



The Brain Charity's #BrainSurvey

Engagement findings report

September 2023

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2 Introduction

The Brain Charity helps people with all forms of neurological condition to lead longer, healthier, happier lives.

There are more than 600 conditions affecting the brain, spine and nervous system - known as neurological conditions.

The Brain Charity is the only charity in the UK to provide practical help, emotional support and social activities for every single one.

For someone newly diagnosed with a neurological condition, life may become very lonely and frightening. It's easy to feel removed from everything around you and for some people this can mean losing control of their lives. Many face unemployment, poverty and social isolation.

We help anyone affected by a neurological condition to rebuild their lives and achieve their potential. We also champion neurodiversity.

We have been running for 30 years and support thousands of people from across the UK each year from our headquarters in Liverpool.

Find out more at www.thebraincharity.org.uk

This report presents the findings of The Brain Charity's 2022 #BrainSurvey – a survey undertaken with people with lived experience of neurological conditions, exploring their experiences of seeking and receiving a diagnosis.

3 Methodology

The evidence in this report is based on The Brain Charity's #BrainSurvey, which invited people affected by neurological conditions to have their say on their experiences of seeking and receiving a diagnosis.

The survey's aim was to help The Brain Charity better understand the difficulties people were facing and how and where improvements could be made.

3.1 How was the survey shared and distributed?

Most people completing the survey did so via an online SurveyMonkey link, which was live between September and November 2022. A small minority of survey respondents completed paper copies of the questionnaire. These were then manually inputted into SurveyMonkey, so all results were captured in the same place.

The #BrainSurvey was distributed via a variety of means, including:

- The Brain Charity's own communications channels, including our website, email mailing lists, social media accounts, printed newsletter and printed leaflets/flyers.
- Via the communications channels of partner organisations and other key stakeholders who shared the survey, mainly within the third and public sectors and NHS.
- Via MPs and other political leaders who were asked to share the survey via their channels, such as social media.

3.2 Who took the survey?

This survey was completed by 827 respondents, 85% of whom have a neurological condition. This included Chronic Fatigue Syndrome (CFS) / Myalgia Encephalomyelitis (ME), epilepsy, fibromyalgia, Functional Neurological Disorder (FND), Attention Deficit Hyperactivity Disorder (ADHD), autism, Multiple Sclerosis (MS), brain tumour and ataxia, amongst others.

3.3 Analysing the data

The survey consisted mainly of closed questions, however there were a number of opportunities for respondents to elaborate further on their responses through free text boxes.

Responses to these free text boxes were analysed using thematic analysis, whereby responses were assigned a code, and codes grouped into themes to allow a quantitative representation of the feedback.

For all closed questions, responses are presented as a proportion of the total sample (N=827). Where multiple response questions have been used and percentages do not equate to 100%, this has been stated.

For open questions, percentages are calculated as a proportion of those who provided a response.

It is important to note that respondents to the survey are self-selecting, representing the views of those who wanted to give their opinion. This is very important opinion but cannot be treated as statistically reliable.

4 Survey findings

4.1 Respondent profile

4.1.1 Overview

A total of 827 individuals responded to the survey. The majority (85%) had been diagnosed with a neurological condition, whilst 8% responded on behalf of someone else who has a neurological condition and 7% don't have a diagnosis but believe that they do have one.

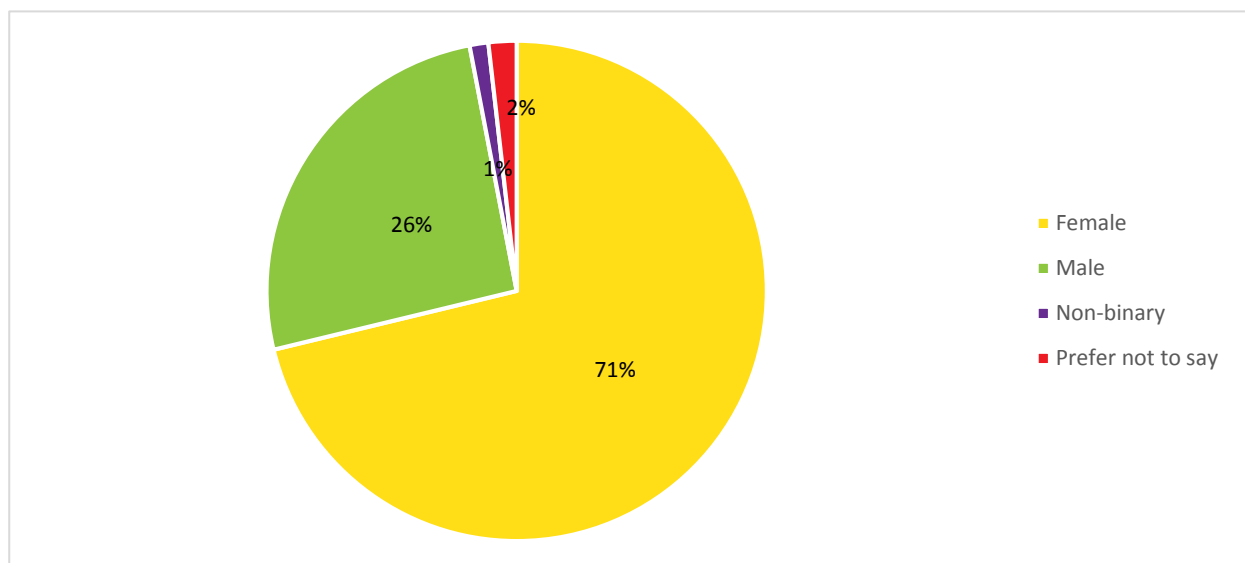
The majority identified as female (71%; 26% male) with approximately half (49%) aged between 45 to 64 years. Slightly smaller proportions were aged 35 – 44 years (18%) and 65 or over (16%).

Whilst there was a wide spread of respondents from all over the UK, the greatest proportion were from the North West (36%) – a finding likely to reflect the wealth of connections that The Brain Charity has in this area.

The majority identified as English / Welsh / Scottish / Northern Irish or British (88%).

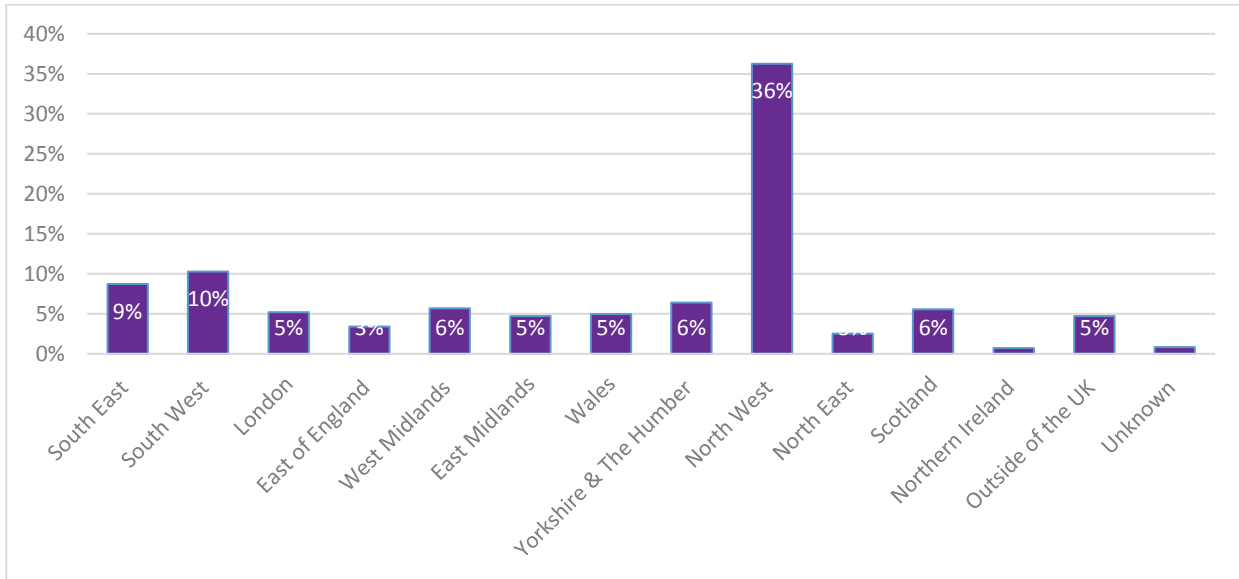
When asked to provide detail of their neurological condition, the most indicated having Chronic Fatigue Syndrome (CFS) / Myalgia Encephalomyelitis (ME) (25%). It was evident that the survey engaged with individuals with a wide range of neurological conditions with 26% providing a diagnosis which was classed as 'other'. Furthermore, 18% indicated they had more than one diagnosis.

