



My Neuro Survey Data Briefing

Experiences by reported sexuality and gender identity

Executive Summary

Using data gathered through My Neuro Survey, the largest patient experience survey of its kind in the UK, The Neurological Alliance has undertaken a short analysis of responses according to reported sexual orientation and gender identity.

Both sexual orientation and gender, including gender reassignment, are protected characteristics under the UK Equality Act 2010. Despite this there is evidence that lesbian, gay, bisexual and trans (LGBT) people in the UK face higher inequalities in health satisfaction and outcomes¹. Trans people often report worse experiences when accessing health services with 40% of trans respondents to the 2018 [National LGBT Survey](#) experiencing at least one listed negative experience when accessing or trying to access public health care services in the UK, compared with just 13% of cisgender respondents¹.

¹Government Equalities Office (2018), National LGBT Survey Research Report
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721704/LGBT-survey-research-report.pdf (accessed 10/08/2022)

In a separate [study by Stonewall](#), 41% of trans people said healthcare staff lacked understanding of specific trans health needs².

What My Neuro Survey tells us

This short analysis, based on the results of My Neuro Survey, highlights the experiences shared with us by people affected by neurological conditions who identify as lesbian, gay, bi or trans. Importantly, we identified areas of variation in experience including around impact on mental wellbeing, access to specialists and delays to treatment and care.

It is vital that we better understand the experiences of LGBT people affected by neurological conditions in order to identify and address additional challenges people may face as a result of their sexuality or gender identity when accessing or trying to access health and care services. We strongly believe we, together with our members and those we work closely with, should seek to understand and provide support to as diverse a range of people as possible – without this, we simply will not achieve our collective vision: that every person affected by a neurological condition can access the right treatment, care and support at the right time.

It is important to acknowledge the small sample size of trans respondents, with 27 responses received. Despite this, it is vital to highlight the experiences of trans people with neurological conditions and encourage further research.

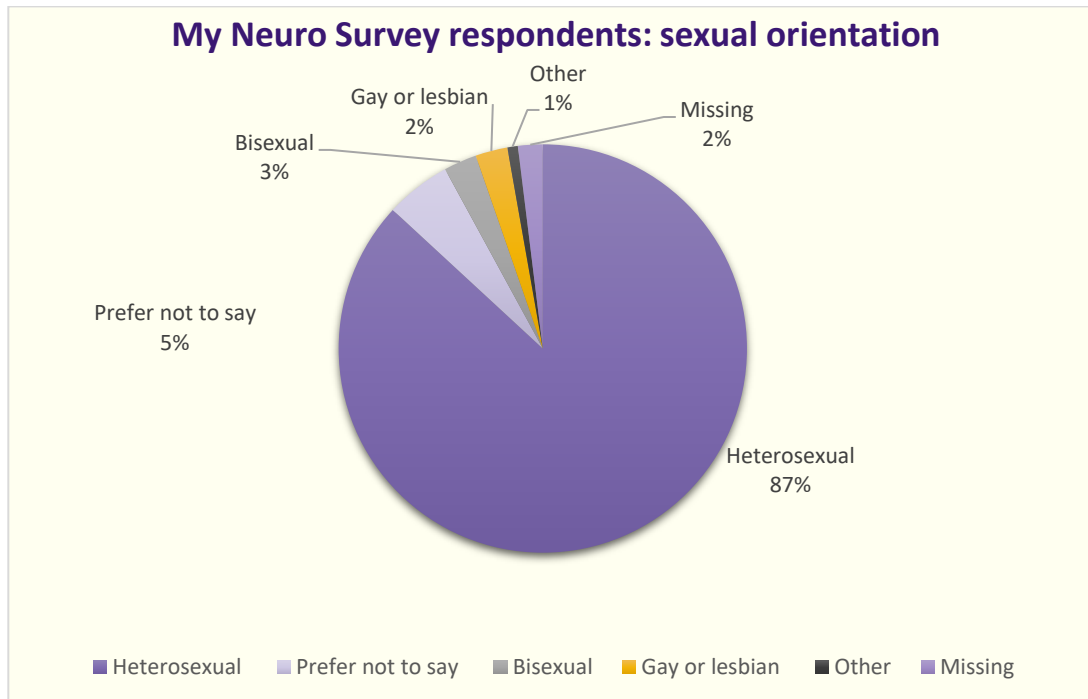
² Stonewall (2018), LGBT in Britain – Trans Report
https://www.stonewall.org.uk/system/files/lgbt_in_britain_-_trans_report_final.pdf (accessed 10/08/2022)

