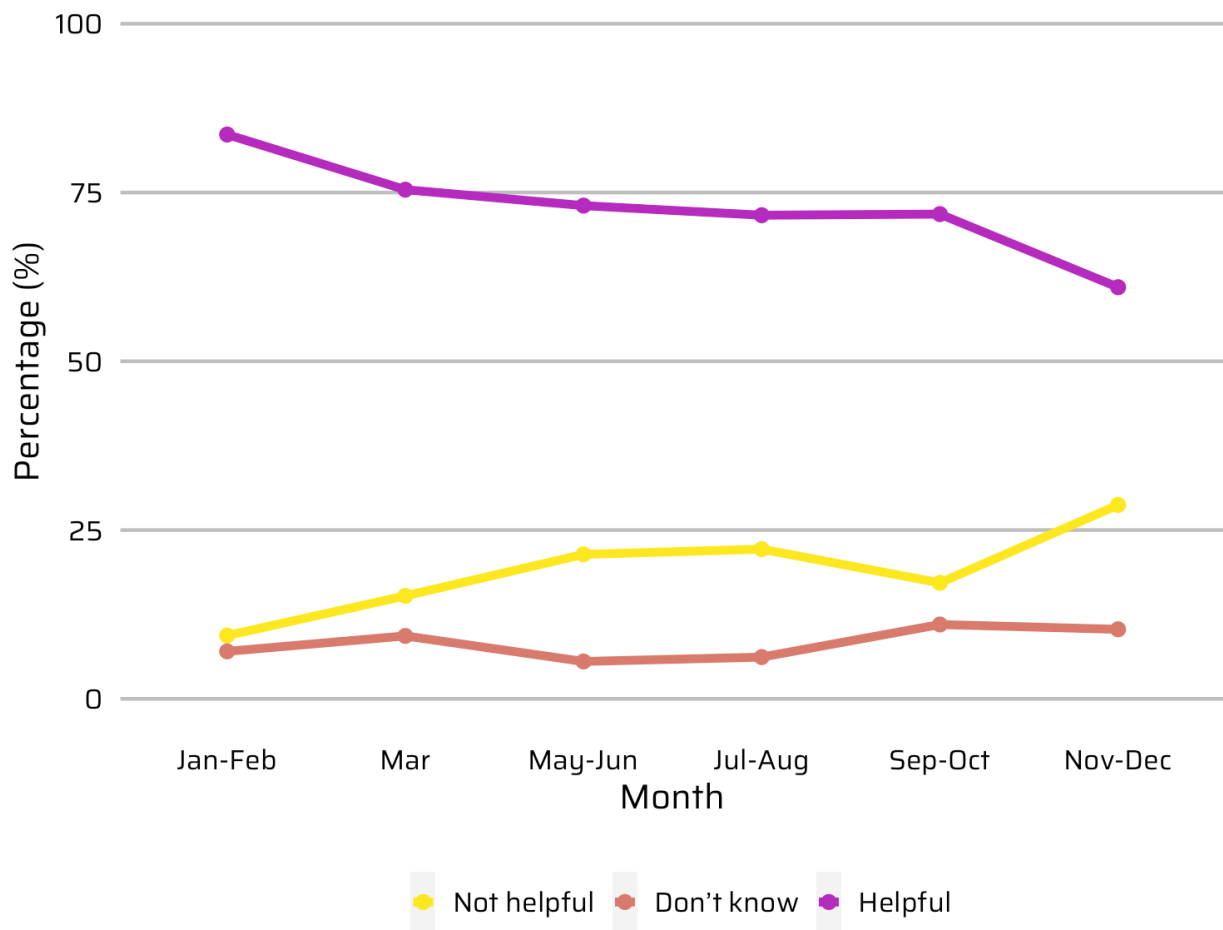


Figure 10: Helpfulness of the medical appointments in the past 8 weeks at the time they answered the questionnaires across months.

Table 10: Helpfulness of the medical appointments in the past 8 weeks at the time they answered the questionnaires across months.

Month	Helpfulness	Respondents	Percentage
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Month	Helpfulness	Respondents	Percentage
January-February	Not helpful	12	9.38
	Don't know	9	7.03
	Helpful	107	83.59
March	Not helpful	18	15.25
	Don't know	11	9.32
	Helpful	89	75.42
May-June	Not helpful	58	21.40
	Don't know	15	5.54
	Helpful	198	73.06
July-August	Not helpful	104	22.17
	Don't know	29	6.18
	Helpful	336	71.64
September-October	Not helpful	78	17.18
	Don't know	50	11.01
	Helpful	326	71.81
November-December	Not helpful	106	28.73
	Don't know	38	10.30
	Helpful	225	60.98

Sought A&E/Emergency support.

On average, 11.05% of the respondents reported to have sought A&E/emergency support from the NHS in the last 8 weeks when asked this question.