4.1.2 Q: How would you describe yourself? (N=827)

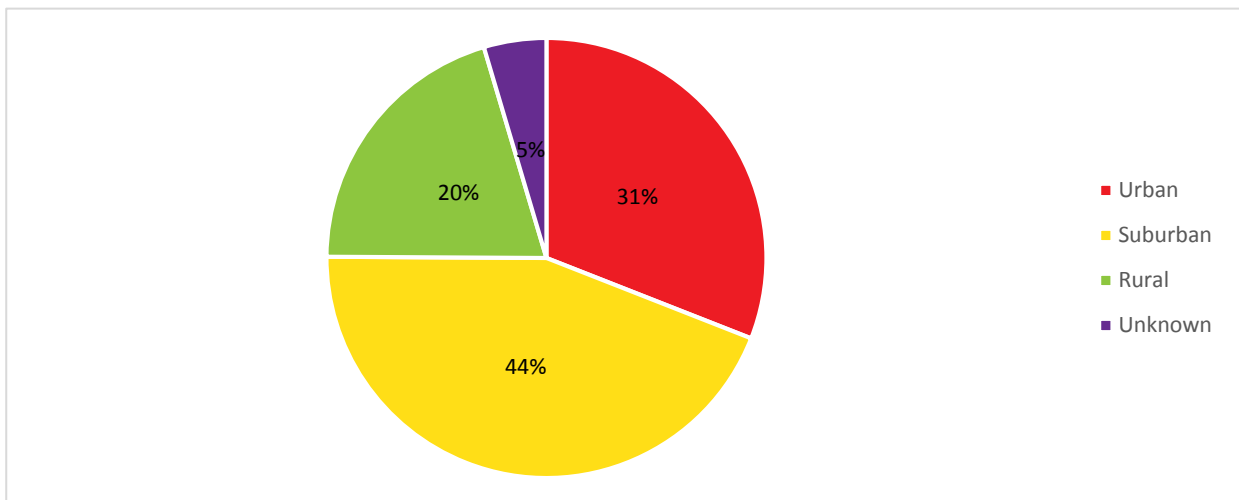


**Presented as a pie chart due to responses equating to 100% and the limited number of categories.*

4.1.3 Q: Where do you live in the UK? (N=827)

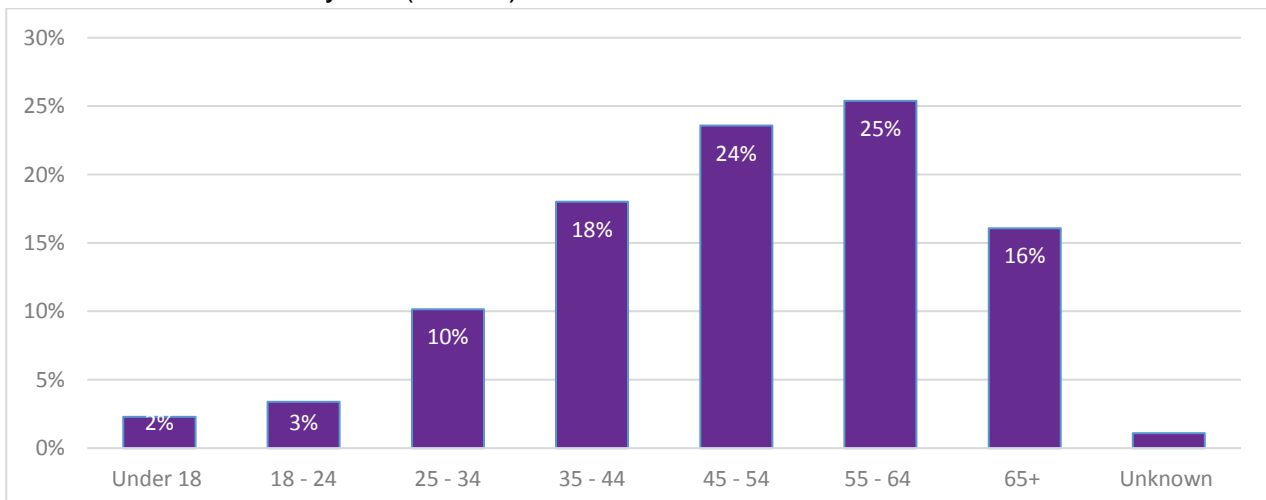


4.1.4 Q: Which of the following best describes where you live? (N=827)

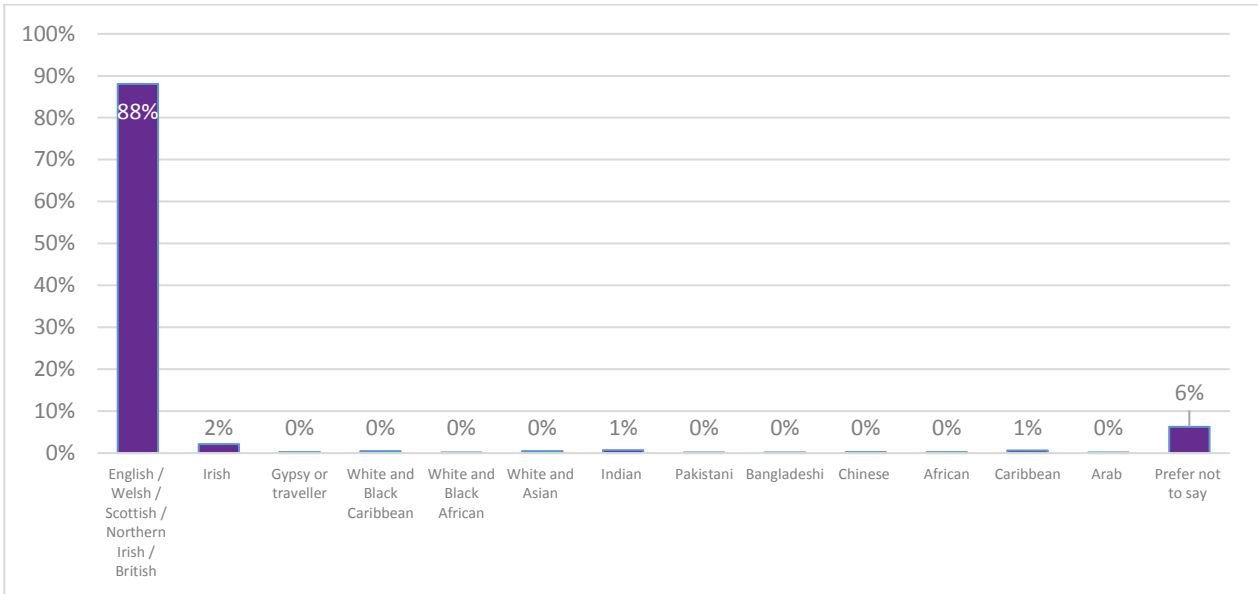


**Presented as a pie chart due to responses equating to 100% and the limited number of categories.*

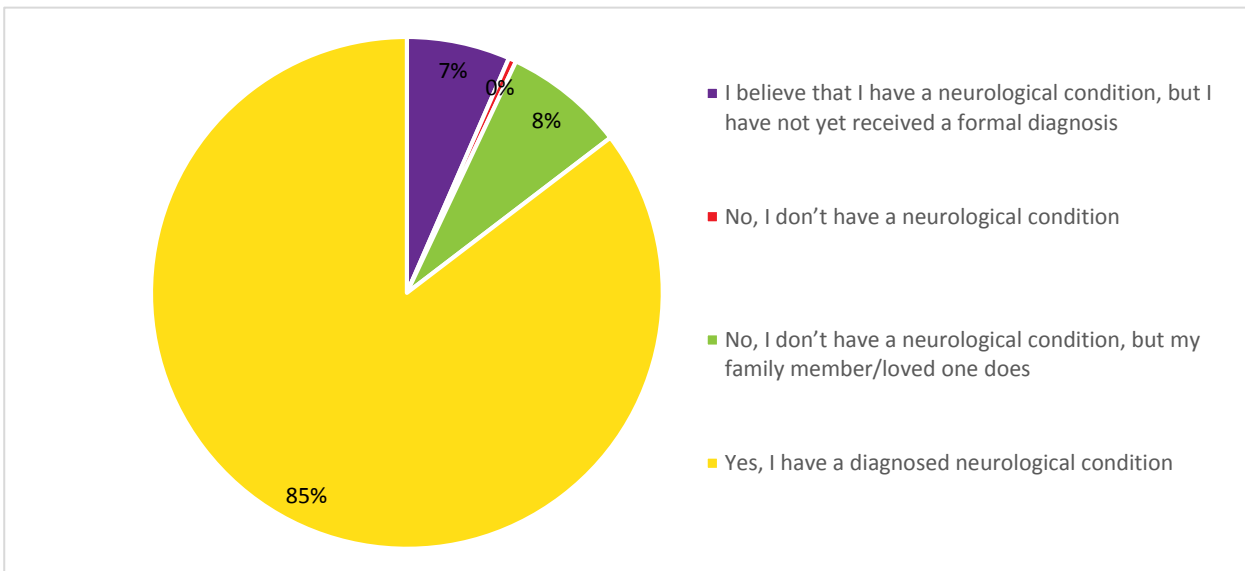
4.1.5 Q: How old are you? (N=827)



4.1.6 Q: Which is your ethnic group? (N=827)



4.1.7 Q: Do you have a neurological condition? (N=827)



**Presented as a pie chart due to responses equating to 100% and the limited number of categories.*

4.1.8 Q: If you have a neurological condition(s) which do you have? (N=827)*

	No.	%
Other condition / deficiency / syndrome, including:	211	26%
- Epilepsy		
- Parkinson's Disease		
- Post-Polio Syndrome		
- Alzheimer's Disease / dementia		
- Hydrocephalus		
- Ataxia / Cerebellar Syndrome		
- Tremors		
- Fibromyalgia		
- Cerebral Palsy (CP) / Progressive Supranuclear Palsy (PSP)		
- Chiari Malformations		
- Neuropathy		
- Sturge-Weber Syndrome		
- Motor Neurone Disease (MND)		
- Mental health condition		
- Complex Regional Pain Syndrome (CRPS)		
- Trigeminal Neuralgia		
Chronic Fatigue Syndrome (CFS) / Myalgia Encephalomyelitis (ME)	205	25%
Multiple diagnoses	148	18%
Autism and/or other learning difficulty	42	5%
Functional Neurological Disorder (FND)	38	5%
Dystonia	39	5%
Brain Injury / damage / trauma / tumour / surgery	36	4%
Multiple Sclerosis (MS)	30	4%
No answer / diagnosis unknown	29	4%
Cluster headaches / migraines / Chronic Paroxysmal Hemicrania	25	3%
Brain aneurysms / haemorrhage / stroke	24	3%
Total	827	100

**Respondents were asked to provide detail of their neurological condition in an open question. Responses were grouped into one of the above categories. Individuals who had more than one neurological condition were categorised as 'multiple diagnoses'.*

