



Is there a gender gap in experiences of, and access to, neurological services in England?

Using the National Neurological patient experience survey, the Neurological Analysis undertook a short analysis of the difference in reported experience of and access to services between female and male respondents. We found key differences in reported experience and access to key services. We know there is unwarranted variability in access to treatment and care, and we would suggest that some of this unwarranted variation could be linked to gender.

We need to work together as a community to understand in more detail the different experiences and needs of women and men, and indeed other groups, in accessing neurological care. We, at the Neurological Alliance, are here to work with the neurological community to undertake this work. We strongly feel that a more detailed and nuanced understanding of possible differences in access and experience of care will allow us to achieve our collective mission of high quality, responsive treatment, care and support for all.

Background

The National Neurological patient experience survey¹ clearly showed variability in access to treatment, care and support across England. Using the same dataset, we have now looked at the variability in reported experience between men and women with neurological conditions when accessing treatment, care and support. Our hypothesis was that there were gender differences in reported access to and experience of treatment, care and support.

Previous evidence has reported differences in access and unmet need between men and women in relation to healthcare. In one study, women with a disability in the UK were found to be more than seven times more likely to have unmet needs due to cost of care or treatment, compared with men with no disability.² A pooled analysis of data from five major stroke trials showed that women are

¹ McIntosh, K, Vibert, S 2018/19 National Neurology Patient Experience Survey https://www.neural.org.uk/resource_library/neuro-patience/ Accessed on 5 March 2020

² Sakellariou D, Rotarou ES Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional dataBMJ Open 2017;7:e016614. doi: 10.1136/bmjopen-2017-016614

more likely than men to survive ischemic stroke, but the women who live have greater disability and poorer health-related quality of life than their male counterparts.³

The 2020 Marmot review recently showed that inequalities in life expectancy have increased since 2010, especially for women. The review also found that life expectancy had declined for women in the more deprived areas of the country.⁴

We found differences in the reported experiences of men and women who responded to our survey. To our knowledge, there is no reasonable explanation why women and men with neurological conditions may experience differences in accessing treatment, care and support. We acknowledge that we haven't done statistical analysis here, so our conclusions are tentative but nevertheless suggestive of worrying differences.

The intention behind this work is to stimulate a conversation within the neurological community as to whether we sufficiently understand or indeed are addressing gender differences in access and experience treatment, care and support. Our mission is to ensure every person with a neurological condition - no matter their gender or any other protected characteristic - get the right treatment, care and support for them. According to our analysis, there is clearly some way to go to make that mission a reality, particularly, perhaps, for women living with a neurological condition.

Key findings

- Men were more likely than women to report that they were given the hospital's own written information (27% of women compared to 17% of men) when first told about their condition.
- A higher proportion of women reported waiting more than 12 months to see a neurologist (32% of women compared to 20% of men).
- A higher proportion of women reported to have seen their GP five or more times before being referred (43% of women compared to 27%). Conversely, a higher proportion of men

³ Carcel C, Wang X, Sandset E C, Delcourt C, Arima H, Lindley R, Hackett M L, Lavados P, Robinson T G, Muñoz Venturelli P, Olavarría V, Brunser A, Berge E, Chalmers J, Woodward M, Anderson C S Neurology Dec 2019, 93 (24) e2170-e2180; DOI: 10.1212/WNL.00000000000008615

⁴ Marmot M, Allen J, Boyce T, Goldblatt P, Morrison J 2020 Health Equity in England: The Marmot Review 10 Years On, <http://www.instituteofhealthequity.org/the-marmot-review-10-years-on> Accessed 25 Feb 2020

reported having seen their GP once or twice before being referred to a neurologist (36% of women to 53% of men).

- A lower proportion of women reported feeling supported by their employer through diagnosis and treatment (47% of women compared to 56% of men). A higher proportion of women reported feeling discriminated against by their employer (36% of women to 27% of men)
- Female respondents were more likely to report delays or problems in accessing services for healthcare (60% of women compared to 42% of men).

About the National Neurological Patient Experience Survey

The [National Neurological patient experience survey](#) is the only pan-neurological survey exploring the views of people across the spectrum of neurological conditions in England. Data collection took place in selected neurology clinics and online (primarily via our membership) from July 2018 to March 2019, with over 10,000 responses received.