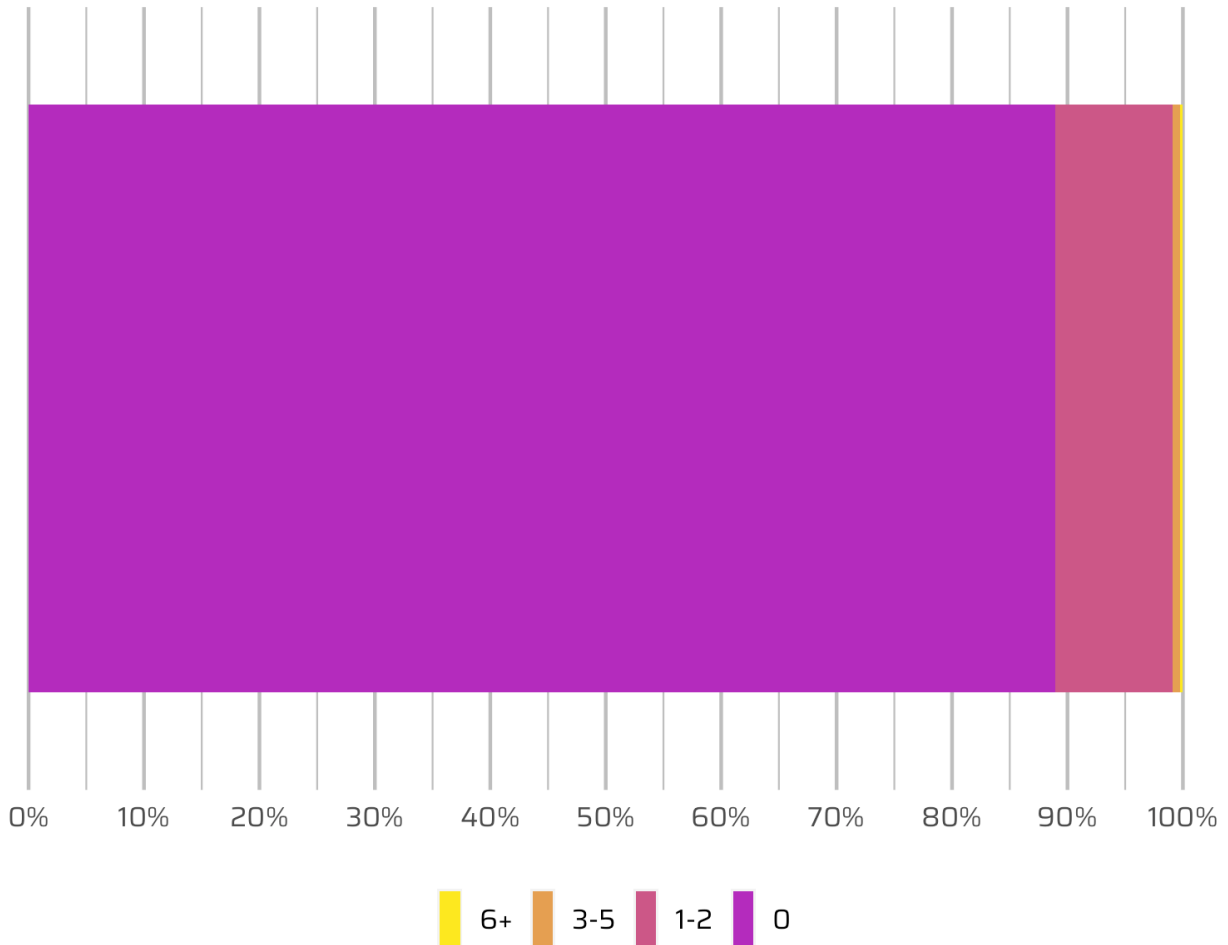


Figure 11: Frequency seeking A&E/emergency support in the past 8 weeks at the time they answered the questionnaires.

Table 11: Frequency seeking A&E/emergency support in the past 8 weeks at the time they answered the questionnaires.

Frequency going to A & E	Respondents	Percentage
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Frequency going to A & E	Respondents	Percentage
6+	3	0.22
3-5	9	0.65
1-2	140	10.17
0	1,224	88.95

There seems to be no drastic change in the trend of seeking A&E/emergency support. It increased slightly from 4.42% in January-February to 13.92% in July-August but decreased to 9.68% in November-December.

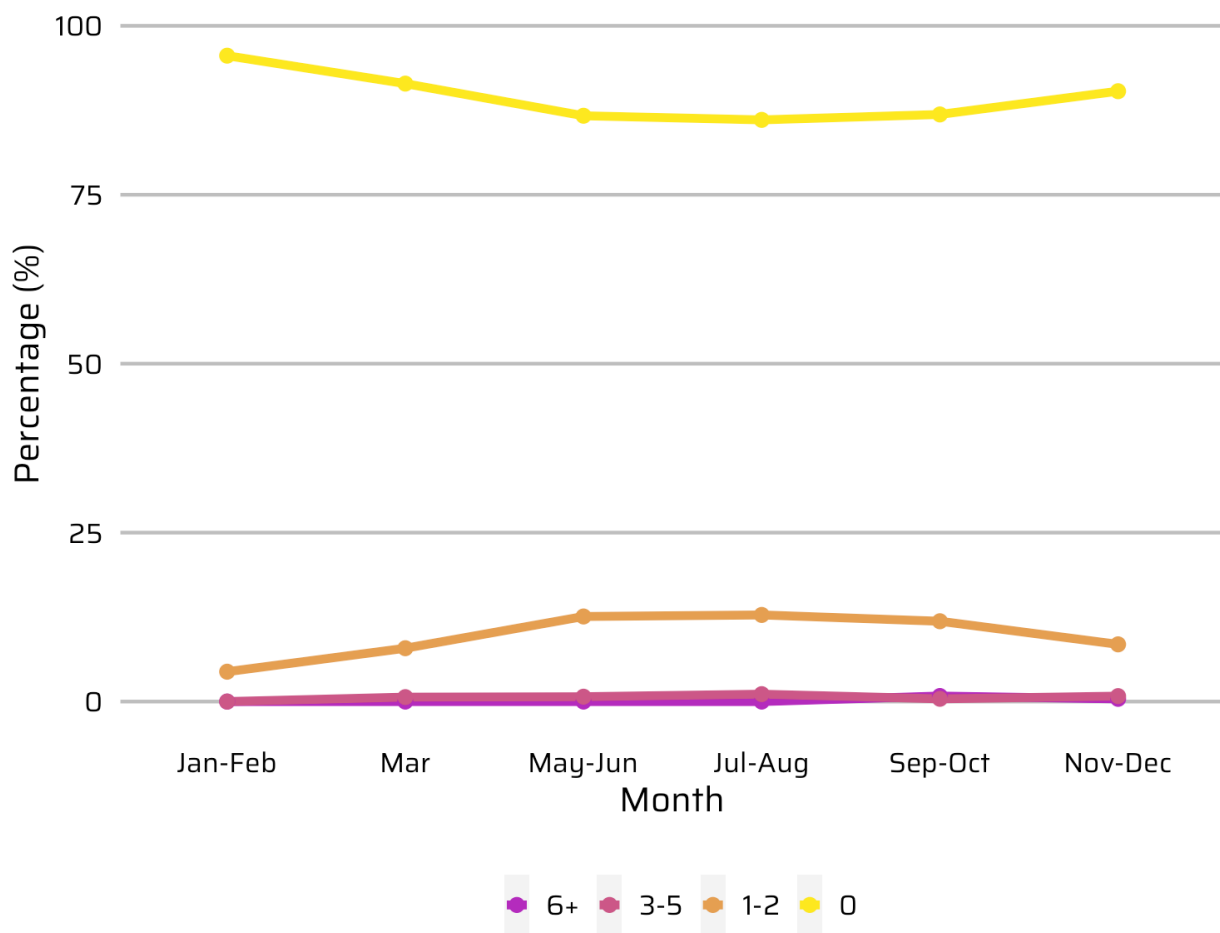


Figure 12: Frequency seeking A&E/emergency support in the past 8 weeks at the time they answered the questionnaires across months.

Table 12: Frequency seeking A&E/emergency support in the past 8 weeks at the time they answered the questionnaires across months.

Month	Frequency going to A & E	Respondents	Percentage
January-February	6+	0	0.00
	3-5	0	0.00
	1-2	8	4.42
	0	173	95.58
March	6+	0	0.00
	3-5	1	0.66
	1-2	12	7.89
	0	139	91.45
May-June	6+	0	0.00
	3-5	2	0.72
	1-2	35	12.59
	0	241	86.69
July-August	6+	0	0.00
	3-5	3	1.10
	1-2	35	12.82
	0	235	86.08
September-October	6+	2	0.82
	3-5	1	0.41
	1-2	29	11.89
	0	212	86.89
November-December	6+	1	0.40
	3-5	2	0.81
	1-2	21	8.47
	0	224	90.32

Mental health

Mental well-being needs met.

Overall, 33.5% of the respondents found that their mental health needs were not met at all. This is close to 1 in 3 people.