4.1 First steps to seeking a diagnosis

4.1.1 Overview

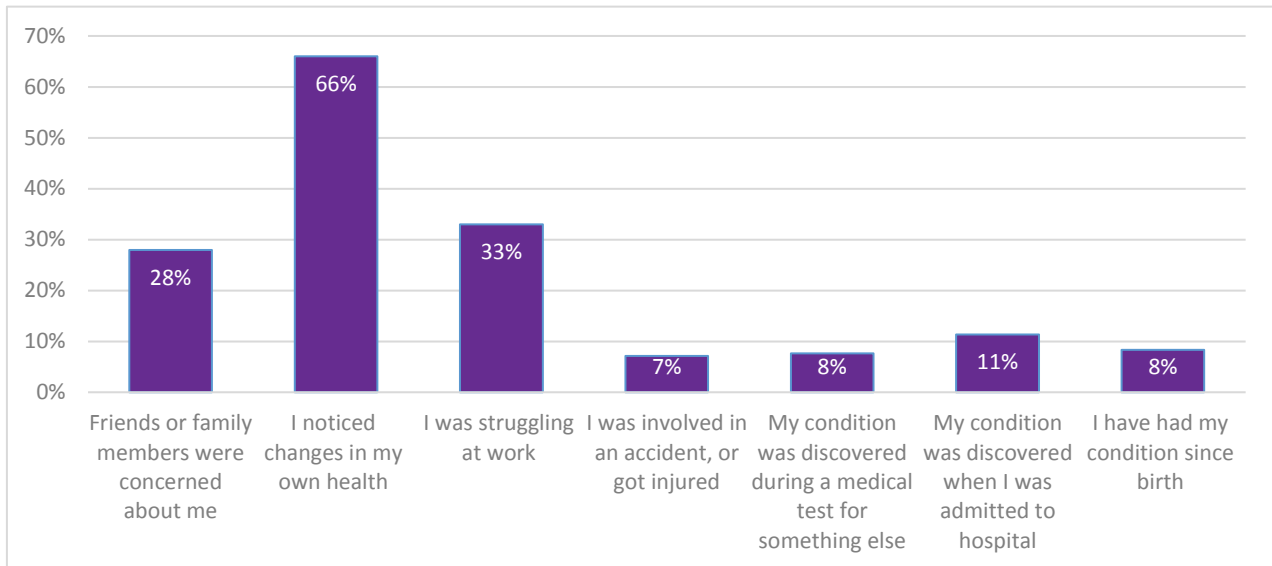
We asked respondents to think back to when they first had concerns about their health. Whilst 66% had noticed changes in their own health, 33% had been struggling at work, and 28% said that family or friends had raised concerns.

As a result, most (76%) decided to make an appointment with their GP, whilst 32% chose to discuss their concerns with family or friends. Furthermore, 24% looked on the internet to find out more information.

Despite an overwhelming proportion reporting that they made an appointment with their GP when they became concerned about their health, there was a noticeable and concerning cohort who delayed seeking help – fewer than 4 in 10 (38%) made an

appointment within a month of becoming concerned about their health, whilst nearly 3 in 10 (28%) waited 6 months or more before seeking help.

4.1.2 Q: Thinking back to when you first had concerns about your health, which of the following statements apply to you?* (N=827)



**Due to the multiple response nature of this question, percentages do not equate to 100%.*

Respondents were given the opportunity to elaborate on their choice to this question, 137 individuals provided a response. Key themes are shown below, with percentages calculated as a proportion of those who provided a response:

- Respondent was **diagnosed / became concerned after contracting a virus, being ill / unwell, or having a surgical procedure** (38%).
- Respondent **diagnosed at birth or during childhood, and/or struggled during childhood / school / college** (23%).
- Respondent commented upon the **length of time it took to receive their diagnosis, and/or being misdiagnosed** (15%).
- Respondent commented upon the **struggles they had with day-to-day life** including feeling weak / tired, and/or not being able to complete normal activities such as driving safely (11%).

Specific comments made by respondents include:

“I didn’t recover fully after having the flu as a teenager”

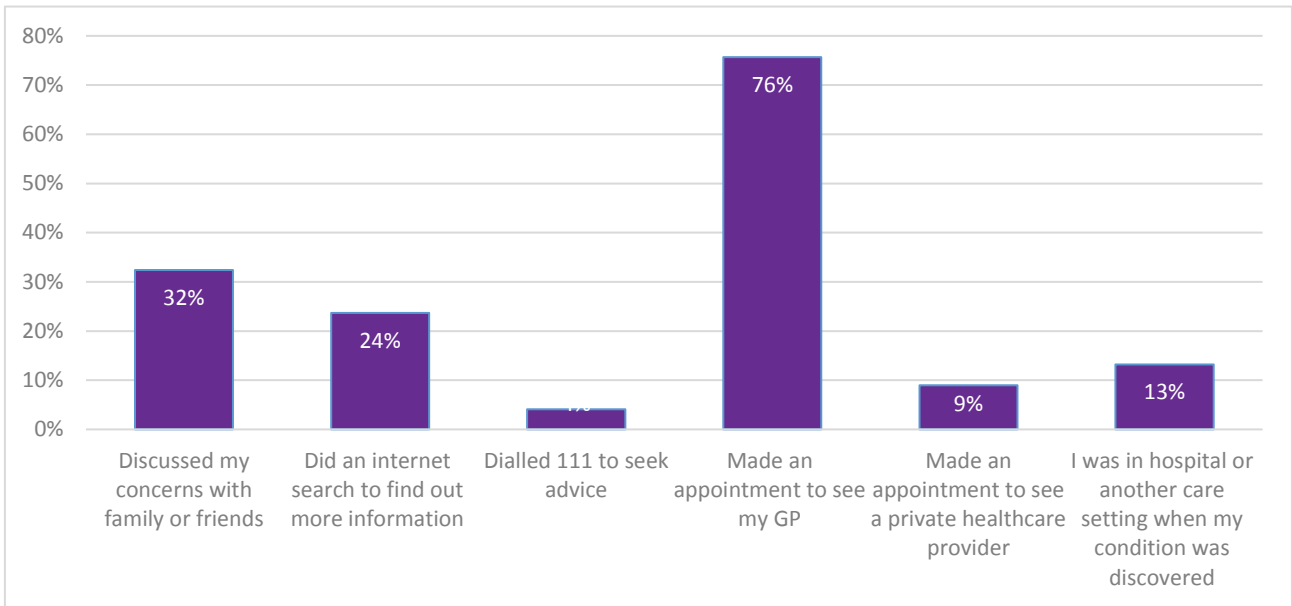
“Following a minor op for nasal repair, suddenly had trauma following operation leaving me with this condition”

“Always ill from 6 months after birth, starting with loose stools for over 18mths that was never figured out, followed by viruses year on year and finally diagnosed after 3 episodes of meningitis at age 14 to 16”

“Kept falling over and eventually diagnosed. Not a quick or easy diagnosis and a lot of time wasted”

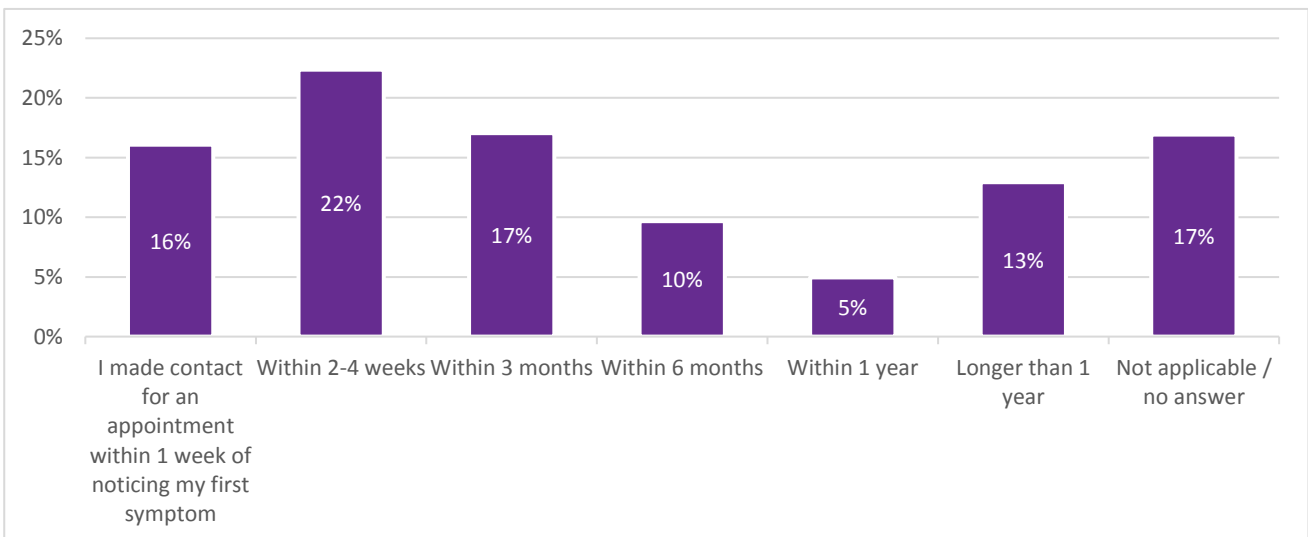
“I couldn’t concentrate anymore, couldn’t focus in work meetings, kept forgetting things, and couldn’t take on new ideas. My short term memory became hopeless. I became irritable and would cry easily”

4.1.3 Q: When you first became concerned about your health, what action(s) did you take? (N=827)



**Due to the multiple response nature of this question, percentages do not equate to 100%.*

4.1.4 Q: If you made a GP, or private healthcare provider appointment, how long was it from when the first symptom was noticed, to making the appointment? (N=827)