A breakdown of respondents by primary neurological condition is available in figure 1. 6631 of respondents identified as female, 3106 as male. The percentage of respondents who identified as male, female, prefer not to say or did not provide this data (unavailable) is listed by primary condition in figure 2.

Given the higher proportion of female respondents, there is a risk of possible bias to this data, although the incidence and prevalence of some neurological conditions is indeed higher amongst women than men. In addition, we noted a much higher proportion of women responding online compared to men (72% of women responded online compared to 27% of men).

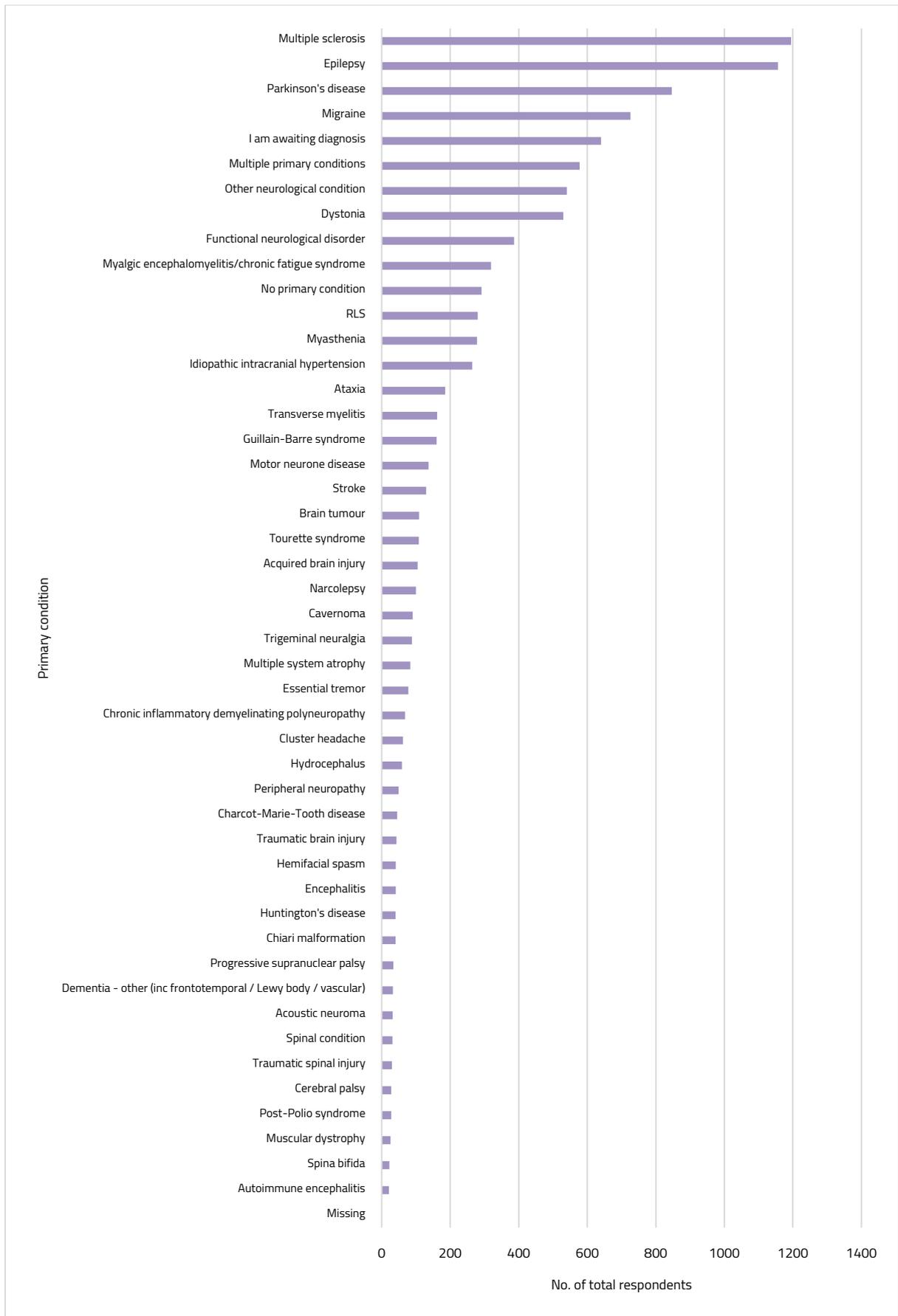


Figure 1: No. of respondents by primary condition

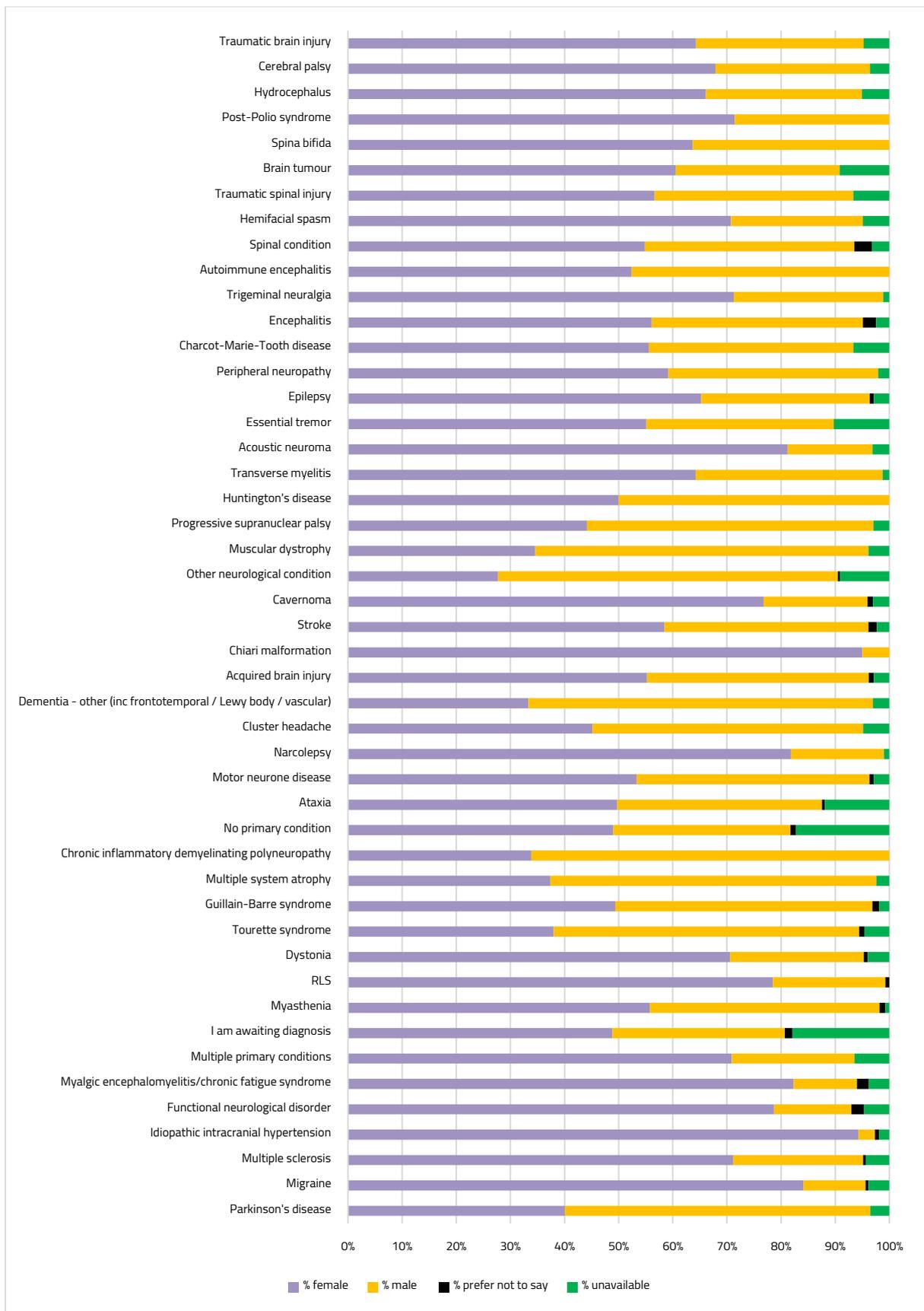


Figure 2: Proportion of men and women respondents by condition

In our original Neuro Patience: still waiting for improvements in treatment and care report, published July 2019, we considered three important principles of care, namely that it is accessible, personalised and holistic. Here we consider those principles again, with a specific focus on differences in reported experience between men and women, with the aim of starting a conversation about the possible reasoning for this.