Summary of findings

- Bisexual respondents were more likely to report experiencing delays to neurological care or treatment in the last 12 months compared with those who identified as gay or lesbian or heterosexual.
- Gay, lesbian, bisexual and trans respondents were more likely to report that their neurological condition made their mental wellbeing much worse, and that the pandemic had worsened their mental health.
- Trans and bisexual respondents who were referred or directed to support for their mental wellbeing were significantly more likely to report that this did not make them feel better or more positive.
- Gay or lesbian and bisexual respondents were more likely to report not being given an explanation or directed to any information when they first found out about their neurological condition.
- Gay or lesbian and bisexual respondents were more likely to report that their health and care was not joined up and centred on their priorities. Along with trans respondents they were also more likely to report that information was not passed effectively between people who care for them.

About LGBT My Neuro Survey respondents

7,881 respondents to the adult version of My Neuro Survey broken down by their identified sexual orientation:



In response to the question "Are you trans" – 27 respondents reported "Yes", 155 respondents reported "Prefer not to say", 7248 respondents reported "No" and 254 respondents were classified as "missing", meaning they did not answer the question.

Neurological conditions reported

The table below shows the top three reported neurological conditions for specific groups:

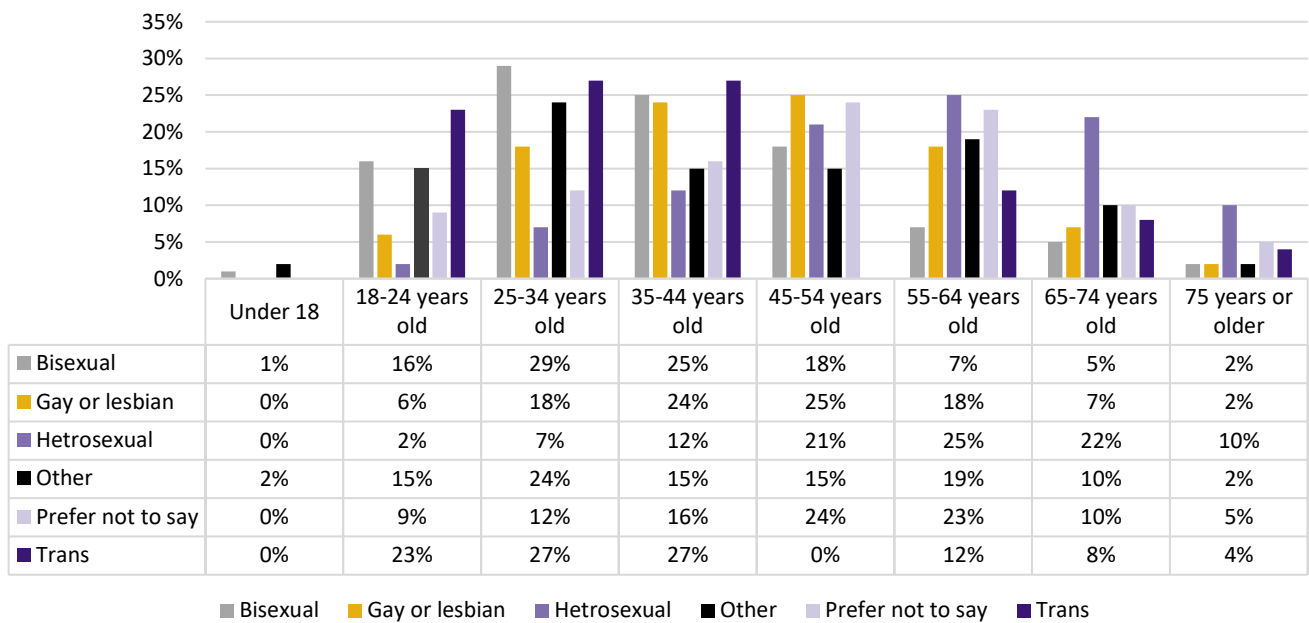
Table 1: conditions reported

	All adult respondents	Bisexual	Gay or lesbian	Heterosexual	Trans
1st most reported	Multiple Sclerosis (MS) 16% (n=1,245)	FND 26% (n=54)	FND 24% (n=48)	MS 16% (n=1126)	MS 22% (n=6) FND 22% (n=6)
2nd most reported	Epilepsy 13% (n=1,006)	Migraine 20% (n=41)	Epilepsy 16% (n=32)	Epilepsy 12% (n=833)	Autism 19% (n=5)
3rd most reported	Migraine 11% (n=851) Functional Neurological Disorder (FND) 11% (n=849)	Epilepsy 16% (n=33)	Migraine 12% (n=25) MS 12% (n=25)	Migraine 10% (n=696) Dystonia 10% (n=676) FND 10% (n=667) Parkinsons 10% (n=653)	Epilepsy 15% (n=4)