4.2 Seeking medical advice for the first time

4.2.1 Overview

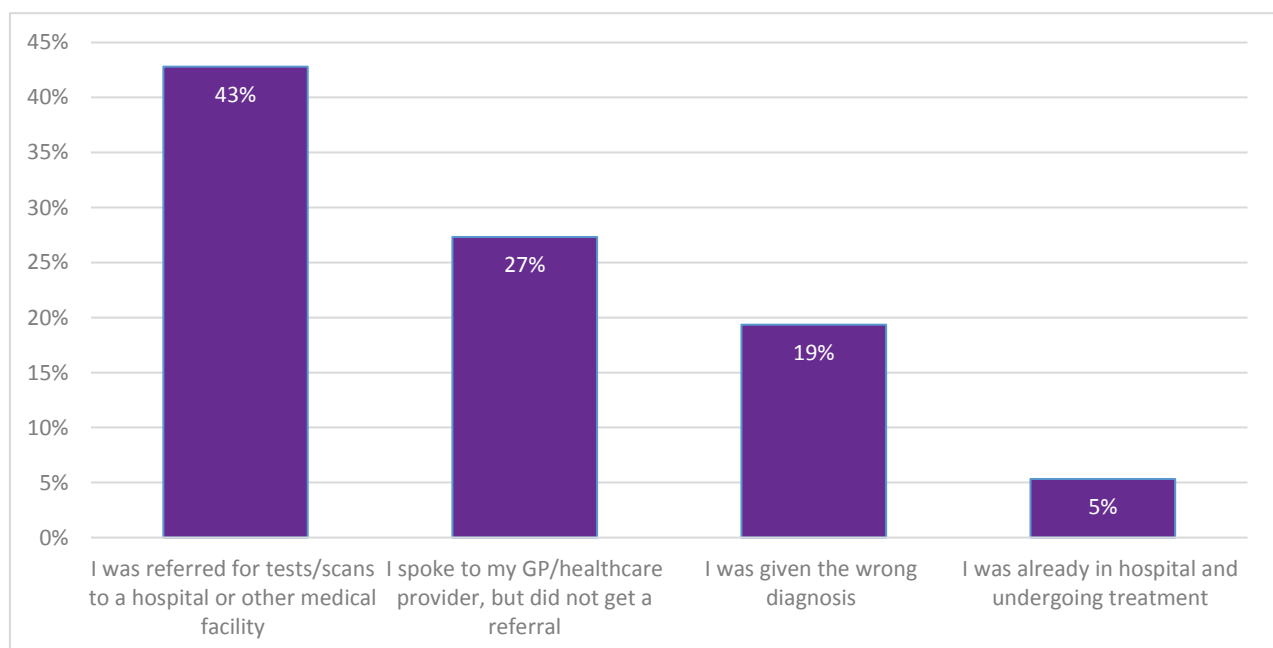
We asked respondents what the outcome was when they saw a GP / healthcare provider for the first time, to which most (43%) said that they were referred for tests / scans at hospital or another medical facility. In contrast, 1 in 4 (27%) were not referred, whilst 1 in 5 (19%) received an incorrect diagnosis.

Although 27% felt that they were taken seriously by the GP / healthcare provider, concerningly just under half (44%) perceived that they weren't and that their concerns / symptoms were dismissed.

Respondents most commonly left their first appointment with a GP / healthcare provider feeling not well informed about the next steps towards their diagnosis / treatment (48%) and unaware of where or who to go to if they had questions / concerns (39%). More than 4 in 10 (44%) had to do their own research to find charities and/or support groups.

The above findings undoubtedly contributed to the high feelings of concern / fear for the future (49%), depression and/or anxiety (38%) and loneliness / isolation (37%) felt among respondents at this stage of their journey.

4.2.2 Q: When you first saw your GP / healthcare provider, what was the outcome? (N=827)



**Due to the multiple response nature of this question, percentages do not equate to 100%.*

Respondents were given the opportunity to elaborate on their choice, 167 individuals provided a response. Key themes are shown below, with percentages calculated as a proportion of those who provided a response:

- Respondent felt the **GP / healthcare provider was not interested, dismissed their symptoms and/or gave an incorrect diagnosis (39%)**.
- Respondent was **referred for tests and/or to a specialist / specialist centre (28%)**
- Respondent commented upon the **length of time and difficulty they had in receiving a diagnosis**, or that they were still waiting for a diagnosis (10%).

Specific comments made by respondents include:

“I had blood tests and had to repeatedly go back. I heard comments about ME not existing”

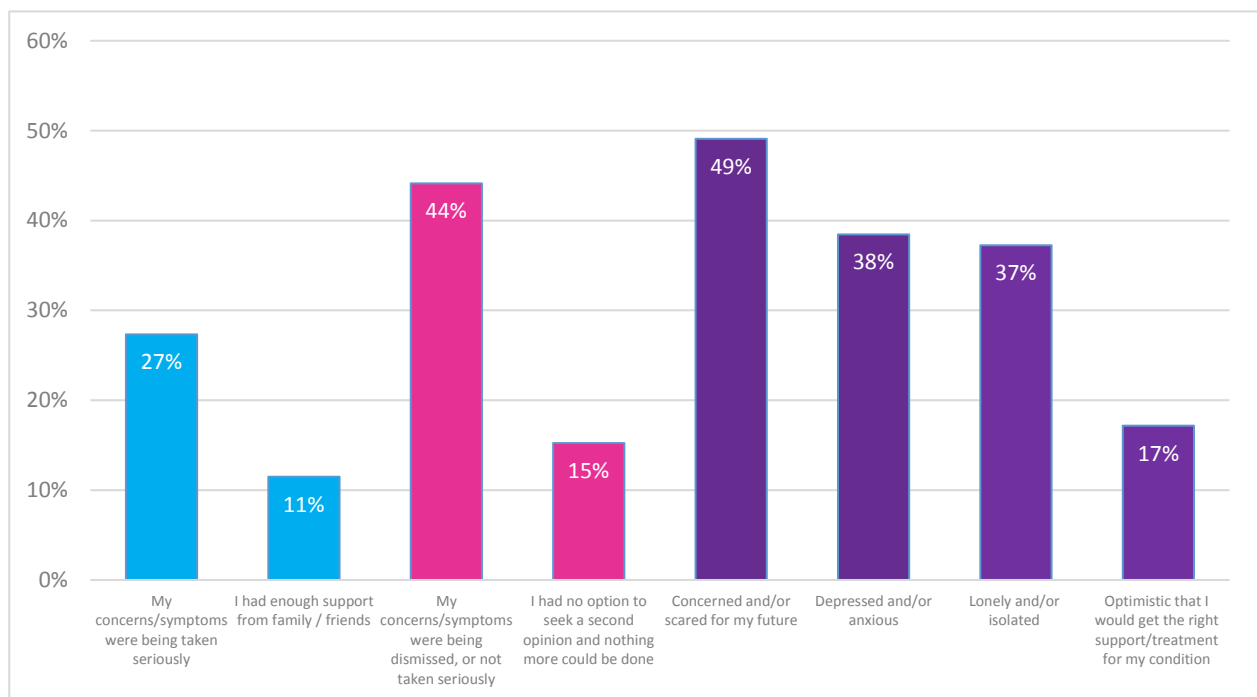
“I was initially diagnosed with exhaustion and prescribed a period of leave from work”

“I was not listened to and I was patronised”

“GP was uncertain about the diagnosis. Uncertainty persisted for nearly 2 years....”

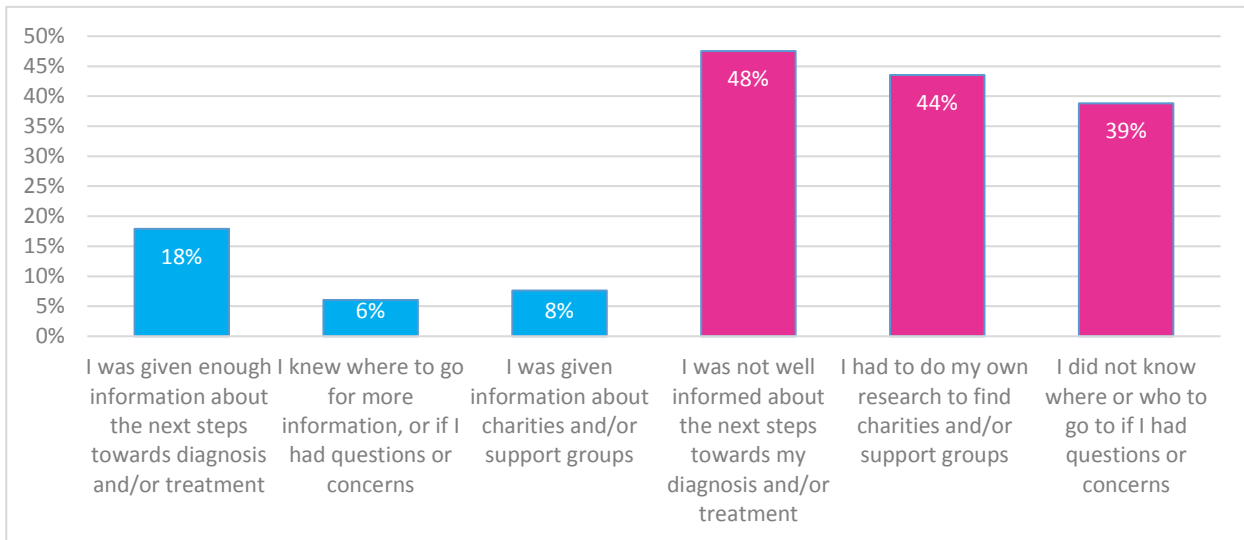
“Process was back and forth passed between different departments for years”

4.2.3 Q: After I first saw my GP / healthcare provider to discuss my condition, I felt... (N=827)



**Due to the multiple response nature of this question, percentages do not equate to 100%. Responses have been colour coded into positive statements (blue), negative statements (pink) and feelings (purple).*