- **Accessible**

Our analysis pointed to worrying differences in the accessibility of care between men and women.

We know that referral to a neurologist often takes time, and we also know there is a real shortage of neurologists in the UK. For some people with suspected neurological conditions referral to a neurologist for diagnosis may not be needed or desirable.

The Association of British Neurologists (ABN) research recently found that for neurology consultants involved in patient care, the number of full-time equivalents (FTEs) is 1.1 per 100,000 (1 per 91,175 population). This is far fewer than expected for similar high-income European countries such as France and Germany, which both have over 1 FTE consultant neurologist per 25,000 population.⁵

Coupled with this, the relatively low prevalence and incidence of many neurological conditions can mean that GPs may not be immediately aware of a possible neurological condition. This is particularly true for those neurological conditions where initial symptoms may be seemingly disparate and unconnected. Our survey also showed that people with rare neurological conditions often experience longer waits before seeing a neurologist compared to those with non-rare conditions. Furthermore, people living in the most deprived areas experienced the longest waits, as compared to those living in less deprived areas.⁶

To our knowledge, however, there is no medical or biological reason why men suspected to have a neurological condition should be referred more quickly or experience shorter waits prior to seeing

⁵ Nitkunan A, Lawrence J, Reilly M M, Neurology Workforce Survey conducted by the Association of British Neurologists 2018-2019 https://cdn.ymaws.com/www.theabn.org/resource/collection/219B4A48-4D25-4726-97AA-0EB6090769BE/2020_ABN_Neurology_Workforce_Survey_2018-19_28_Jan_2020.pdf Accessed 5 March 2020

⁶ McIntosh, K, Vibert, S 2018/19 National Neurology Patient Experience Survey https://www.neural.org.uk/resource_library/neuro-patience/ Accessed on 5 March 2020

a neurologist. Despite this, our evidence shows that female respondents were more likely than male respondents to report visiting their GP five or more times before being referred to a neurologist (43% of women compared to 27% of men). Conversely, a higher proportion of men reported having seen their GP once or twice before being referred to a neurologist (36% of women to 53% of men).

In addition, a higher proportion of female respondents compared to male respondents reported waiting a year or more to see a neurologist after referral (32% of women compared to 20% of men).

Female respondents were also less likely to have seen a specialist nurse despite needing to do so (41% of women compared to 29% of men). As is shown in Figure 2, female respondents were less likely than men to report being offered multiple treatments and therapies, including physiotherapy, speech and language therapy and occupational therapy.