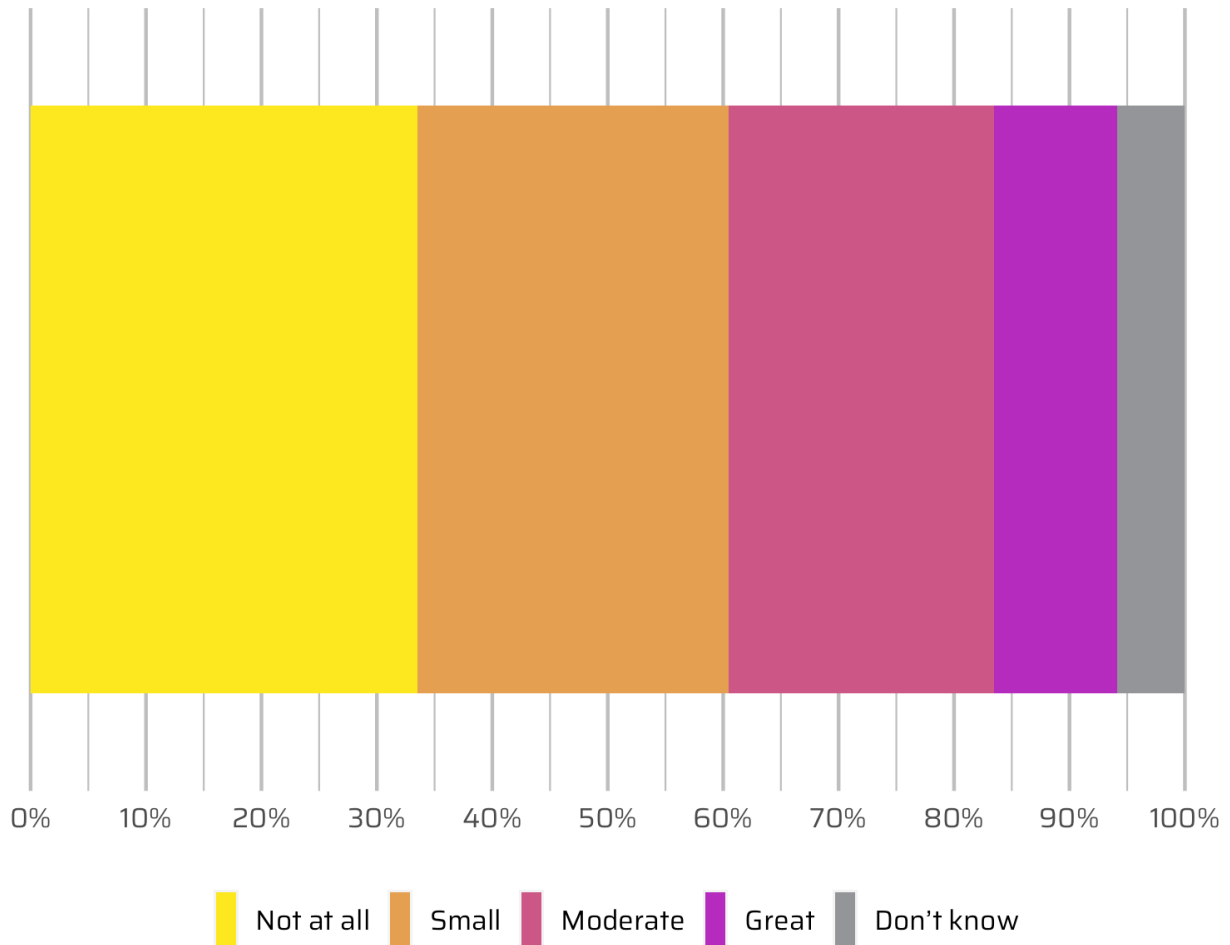


Figure 13: Extent mental health needs are met.

Table 13: Extent mental health needs are met.

Mental health needs met	Respondents	Percentage
Don't know	81	5.90
Great	146	10.64
Moderate	315	22.96
Small	370	26.97

Mental health needs met	Respondents	Percentage
Not at all	460	33.53

Those who think that their mental well-being needs are not met have increased from 28.3% in January-February (1 in 4 people) to 39.5% (1 in 3 people) in November-December.

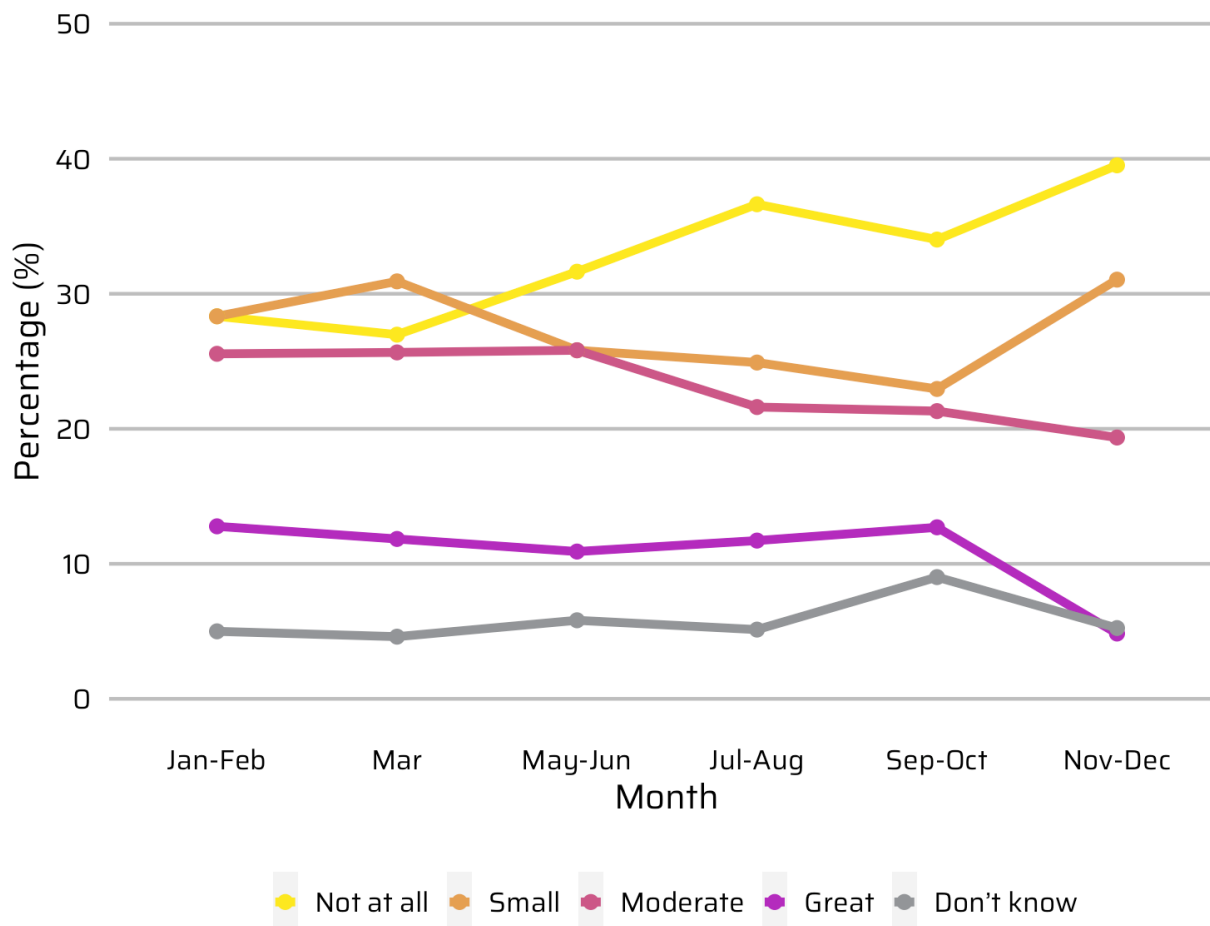


Figure 14: Extent mental health needs are met across months.

Table 14: Extent mental health needs are met across months.