4.2.4 Q: After you first saw your GP/healthcare provider to discuss your condition, how well informed did you feel? (N=827)



**Due to the multiple response nature of this question, percentages do not equate to 100%. Responses have been colour coded into positive (blue) and negative statements (pink).*

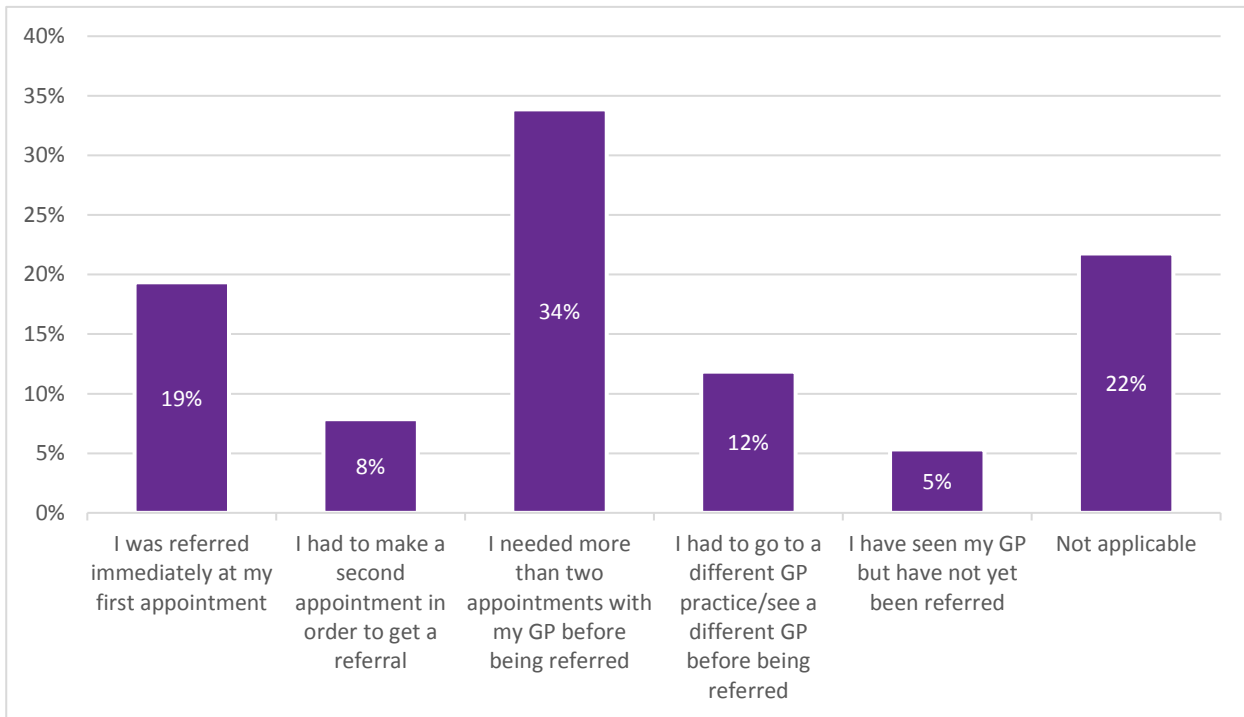
4.3 Referral to a specialist

4.3.1 Overview

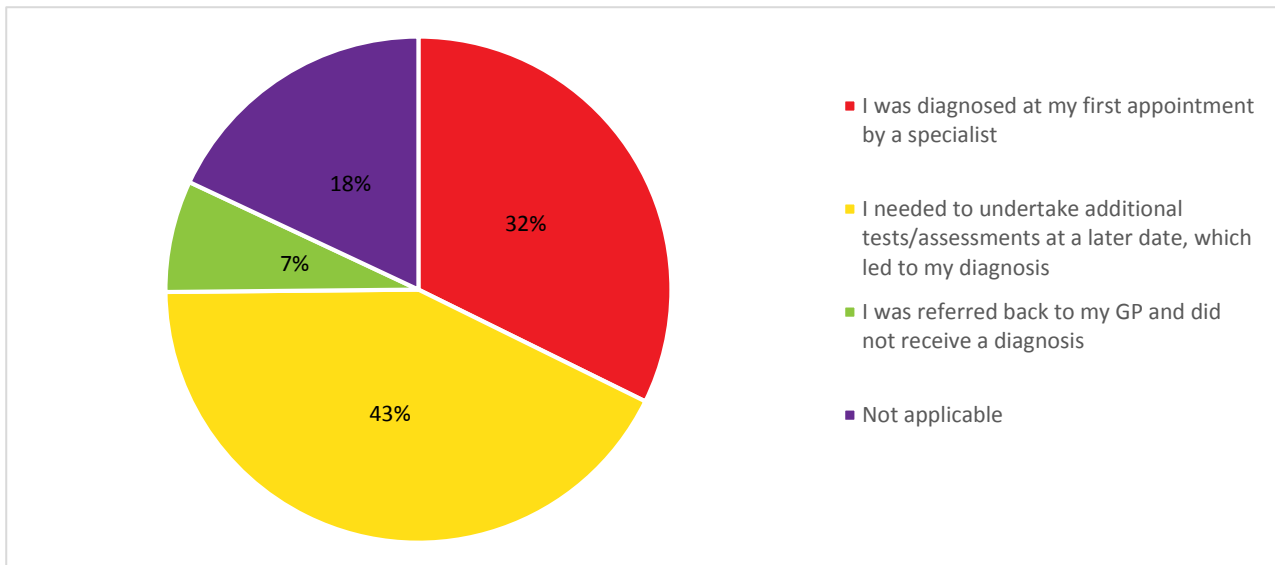
We asked respondents how long they had to wait to get a referral to a specialist, following their initial appointment with a GP. Whilst 1 in 4 (27%) were referred after their first or second appointment, 1 in 3 (34%) needed more than two appointments and 1 in 10 (12%) had to go to a different GP practice or see a different GP before being referred.

Once referred to a specialist, 32% were diagnosed at their first appointment, whilst 43% had to undertake additional tests / assessments at a later date, which led to their diagnosis.

4.3.2 Q: If your first step towards diagnosis was an appointment with a GP, how long did it take for you to be referred to a specialist? (N=827)



4.3.3 Q: Once you had been referred to a specialist, what was the outcome? (N=827)



**Presented as a pie chart due to responses equating to 100% and the limited number of categories.*

4.4 Receiving a diagnosis

4.4.1 Overview

We asked respondents how long it took them to get a diagnosis from their first contact with a GP / healthcare provider. Whilst 51% said it took less than a year, 18% indicated it took 2-3 years, 4% 4-5 years and 15% more than 5 years.

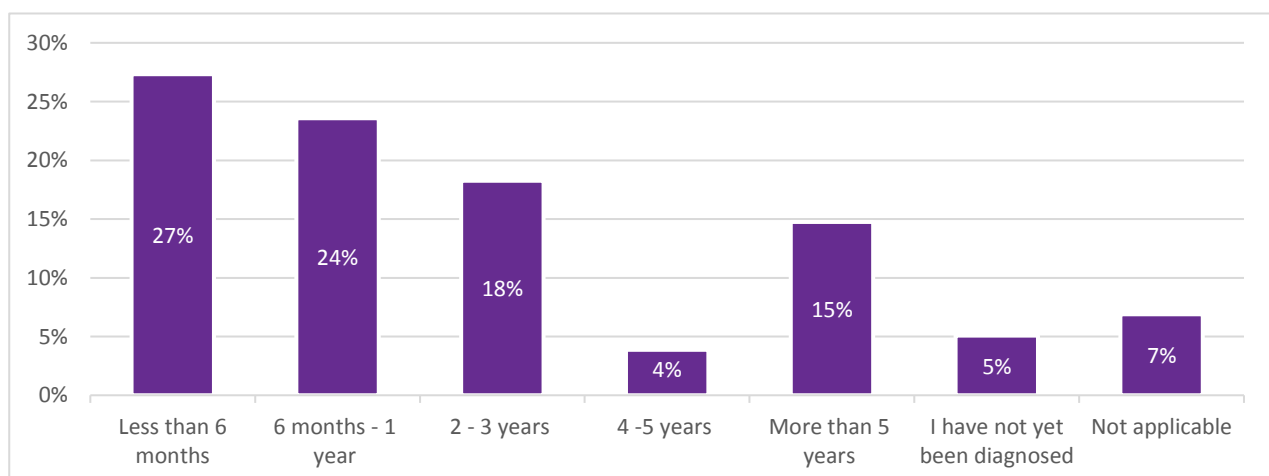
Although, 1 in 3 (31%) felt every appointment was a logical 'next step' towards their diagnosis, 37% felt that they could / should have been diagnosed quicker, or with fewer appointments, and 16% that they had far more appointments than should have been necessary.

Similarly to when they first sought medical advice about their concerns, respondents reported feeling not well informed about the next steps towards their diagnosis / treatment (41%) and unaware of where or who to go to if they had questions / concerns (32%) following their diagnosis. Furthermore, 1 in 2 (49%) reported having to do their own research to find charities and/or support groups.