Age and gender

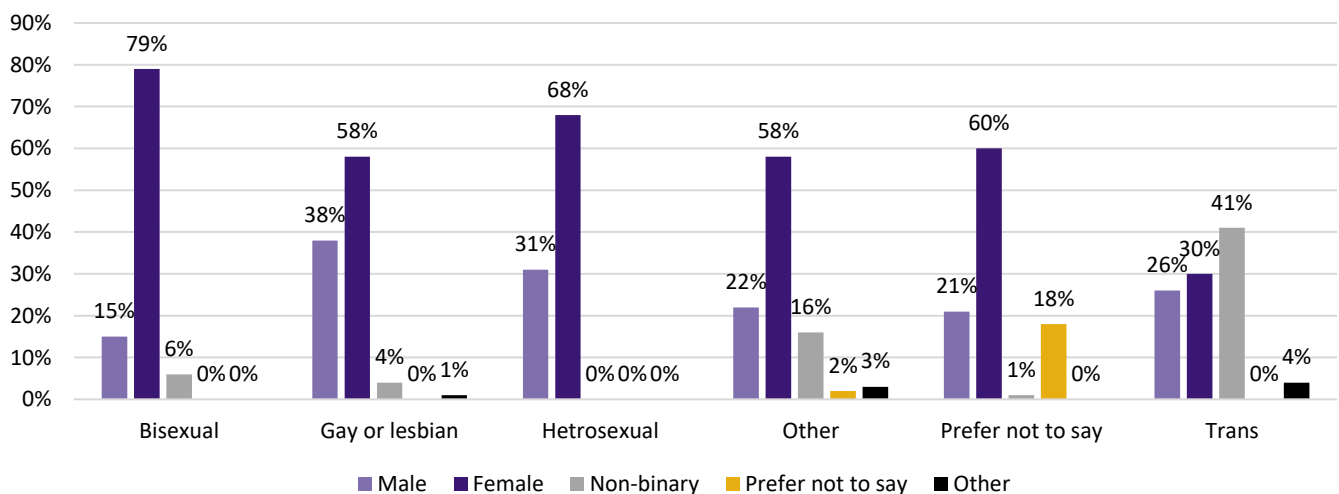
The graphs below show a breakdown by age and gender of those groups whose experiences are analysed in this briefing.

Figure 1: respondents by age group



■ Bisexual ■ Gay or lesbian ■ Hetrosexual ■ Other ■ Prefer not to say ■ Trans

Figure 1: repondents by gender and sexual orientation



■ Male ■ Female ■ Non-binary ■ Prefer not to say ■ Other

Analysis

We have highlighted specific themes explored in the survey, and questions where there is a notable variation of more than 5% between the reported experiences of LGBT respondents and those who identified as heterosexual.

Given the small sample size of trans respondents (n=27), the data and any inferences should be used with caution. Despite this it is vital that we highlight the experiences of trans people with neurological conditions. We have highlighted a number of areas where their experiences differ.

Delays to treatment and care

Bisexual respondents were more likely to report experiencing delays to neurological care or treatment in the last 12 months compared with those who identified as gay/lesbian or heterosexual.

Experienced a delay to a first appointment with a neurologist:

Bisexual – 51% (n=50)

Gay or lesbian – 37% (n=33)

Heterosexual – 32% (n=890)

Prefer not to say – 38% (n=63)

Experienced a delay to a routine appointment with a neurologist:

Bisexual – 59% (n=79)

Gay or lesbian – 58% (n=81)

Heterosexual – 54% (n=2555)

Prefer not to say – 59% (n=157)

Experienced a delay to a first appointment with a specialist nurse:

Bisexual – 41% (n=24)

Gay or lesbian – 33% (n=21)

Heterosexual – 27% (n=521)

Prefer not to say – 30% (n=37)

Experienced a delay to a mental health appointment:

Bisexual – 68% (n=65)

Gay or lesbian – 59% (n=52)

Heterosexual – 41% (n=753)

Prefer not to say – 54% (n=81)

Experienced a delay to a scan:

Bisexual – 62% (n=65)

Gay or lesbian – 56% (n=53)

Heterosexual – 37% (n=1004)

Prefer not to say – 40% (n=66)

Mental health and wellbeing

Bisexual and gay or lesbian people were significantly more likely to report **that the**

COVID–19 pandemic made their mental health worse:

Bisexual – 69% (n=127)

Gay or lesbian – 62% (n=112)

Heterosexual – 42% (n=2520)

Prefer not to say – 52% (n=179)

80% (n= 20) of trans respondents reported that the pandemic made their mental health worse.