Month	Mental health needs met	Respondents	Percentage
January-	Not at all	51	28.33

Month	Mental health needs met	Respondents	Percentage
February	Small	51	28.33
	Moderate	46	25.56
	Great	23	12.78
	Don't know	9	5.00
March	Not at all	41	26.97
	Small	47	30.92
	Moderate	39	25.66
	Great	18	11.84
May-June	Don't know	7	4.61
	Not at all	87	31.64
	Small	71	25.82
	Moderate	71	25.82
July-August	Great	30	10.91
	Don't know	16	5.82
	Not at all	100	36.63
	Small	68	24.91
September-October	Moderate	59	21.61
	Great	32	11.72
	Don't know	14	5.13
	Not at all	83	34.02
November-December	Small	56	22.95
	Moderate	52	21.31
	Great	31	12.70
	Don't know	22	9.02
	Not at all	98	39.52
	Small	77	31.05
	Moderate	48	19.35
	Great	12	4.84
	Don't know	13	5.24

Anxiety and hopelessness

Overall, 64.4% of the respondents reported that they had either been anxious or hopeless. This is equivalent to about 2 in 3 people.

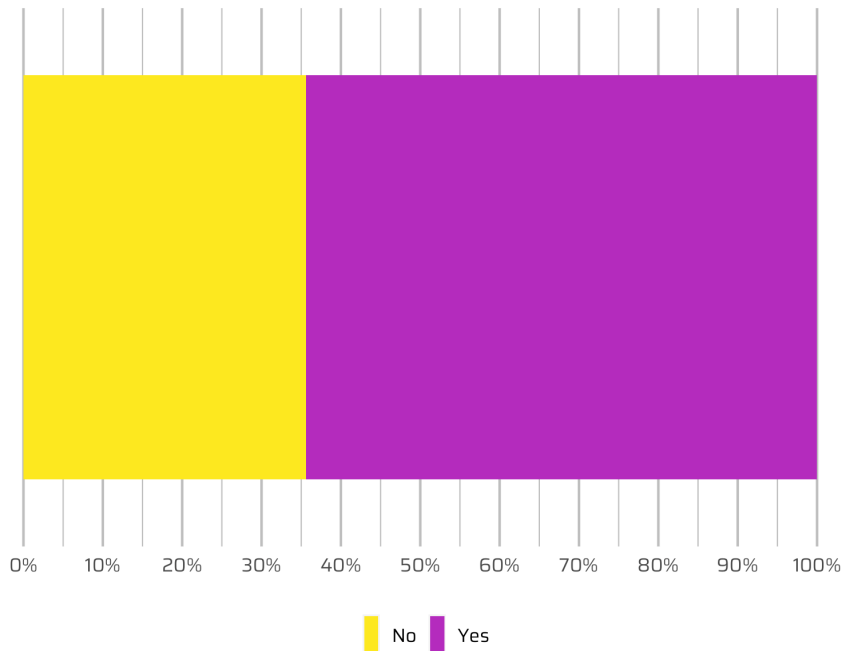


Figure 15: Feelings of anxiety or hopelessness

Table 15: Feelings of anxiety or hopelessness

Anxiety or hopelessness	Respondents	Percentage
Yes	886	64.39
No	490	35.61

There has been a slight increasing trend for those who reported to be either anxious or hopeless, from 59.1% in January-February to 67.7% in November-December.

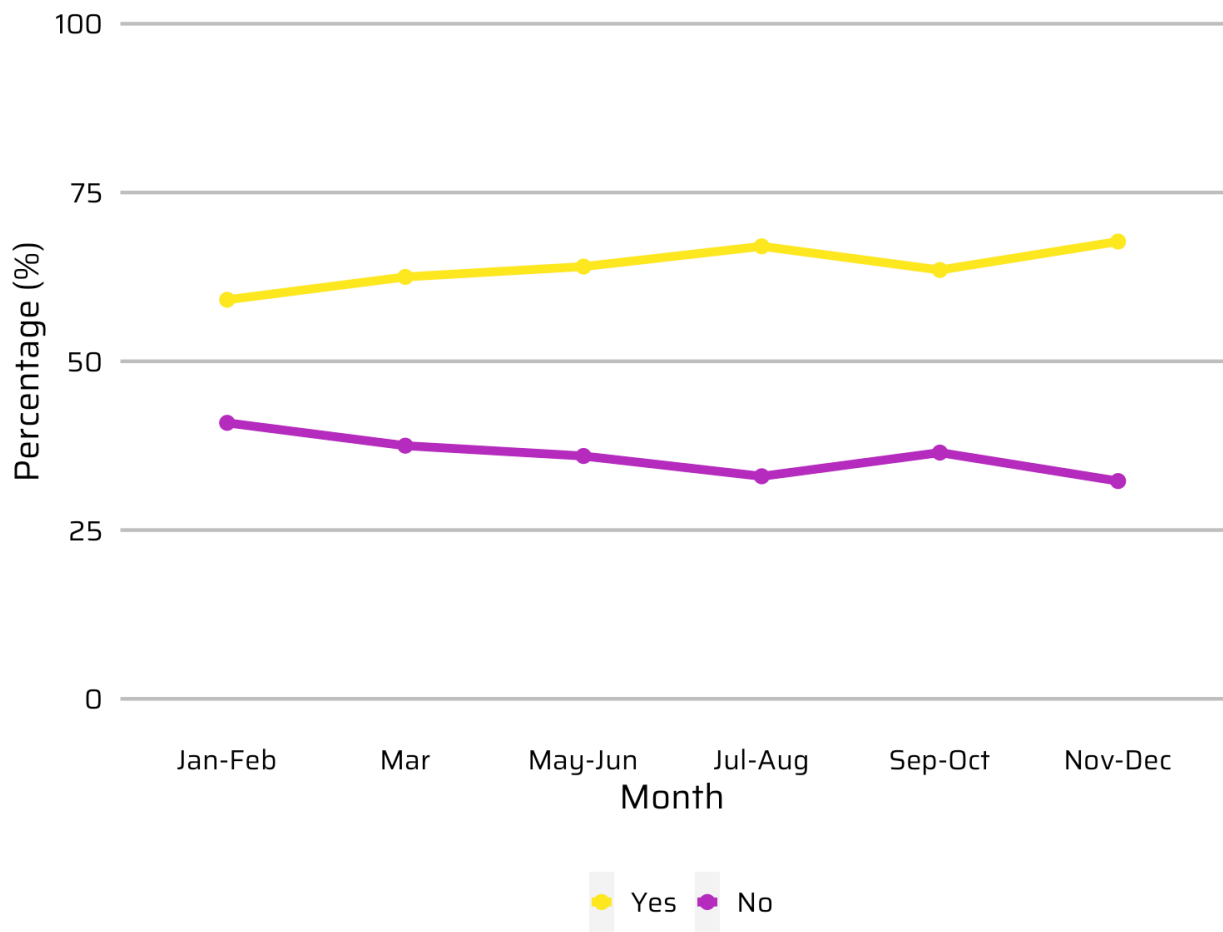


Figure 16: Feelings of anxiety or hopelessness across months

Table 16: Feelings of anxiety or hopelessness across months

Month	Anxiety or hopelessness	Respondents	Percentage
January-February	Yes	107	59.12
	No	74	40.88
March	Yes	95	62.50
	No	57	37.50
May-June	Yes	178	64.03
	No	100	35.97
July-August	Yes	183	67.03
	No	90	32.97
September-October	Yes	155	63.52
	No	89	36.48
November-December	Yes	168	67.74
	No	80	32.26

Demographics

Sample size

In total, there are 1376 questionnaires completed in 2022 across 6 reports, with the highest number of responses in the May-June survey.