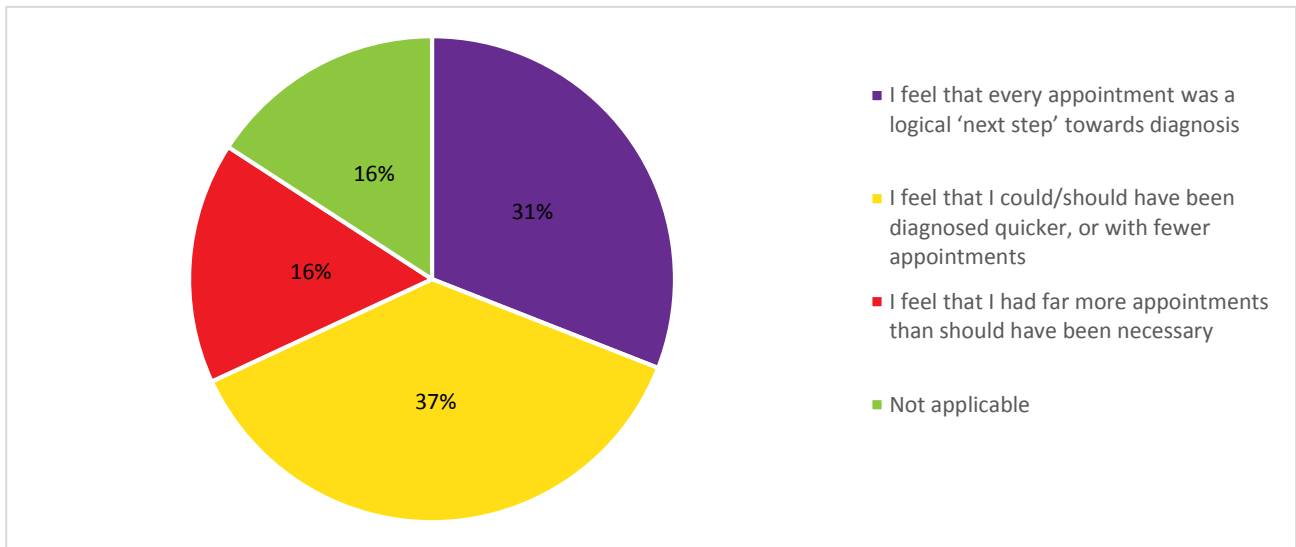
Feelings of concern / fear for the future (66%), depression / anxiety (44%) and loneliness / isolation (43%) were again commonly felt, but to a greater extent than when respondents initially sought medical advice.

Approximately two thirds (62%) agreed to some extent that there were unnecessary or unreasonable delays or problems in the process of getting a diagnosis. Exploring this further, 40% told us that they were delayed / had a long wait to see a specialist / have diagnostic tests and 39% that their symptoms were initially diagnosed as something else. Additionally, 39% said that their symptoms were not taken seriously by the GP and 31% that they were not taken seriously by the consultant / specialist.

4.4.2 Q: From your first contact with your GP / healthcare provider, how long did it take to get a diagnosis? (N=827)

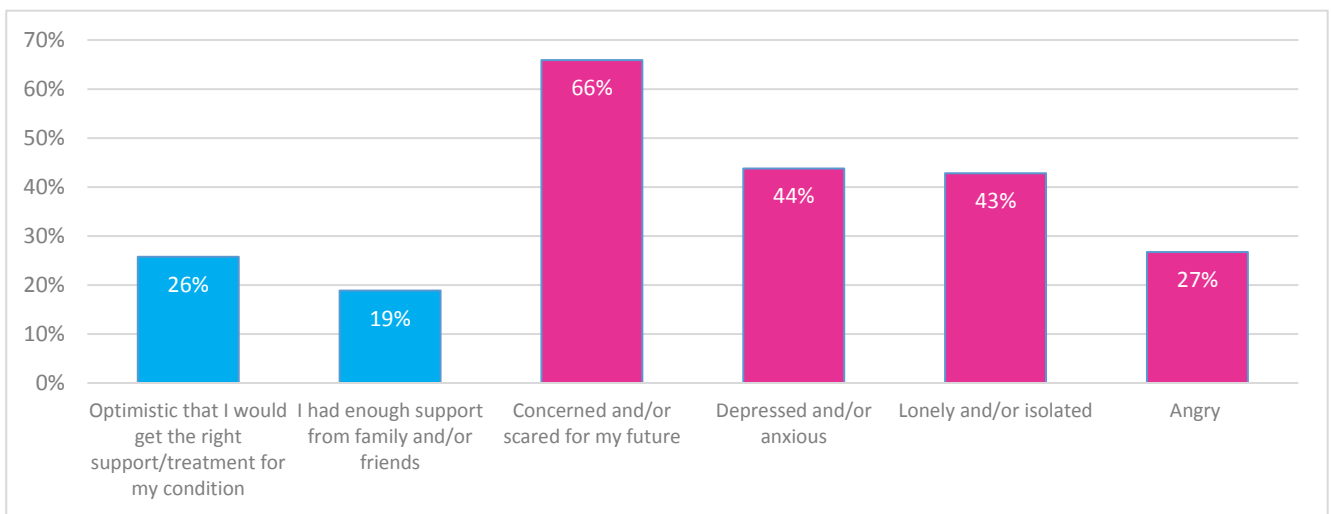


4.4.1 Q: Looking back at the appointments you attended, do you feel they were all relevant or appropriate (or not) for getting a diagnosis? (N=827)



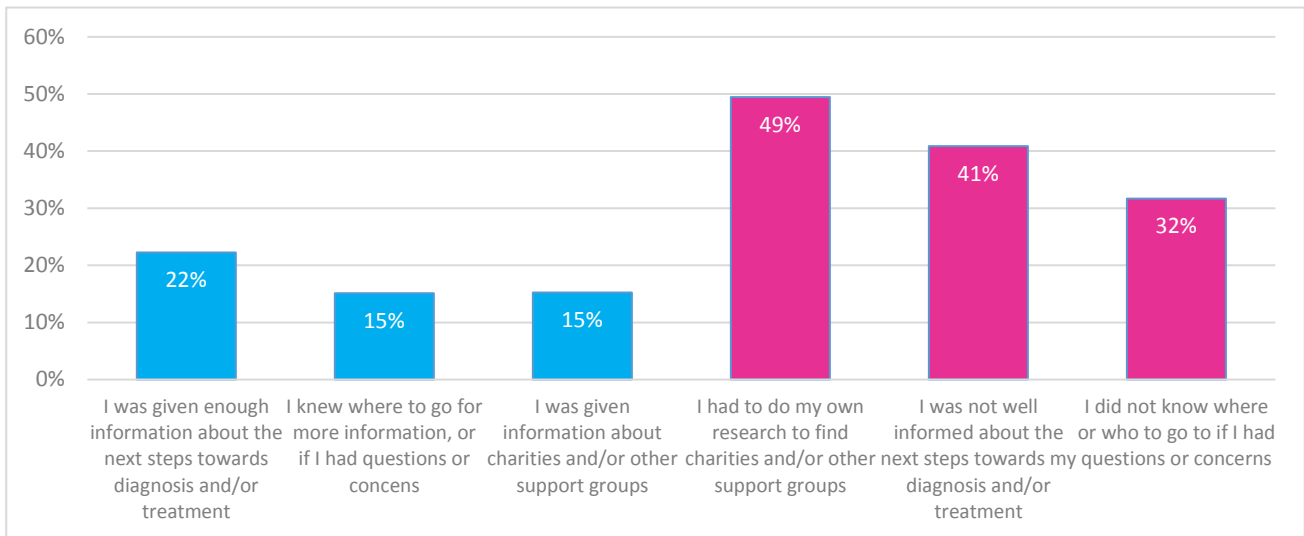
**Presented as a pie chart due to responses equating to 100% and the limited number of categories.*

4.4.2 Q: When I received my diagnosis, I felt... (N=827)



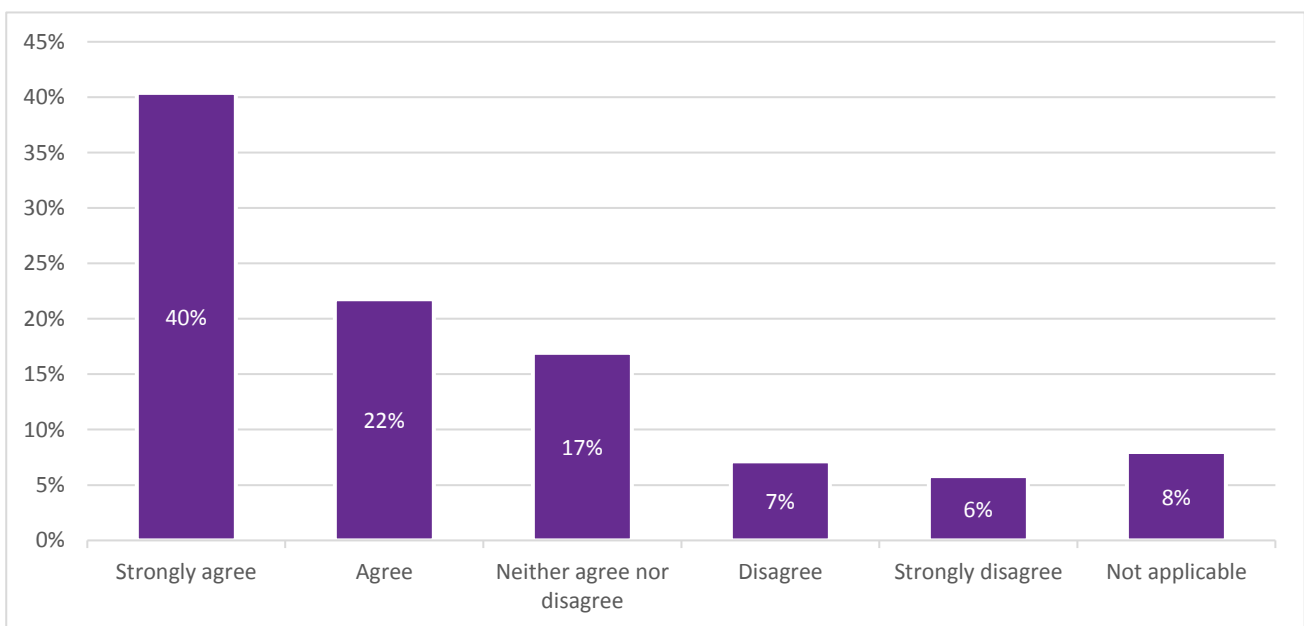
**Due to the multiple response nature of this question, percentages do not equate to 100%. Responses colour coded into positive (blue) and negative feelings (pink).*