Bisexual and gay or lesbian people were more likely to report that **their neurological condition made their mental health much worse:**

Bisexual – 56% (n=111)

Gay or lesbian – 47% (n=93)

Heterosexual – 34% (n=2180)

Prefer not to say – 42% (n=164)

59% (n=16) of trans respondents reported that their neurological condition made their mental wellbeing much worse.

Bisexual and gay or lesbian people were more likely to have been **asked about their mental wellbeing by a health or social care professional** in the last three years:

Bisexual – 52% (n=101)

Gay or lesbian – 53% (n=99)

Heterosexual – 39% (n=2491)

Prefer not to say – 42% (n=154)

73% (n=19) of trans respondents reported being asked about their mental wellbeing by a health or social care professional in the last 3 years.

Bisexual (54%) respondents who were referred or directed to support for their mental wellbeing were significantly **more likely to report that the support they received did not make them feel better or more positive** compared with gay or lesbian (40%) and heterosexual (38%) respondents.

Trans respondents (64%) were even more likely to report that the support they were referred or directed to for their mental wellbeing did not make them feel better or more positive.

50% (n=95) of bisexual respondents reported **feeling that their mental wellbeing needs are not being met at all** compared with 43% (n=71) of gay or lesbian respondents and 41% (n=2073) of heterosexual respondents.

46% (n=12) of trans respondents reported feeling that their mental wellbeing needs were not being met at all.

Information and support from diagnosis

Bisexual and gay or lesbian people **were more likely to report not being given an explanation when they were diagnosed or when they were first told about their condition:**

Bisexual – 27% (n=40)

Gay or lesbian – 26% (n=34)

Heterosexual – 19% (n=733)

Prefer not to say – 24% (n=54)

10% of trans respondents (n=2) reported not being given an explanation when they were diagnosed.

Gay or lesbian people were more likely to report not being offered or directed to any information when they were first told about their condition:

Bisexual – 39% (n=58)

Gay or lesbian – 49% (n=66)

Heterosexual – 37% (n = 1484)

Prefer not to say – 41% (n=100)

20% (n=4) of trans respondents reported not being offered or directed to any information.

Bisexual (32%) and gay or lesbian (31%) respondents were more likely to rate the quality of the information they received as poor compared with heterosexual people (24%).

Joined up care and access to services

Bisexual respondents (53%) were significantly more likely to report not having an appointment with a specialist nurse for their neurological condition (but would like this) compared with gay or lesbian respondents (44%) and heterosexual respondents (34%).

As above, but for **occupational therapy** – bisexual respondents (59%), gay or lesbian respondents (52%), heterosexual respondents (44%).

As above, but for **rehabilitation as an inpatient** – bisexual respondents (73%), gay or lesbian respondents (73%), heterosexual respondents (51%).

As above but for **rehabilitation as an outpatient** – bisexual respondents (70%), gay or lesbian respondents (75%), heterosexual respondents (56%).

As above, but for **speech and language therapy** – bisexual respondents (67%), gay or lesbian respondents (47%), heterosexual respondents (34%).

Bisexual (51%) and gay or lesbian (45%) respondents were more likely to report that their health and care was not joined up and centred on their priorities compared with people who identified as heterosexual (37%).

Bisexual (51%) and gay or lesbian (45%) respondents were more likely to report that information about their condition was not passed effectively between people who cared for them compared with those who identified as heterosexual (37%).

52% (n=13) of trans respondents reported information was not passed effectively between the people that care for them.

Other areas of notable variation

Bisexual (27%) and gay or lesbian (20%) respondents were more likely to report having experienced difficulties affording their prescriptions compared with heterosexual respondents (13%).

28% (n=5) of trans respondents reported having difficulties affording their prescriptions.

Bisexual and gay or lesbian respondents were more likely to report having an emergency admission due to their neurological conditions in the last two years. 62% (n=126) of bisexual respondents reported they had not had an emergency admission in the last two years compared with 66% (n=133) of gay or lesbian respondents and 75% (n=5029) of heterosexual respondents.