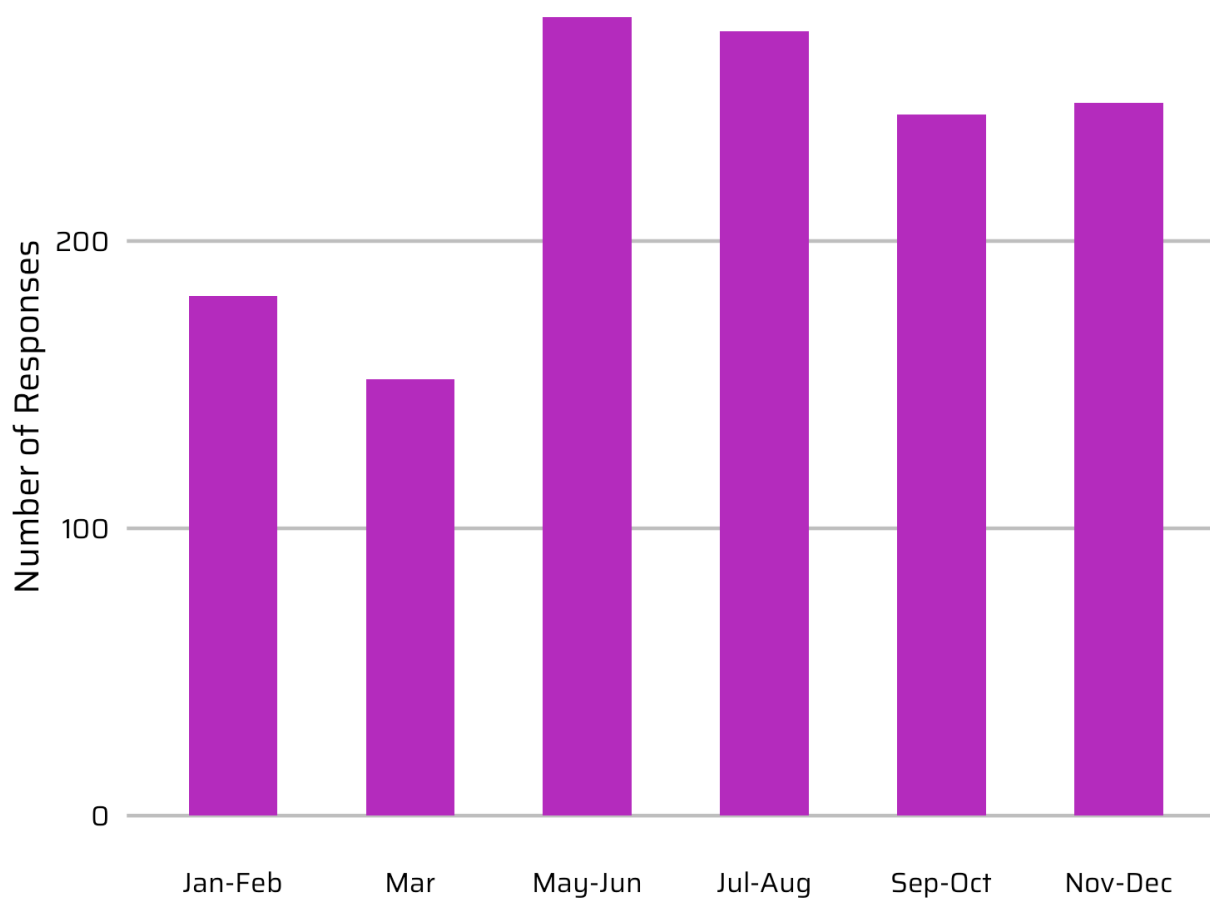


Figure 17: Number of responses for each month

Table 17: Number of responses for each month

Month	Number of responses
January-February	181
March	152

Month	Number of responses
May-June	278
July-August	273
September-October	244
November-December	248
Total	1,376

Note that for March, responses were only collected for March but not March-April

Number of conditions represented.

In total, 112 conditions were represented. The top 20 conditions are shown in Figure 2.

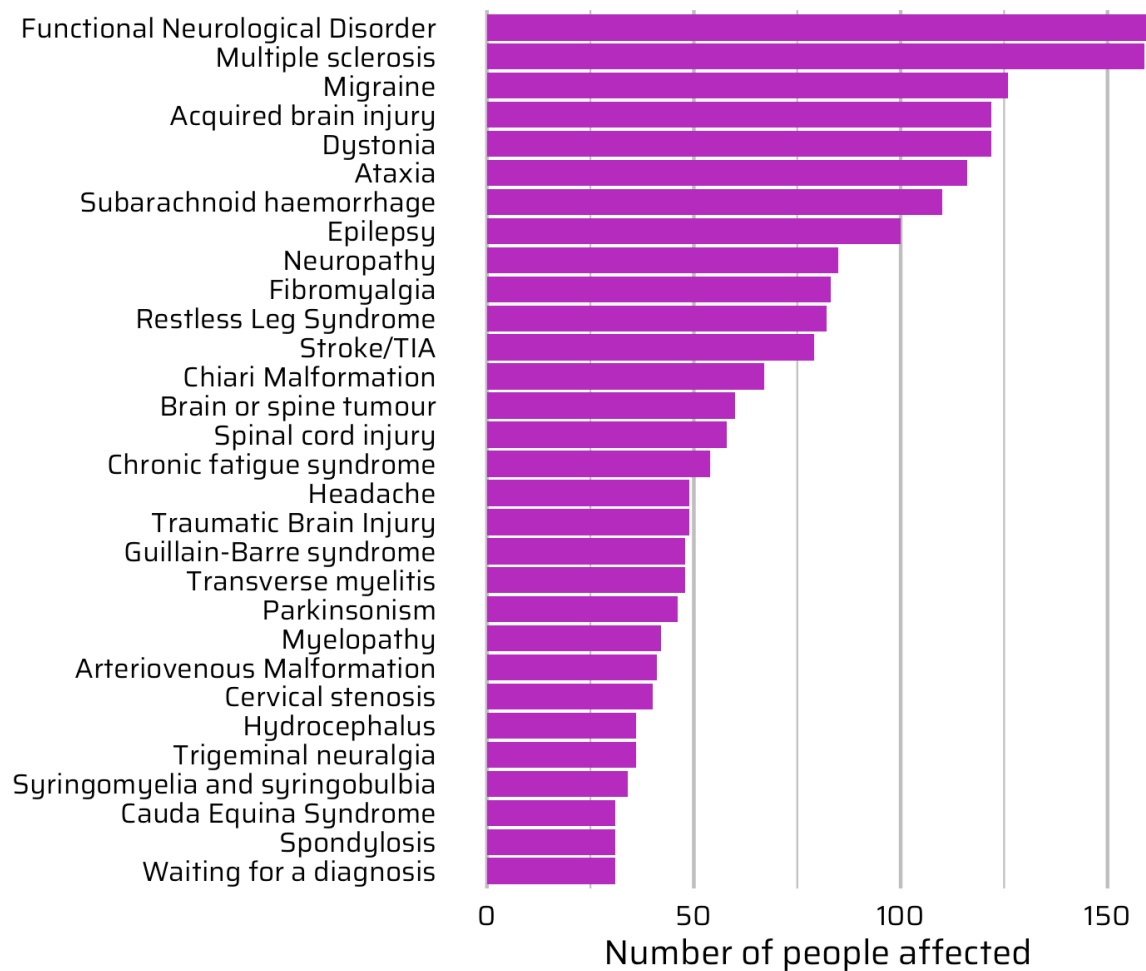


Figure 18: All neurological conditions represented.