4.4.3 Q: After you received your diagnosis, how well informed did you feel? (N=827)

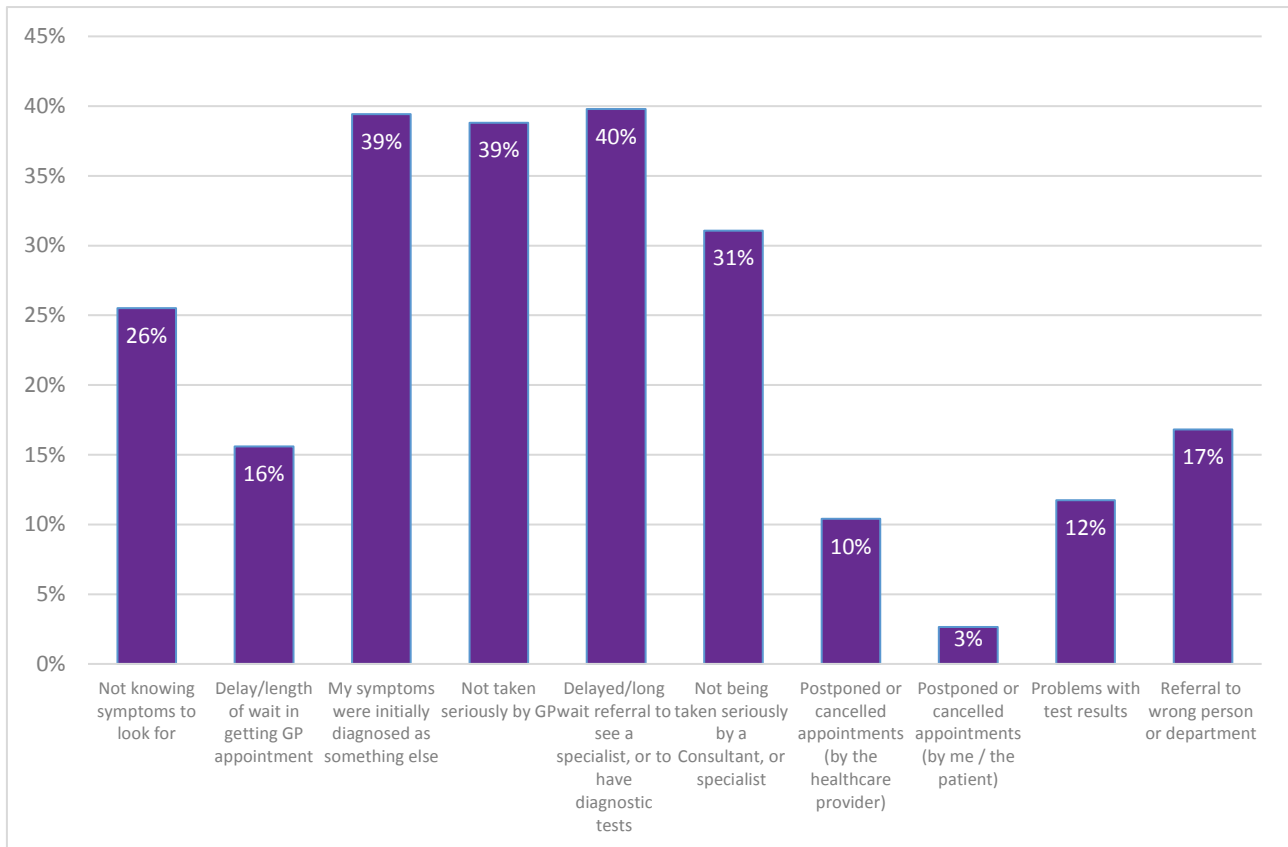


**Due to the multiple response nature of this question, percentages do not equate to 100%. Responses colour coded into positive (blue) and negative (pink) statements.*

4.4.1 Q: To what extent do you agree or disagree that there were unnecessary or unreasonable delays or problems in the process to getting a diagnosis? (N=827)



4.4.2 Q: Do you feel any of the following issues delayed or hindered you receiving your diagnosis? (N=827)



**Due to the multiple response nature of this question, percentages do not equate to 100%.*

Respondents were given the opportunity to elaborate on their choice to this question, 143 individuals provided a response. Key themes are shown below, with percentages calculated as a proportion of those who provided a response:

- Respondent commented upon the **lack of medical knowledge, treatment and support they received from healthcare providers and/or NHS services** (41%). This was particularly the case for:
 - Those that were diagnosed many years ago when medical knowledge / testing wasn't as advanced i.e., those diagnosed with Post-Polio Syndrome.
 - Neurological conditions that are particularly rare, and where the research is felt to '*not be available*'.
 - Chronic Fatigue Syndrome / Myalgia Encephalomyelitis, where respondents highlighted the lack of knowledge that healthcare professionals have about the condition, the lack of specialist / support services, as well as the stigma that exists.

For many, there was a feeling that once their diagnosis was received, they were '*left to get on with it*'.

- Respondent discussed how their **condition was misdiagnosed**, and how they were initially given medication or sent for different tests to rule out other conditions (17%). In some cases this was felt to be justified based on the symptoms being experienced.
- Respondent commented on the **incompetence of healthcare providers in terms of recognising and supporting them with their diagnosis** (13%). Many commented upon the volume of appointments they have been to, how they have had to seek advice from a different GP / healthcare provider or pursue private healthcare.

Specific comments made by respondents include:

“My original GP left and the next one I saw completely dismissed my symptoms and treated me with contempt. I had to wait eight months and a major relapse that left me with permanent problems before I was referred to a specialist”

“For two years I was told my son would grow out of his tics, that it was just a phase. I had to go private for a diagnosis because no one within the NHS were interested”

“GPs I saw were not well informed about ME. They did not recognise my post exertional malaise, which is a defining symptom of ME. I had never heard of PEM so did not spot it either”

“Ignorance, incompetence and laziness on many doctors part to do proper diagnosis and treatment”

4.5 The overall journey to diagnosis

4.5.1 Overview

Since being diagnosed with a neurological condition, more than 1 in 3 (35%) told us they have been diagnosed with depression or anxiety. This is on top of the 16% who already had a diagnosis of depression or anxiety. Furthermore, 11% felt that the length of time it took for them to be diagnosed has made their depression or anxiety worse.

During their journey to diagnosis, respondents most frequently felt worried (64%), frustrated (62%), scared (50%), lonely (48%), and ignored (43%). Notably, significantly smaller proportions felt understanding of the challenges medical teams face diagnosing patients (18%), respected and listened to (15%) and supported (9%).

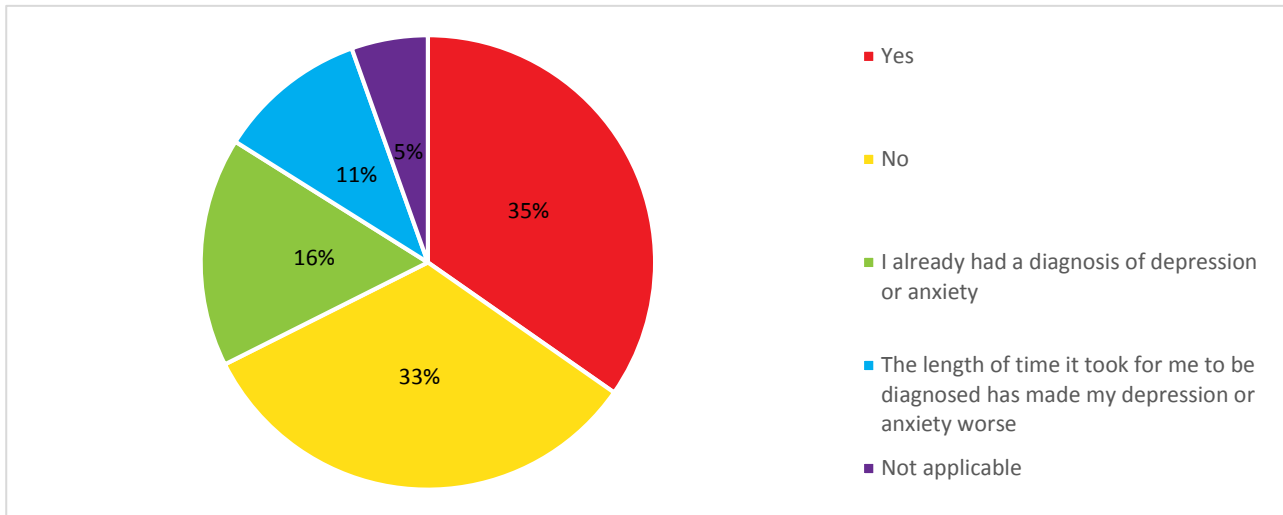
Whilst only small proportions, elements of the journey that respondents were most likely to rate as very good or good included:

- Knowledge of the specialist / consultant (35% rating as very good or good)
- Getting a GP appointment / appointment with a private healthcare provider (23% rating as very good or good).