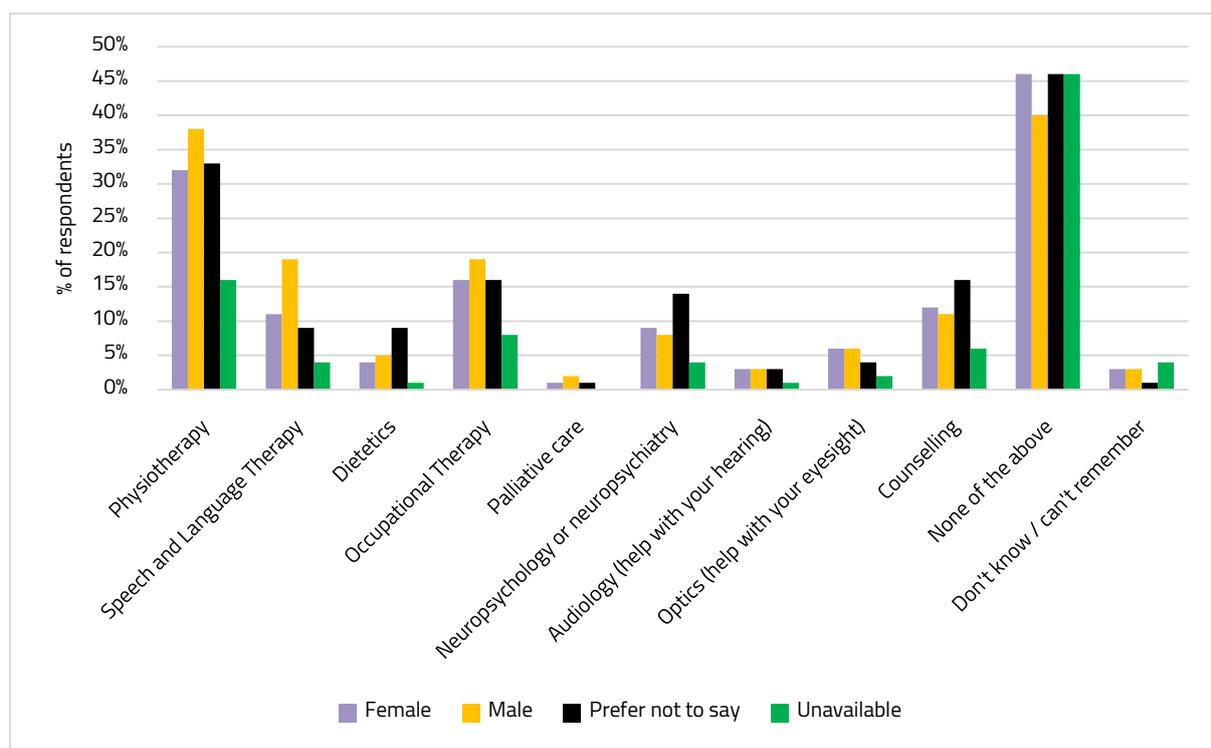


Figure 3: Treatments and therapies offered by identified gender

Waiting for a diagnosis can be exhausting, frightening and anxiety-inducing. For some neurological conditions, swift referral and initiation of treatment improves health outcomes. Timely treatment, care and support from a multi-disciplinary team can support people to maintain their independence, as well as reduce pain and discomfort. Ensuring good, effective referral pathways, supported by efficient use of valuable specialist expertise, needs to be commonplace. Our analysis would also

suggest services and system leaders ought to particularly consider the unique needs and experiences of women during service redesign.

- **Personalised**

The hallmarks of personalised care, such as the right information and support, excellent care planning and good care coordination across a multi-disciplinary team make all the difference to someone's experience of care. Our analysis, however, would seemingly point to variability in the personalisation of care for women with neurological conditions compared to men, with women less likely to report feeling in control of their care.

Male respondents were more likely than female respondents to report that they were given the hospital's own written information (27% of women compared to 17% of men) when first told about their condition. 47% of women compared to 35% of men reported not being offered written information at diagnosis. Multiple National Institute for Health and Care Excellence (NICE) treatment and care guidelines for neurological conditions highlight the need to provide written information at diagnosis – every person with a neurological condition, regardless of their gender, ought to be provided with this information.

We previously reported that just 10% of all survey respondents had been offered a care plan to help manage their condition. 29% of women respondents told us they didn't have a care plan but would like one, compared to 22% of men. We hear from some healthcare professionals that care plans are often in place but are not recognised as such by people with neurological conditions. Whilst this may be true, all parties involved in a good, co-produced care plan, including people with neurological conditions, absolutely should recognise it as such. There seems therefore to be room for improvement for almost every person living with a neurological condition. The National Neurological Advisory Group (NNAG) intends to look at this issue in more detail.

Around half (49%) of female respondents agreed that information about their specialist treatment and their condition is effectively passed on to the people that care for them (such as their GP, nurse, or family carer), while 59% of male respondents agreed with this statement. Similarly, 31% of female respondents disagreed with this statement compared to 21% of male respondents.

Men and women also reported different levels of satisfaction with their care – 47% of female respondents agreed that they are satisfied with the care they receive compared to 59% of male respondents. 31% of female respondents disagreed with this statement compared to 21% of men.

Finally, female respondents were less likely to agree that they were being seen often enough for their needs compared to male respondents. Conversely, a higher proportion of female respondents disagreed that they were being seen often enough for their needs compared to men, as shown in Table 2.