Table 18: All neurological conditions represented.

Condition	Number of people affected
Functional Neurological Disorder	160
Multiple sclerosis	159
Migraine	126
Acquired brain injury	122
Dystonia	122
Ataxia	116
Subarachnoid haemorrhage	110
Epilepsy	100
Neuropathy	85
Fibromyalgia	83
Restless Leg Syndrome	82
Stroke/TIA	79
Chiari Malformation	67
Brain or spine tumour	60
Spinal cord injury	58
Chronic fatigue syndrome	54
Headache	49
Traumatic Brain Injury	49
Guillain-Barre syndrome	48
Transverse myelitis	48
Parkinsonism	46
Myelopathy	42
Arteriovenous Malformation	41
Cervical stenosis	40
Hydrocephalus	36
Trigeminal neuralgia	36
Syringomyelia and syringobulbia	34
Cauda Equina Syndrome	31
Spondylosis	31
Waiting for a diagnosis	31

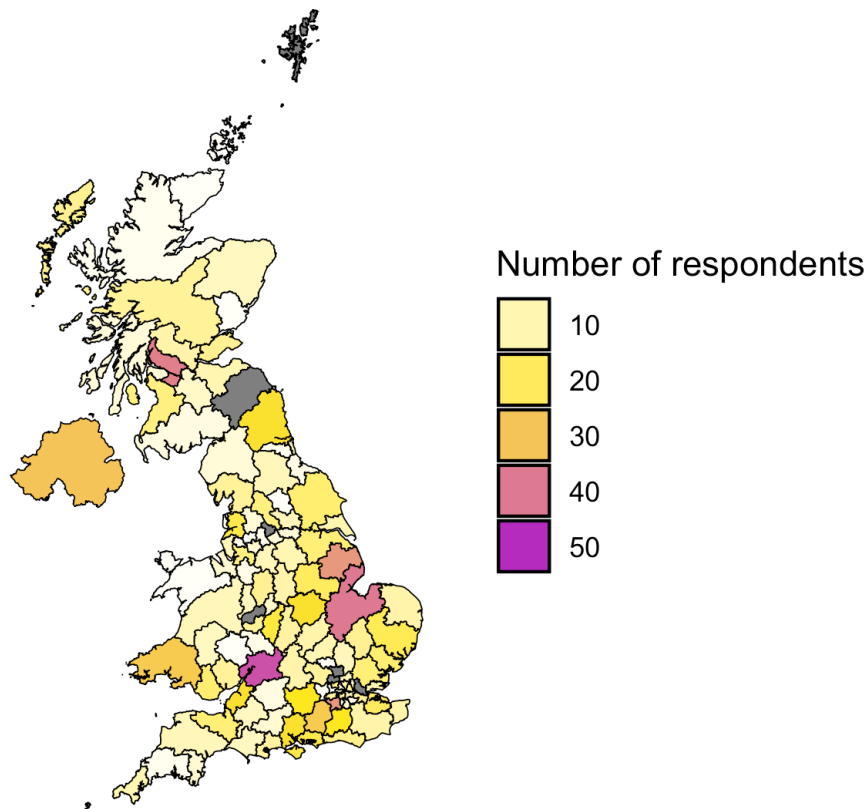
Condition	Number of people affected
Chronic pain	30
Tremor	29
Cerebral Aneurysms (Ruptured/Unruptured)	25
Arnold-Chiari syndrome	24
Rare and other neurological diseases	24
Myalgic encephalomyelitis (ME)	21
Multiple system atrophy	19
Motor neurone disease	17
Radiculopathy	16
Dysphasia and aphasia	15
Spina Bifida	15
Cerebrospinal fluid leak	13
Brain injury	12
Long COVID	12
ADHD	11
Intacranial hypertension	11
Meningitis	11
Tethered Cord	11
Chronic Inflammatory Demyelinating	10
Polyneuropathy	10
Disorders of other visual pathways	10
Dyslexia and alexia	10
Myasthenia Gravis	10
Autism	9
Encephalitis	9
Myalgic encephalomyelitis/chronic fatigue syndrome	9
Tarlov Cysts	9
Dysexecutive Syndrome	8
Ehlers Danlos Syndromes	8
Idiopathic intracranial hypertension	8

Condition	Number of people affected
Acute poliomyelitis	7
Apraxia	7
Bell's palsy	7
Demyelinating disease	7
Hereditary Spastic Paralegia	7
Disorders of vagus nerve	6
Neurofibromatosis	6
Paraplegia and tetraplegia	6
Post-polio syndrome	6
Carpal tunnel syndrome	5
Cavernoma	5
Cerebral Aneurysms (Ruptured/Unruptured)	5
Hemiplegia	5
Split Cord	5
Tourette Syndrome	5
Brown-Séquard syndrome	4
Cerebral cysts	4
Charcot-Marie-Tooth Disease	4
Cluster headache	4
Epidemic vertigo	4
Essential tremor	4
Sleep disorder	4
Traumatic spinal injury	4
Bipolar	3
Clonic hemifacial spasm	3
Hemicranial Corrina	3
Hemifacial Spasm	3
Myopathy	3
No diagnosis	3
Chagas' disease	2
Cranial nerve disorder	2

Condition	Number of people affected
Disorders of multiple cranial nerves	2
Disorders of other specified cranial nerves	2
Down's Syndrome	2
Muscular dystrophy	2
Nerve Tumour	2
Neuromyelitis optica	2
Short Fibre Neuropathy	2
Spinal instabilities	2
Acoustic neuroma	1
Cerebral infarction	1
Dementia	1
Disorders of optic chiasm	1
Disorders of visual cortex	1
Faetal Alcohol Spectrum Disorders (FASD)	1
Huntington's disease	1
Intracranial and intraspinal phlebitis and thrombophlebitis	1
Kennedy's disease	1
Malaria	1
Nerve palsy	1
Papilloedema	1
Refsum's Disease	1
Vascular myelopathies	1

Postal area

Across all postal areas, 94.21% of the postal areas have been covered in the survey, with the top 20 postal areas shown in the table below.



Figure

19: Number of respondents in each postal area
 *Postal areas in grey are areas that were not covered.