In contrast, aspects that respondents felt were particularly poor included:

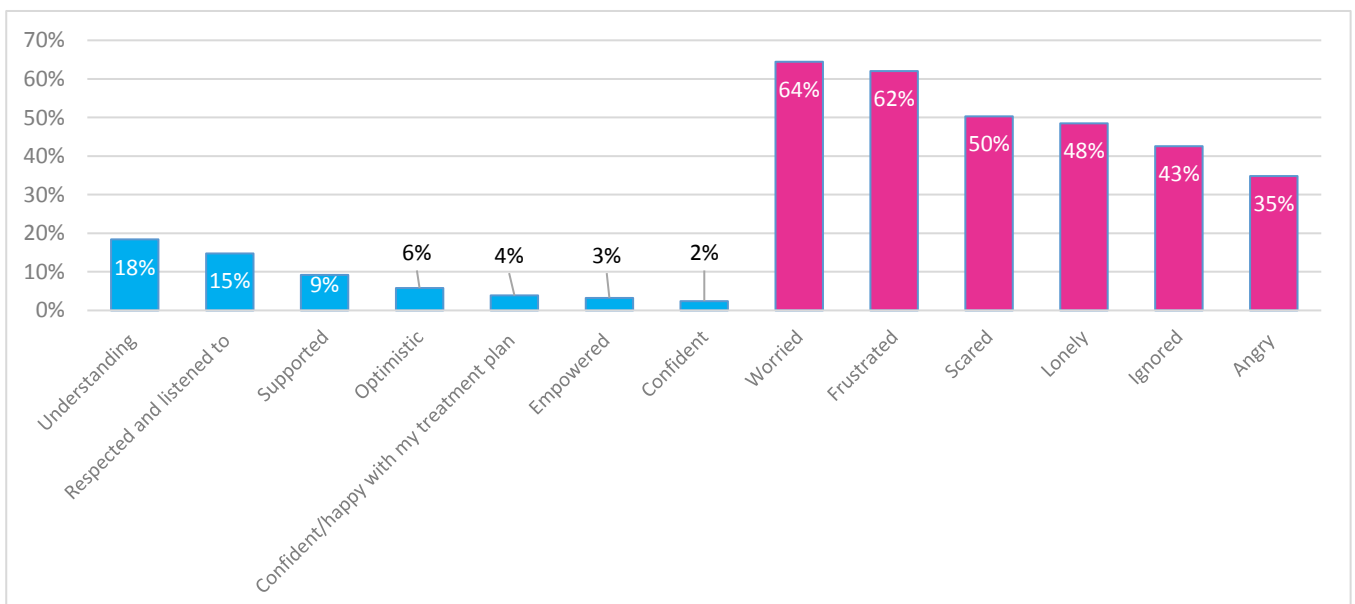
- Knowledge of GP / private healthcare provider (52% rating as very poor or poor)
- The support received following their diagnosis (51% rating as very poor or poor)
- The waiting time to see a specialist (49% rating as very poor or poor)
- The information / advice received after seeing a GP (48% rating as very poor or poor).

4.5.1 Q: Have you been diagnosed with depression or anxiety since seeking a diagnosis for a neurological condition? (N=827)



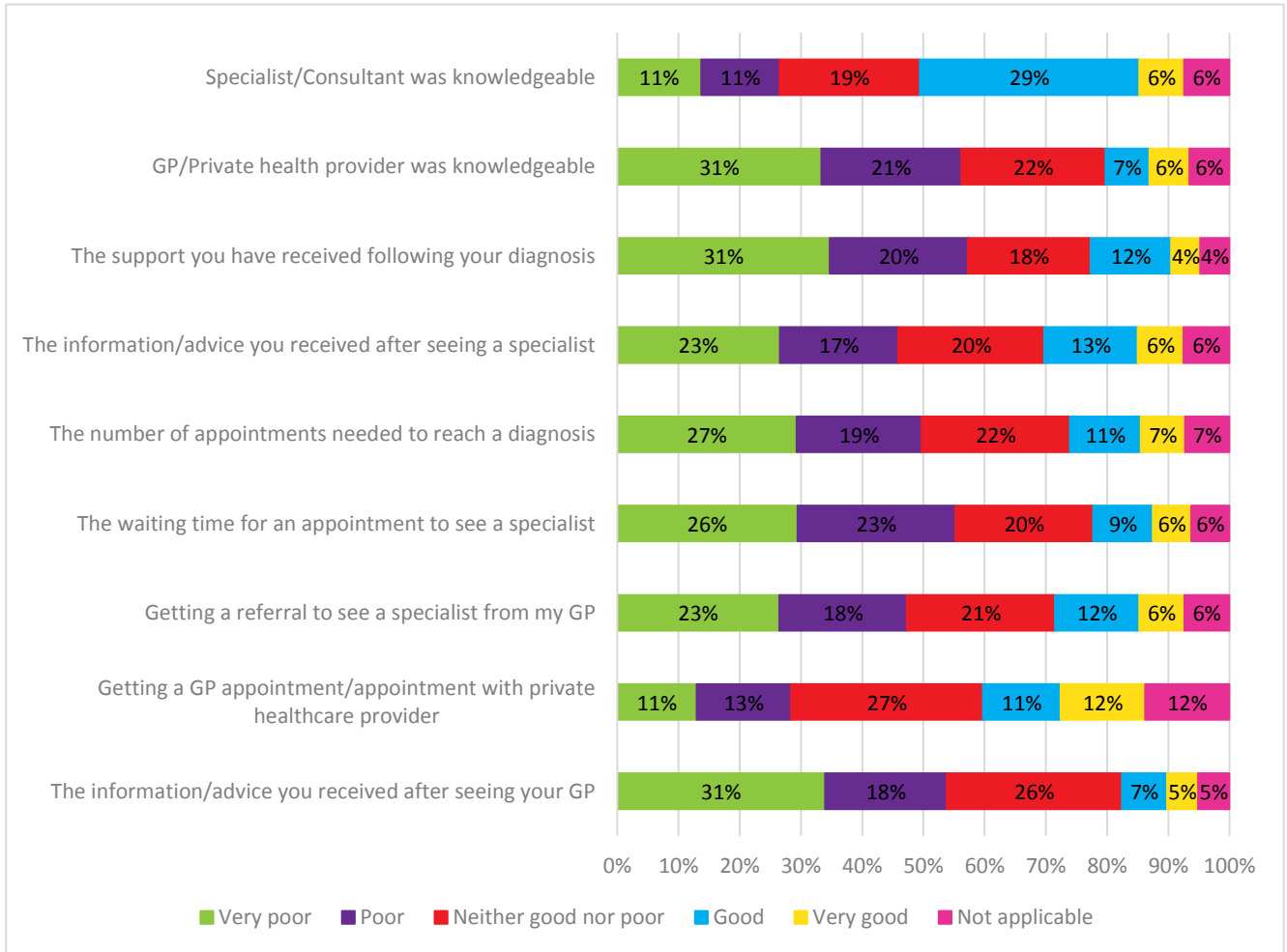
**Presented as a pie chart due to responses equating to 100% and the limited number of categories.*

4.5.2 Q: Which of the following sums up how you felt through your journey to diagnosis? (N=827)



**Due to the multiple response nature of this question, percentages do not equate to 100%. Responses are colour coded into positive (blue) and negative (pink) feelings.*

4.5.3 Q: How would you rate each part of the journey to your diagnosis? (N=827)



5 Discussion of findings

The findings provide a valuable insight into the challenges that individuals face when seeking and receiving a diagnosis of a neurological condition.

When experiencing changes in their own health or facing struggles in work or with normal daily activities, the response from most is to make an appointment with their GP / healthcare provider (76%). Smaller proportions will discuss their concerns with family or friends (32%) or look for information on the internet (24%).

Concerningly, this action is not always immediate, with fewer than 4 in 10 respondents (38%) making an appointment within a month of becoming concerned about their health, whilst nearly 3 in 10 (28%) waited 6 months or more.

The outcome from these initial appointments is variable – 43% were referred for tests / scans at hospital or another medical facility, whilst 27% were not referred and 19% were misdiagnosed.

Of greater concern are the findings that 52% rated the knowledge of the GP / healthcare provider as very poor or poor – this aspect of the overall journey to diagnosis being the most poorly rated of all, and further how 44% did not feel that their concerns / symptoms were taken seriously.

Respondents reported most commonly leaving their first appointment with a GP / healthcare provider feeling not well informed about the next steps towards their diagnosis / treatment (48%) and unaware of where or who to go to if they had questions / concerns (39%). This lack of support and information evidently leading to high feelings of concern / fear for the future (49%), depression and/or anxiety (38%) and loneliness / isolation (37%).

For 1 in 3 (37%) it took two or more years from their initial appointment to receive a diagnosis of a neurological condition. This finding as well as others show that for many, the journey to receiving a diagnosis is not straightforward and one that takes a significant amount of time and perseverance.

- 1 in 3 (34%) needed more than two appointments with their GP / healthcare provider before being referred to a specialist, with an additional 12% having to go to a different GP practice or see a different GP before being referred.
- Once referred to a specialist, more than 4 in 10 (43%) had to undertake additional tests / assessments at a later date, which led to their diagnosis.
- 1 in 2 (53%) felt that they could / should have been diagnosed quicker, or with fewer appointments, or that they had far more appointments than should have been necessary.

- 2 in 3 (62%) agreed that there were unnecessary or unreasonable delays or problems in the process of getting a diagnosis.

Delays or waiting times to see a specialist / have diagnostic tests (40%), misdiagnosis (39%) and symptoms not being taken seriously by the GP (39%) or the Consultant / specialist (31%) were most frequently put forth as reasons to respondents' delayed diagnosis.

The second most poorly rated aspect of the journey to diagnosis was the support received following a diagnosis, with 51% rating this as very poor or poor. Similarly to when they sought medical advice for their first time, respondents reported feeling not well informed about the next steps towards their diagnosis / treatment (41%) and unaware of where or who to go to if they had questions / concerns (32%) following their diagnosis. 49% reported having to do their own research to find charities and/or support groups.

The impact of a diagnosis on the mental health of an individual was evident with respondents again commonly reporting that they felt concerned / scared for their future (66%), depressed / anxious (44%) and lonely / isolated (43%) once a diagnosis was received. Furthermore, 35% told us that since being diagnosed with a neurological condition, they have also been diagnosed with depression or anxiety. This is on top of the 16% who already had this.

Taken together the findings illustrate the lack of information and support that is available to individuals throughout their journey to diagnosis, as well as the length of time, and the impact the process and the diagnosis has on an individuals' mental health.