Table 1: To what extent do respondents feel they are being seen often enough for their needs (by identified gender)

| I am seen often enough for my needs. | Female | | Male | | Prefer not to say | | Unavailable | |
|--------------------------------------|--------|-----|------|-----|-------------------|-----|-------------|-----|
| | | | | | | | | |
| Agree | 2833 | 46% | 1614 | 57% | 23 | 38% | 162 | 45% |
| Neither agree nor disagree | 1044 | 17% | 504 | 18% | 7 | 11% | 60 | 17% |
| Disagree | 2257 | 37% | 723 | 25% | 31 | 51% | 139 | 39% |
| Not applicable | 311 | 5% | 123 | 4% | 5 | 8% | 21 | 5% |

- **Holistic**

We originally found that having a neurological condition impacts overall quality of life – of the respondents who rated the impact of their condition on their quality of life, almost half (46%) said it impacted them to a great extent, and a further third (35%) said it impacted them to a moderate extent.

Having a neurological condition may impact every part of your life, your relationships, mental and emotional wellbeing, physical wellbeing and financial wellbeing. Getting the right treatment, care and support to help manage all these aspects of life, to live life as independently as possible, is paramount.

Again, additional analysis highlighted differences between men and women respondents. 40% of respondents said that their mental wellbeing needs weren't being met at all. A higher proportion of female respondents reported this (41%) compared to men (37%), although these are worrying findings all round. The Neurological Alliance, together with NNAG and the sector more broadly, are committed to improving mental health support, be this through improved screening, bespoke training for healthcare professionals on the unique needs of people with neurological conditions or

ensuring appropriate signposting. Our Mental Health consensus statements⁷ outlines further detail of what we, together with our membership, feel ought to change.

We found no significant differences between male and female respondents in the extent to which they felt their condition affected their quality of life or day to day activities. Worryingly however, a higher proportion of female respondents reported their condition causing pain and discomfort to a great extent (35%) compared to male respondents (24%).

A higher proportion of female respondents reported being in employment compared to male respondents (38% to 27%). However, a lower proportion of female respondents (26%) agreed that they had been able to work as normal since their diagnosis compared to men (32%). Women respondents were less likely to agree that their employer has supported them through their diagnosis and treatment (47%) compared to men (56%). Similarly, female respondents were more likely to disagree that their employer had supported them compared to male respondents.

We also looked at the extent to which financial needs were being met. Female respondents were less likely to report their financial needs being met (56% to 61%). Overall however, 4 in ten respondents reported that their financial needs were not being met. Given that we know a neurological condition can cost up to £200 in extra costs per week⁸, it's vital that support is available to manage these extra costs, for both those living with a neurological condition and those closest to them.

Finally, female respondents were also more likely than men to report being discriminated against due to their neurological condition in relation to their employment (36% vs 27%).

- **Final thoughts**

To our knowledge, this is the first analysis of its kind in relation to people with neurological conditions. We therefore hope this is the start of a much-needed conversation about how people of different genders, race, sexual identity, religious backgrounds and cultures may experience neurological care differently.

⁷ Neurological Alliance 2019, Consensus statement on mental, emotional and cognitive health provision

https://www.neural.org.uk/resource_library/mental-health-consensus-statement/ Accessed on 16 March 2020

⁸ Extra Costs Commission 2015, Driving down the extra costs disabled people face: final report

<https://www.scope.org.uk/scope/media/files/campaigns/extra-costs-commission-final-report.pdf> Accessed on 12 March 2020

Ensuring the right treatment, care and support for people with neurological conditions is paramount. And, it is extremely complex given the highly personalised nature of living with a neurological condition. This analysis therefore needs to be used cautiously, as there may well be reasonable factors as to why there are gender differences in access to and experience of health and care.

In addition, this is just one way to consider different experiences of treatment, care and support – we have not yet looked in detail at how people from BME groups, or women from BME groups, for example, may experience and access care differently to the wider population.

However, this analysis suggests that there are differences in how women and men experience and access support. We know there is unwarranted variability in access to treatment and care, and we would suggest that some of this unwarranted variation could be linked to gender.

We need to work together as a community to understand in more detail the different experiences and needs of women and men in accessing neurological care. We need to look more specifically at why women often experience longer waits to see a specialist, multiple visits to their GP, are more likely to experience discrimination and less likely to get the support they need in the workplace. We, at the Neurological Alliance, are here to work with the neurological community to undertake this work – we strongly feel that only then will we truly be able to achieve our collective mission of high quality, responsive treatment, care and support for all.

Georgina Carr, Chief Executive, Neurological Alliance

Katharine McIntosh, Policy and External Affairs Manager, Neurological Alliance