Table 19: Number of respondents in each postal area

Area Name	Postal Area	Number of respondents
Gloucester	GL	45
Peterborough	PE	40
Glasgow	G	39
Kingston upon Thames	KT	36
Lincoln	LN	36
Northern Ireland	BT	30
Guildford	GU	29
Swansea	SA	29
Bristol	BS	26
Leicester	LE	26
Newcastle upon Tyne	NE	26

Area Name	Postal Area	Number of respondents
Southampton	SO	26
Reading	RG	25
Redhill	RH	25
Birmingham	B	23
Portsmouth	PO	22
Preston	PR	22
Ipswich	IP	21
Medway	ME	20
Nottingham	NG	20
Cardiff	CF	18
Colchester	CO	18
York	YO	18
Chelmsford	CM	17
Doncaster	DN	17
Taunton	TA	17
Bradford	BD	16
Kilmarnock	KA	16
Warrington	WA	16
Brighton	BN	15
Harrow	HA	15
Cambridge	CB	14
Outer Hebrides	HS	14
Kirkcaldy	KY	14
Stoke-on-Trent	ST	14
Dartford	DA	13
Dudley	DY	13
London - E	E	13
Hemel Hempstead	HP	13
Lancaster	LA	13
Newport	NP	13
Perth	PH	13
Bournemouth	BH	12
Coventry	CV	12

Area Name	Postal Area	Number of respondents
London - SW	SW	12
Twickenham	TW	12
Canterbury	CT	11
Derby	DE	11
Falkirk	FK	11
Northampton	NN	11
Norwich	NR	11
Oxford	OX	11
Tonbridge	TN	11
Edinburgh	EH	10
Hull	HU	10
Milton Keynes	MK	10
London - N	N	10
Sheffield	S	10
Sunderland	SR	10
Southend-on-Sea	SS	10
Truro	TR	10
Darlington	DL	9
Enfield	EN	9
Exeter	EX	9
Liverpool	L	9
Leeds	LS	9
London - SE	SE	9
Stevenage	SG	9
Stockport	SK	9
Shrewsbury	SY	9
Aberdeen	AB	8
Bath	BA	8
Dorchester	DT	8
Llandrindod Wells	LD	8
Telford	TF	8
Motherwell	ML	7
Walsall	WS	7

Area Name	Postal Area	Number of respondents
Chester	CH	6
Croydon	CR	6
Ilford	IG	6
Manchester	M	6
Salisbury	SP	6
Torquay	TQ	6
Blackburn	BB	5
Carlisle	CA	5
Huddersfield	HD	5
Paisley	PA	5
Wakefield	WF	5
Dumfries and Galloway	DG	4
London - NW	NW	4
Sutton	SM	4
Swindon	SN	4
Bromley	BR	3
Crewe	CW	3
Teeside	TS	3
Worcester	WR	3
Durham	DH	2
The Fylde	FY	2
Inverness	IV	2
Oldham	OL	2
Plymouth	PL	2
London - W	W	2
Wigan	WN	2
Bolton	BL	1
Dundee	DD	1
London - EC	EC	1
Harrogate	HG	1
Hereford	HR	1
Kirkwall	KW	1
Llandudno	LL	1

Area Name	Postal Area	Number of respondents
Luton	LU	1
Slough	SL	1
Uxbridge	UB	1
London - WC	WC	1

The 7 postal areas (5.79% of all postal areas across the UK) that have not been covered are the following:

Table 20: Postal areas not covered:

Area Name	Postal Area	Number of respondents
St Albans	AL	0
Halifax	HX	0
Romford	RM	0
Teviotdale	TD	0
Watford	WD	0
Wolverhampton	WV	0
Lerwick	ZE	0

Age

The 55-64 years age group is the most frequent one (31.54%).

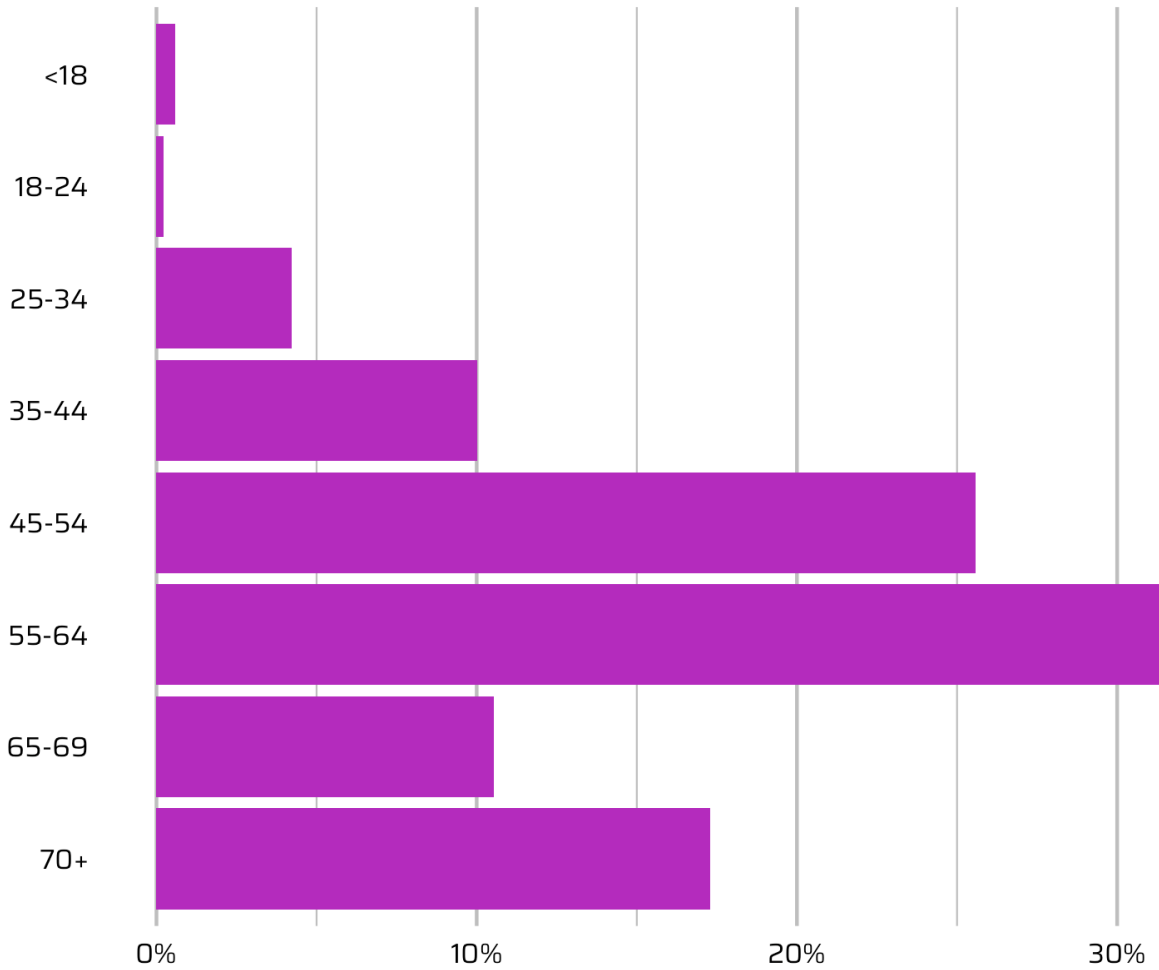


Figure 20: Age distribution

Table 21: Age distribution

Age	Respondents	Percentage
<18	8	0.58
18-24	3	0.22
25-34	58	4.22
35-44	138	10.03
45-54	352	25.58
55-64	434	31.54
65-69	145	10.54
70+	238	17.30

Gender

In total, there are 353 males, 1009 females, 7 prefer to self-describe, and 7 prefer not to say.

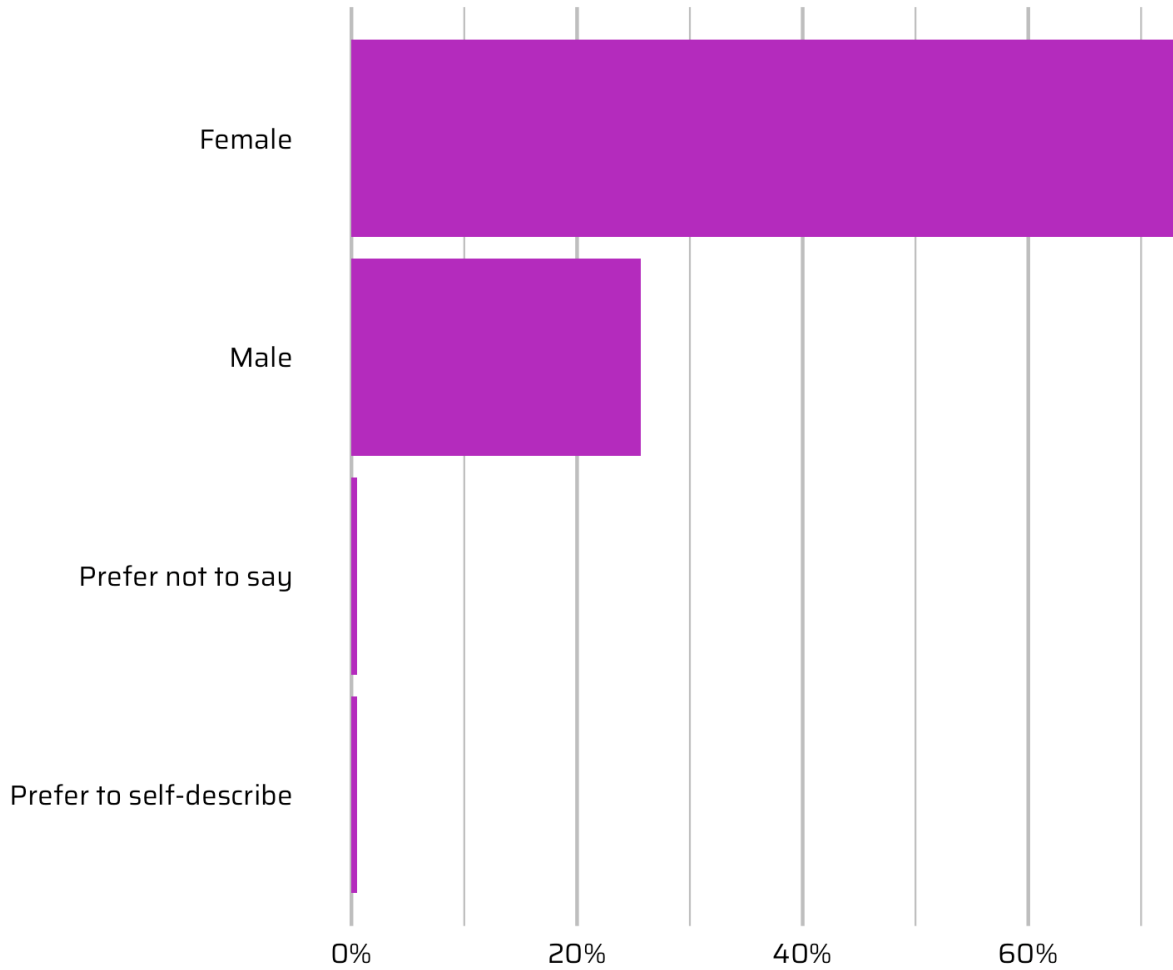


Figure 21: Gender distribution

Table 22: Gender distribution

Gender	Respondents	Percentage
Female	1,009	73.33
Male	353	25.65
Prefer not to say	7	0.51
Prefer to self-describe	7	0.51

Ethnicity

96.66% of the respondents are White.

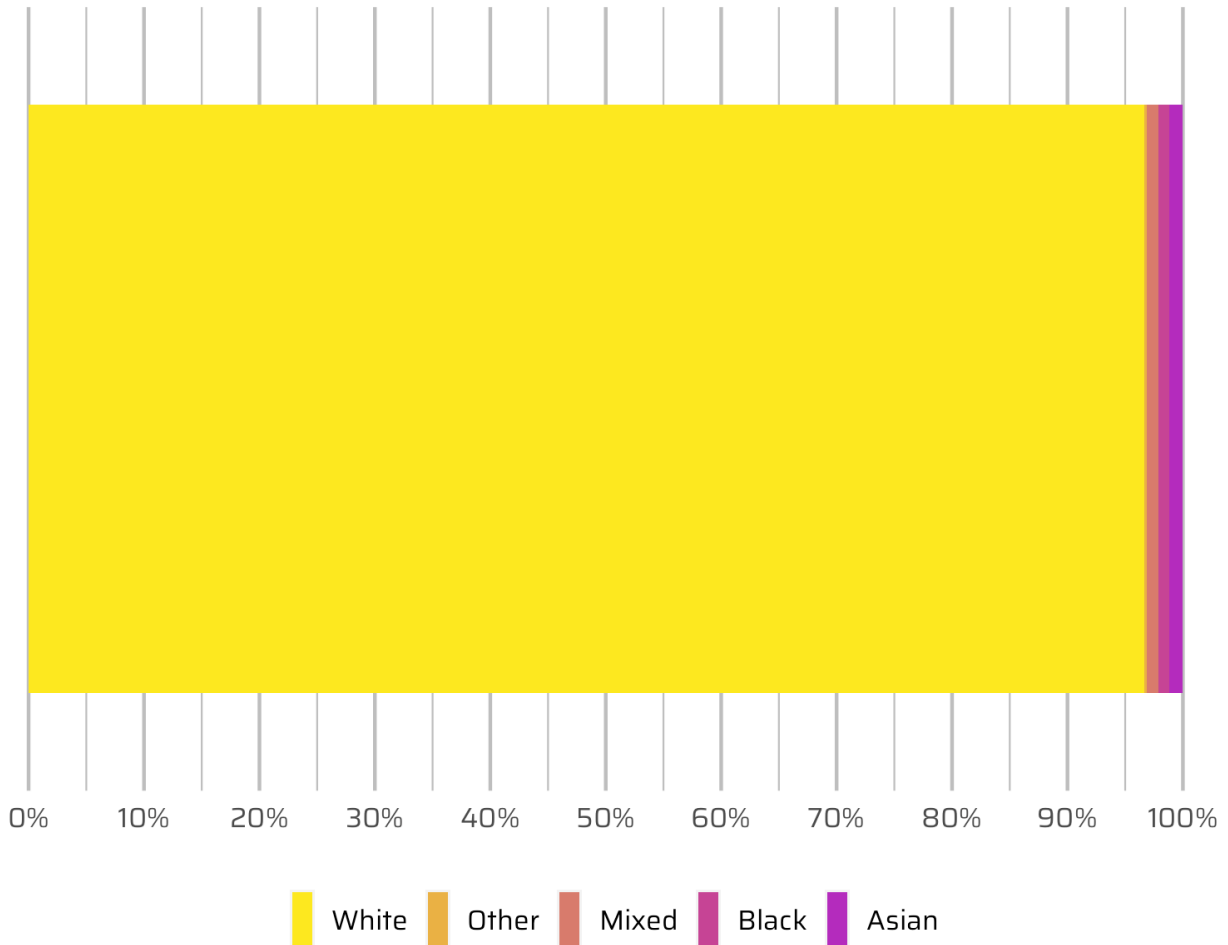


Table 22: Ethnicity distribution

Table 23: Ethnicity distribution

Ethnicity	Respondents	Percentage
Asian	16	1.16
Black	13	0.94
Mixed	14	1.02
Other	3	0.22
White	1,330	96.66